Children's Adjustment to Asthma or Diabetes and Treatment Adherence

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ABSTRACT

This thesis had two main aims. Firstly, to develop separate questionnaires for children with asthma and children with diabetes and their parents, which assess children's adjustment to the illness and treatment adherence. Secondly, to test the hypothesis of an association between children's adjustment and treatment adherence.

The essence of asthma and diabetes treatment is self-care and consequently children with asthma or diabetes have to learn to cope with the long-term demands and responsibilities of complying with a strict and complex treatment regimen. It is currently recognized that a major problem in paediatrics is poor treatment adherence, which can result in serious health consequences. This led to a shift in paediatric medicine, from focusing only on the physical treatment of the illness to exploring the psychological impact of the illness and how it affects children's socio-emotional adjustment. However, there is a shortage of adjustment and treatment adherence measures; existing ones have major limitations. Thus, the new questionnaires aimed at assessing both children's adjustment and treatment adherence.

Four interlinked studies utilising qualitative and quantitative methods were carried out. Study 1 and study 3 were parallel but separate studies and involved interviewing a group of 15 children with asthma and 15 children with diabetes, their parents and paediatric nurses about the children's experiences and feelings in a range of contexts.
The interviews showed that there were commonalities in stressors across children but differences in adjustment and treatment adherence levels.

On the basis of these interviews separate questionnaires for children with asthma (study 2) and children with diabetes (study 4) and their parents were developed and administered to a sample of 60 children and their parents. The new questionnaires proved to be reliable and valid and confirmed the hypothesis of a significant relation between children's adjustment and treatment adherence.

The development of a new assessment tool involves several steps: This work represents the first steps in developing a new assessment tool. As with any new assessment instrument, further development will be required to examine its validity and reliability.

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CHAPTER 1

INTRODUCTION

1.1 Aims of the Thesis

The first aim of this thesis was to develop assessments to measure socio-emotional adjustment in children who suffer from asthma or diabetes. Socio-emotional adjustment represents a major psychological aspect of quality of life in chronically ill children (Eiser & Morse, 2001) and is an essential component of the definition of 'health'. Despite numerous generic measures to assess children's quality of life, there is a shortage of measures to assess the quality of life of chronically ill children specifically for children with asthma or diabetes. Childhood asthma and diabetes are the most common chronic childhood diseases and the management of both conditions requires the child and family to follow a long-term, strict and complex treatment regimen, hence there is an urgency to investigate this area further. Therefore, the study aimed to provide a set of easy to administer and time-economical instruments to follow up a child's psychological adjustment to a chronic illness in the same way that medical tests are used to follow up a child's physical condition. The development of these measures was accomplished through the integration of medical health professionals' information on physical aspects of a child's health and child psychologists' analyses of how stress and distress is manifested in a variety of situations relating to children and chronic illness.

The second aim of this thesis was, by using these new measures, to test the hypothesis of an association between children's socio-emotional adjustment to the illness and their treatment adherence. Treatment adherence in chronically ill paediatric populations is a major problem and poor adherence is related to high levels of stress thus affecting children's quality of life and adjustment to the illness. This study will provide an initial insight into how chronically ill children's adjustment relates to adherence with their treatment. Therefore, this research will represent a progress towards the understanding of the relationship between physical and psychological aspects of an illness.

The development of a new assessment tool involves several steps: This work represents the first steps in developing a new assessment tool. As with any new assessment instrument, further development will be required to examine its validity and reliability in the clinical setting. In the longer term it is envisaged that the new instrument will play a part in aiding health professionals to promote and improve well-being in chronically ill children through the early identification of adjustment and treatment adherence problems and ongoing assessment of the child's psychosocial needs.

1.2 Background

1.2.1 Chronic Illness and Quality of Life in Modern Times

In society today housing conditions and diet have been enhanced, and the introduction of vaccination programs for most infectious diseases and epidemics, together with an improved neonatal and postnatal care system have led to lower mortality rates and to better general health and resistance to illnesses. In parallel with these improvements are great medical advances and breakthroughs in the treatment of potentially fatal diseases in children. For example, the discovery of insulin enabled diabetes patients to have a normal life-expectancy i.e. virtually the same as for the rest of the population (Eiser, 1993). Other examples are the development of antibiotics, anti-leukaemic drugs, radiation and surgical procedures that are technologically far superior to historical methods. As a result of these changes many children who suffer from chronic physical conditions in the past died at a very young age but can now live much longer lives, often into late adulthood (Roberts, 2003). Thus a great deal of paediatricians' and other health professionals' work involves the care for children with chronic illnesses as formerly fatal threats to the child's existence have become chronic physical conditions to be coped with throughout life.

In line with medical advances in the treatment of illnesses, professional thinking about health has also changed: Health can be defined as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (World Health Organization, 1948). This definition was further expanded in later publications that define Quality of Life: According to the World Health Organization Quality of Life (WHOQOL) Group, "QOL is an individual's perceptions of their position in life, in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, and their relationship to the salient features of their environment" (WHOQOL Group, 1993, 1994).

This bio-psychological approach to health has strongly influenced the development of the construct of Quality of life (QoL) and has been widely adopted. Wallander (2001), for example, defined QoL as "the combination of objectively and subjectively indicated well-being in multiple domains of life considered salient in one's culture and time, while adhering to universal standards of human rights" (Wallander, 2001, p. 34). Therefore, the goals and outcomes for children should not be evaluated in terms of only surviving a chronic physical condition but also in terms of the psychological consequences. Thus, parallel to the significant progress made in treating the physical condition of children with chronic illnesses over the last few decades, it has been acknowledged that the consequences of the illnesses for the children's psychological states need to be investigated further.

According to Stenner (2003), the difficulty of measuring Quality of Life as part of the concept of health is related to the subjective aspects that must be encompassed in the measure: "The challenge, therefore, has been to design an instrument capable of establishing what difference a given illness or condition makes to the life of a patient, or the related question of what difference a treatment makes. We can consider this as 'subjective' since such a question can only be adequately answered from the patient's point of view. Of course, as Hughes, Hwang, Kim, Eisenman, and Kilian (1995) suggest, it may be possible to infer QOL from more observable measures such as whether one has a job, a car, a home, and so on. However, such inferences, as Lindström (1992) points out, will always be troubled by the distinction between perceptions of objective conditions, such as material resources, and perception of subjective conditions, like the degree of satisfaction with one's resources" (Stenner, 2003, p 2161). Although it may seem implausible to a healthy person that anyone can actually adjust well to an illness or a disability and feel perfectly happy, one should take into account the view of the person or the group under consideration. With respect to deafness, for example, it is now widely accepted by researchers that there are two definitions of deafness: one medical, according to which deaf people are "disabled" because they cannot hear, and one cultural, according to which Deaf people (i.e. those who sign and are part of the Deaf community) are "at a disadvantage" in a community where oral language is used, but they are neither disabled nor at a disadvantage in their own community, where signed language is preferred (see, for example, Ladd, 2003; Padden, 2000). This cultural definition of deafness recognises that a language is the cultural system of communication used in a community: Deaf people are no more disabled in a hearing community than English monolinguals in a Chinese speaking community.

Similar distinctions can be used in the subjective understanding of adjustment to an illness at a personal level. A boy whose best friends play rugby and who cannot play rugby because of his asthma may feel "disabled" but another child who has no interest in sports and prefers TV, video-games and the cinema is unlikely to perceive the recommendation not to exercise too vigorously as a restriction to his interests and his life. Thus, it is important to take into account children's perspectives if one seeks to understand adjustment not by inferring the child's perspective from the objective limitations to the child's life but as the degree of satisfaction with one's resources, as suggested by Stenner (2003).

The concept of Quality of Life used in the medical sciences is essentially the same as socio-emotional adjustment, which is used more commonly in psychology because it can be applied to healthy children growing up in poverty (e.g. Evans & English, 2002; McLoyd, Ceballo, & Mangelsdorf, 1996) or whose parents have an illness (e.g. Aikens, Coleman, & Barbarin, 2008).

Concerning a definition of adjustment there are, as in many research areas, fundamental assumptions and sometimes lack of clarity about key terms and concepts, and research in the field of chronically ill children is no exception. Researchers variously refer to adjustment, adaptation and psychological functioning, without necessarily clarifying their differences and similarities, hence using the terms interchangeably (Eiser, 1990). The way in which the concept to be investigated is defined should relate to its theoretical origins and subsequently the choice of methodology and measures. For example, in this field, studies that conceptualise adjustment or maladjustment in terms of degrees of depression, anxiety or self-esteem would use measures reflecting these.

In the context of chronic illness, we understand adjustment to be the psychological and behavioural response of an individual or family to the internal and external stressors associated with the illness experience, which will be influenced by their coping skills and resources (Thompson & Gustafson, 1996). Adaptation is similarly and widely understood to be the level to which children "cope psychologically, socially and physiologically with the chronic illness" (Hentinen & Kyngaes, 1998, p. 317). The meanings of the terms are therefore very similar and not to confuse matters it was decided to use the term „adjustment" in this thesis as „it implies a broad range of levels of functioning, can incorporate a clinical range in terms of maladjustment, and inherently suggests temporal and situational variability" (Roberts 2003, p. 143).

It has been proposed in the United Kingdom (UK) national policy documents for the past two decades to involve patients in the planning and delivery of healthcare services (Department of Health, 2001; NHSE, 1996). Specifically, the Department of Health (2000) sets out the vision that children, teenagers, parents, caregivers, and families are entirely involved in choices about their treatment and care, and are prepared to play an active role in the daily tasks to manage the illness. In the area of paediatrics one component of this explicit commitment is recorded in the National Service Framework (NSF) for children (Dept. of Health, 2004). It involves a ten-year plan and strategy, intended to raise standards in hospitals and all other related institutions. The NSF sets out clear standards which at its heart address a fundamental change in the way of thinking about children's health and social care services with a shift in services being designed and delivered towards the needs of the child. Key to these standards is the need to "hear children's voices" and consider the impact that their condition has on the psychosocial well-being of their family as well as themselves. For instance in the case of children with chronic illnesses, the aim is to not only look at the illness or the problem but rather to be child-centred hence consider the whole child. Also, it is important that children and families receive high quality services which are coordinated around their needs and most importantly take account of their views. Services are aimed to provide information to children and families and listen and respond to them in relation to their individual treatment. The aim is to support children and parents in self-care of their illness in partnership with professionals by sufficiently informing them about their illness and how, when and who to ask for help.

This has resulted in yet another change in a concept central to health care. The concept of treatment compliance has been replaced by concordance, where there is shared decision-making between parents, children, and health professionals.

Accordingly, the measurement of concordance is now to be conceived differently from earlier measures. According to La Greca and Schuman (1995), the most widely cited definition of compliance is Hayne's (1979): the extent to which a person's behaviour coincides with medical or health advice. However, La Greca and Schuman point out that most measures do not actually measure a person's behaviour in relation to a prescribed regimen. In complex treatment regimens, such as those for asthma and diabetes, measures that are appropriate for short term treatment regimens, such as counting the number of pills taken, cannot be used. Specifically in the case of diabetes, Bissell, May, and Noyce (2004) suggest that the interactions between the professionals and the patient should not be seen as occasions to reinforce instructions around treatment but rather as opportunities to pool together the expertise of the professional and the patient. The treatment regimen should be based on informed decisions about what to do and what not to do in different circumstances. Children's reactions to the same event might differ: For example, one child with diabetes might be able to have more exercise than another child without having to eat and one child might not like to have to eat snacks during class, when no one else is eating, whereas another sees it as a privilege. Thus, health professionals must be sensitive to the children's physical and psychological reactions and find a treatment regimen that is feasible and effective for the child. By putting time and effort in a concordant discussion between health professionals and the child and family about the treatment the aim is to achieve a more effective use of medicine. It is hoped that by 2014 health, social and educational services have met the standards set in the NSF for children.

In this thesis, the term treatment adherence will be used; compliance is too strongly associated with the idea of obedience and concordance and does not seem to be well established in the literature (e.g. a search for the term adherence in the journal Social Science and Medicine identified 929 papers; a search for concordance in the same journal identified 305 but in a large number the term was used to refer to agreement between different people, such concordance between husband and wife).

In summary, with increasing medical advances in the control of physical aspects of illnesses, definitions of health have evolved to consider subjective aspects. Health is no longer seen as the absence of illness but involves objective and subjective aspects of well-being. Subjective aspects cannot be simply inferred from objective conditions as they vary with a person's perceptions of his or her position in life, goals, expectations, standards and concerns. In the same perspective, the concept of compliance has been modified and health professionals now seek treatment concordance, which takes the patient's view into account.

1.2.2 Definition of Chronic Illness and Prevalence, Treatment and Description of Asthma and Diabetes

When studying the literature about chronic illness it becomes apparent that there are a number of different definitions of this term. According to Pless and Pinkerton (1975) chronic illness is "a physical condition, usually a non-fatal condition, which lasts longer than three months in a given year, or necessitates hospitalisation of more than one month in a year" (Pless and Pinkerton, 1975, p.

90). Eiser describes a chronic physical condition as being characterised by "affecting children for extended periods of times, often for life. These diseases can be "managed" to the extent that a degree of pain control or reduction in attacks (of asthma) can be generally achieved. However, they cannot be cured." Eiser, 1990, p.3). Yet another definition of a chronic disorder is by Hobbs and Perrin who describe it as a condition "that lasts for any substantial period of time, or has sequelae that are debilitating for a long period of time" (Hobbs and Perrin, 1985, p.2). They further point out that chronic conditions "persist for a number of years of pain control or reduction in attacks (of asthma), bleeding episodes (in haemophilia) or seizures (in epilepsy) can be generally achieved. However, they cannot be cured (after onset and have a variable course with some improving, some remaining stable and some becoming progressively worse" (Hobbs and Perrin, 1985, p.2).

Therefore, there is an overall agreement as to what constitutes a chronic disease, which is that the condition is long-term and has various adverse effects on the child's life. However, there is inconsistency across researchers in the emphasis placed on the severity and chronicity of the illness (Bradford, 1997). In the case of asthma there are varying degrees of severity ranging from very mild and occasional/temporal asthma with very serene symptoms to very severe life-threatening asthma. For the purpose of this study, a synthesis of these definitions of chronic physical disorder was used. Thus, the criteria of this study exclude Pless and Pinkerton's definition that a chronic condition has to last longer than three months a year or requires hospitalisation of more than one month a year. Concerning the chronicity of disease, Hobbs and Perrin (1985, p.2) stated above that different conditions have variable courses with some improving over time and some remaining stable or becoming even worse.

This can be exemplified very well in the case of asthma and diabetes. Whereas in asthma there is a chance that children stop having symptoms with increasing age or “grow out” of the disease, children with diabetes are affected by the disease for life. Lemanek (1990) found that 50% of asthmatic children become asymptomatic as adolescents. Lastly, this study does not concur with the criteria of Eiser’s (1990) definition with regard to a chronic condition not being curable because in the case of asthma there is a possibility of cure as some children grow out of the disease. Also due to medical advances in the course of history there might be a cure for diabetes.

Due to the differences in the definition of terminology, there is a noticeable discrepancy in the number of children that are thought to have a chronic illness. One estimation is that nowadays, up to 20% of all children in the world develop a chronic physical illness at some point in their childhood (Aron, Loprest, & Steuerie, 1996; Newacheck et al., 1998).

The rationale for selecting and comparing children with asthma to children with diabetes was based on several points. Firstly, these conditions are two of the most common chronic childhood illnesses; in fact asthma is by far the most common childhood disease (Roberts, 2003). Secondly, the morbidity of both illnesses is steadily rising, hence the impact of these illnesses on the children’s psychological well-being needs urgent attention. Thirdly, the management of both conditions is comparable in that both require the child and family to follow a long-term strict and complex treatment regimen. Fourthly, both represent “invisible” conditions which are not obvious to others from the child’s appearance and children have to remind themselves of the treatment restrictions. Fifthly, children can "get away" with minor non-compliant behaviour (e.g. in asthma omitting once the use of a preventative inhaler, in diabetes eating modest amounts of food containing sugar) without serious consequences to their health in contrast to other diseases like cancer where non-compliant behaviour could be life-threatening. Lastly, including a sample of children with asthma and a sample of children with diabetes allowed for on the one hand exploring differences between the two illnesses but on the other hand also allowed for exploring commonalities, which allowed for a more general statement about children with chronic illnesses.

1.2.2.1 Asthma

The most common condition by far is childhood asthma, which is a chronic inflammatory disorder of the airways involving intermittent and variable periods of airway obstruction (Le Coq, Colland, Boeke, Bezemer & van Eijk, 2000). The illness is characterised by periods in which the asthmatic child does not have noticeable symptoms whereas at other times the child experiences asthma exacerbations, which are marked by active symptoms of coughing, wheezing, shortness of breath, and chest tightness. Normally symptoms occur as a result of airway hyper-responsiveness to a number of triggers, which might be environmental (e.g. dust), seasonal (e.g. cold weather), respiratory infections, cigarette smoke and animal dander. Paediatric asthma affected 21 % of children between 2 and 15 years of age in the UK in 1996. Research is indicating that the prevalence and severity of childhood asthma has increased substantially in recent years and is expected to rise further. Rates of mortality from asthma during childhood (patients aged 5 to 14 years) amount to two per million each year (Office of National Statistics, March 2008).

The medical treatment for chronically ill children is aimed at reducing as many symptoms of the disease and treatment side-effects as possible, to allow as much as possible for a healthy way of life. Since asthma is a chronic illness, the essence of treatment is self-care and parents are taught to undertake much of the treatment themselves with only intermittent physician or nursing support and advice. Thus, the treatment demands constant adherent behaviour from the side of the patient i.e. the child. With increasing age children are asked to assume more and more responsibility in order to encourage a certain amount of independence from parents and health professionals. However, patients and their parents have to follow a daily and very complex treatment regimen.

Asthma management involves identifying and managing exacerbations and symptoms, identifying and avoiding triggers, and taking medication on a regular basis. Very common are also sudden and unexpected attacks and very immediate actions are required. Consequently, children with asthma are subjected to a large number of stressors. One example is that a common trigger in children with asthma is animal hair. Hence, they have to stay away from animals while their friends are touching, stroking and playing with their pets. Children with asthma are also restricted in participating fully in school activities. For example on sports-day they often have to stop running or swimming as they get out of breath more easily and therefore may not perform as well as their peers. This is particularly likely to be the case if they have not taken their preventive medication on a regular basis as is often the case.

1.2.2.2 Diabetes

Another very common condition is childhood diabetes, which is one of the most serious health problems occurring in 1 out of 500-600 children with the incidence likewise increasing remarkably fast (Roberts, 2003). Almost all diabetic children have Type 1 diabetes, which is also called Insulin dependent diabetes mellitus (IDDM). IDDM results from an autoimmune destruction of pancreatic islet cells that produce insulin, ending in permanent insulin deficiency. Insulin controls sugar metabolism, which is fundamentally important for growth, activity, wound healing, and brain function, thus insulin replacement is essential for survival. The other form of diabetes is called Type 2 or non-insulin-dependent diabetes mellitus, which is mainly found in adults who are overweight and 40 years and older. In Type 2 the body either does not produce enough insulin or the cells cannot use the insulin that is naturally produced by the body. However, as more children become overweight Type 2 has started to occur already in younger people accounting for 10-20% of new cases (Roberts, 2003). This study though only focuses on children with IDDM.

Diabetes can also be fatal. In the United Kingdom alone, 83 children and adolescents with IDDM (Insulin dependent diabetes mellitus) less than 20 years of age died between the years 1990 and 1996. The majority of these children (69) died of hyperglycaemia, which happens when blood sugar levels rise too high (Edge, Ford-Adams, Dunger, 1999).

As in the case of asthma, diabetes management requires a multifaceted and demanding treatment regimen. It consists of blood glucose monitoring several times a day to detect abnormally high (hyperglycaemia) or low (hypoglycaemia) blood glucose levels and to subsequently adjust the regimen accordingly. Children with diabetes also have to follow a dietary regimen which includes a certain daily carbohydrates allowance and do regular exercise to reduce insulin requirements. The aim of the treatment is to maintain close to normal blood sugar levels to reduce the risks of complications to levels that equal those of the general population. Not surprisingly, as a result of the complexity of the treatment regimen children with diabetes are subjected to a potential source of psychological stress.

One example in the case of diabetes is, that children have to keep a restricted diet and are not allowed unlimited amount of foods they traditionally like to eat (chocolate, cakes, sweets, etc), which may pose a major problem for instance when they go to friends' birthday parties.

1.2.3 The Effect of Chronic Illnesses on Children's Personal and Social Adjustment

Due to the impact of the illness on children's lives it is not surprising that research indicates that this population has an increased risk for developing all kinds of adjustment problems and has rightly become a matter of concern. Wallander and Varni (1998) define positive adjustment of children as "behaviour that is age-appropriate, normative, and healthy, and that follows a trajectory toward positive adult functioning" whereas maladjustment is evidenced "in behaviour that is inappropriate for the particular age, especially when this behaviour is qualitatively pathological or clinical in nature" (Wallander & Varni, 1996, p.30). In the context of the previous discussion of well-being and chronic illness, we understand socio-emotional adjustment to be not only the behavioural responses of the child or family to the internal and external stressors associated with the illness experience, but to include also their perceptions of how these stressors affect them, which will be influenced by their coping skills and resources (Thompson & Gustafson, 1996). In general, children with chronic illnesses have been found to be at increased risk for adjustment problems but, there are individual differences in the nature and extent of children's responses, which result in considerable variability in adjustment (Roberts, 2003). As a result there has been ample research into the risk and resilience factors that might explain these individual differences in children's adjustment to disease. Two conceptual models have been proposed to organize the systematic investigation of the correlates of adjustment to chronic illnesses. One model is the transactional stress and coping model by Thompson, Gustafson et al. (1996) in which a chronic disease is viewed as a potential stressor to which the child endeavours to adapt. The relationship between the chronic illness and adjustment is a function of the transaction of biomedical, developmental, and psychosocial processes. The focus of coping models is on the contribution of child and family adaptation that is hypothesised to influence the psychological adjustment of children, above the contribution of biomedical and developmental parameters. Examples of psychosocial processes are expectations of self-esteem, health locus of control, coping behaviours, and maternal adjustment. The model was not developed to be entirely generic regarding the type of disorder and has only been tested with sickle cell disease and cystic fibrosis.

The second model is the disability-stress-coping model delineated by Wallander and Varni (1998) which is illness-generic. In this model the range of variables hypothesised to play a role in adjustment are organised into a risk-and-resilience framework. Chronic illness is conceptualised as an ongoing strain for both children and parents. Chronic strains are described as persistent objective conditions which necessitate continual re-adjustment. Risk factors include disease parameters, functional dependence in the activities of daily living, and psychosocial stressors. Resistance factors consist of intrapersonal factors (competence, problem-solving ability), social-ecological factors (social support, family adaptation), and stress-processing factors (cognitive appraisal, coping strategies).

Both models lead to the prediction of individual variation in how children adjust to a chronic illness: The aim of this thesis is to develop assessments to describe these individual differences. In the sections that follow, a review of results on children's socio-emotional adjustment to chronic illness is presented.

Two different empirical approaches have been utilised when investigating if chronically ill children are at increased risk of maladjustment in comparison to healthy children. One approach is by means of epidemiological surveys, which entail comparing a population of children with chronic illnesses to a sample of general population. Cadman, Boyle, Szatmari, and Offord (1987) studied randomly selected samples of families and found that children with chronic illnesses have a two- or three-fold higher risk for psychiatric disorders.

The other approach involves clinical studies which investigate samples of one or more chronic conditions.

When reviewing the literature whether children with chronic illnesses are at higher risk for adjustment problems Wallander, Varni, Babani, Banis, and Wilcox (1988) compared children with various chronic illnesses and found that they showed significantly more internalizing and externalizing behaviours as well as more difficulties in social functioning compared to general norm population. Moreover, Lavigne and Faier-Routman (1992) conducted a meta-analysis of the empirical literature on psychosocial adjustment in chronically ill children on research published between 1928 and 1990. When comparing children with and without a chronic illness they found that children with chronic illnesses yielded effect sizes that were significantly different from zero for overall adjustment, self-esteem as well as internalizing and externalizing difficulties. Very large effect sizes of .75 and more between disorders and study controls were found for inflammatory bowel disease, seizure disorders, burns, and deafness. Large effect sizes i.e. .50 to .74 were uncovered for diabetes, cerebral palsy, cardiac disorders, other neurological (non-seizure) disorders, dwarfism, blindness, myelomeningocele, and pooled disorders. Moderate effect sizes i.e. .25 to .49 were detected for cystic fibrosis, asthma, cancer, juvenile rheumatoid arthritis, and orthopaedic disorders. Thus, children with a chronic illness showed on average more psychological difficulties than their healthy peers.

On the basis of the above findings one can conclude that children with chronic diseases are at a higher risk of developing adjustment problems but that this relationship is not of a straightforward nature i.e. there are various factors that mediate the connection between chronic illness and adjustment. Due to the major impact on everyday life and stress that chronic illnesses place on these children, a number of different responses are to be anticipated as there is no direct relationship between a chronic illness and subsequent adjustment (Roberts, 1995). As will be seen in the literature review (Chapter 2), later studies have concentrated more on identifying factors that account for such variability in psychological adjustment, such as disease parameters, age and age of onset, duration, sex. In the case of asthma interpreting results is even more complicated due to how the illness is clinically manifested. Renne and Creer (1985) pointed out that asthma is characterised by being intermittent (varies in the frequency of attacks), variable (attacks vary in severity), and reversible (children experience abnormal breathing during an attack whereas other times their breathing is normal).

Lavigne and Faier-Routman (1992) also noted that despite the fact that many studies have been conducted aiming at investigating adjustment of chronically ill children, the results when exploring the studies individually are contradictory. This is due to studies 1) having different definitions of adjustment and consequently using different or not adequate measures, and 2) the use of a generic or categorical approach and the investigation of different samples across studies.

1. Different definitions and measures of adjustment

Some studies do not specifically mention adjustment or adaptation, but it can be explicitly or implicitly inferred from combinations of other measures, such as psychosocial problems, adherence to treatment, quality of life, etc. making matters even more complicated. Regarding the application of inadequate measures Kazak, Segal-Andrews, and Johnson (1995) pointed out, that measures developed for healthy children include statements that are indicators of poor adjustment for healthy children (e.g., I often suffer from headaches; I don't have as much energy as other children; I worry about my health) but which have a different meaning in the case of chronically ill children, because they do not represent psychosomatic symptoms for them. Furthermore, measures developed for healthy children fail to provide information about how chronically ill children cope with stressors that the illness brings into their lives. One example of a widely used assessment tool for measuring psychosocial functioning in chronically ill children is the Child Behaviour Checklist (CBCL; Achenbach & Edelbrock, 1983). Perrin, Stein, and Drotar (1991) highlighted several key problems in using that scale with chronic paediatric samples as the measure was not explicitly developed for this use. Firstly, the scale comprises of various items that directly tap physical health problems (child has aches), which a chronically ill child is very likely to experience, leading to their scores being elevated compared to healthy children, thus giving the impression that they encounter more psychological problems. Secondly, the CBCL was developed to identify children with significant emotional and behavioural disorders and subsequently might have limited sensitivity to children with minor adjustment problems, which nonetheless pose a problem to these children and their families. Finally, in addition to behavioural and emotional problems, the CBCL assesses a child's "social competence", which might be very misleading in chronically ill paediatric populations. This is due to the scale asking about the child's accomplishments and participation in activities where chronically ill children are often restricted and therefore it is wrong to conclude that they show less social competence.

2. The use of a generic or categorical approach and the investigation of different samples across studies

Above and beyond the issue of the use of a variety of measures, studies can differ in their use of a non-categorical (generic) approach, a categorical (disease-specific) approach or both.

The non-categorical approach is based on the assumption that there are generic factors which are common to the experience of different types of chronic illnesses. These commonalities include the nature of onset and course, life threat, potential intrusiveness or pain and discomfort of treatment, visibility and social stigma, stability versus crisis, illness brings an element of uncertainty, treatment necessitates the involvement of health professionals, secondary functional and cognitive disability, child misses out on school. Thus, the non-categorical approach assumes that it is the variability within each of these dimensions that has implications for adjustment rather than the different diagnosis. Studies based on this approach include several different types of chronically ill children within a research sample, with the aim to increase the ability to discover commonly shared experiences across several illness types (e.g. frequent hospital visits) and how these relate to adjustment or maladjustment in the children.

There are two advantages of this approach. Firstly, a focus on the common psychosocial variables across illnesses may yield powerful and widely generalisable assessment and intervention measures and programmes. Secondly, greater statistical power can be obtained through the combination of discrete differing clinical samples.

Nevertheless, some researchers consider that not all illness experiences share commonalities. Thus, the categorical approach is based on the assumption that each chronic physical condition has a distinct biological process and results in very diverse treatment regimens. According to Mullins et al. (1995) research that focuses on a single diagnostic category allows for greater precision in modelling interrelationships between variables. The significance of disease-specific characteristics relating to illness course, task demands, phase of disease, functional limitations and developmental stage for adjustment may be determined to a greater level. For example, Walker, Van Slyke, and Newbrough (1992) found that specific disease features (whether the outcome would be fatal or if a cognitive impairment was associated with the illness) were associated with different stressors and responses, thus differences in adjustment.

Finally, it is noted that in order to measure a child's adjustment it may be necessary to work with multiple methods and informants. For instance, Thompson, Merritt, Keith, Murphy, and Johndraw (1993) pointed out that in order to distinguish the association between maternal adjustment and child adjustment from that between maternal adjustment and mothers' perception of their children's adjustment, requires the assessment of both mother and child.

The current study addresses this issue by separately assessing the child and the parent about the child's adjustment to the illness. Through this procedure it is possible to obtain information from the child directly as well as from the parent, who provides further data on the same issues from a different perspective.

1.3 Socio-Emotional Adjustment of Children and Treatment Adherence

As mentioned previously, children with asthma or diabetes and their families have to follow a strict and complex treatment regimen and often experience treatment adherence challenges. In fact, treatment adherence is poor amongst chronically ill children - e.g. suffering from asthma (Baum & Creer, 1986) and diabetes (Johnson, Silverstein, Roosenbloom, Carter, & Cunningham, 1986). The most widely accepted definition of treatment adherence is "the extent to which a person's behaviour ... coincides with medical advice" (Haynes, 1979, pp. 2-3). Children's non-adherence with medical treatment regimens has serious consequences for their health and as a result causes a major problem for parents, families and health professionals who work with them. Problems in adherence might be as mentioned previously due to the fact that in most chronic illnesses the treatment management regimen is very complex. In childhood diabetes for example, the treatment regimen requires numerous daily behaviours in the area of insulin injections, glucose testing, diet, and exercise. However, the treatment regimen is made even more complex due to the relationship <u>between</u> regimen behaviours, such as the insulin injections which must be timed in relationship to meals. Thus, the patient might adhere to one regimen task (e.g. insulin administration), but not to another (e.g. blood glucose monitoring) and therefore separate adherence indices are needed to investigate chronic disease like asthma and diabetes with their multi-component regimens.

In asthma the treatment involves several daily behaviours in the area of keeping a record of the children's peak flow measures, and children are prescribed preventative and reliever medicine that they need to use <u>regularly</u>. Furthermore, children with asthma have to identify and avoid environments that might trigger an asthma attack (cold air, pollen, animals). Also, they have to avoid infections as the common cold can be a trigger for an asthma attack.

Children's quality of life is affected by how they cope with illness-related stressors and poor adherence is also, in some illnesses, related to high levels of stress. Previous research supporting the hypothesis of a possible connection between socio-emotional functioning and treatment adherence was shown by Pretzlik (1997), who found that children who were distressed during medical procedures (e.g., a blood test) also tended to avoid them. It is therefore possible that children's socio-emotional adjustment does not only influence their coping with distress during medical procedures but might also play an important role in their treatment adherence. Thus, the hypothesis is that children's socio-emotional adjustment to the illness plays a significant role by influencing their adherence with the treatment. One outcome could be that poor socio-emotional functioning of a child results in less or even no adherence with the treatment, while good socio-emotional adjustment results in good treatment adherence. Therefore, the contribution of this study is to investigate, by utilising the newly developed measures, if there is an association between children's socio-emotional adjustment to the illness and their treatment adherence. However, it is beyond the scope of this study to determine the direction of causal effect.

1.4 Aim and Research Strategy

To summarise, previous research indicates a shortage of specific measurements for the assessment of children's socio-emotional adjustment to chronic illness, an illness that represents a major aspect of the quality of life in children.

Therefore, the aim of this study is to address this very important issue by developing assessments to measure the socio-emotional adjustment of children with asthma and children with diabetes to their illness and how it affects their quality of life. As opposed to the generic measures that are normally used to assess chronically ill children, this study aims at developing disease-specific i.e. separate instruments (in the form of questionnaires) for children with asthma or diabetes and their parents.

Due to the course of asthma and diabetes, the essence of treatment is self-care i.e. patients and their parents take most of the responsibility for following a very complex regimen. Thus, these newly developed measures will tap these areas by identifying stressors that the children and families are facing, how they successfully cope with these stressors and where future interventions are needed. They also at the same time represent an economical way of assessing child adjustment and it should be possible to obtain the same important information as in longer clinical interviews. Consequently, the construction of these new instruments represents the first steps towards developing a tool that is hoped will help health professionals to identify children who are at risk of developing adjustment and/or treatment adherence problems. Ideally, when a new instrument is constructed, it is validated against other instruments. This was not possible in the present case, as there were no instruments that could be used for the validation. However, there were isolated relevant items in previous instruments, and these were taken as a starting point for posing questions in the interviews. The items generated on this basis were included with other items in the scales, and these were checked for their inter-correlations in the analyses of internal consistency. This is a first step towards testing whether the new items can be used to assess the children's adjustment and compliance.

The second aim is to use these new measures, to test the hypothesis of an association between children's socio-emotional adjustment to the illness and their treatment adherence. Previous research found a connection between socio-emotional functioning and treatment adherence (e.g. Pretzlik, 1997) and this study will investigate this relationship further.

As will be shown in the literature review, the predominant design in the search for associations between variables so far has been cross-sectional (e.g. Peds QoL, Varni et al, 2003 and 2004; Exeter QoL Scale by Eiser, Vance, & Seamark, 1999; Perceived illness Experience Scale, Eiser, Havermans, Craft, & Kernahan, 1995). This is most certainly due to the fact that such studies are still at an exploratory phase: They involve both the development of new measures and the analysis of the associations between them. This study adopted a cross-sectional design for the same reasons: The level of investment required for a longitudinal study, which could go beyond finding associations to identify possible causal connections, can only be justified when more established measures are available.

The research strategy of this study consists of four inter-linked studies. Study 1 and study 3 were separate but parallel studies. Study 1 involved interviewing a group of children with asthma and study 3 a group of children with diabetes and their parents about the children's experiences and feelings about having a chronic illness. Children and parents were seen as content experts whose views would provide the starting point in the search for items for a scale measuring children's socio-emotional adjustment to the illness. Stewart, Lynn, and Mishel (2005) consider this a "promising method for developing valid children's self-report measures" (p. 414). Some researchers have successfully used such interviews for this purpose and paved the way for moving from qualitative research to quantitative measurement with adults and children. In doing so they have established the legitimacy for this approach to a certain extent (e.g. Stewart, 2003; Tilden, Nelson, & May, 1990; Varni, Katz, Colegrove, & Dolgin, 1995). In this thesis in the interviews parents and children were asked about how they perceived the illness and how the child reacted emotionally to illness-related stressors. Roberts pointed out that it is "important to understand individuals within their social contexts, including their involvement with peers, school, and the health care team" (Roberts, 2003, p.310). Hence the interview schedule also assessed the child's adjustment in the family, in medical environments and at school. In this phase paediatric nurses were also interviewed about the child's adjustment in order to gain crucial information from a health professional's perspective i.e. how the illness affects the child's life and factors that may affect treatment adherence.

On the basis of qualitative analyses of the children's, parents', and nurses' replies to the interviews, study 1 (children with asthma) and study 3 (children with diabetes) led to the development of the new questionnaires to assess children's adjustment to the illness. Studies 2 and 4 reported the results of quantitative analyses of the responses by a larger number of children (n=60) and parents to determine reliability, and content validity.

Finally, the association between children's socio-emotional functioning and treatment adherence in this sample was investigated.

In Study 5 construct validity was investigated by means of a factor analysis of the child and parent questionnaires. Specifically, it was explored whether child adjustment consisted of a single underlying factor or multiple factors.

The chapter that follows consists of a review of the literature on children's adjustment to chronic illness and research conducted on children's adherence with their treatment regimen.

This is then followed by a chapter about the rationale and research strategy of this thesis (Chapter 3) outlining the organisation of the remaining chapters.

CHAPTER 2

LITERATURE REVIEW

2.1 Children's Adjustment to Chronic Illness and Treatment Adherence

The first aim of the following review was to report on research conducted in the area of the prevalence and severity of socio-emotional adjustment problems in children with chronic illnesses focusing in particular on children with asthma and diabetes. The survival rate of children with many chronic childhood diseases has improved remarkably over the last 20 to 30 years with about 80% of these children surviving into adulthood (Geist, Grdisa, & Otley, 2003). These medical advances resulted in a greater need for understanding the psychological development of these children as they master the normal developmental tasks of childhood while at the same time having to cope with the long-term demands and responsibilities associated with their illness. Therefore an important focus of study has been the examination of chronically ill children as a population at risk for the development of behavioural disorders indicating adjustment difficulties due to the significant stresses associated with having a chronic illness. The literature in this review was analysed in two ways. Firstly, results were reported from epidemiological studies i.e. large scale studies exploring a population of children in a particular region as well as findings of clinical studies focusing specifically on children with asthma or diabetes.

Secondly, research was reported exploring correlates of socio-emotional adjustment of these children i.e. aiming at identifying risk factors that might cause maladjustment. The review then continued by describing the shift from utilising traditional outcome measures to evaluate psychosocial functioning to focusing on Quality of Life measures in order to assess children's adjustment to chronic illness.

The second aim of this review was to report on existing instruments measuring treatment adherence behaviours for use with children with chronic illnesses. Previous research indicated that there might be a possible connection between children's adjustment to their illness and how this affects their disease management i.e. treatment adherence.

The following literature review was divided into two main parts. The first part reviewed research on children's adjustment to chronic illness. Specifically, studies were reviewed which investigated if children with chronic illness were at increased risk for adjustment difficulties and the methods utilized to measure adjustment.

The second part of the literature review showed how adjustment might be associated with treatment adherence. It continues by describing how treatment adherence has been assessed in children with chronic diseases and issues of measurement.

2.2 Children's Adjustment to Chronic Illness

There have been numerous studies exploring psychological adjustment in chronically ill children.

However, as in many research areas, there are fundamental assumptions and sometimes lack of clarity about key terms and concepts, and this field is no exception. Researchers variously refer to adjustment, adaptation and psychological functioning, without necessarily clarifying their differences and similarities. The way in which the concept to be investigated is defined should relate to its theoretical origins and subsequently the choice of methodology and measures. For example, in this field, studies that conceptualise adjustment or maladjustment in terms of degrees of depression, anxiety or self-esteem would use measures reflecting these.

In the context of chronic illness, we understand adjustment to be the psychological and behavioural response of an individual or family to the internal and external stressors associated with the illness experience, which will be influenced by their coping skills and resources. Adaptation is similarly and widely understood to be the degree to which children cope psychologically, socially and physiologically with the chronic illness. The meanings of the terms are therefore very similar, and studies that refer to either have been included. There are also some studies that do not specifically mention adjustment or adaptation, but this can be explicitly or implicitly inferred from combinations of other measures, such as psychosocial problems, behavioural disorders, abnormal behavioural symptoms, emotional functioning etc., and are therefore included as well.

Research studies in the area of children with chronic illness reflect primarily the following two research strategies: 1) epidemiological and 2) clinical studies. Epidemiological studies are large-scale studies of a population of children in a particular region, while clinical studies are small scale studies exploring children with single conditions or pooled disease groups (Wallander & Thompson, 1995).

2.2.1 Epidemiological Studies

Pless and Roghmann (1971) were among the first to report poorer psychological adjustment in chronically ill children compared to the general population. They investigated psychological consequences of chronic illness in children by reviewing three epidemiological studies. Amongst them were the UK National Survey of Health and Development (Douglas & Bloomfield, 1958) and the Isle of Wight study (Rutter, Tizard, & Whitmore, 1970), which compared chronically ill children with randomly selected healthy children, and the Rochester Child Health Survey (Roghmann & Haggerty, 1970), which compared chronically ill children with a matched control group of healthy children.

In the Isle of Wight study psychological functioning in every child was assessed by a psychiatrist, parents, and teachers who all completed rating scales. In the UK National Survey the assessment included a behavioural symptom questionnaire, which was filled in by the children, the parents, and the teachers. In the Rochester Child Health Survey, children completed a number of psychological tests, parents provided information about emotional symptoms and additional information was gained from teachers, and peers. Each of these studies found a higher number of psychological adjustment problems in chronically ill children in comparison to their healthy peers. In the Isle of Wright study, psychiatric disorder came to 17% in children with chronic disease compared to 7% in the healthy sample and results from parents' and teachers' ratings showed elevated rates of deviant scores. The UK National Survey found that 25% of chronically ill children had two or more behavioural symptoms compared to only 17% in the healthy sample. Teacher ratings of nervous and aggressive behaviour revealed that deviant scores in chronically ill children were 39% compared to 31% in the group of healthy children. Findings from the Rochester Survey showed that 23% of chronically ill children between the ages of six and ten years of age had two or more abnormal behavioural symptoms compared to 16% of healthy children in the same age group. In the 11 to 15 year-old age group 30% of chronically ill children showed two or more abnormal behavioural symptoms compared to 13% in the healthy sample. This study as well as the UK National Survey also found that chronically ill children had more social adjustment difficulties as well as problems at school compared to their healthy peers. Lastly, there were differences found between children with different types of chronic illness. Children with sensory disorders showed the highest rates of abnormal behavioural symptoms. Based on these findings Pless and Roghmann (1971) concluded that 30% of children who develop a chronic disease before the age of 15 were anticipated to experience some form of secondary psychological adjustment difficulties.

Another epidemiological survey was the Ontario Child Health Study (OCHS; Cadman, Boyle, Szatmari, & Offord, 1987), which included a sample of 3294 children between the ages of 4 and 16 years drawn from a general community in the Province of Ontario (Canada). The study investigated the relationship between chronic illness, medical condition, and long-term behavioural and emotional functioning and social adjustment in children. The Survey Diagnostic Instrument (SDI) was used as a mental health measure and included items from the Child Behaviour Checklist (CBCL, Achenbach & Edelbrock, 1983). Modifications were made which enabled the classification of all children into psychiatric diagnostic categories based on the third edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-III) including neurotic disorder (overanxious disorder, depression, and obsessive-compulsive disorder), conduct disorder, and attention deficit hyperactivity disorder (ADHD). SDI data for each child were obtained from parents for all children in the 4- to 16-year-old age range, through child self-reports for children between 12 and 16 years of age, and teacher reports for children between 4 and 11 years of age. The chronic diseases of the children included total blindness, visual problems even with glasses, deafness or other hearing problems, absence of speech or other speech problems, persistent moderate or severe pain, asthma, heart problems, epilepsy or convulsions without fever, kidney disease, arthritis, cerebral palsy or other paralysis, muscular dystrophy or other muscle disease, spina bifida, diabetes, cancer, cystic fibrosis, missing limbs, physical deformities, and other health problems of comparable severity and chronicity. Children were classified into one of three levels of physical health: (1) chronic illness with (one or more) disability (n=110), (2) chronic illness without disability (n=418), and (3) physically healthy (n=2766). It was found that chronically ill children with disability had a 3.4 times higher risk for psychiatric disorder compared to healthy children and 31% of these children had at least one psychiatric disorder. Chronically ill children without disability had a 2.1 times higher risk for psychiatric disorder compared to their healthy peers and 22% of them had at least one psychiatric disorder compared to only 14% in the healthy sample of children. Amongst the most frequent disorders were neurotic disorders and ADHD, particularly in the sample of chronically ill children with disability. Chronically ill children with disability were also at greater risk for social adjustment problems, whereas chronically ill children without disability were only slightly more likely to have adjustment difficulties compared to their healthy peers. Lastly, school difficulties were more prevalent among children with chronic illness and disability. A shortcoming of this study was that it did not control for SES of the children.

Gortmaker, Walker, Weitzman, & Sobol (1990) also conducted an epidemiological study using data from the 1981 National Health Survey and Child Health Supplement to investigate if children and adolescents with chronic health conditions are at greater risk for behavioural problems. The data consisted of parents' reports of behaviour problems from a nationally representative sample of 11699 children and adolescents between 4 and 17 years of age in the US. The Behaviour Problem Index (BPI; Peterson & Zill, 1986) was administered to parents to measure behaviour problems, which was adapted from the Child Behaviour Checklist (CBCL, Achenbach & Edelbrock, 1983) but is a much shorter version. The BPI consists of the following subscales: headstrong, antisocial behaviour, anxious/depressed mood, hyperactive behaviour, peer conflict/social withdrawal, and immature dependency (the last subscale was for children between 4 and 11 years of age only). Chronic health conditions were assessed on the basis of a 59-item chronic health condition checklist containing 19 chronic condition categories (arthritis, asthma, blindness, cancer, cardiac diseases, cerebral palsy, cystic fibrosis, deafness, deformed body parts, diabetes, cleft palate, harelip, epilepsy, gastrointestinal colitis or ulcer, hearing problems, missing body parts, curvature of spine, clubfoot, paralysis, sickle cell anaemia, vision problems). In order to control for the possible confounding variable of socio-economic status (SES), they also assessed socio-demographic variables of the child's family. The results confirmed that children with chronic health conditions were at significant risk for behavioural problems independent of their SES. Extreme behaviour problems were 1.55 times more likely in children and adolescents with chronic health conditions compared to healthy children. The chronically ill sample mainly showed internalizing difficulties such as anxiety or depression and social adjustment problems such as peer conflict or social withdrawal. Additionally these children were more at risk for school/ academic difficulties (placement in special schools, having to repeat a grade, and being expelled or suspended).

2.2.2 Conclusion

In summary, Pless and Roghmann (1971) on the basis of a review of three epidemiological studies concluded that 30% of chronically ill children who develop the disease before the age of 15 years showed behavioural adjustment problems. The Ontario Child Health Study (Cadman et al., 1987) found that chronically ill children without disability had a 2.1 times higher risk for psychiatric disorder compared to their healthy peers. Finally, Gortmaker et al. (1990) uncovered that children with chronic health conditions were at 1.55 times higher risk for behavioural problems independent of their SES compared to healthy children. Taken together, the above results from epidemiological studies convincingly revealed that children with chronic diseases were at increased risk for adjustment difficulties. The findings provided strong evidence for an association between chronic health illness and adjustment difficulties or mental health problems especially in the areas of emotional and behavioural adjustment, social adjustment amongst peers, and academic adjustment. However, even though the prevalence of maladjustment in chronically ill children was higher, the findings indicated that this was not the most common outcome i.e. only a minority of children showed adjustment problems.

Therefore, children with chronic illness constitute a group vulnerable for adjustment problems and at risk due to the additional stresses associated with a chronic illness.

2.2.3 Clinical Studies

Clinical studies explore psychological adjustment in chronically ill children on the bases of clinic-based samples i.e. a sample of paediatric patients with a single disease or a pooled illness group that is compared to a control group of healthy children or normative data representing a healthy population. A different method that has been utilised in previous research to explore the adjustment of children with chronic diseases is to compare findings across a large quantity of studies by utilising meta-analytic approaches. Meta-analysis is a technique for summarizing a research literature by using established quantitative methods. This section will be divided into 1) findings from meta-analyses on children with various chronic illnesses and 2) findings from clinic-based samples of children with asthma or diabetes.

2.2.3.1 Meta Analyses

Lavigne and Faier-Routman (1992) conducted a meta-analytic review on the adjustment of children with asthma or diabetes and numerous other physical disorders. They selected 87 studies from over 700 published articles between 1928 and 1990 that included some form of comparison group and a quantifiable outcome measure of overall adjustment. Studies to be included had to meet the criteria of 1) studying a sample of children or adolescents with a specific chronic physical disorder or a sample of children with identified chronic physical disorders that have been "pooled" together for data analysis, 2) including a quantifiable outcome measure of overall adjustment such as interviews or behavioural and emotional measures or else measures of child self-concept, and 3) containing data that enabled the calculation of effect sizes through comparison with a control group or normative data. Other dimensions of adjustment like school adjustment were excluded as they were beyond the scope of the study. Also social functioning was not included as there were not enough studies assessing this outcome dimension. The results showed that effect sizes were significantly different from zero, indicating that children with physical disorder have greater total adjustment problems and internalizing and externalizing difficulties as well as lower levels of self-esteem. These findings were independent of whether comparisons were made against within-study controls or normative data. Irrespective of how adjustment was operationalized, it was found that on average twice the number of chronically ill children exhibited adjustment difficulties compared to healthy children.

Another meta-analysis was conducted by Bennett (1994), who explicitly focused on depressive symptoms and diagnosis, which represents one form of internalizing problem in children and adolescents with either asthma or diabetes or other chronic medical conditions. The meta-analysis, which included 46 studies, confirmed that chronically ill children showed higher ratings of depressive symptoms with the difference being 0.27 standard deviations above the mean of healthy controls. However, when reviewing 18 studies that used diagnostic interviews to measure depression i.e. major depressive disorder or dysthymia, the median prevalence rate across studies was 9% compared to 1-5% generally reported for samples of children from the community (Fleming &

Offord, 1990). This finding indicates that while chronically ill children constitute a population that is at a somewhat higher risk for depressive symptoms, the majority of them appear not to be clinically depressed. This result suggests that there are significant within-group variations i.e. individual differences in response to the illness. Therefore, there might be a diversity of factors that increase the risk of psychopathology or on the contrary have a protective effect on the adjustment of children with chronic illnesses. Thus, the identification of factors that contribute to the psychological morbidity associated with chronic illness is of utmost importance.

It was also found that although there were only a few studies on any given disorder, there was evidence of greater risk for depressive symptoms in some diseases relative to others. Children with asthma, recurrent abdominal pain, and sickle cell anaemia showed to be at higher risk for depressive symptoms than children with cancer, cystic fibrosis, and diabetes.

McQuaid, Kopel, and Nassau (2001) carried out a meta-analysis focusing on behavioural adjustment in children with asthma. In particular, this meta-analysis investigated whether asthmatic children were at a higher risk for behavioural adjustment difficulties. It was also explored whether adjustment difficulties were mainly in the internalizing domain and the degree to which disease severity was associated with behavioural adjustment difficulties. The search only included research published after 1975 and inclusion criteria were the following: 1) studies that contained a sample of children and/or adolescents with asthma, 2) utilized a method of quantifying child adjustment that had established reliability and validity, 3) reported statistics that allowed for calculating effect sizes through comparison with either a control group or normative data. In total 78 studies were reviewed from which 26 were included reflecting data on 4923 asthmatic children between 4 and 9 years of age. In order to compare the results across studies, effect size estimates were calculated using standard methods. Overall, the results showed that children with asthma had more adjustment problems relative to a reference group with the difference being around one half to two-thirds of a standard deviation. Children with asthma had more internalizing and externalizing problems compared to controls or norms. Furthermore, adjustment difficulties increased as disease severity increased. Internalizing problems increased with increasing disease severity with the same trend for externalizing problems but with a smaller difference. Therefore, it is possible that children with mild asthma have slight or no adjustment problems compared to controls and norms, whereas children with moderate or severe asthma are at higher risk for adjustment difficulties and may require psychosocial intervention.

Lastly and briefly mentioned is a recent study by Barlow and Ellard (2006) who summarised the findings of the current literature on the psychosocial well-being of chronically ill children by reviewing meta-analyses, systematic reviews, and overviews based on traditional reviews of the published literature. They showed that findings from single studies and traditional reviews found mixed results whereas findings from studies utilising a more methodologically rigorous technique as in the case of meta-analysis consistently showed that chronically ill children were at more risk for psychological distress. However, the number of children who fell within the range of clinically significant psychological or psychiatric disorders was small.

2.2.3.2 Findings from Clinic-Based Samples of Children with Asthma or Diabetes

Nassau and Drotar (1995) compared social competence in peer relations in 25 children with IDDM, 19 asthmatic and 24 physically healthy children. Social competence included three domains: social adjustment assessed by Taxonomy of Problematic Situations (TOPS; Dodge, McClaskey, & Feldman, 1985), social performance measured on the basis of the Friendship Questionnaire (FQ; Bierman & McCauley, 1987) and social skills which was determined on the basis of the Children's Self-Efficacy for Peer Interaction Scale (CSPI; Wheeler & Ladd, 1982). Information on social competence was obtained from the children themselves, their primary caretakers, and their primary teachers. It was found that children with IDDM and asthma did not differ on any of the three social competences in peer relation measures.

Kashani, Konig, Sheppard, Wilfley, and Morris (1988) examined the adjustment of 56 asthmatic children between 7 and 16 years of age by comparing them to 56 control children with no chronic medical condition matched for age, race, and sex. Children were assessed on the basis of the Diagnostic Interview for Children and Adolescents (DICA; Herjanic, Herjanic, Brown, & Wheatt, 1975) and the parents on the basis of the Diagnostic Interview for Children and Adolescents – Parent Version (DICA-P; Herjanic & Reich, 1982) to determine the presence or absence of psychiatric diagnoses in the children. They also completed the Child Behaviour Checklist (CBCL; Achenbach & Edelbrock, 1979), the Hopelessness Scale (Kazdin, French, Unis, & Esveldt-Dawson, 1983), and the Piers-Harris Children's Self-Concept Scale (Piers, 1969). According to children's reports there was no significant difference between asthmatic children and the control group in the diagnostic interview, the type of diagnosis obtained, helplessness and self-concept. However, parents' reports revealed that asthmatic children compared to control children displayed significantly ($t(110) = 1.95$, $p<.05$) more psychiatric symptoms. Results of the CBCL completed by the parents also showed that asthmatic children have more internalizing and externalizing behaviour problems.

Hammlett, Pellegrini and Katz (1992) investigated amongst other variables psychological adjustment of children with asthma and diabetes. The sample consisted of 30 mothers of children with asthma or diabetes and 30 mothers of same-aged physically healthy children. Children's psychological adjustment was assessed on the basis of the behaviour problem items of the Child Behaviour Checklist (CBCL; Achenbach & Edelbrock, 1979). Mothers of asthmatic children reported significantly more internalizing problems in their children than in the healthy group.

McLean, Perrin, Gortmaker, and Pierre (1992) also reported that children with asthma were at greater risk for poor psychological adjustment. The study assessed the adjustment of 81 children with asthma between 6 and 14 years of age and explored the impact of background variables (age, gender, SES), recent stressful life events and illness severity. Children's psychological adjustment was measured on the basis of the Child Behaviour Checklist (CBCL; Achenbach & Edelbrock, 1983) and their perceived stress on the basis of the Life Events Checklist (Johnson & McCutcheon, 1980). Poor adjustment was found in 11.5% of the children who scored above the 98th percentile which was directly related if the asthma was severe and was compounded by low socioeconomic status and the occurrence of negative life events.

The above studies demonstrate varying estimates of the prevalence of psychological problems, which might be due to different measurement approaches. In the Hamlett et al. (1992) and MacLean et al. (1992) studies results showed more psychological difficulties in children with asthma compared to health controls. However, the children's data derived primarily from parent reports. Also, when differences were found (Kashani et al., 1988), the problems reported were generally minimal and fell in the range between normal behaviour and diagnosable disorder.

Taking these points into account, Klinnert, McQuaid, McCormick, Adinoff, and Bryant (2000) looked into the behavioural adjustment and emotion regulation in a sample of 81 children with asthma and 22 healthy controls (aged between six and seven years). Parents completed the Child Behaviour Checklist (CBCL; Achenbach, 1991) and children the Semi-structured Clinical Interview for Children and Adolescents (SCICA; McConaughy & Achenbach, 1994) to assess the child's behavioural functioning. To determine emotion regulation, parents and children were assessed by the System for Coding Affect Regulation in the Family (SCARF; Lindahl, Clements, & Markman, 1993) measuring child behaviour and parent-child interaction during a challenging or frustrating experience. Mothers of asthmatic children reported significantly more total behaviour and internalizing problems. There were no significant differences between the two groups for emotion regulation.

Additionally, there is research indicating that children with more severe asthma evidence more behaviour difficulties in comparison with children with milder forms of the disease (Klinnert, McQuaid, McCormick, Adinoff, & Bryant, 2000; Wamboldt, Fritz, Mansell, McQuaid, & Klein, 1998; McLean, Perrin, Gortmaker, & Pierre, 1992). However also in this respect, findings are inconsistent as there is also research showing that severity of asthma appears to be unrelated to psychiatric problems (Kashani et al., 1988). One plausible explanation for the differences in findings might be due to the fact that different studies used different methods to diagnose asthma severity i.e. there is no uniformity amongst researchers as to how classifications of severity are made. Consequently, it is impossible to compare results across studies using different methods for defining asthma severity.

Similarly, the literature is not consistent regarding children's adjustment to diabetes. Johnson's (1995) review uncovered that children with IDDM showed patterns of general psychological adjustment that were similar to those of their healthy peers.

Even though stressors associated with the disease do not necessarily threaten the psychological adjustment of patients it is important to recognize that there are cases which result in clinically significant psychological or psychiatric disorders. Kovacs, Goldston, Obrosky, and Bonar (1997) investigated prevalence rates, associated features, and risk factors for psychiatric disorders in youths with IDDM. They examined a sample of 92 youths with newly diagnosed IDDM between the ages of 8 and 13 years of age longitudinally from diagnosis for a median interval of nine years. They focused on psychiatric disorders that began after the onset of IDDM and therefore were secondary to the medical condition. Patients' psychiatric status was assessed on the basis of The Interview Schedule for Children and Adolescents (ISCA; Kovacs, 1985), and patients and parents were assessed several times a year in the beginning and then once a year for a nine-year period. The results showed that by the 10th year after the diagnosis with IDDM, an estimate of 47.6% of patients developed at least one episode of psychiatric disorder, which could be grouped into the broad categories of depressive, anxiety, and behaviour disorder. Major depression was the most prevalent disorder with approximately 27.5% of youths experiencing at least one episode of major depression by the 10th year after the diagnoses of IDDM. During the first year after diagnosis of IDDM was the highest incidence rate of psychiatric disorder.

Although these findings from clinic-based samples of children with asthma or diabetes show that children with asthma adapt to the stressors associated with asthma without developing significant psychological difficulties one should consider the following example of Jimmy, a 10-year-old boy with severe asthma who struggles with his anxiety concerning asthma attacks. Several months ago, he had experienced a particularly severe attack that required hospitalization. Since that time, his anxieties have increased, which have interfered with the management of his asthma. For example, he has begun to panic at the first sign of symptoms. In addition, he has limited his activities outside his home because he wanted to make sure his mother is available to help him with his symptoms. Children like Jimmy are not unusual and have to be identified as they are in need of intervention (Drotar, 2006).

2.2.3.3 Conclusion

The findings based on meta-analyses of children with a range of chronic disorders and clinic-based samples of children with asthma or diabetes once again reinforce the conclusion that children with asthma or diabetes or other chronic physical conditions constitute a group vulnerable for behavioural and emotional adjustment difficulties. Specifically, it was found that these children are at increased risk for internalising problems or a combination of both internalising as well as externalising difficulties.

Lastly, all the above clinic-based studies were comparing a group of chronically ill children to a group of healthy children or existing normative data, which allows for exploring possible differences in adjustment between both groups. However, this type of study does not provide any information on within-group differences i.e. variations in adjustment among children with asthma or diabetes.

2.3 Correlates of Adjustment

As can be seen from the above findings, there is considerable variability in the adjustment of chronically ill children. In order to acquire a better understanding of adjustment and to develop interventions, researchers attempted to identify correlates of adjustment. Lavigne and Faier-Routman (1993) carried out a meta-analysis to integrate findings on correlates and factors that mediate or moderate the adjustment of children with asthma or diabetes or various other physical disorders. They reviewed over 700 articles but only 38 met the criteria to be included in the review. The criteria were the following: 1) studies that comprised of a sample of children or adolescents with a specific chronic illness or a sample that has been pooled for data analysis, 2) studies that investigated a risk or resistance factor in connection with a quantifiable outcome measure, 3) studies that contained a quantifiable outcome measure of overall adjustment based on interview or questionnaire data. The following sets of variables were explored: 1) Disease/disability variables which included severity, poor appearance, increasing duration, poor prognosis or instability of disease course, and diminished functional status, 2) Parent/ Family variables which comprised of maternal and paternal adjustment, marital/ family adjustment or conflict, and family support or cohesiveness, 3) Stress variables which contained ratings of life stress and negative life events, and socioeconomic status (SES), 4) Child Psychological variables which included self-concept, difficult temperament, poor coping, and low IQ, 5) "Other" variables which included the child's age and gender. Correlation analysis between sets of variables and child adjustment revealed that disease/disability variables, child variables, and family/parent variables were significantly different from zero, except stress variables. Furthermore, within each set correlations were explored for each individual variable. Results showed that within the disease/disability set, correlations with severity (.16), prognosis (.10), and functional status (.23) significantly correlated with child maladjustment. Within the parent/family set, maternal maladjustment (.40), marital/family adjustment (.21), and family support (.38) were all significantly correlated with child adjustment but paternal adjustment was not. Within the stress set, increased life stress (.25) was significantly correlated with child maladjustment but SES was not. Within the child set, self-concept (.52), poor coping (.43) and, low IQ (.56) were significantly related to child maladjustment. Lastly, among the "other" variable age (.11) and sex (.49) were significant predictors of child adjustment: girls have less adjustment problems than boys. Generally, most of the correlations were low (.30 or lower) suggesting that the variables being investigated did not account for a great amount of variance in adjustment, but they were nevertheless in the anticipated direction. Overall, the findings of this meta-analysis highlight the importance of focusing more on life stress, parent/family variables, and child variables as it seems that these hold the best predictive ability in connection to child adjustment.

Another meta-analysis was conducted by Thompson and Gustafson (1996), which extended the results of Lavigne and Faier-Routman (1993) by including additional studies that explored one or more potential correlates of empirically assessed adjustment. The review focused on representative studies which were carried out within the past ten years. They concluded that there were many potential variables which could be correlates of the psychological adjustment of chronically ill children. However, specific variables have very frequently only been explored in one study and in instances where correlates have been studies in more than one study inconsistencies have been found across studies even when they applied the same child adjustment assessment. Thus, even though knowledge is limited the overall findings suggested that brain development, child reports of high levels of stress and low levels of self esteem, family functioning characterized as low in cohesion and supportiveness or high in conflict, and maternal distress were correlates of maladjustment in chronically ill children. Consequently they emphasised that there is a great need for future research to replicate findings. Particularly, the role of child parameters has to be studied further and the interrelationship among condition, child, and social-ecological parameters.

2.3.1 Conclusion

The meta-analysis by Lavigne and Faier-Routman (1993) found that there were a wide range of outcomes within and across studies suggesting that there were significant individual variations in response to the illness. Thompson and Gustafson (1996) confirmed that there were many potential variables that might correlate with adjustment but demonstrated inconsistencies in findings. This reinforces the conclusion that future research is needed in order to identify those factors that increase psychopathology as well as protective factors that contribute to the adjustment of children with chronic illness.

2.4 Quality of Life Assessments

Most of the above studies used the Child Behaviour Checklist (CBCL; Achenbach, 1983) and related instruments to measure psychosocial functioning in chronically ill children. However, as mentioned previously Perrin, Stein, and Drotar (1991) highlighted several key problems in using that scale with chronic paediatric samples as it was developed to detect behavioural problems in the general population. Firstly, the scale comprises of various items that refer to physical symptoms, for example “feels dizzy” which is a common symptom of hypoglycaemia in children with diabetes leading to children’s scores being elevated compared to healthy children, thus giving the impression that they encounter more psychological problems. Secondly, the CBCL was designed to identify psychopathology and consequently might have limited sensitivity to children with minor adjustment problems, which are in the normal range. However, minor adjustment problems can nonetheless pose a problem to these children and their families. Finally, in addition to behavioural and emotional problems, the CBCL assesses a child's "social competence", which might be very misleading in chronically ill paediatric populations. To assess "social competence" the scale assesses the child's participation in peer relationships, school, sports and other activities where chronically ill children are often restricted. It is therefore wrong to conclude that children with chronic diseases show less "global social competence" (Perrin, Stein, & Drotar, 1991).

On the basis of this criticism, given extent and range of physical and psychological effects reported, and the shifting epidemiology of childhood disease from acute to chronic and from incurable to palliative, researchers realised that traditional outcome measures focusing on depression, anxiety and other psychiatric disorders are no longer adequate. Existing measures are limited and do not capture the entire range of ways in which a chronically ill child may be affected by the illness or the treatment. In place of these approaches Quality of Life (QoL) became an emerging concept when exploring children's adjustment to their chronic illness, even though consensus has yet to be reached on definition of QoL. The concept of QoL can be divided into the narrower Health-Related Quality of Life (HRQoL) and general QoL (Wallander & Varni, 1996). HRQoL is characterised as being a multidimensional conception that incorporates functional status, psychological and social well-being, health awareness, and illness- and treatment-related symptoms. General QoL also includes in addition to the above the effects of the social environments (family, friends, school, etc.). It is argued that when studying chronically ill children one should consider their general QoL as it is important to understand these children not only on the basis of medical repercussions but as children in their social environment (Wallander & Varni). Thus, researchers became increasingly interested in measuring how far chronic illness and its treatment compromised the overall QoL of these children. The most commonly used definition of the concept of QoL is based on a number of key ideas. Firstly, is the belief that each individual has his own distinctive viewpoint on QoL, relying on lifestyle, past experiences, future hopes, and ambitions. Secondly, as the World Health Organisation (WHO) defines health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" QoL is conceptualized as a multidimensional construct including numerous domains. Thirdly, QoL comprises of objective as well as subjective perspectives in each of these domains with the objective measurement assessing what the person can do and the subjective evaluation embracing the individual's perception or appraisal of QoL (Eiser and Morse, 2001).

2.4.1 Measuring Quality of Life in Children with Asthma and Children with Diabetes

A review of the literature on how QoL in chronically ill children has been assessed shows that there are two general approaches: 1) generic QoL measures and 2) disease-specific QoL measures. Generic measures aim to be broadly applicable for disparate diseases and disease severities, across different medical and health interventions, and across demographic and cultural subgroups. Consequently they are utilized when comparisons have to be made for large groups of patients with diverse medical health conditions and backgrounds. Disease-specific measures on the other hand appraise QoL for a specific diagnostic group such as children with asthma or diabetes and are supposed to be more sensitive to changes within a homogenous group of patients (McSweeny & Creer, 1995). This section is divided into two parts. The first part reviews generic measures, which can be used to assess QoL in children with asthma or diabetes and other chronic medical conditions. This part is then followed by a review on disease-specific measures designed to asses QoL in children with asthma or diabetes.

2.4.1.1 Generic Measures of QoL

As mentioned previously generic measures allow for the comparison of QoL outcomes across diseases and disorders. This is particularly important when working with paediatric populations given the difficulty any one investigator typically encounters when attempting to obtain sufficiently large samples within specific disease populations. Second, generic measures are designed to assess all areas of childhood functioning most likely to be affected by an illness and its treatment and are thus more comprehensive.

The following section consists of a review of existing generic measures, which can be applied in the QoL assessment of children with asthma or diabetes and other chronic disease.

The RAND Health Status Measure for Children (HSMC; Eisen, Ware, Donald, & Brook, 1979) and the Functional Status-II-R (FR II-R; Stein & Jessop, 1990) are both generic measure of QoL for the use with children with asthma and diabetes and other chronic conditions. The HSMC is a questionnaire, which is completed by parents and assesses the following four core QoL domains: disease state, physical-, psychological-, and social functioning as well as general health perceptions and behaviour difficulties. The Functional Status-II-R is a parent interview assessing communication, mobility, mood, energy, play, sleep, eating, and toileting. However, both measures only rely on parent-reports.

A child-report measure was developed by Eiser, Vance, and Seamark (2000), the Exeter QoL scale (Exqol), which is a generic measure of QoL in children with diverse chronic conditions. The Exqol is computer delivered and suitable for self-completion for children between 6 and 12 years of age. The scale consists of 12 items which were developed on the basis of a literature review and the authors' clinical experience with children. The Exqol is based on the theoretical model that poorer QoL is the result of the discrepancy between what a person could do (actual self) and what they would like to be able to do (ideal self). This is in line with Calman's (1984) definition of QoL as being the "perceived differences between an individual's hopes and expectations and their present experience". Thus, the hypothesis is that the better the QoL of an individual the smaller the difference between a person's perceived current functioning and expectations for the future. In order to test the psychometric properties of the Exqol, the authors compared the scores of the Exqol of 58 children with asthma to 69 healthy children. Both children with asthma and healthy children were white and came from a wide range of social backgrounds. To test the validity of the Exqol children with asthma and their mothers completed the Childhood Asthma Questionnaire (CAQ, French, Christie, & West, 1994). Mothers of children with asthma also completed the Paediatric Asthma Caregiver's QoL Questionnaire (PACQLQ, Juniper et al., 1996), assessing caregivers QoL and the Child Vulnerability Scale (Forsyth, Horwitz, Leventhal, Burger, & Leaf, 1996), which is a measure of parental perceptions of their child's vulnerability to health problems. The results showed that children with asthma showed higher discrepancies indicating poorer QoL than healthy children ($p<.05$). Furthermore, the relationship between discrepancy scores and QoL (CAQ scores) was investigated by means of correlations. Significant correlations were found between discrepancy scores and the severity ($r_s=0.48$, $p<.001$) and distress ($r_s=0.31$, $p<.05$) subscale of the CAQ, supporting the view that discrepancy reveals QoL. Significant inverse correlations were found between children's ratings of asthma severity and actual self ($r_s=-0.61$, $p<.05$), indicating that those children who rated their asthma as more severe had lower actual self scores than children who rated their asthma as being less severe.

Eiser, Havermans, Craft, & Kernahan (1995) designed an assessment that includes both children's self-reports as well as a parallel version for parent reports. Specifically they developed a method to measure the child's perception of the illness experience (PIE), which is one aspect of the multidimensional concept of QoL. The authors claim that while PIE is acknowledged to be central in many definitions of QoL, it tends to be neglected in measurement instruments. The PIE Scale was developed on the basis of interviews with children, who were undergoing treatment for cancer or had recently completed treatment. The interview schedule contained questions asking the patient to recall their experiences at specific critical points of the illness (diagnosis, return to school, and completion of maintenance treatment). In total a set of 78 statements were derived and from these interviews and 34 were selected for the PIE Scale covering the following areas: physical appearance, interference with activity, peer rejection, integration in school, manipulation or use of the illness to avoid obligations, parental behaviour, disclosure of illness, preoccupation with illness, and impact of treatment. The respondent was asked to choose a reply on a 5-point Likert-type scale ranging from agree to disagree. Additionally a parallel parent version was developed asking parents to rate how they think the child perceives the illness. The sample consisted of 41 paediatric oncology patients and 35 of their parents. The scale showed adequate internal reliability and validity. Significant correlations between parent and children were found on all subscales except disclosure of illness and impact of treatment.

Eiser, Kopel, Cool, and Grimer (1999) conducted a study to report further reliability and validity for the PIE scale in a sample of children who were successfully treated by limb salvage procedures. To validate the child version of the PIE, it was assessed in relation to the Short Form 36 (SF-36, Jenkinson, Coulter, & Wright, 1993) a measure of general well-being and the Functional Evaluation of Reconstructive Procedures (Enneking, Dunham, Geghardt, Malawar, & Pitchard, 1993) a standard instrument for measuring outcome following limb-salvage surgery. Construct validity was shown by significant correlations obtained between the PIE and SF 36 and between three of the eight subscales of the PIE and the Functional Evaluation of Reconstructive Procedures. Results of the internal reliability of the PIE subscales showed that children's and parents' PIE data showed acceptable reliability except for the interference with activity subscale.

Briefly mentioned here was the TACQOL (Verrips et al., 1997) which was designed for children aged 7-17 years old. It has a child- and a parent-report version. However, it is a Dutch Quality of life measure and has not yet been formerly translated into English.

Overall, as much as generic measures are designed to assess all areas of functioning deemed to be directly affected by an illness and its treatment, they fail to tap specific restrictions and physical symptoms associated with a particular disease condition. For instance, in diabetes QoL might be affected by the need for daily injections or regular and frequent meals whereas other diseases are characterised by different restrictions. Thus, it is likely that disease-specific measures might be more useful (Eiser & Morse, 2001) as they allow the measurement of specific QoL issues (e.g. restrictions of treatment regimen), which are of importance for a specific medical illness. Additionally, disease-specific measures might help to highlight where interventions may be targeted optimally.

2.4.1.2 Specific Measures of QoL

As mentioned above disease-specific measures assess the QoL for a specific disease condition and are presumed to be more sensitive to variations within an illness group, allowing for the assessment of QoL issues of specific relevance to a certain medical illness. The following section reviews two QoL measures for diabetes and four of the most commonly used QoL assessments for asthma for use in paediatric populations.

2.4.1.2.1 Diabetes

The most widely used disease-specific measure for diabetes is the Diabetes Quality of Life Measure (DQL, DCCT Research Group, 1988), which assesses the following four rationally-derived subscales: 1) Satisfaction, 2) Impact, 3) Worry-Diabetes Related, and 4) Worry-Social Vocational. The scale consists of 46 core items and 13 additional items to utilize with adolescent populations. However, with the exception of a modified version for children between 11 and 15 years of age (Ingersoll & Marrero, 1991), and a modified version for young adults between 15 and 25 years of age (Eiser et al., 1992) the DQL has been mainly used in adult populations. Thus, the appropriateness of the DQL as an assessment instrument for children with IDDM needs to be clarified.

A further criticism of the DQL (Johnson & Perwien, 2001) is that it does not cover the typical domains addressed by QoL measures, which are illness and treatment-related symptoms, functional status, and psychological- and social functioning. Rather, four rationally-derived domains are assessed, which are satisfaction, impact, worry-diabetes related, and worry-social vocational, which complicates the matter of placing findings from the DQL within the context of the wider QoL research.

Another measure is the Pediatric Quality of Life Inventory (PedsQL) measurement model (PedsQL, Varni, Seid, & Rode, 1999), which was designed to integrate the merits of generic core scales and disease-specific modules into one measurement system. It was developed in the US for assessing health-related quality of life (HRQOL) non-categorically across healthy and paediatric patient populations. This first version (PedsQL 1.0) derived from a cancer database and was followed by versions 2.0 and 3.0 which incorporated further constructs and items. They also included a more sensitive scaling range and assessed a wider age range. This led to the development of the PedsQL 4.0 Generic Core Scales (Varni, Seid, & Kurtin, 2001), which resulted from this iterative process and assesses the physical, mental, and social health dimensions delineated by the World Health Organization (WHO) as well as school functioning. The PedsQL 4.0 Generic Core Scales comprises of a child self-report for ages 5-18 years and a parent proxy-report for ages 2-18 years. The items for both scales derived from the measurement properties of the child self-report scales with the parent proxy-report being constructed in a way that it directly parallels the child self-report by assessing parent's perceptions of their child's HRQOL. Thus both versions are fundamentally the same. It was developed on the basis of focus groups, cognitive interviews, pre-testing, and field testing measurement development protocols.

The child self-report format comprises of three versions – for children between 5 and 7 years, 8 and 12, and 13 and 18 years of age. The parent proxy report has four versions which are for parents of children between 2 and 4 years, 5 and 7, 8 and 12, and 13 and 18 years of age. The scale consists of 23 items measuring 1) physical functioning (8 items), emotional functioning (5 items), social functioning (5 items), and school functioning (5 items) with higher scores indicating better HRQOL. Children and parents rated how much of a problem each of the 23 items has been during the past 1 month and they are asked to select a response on a 5-point Likert scale ranging from "never a problem" to "almost always a problem". The child self-report version for children between 5 and 7 years of age is reworded and only has a 3-point response scale ranging from "not at all a problem" to "a lot of a problem". There is only a parent proxy-report for children between 2 and 4 years due to developmental limitations in self-reports in that age group.

Varni et al. (2001) explored the measurement properties of the PedsQL 4.0 Generic Core Scales by investigating their reliability and validity in a paediatric population of healthy- and acutely or chronically ill children and their parents. The sample consisted of 963 children between the ages 5 and 18 years of age and 1629 parents of children between the ages 2 and 18 years of age. The results showed that the internal consistency reliability of all self-report scales and proxy-report scales exceeded the minimum reliability standard of .70 (except school functioning of the self-report scale .68). The self-report and proxy-report of the Total Scale Score (α=.88, .90 respectively), the Physical Health Summary Score (α=.80, .88), and the Psychosocial Health Summary Score (α=.83, .86) reached acceptable levels for group comparisons. Construct validity was determined by means of the known-groups method. The PedsQL self-report and proxy-report differentiated between healthy children and children with acute or chronic health conditions with healthy children showing better HRQOL than the other two groups (p<.001). Secondly, construct validity was further examined by correlations between the PedsQL scales and indicators of morbidity and burden of illness. Finally construct validity was assessed by means of a multitrait-multimethod (MTMM) analysis of the PedsQL subscales and factors of the PedsQL items. MMTM presumes that heterotrait-monomethod correlations ought to be lower than monotrait-heteromethod correlations. It was found, as hypothesized, that self-report and proxy-report heterotrait-monomethod correlations were in the medium to large effect size range as well as parent/child concordance for the same subscale. This confirms the conceptualization of the PedsQL as assessing an integrated multidimensional construct. The factor analysis revealed a five factor solution for self-report and proxy-report accounting for 52% and 62% of the variance, correspondingly, which is on the whole consistent with the *a priori* conceptually-derived scales. To summarise, the PedsQL 4.0 Generic Core Scales are reliable and valid instruments to measure HRQOL in both healthy and paediatric patient populations. According to the knowledge of the authors it is the only generic measure of children's HRQOL that covers a wide age span of 2-18 years for self-report and proxy-report while maintaining item and scale construct consistency.

The PedsQL 4.0 Generic Core Scales distinguish between healthy children and paediatric patients with acute or chronic health conditions, and they have demonstrated sensitivity, responsiveness, and have had an impact on clinical decision-making (Varni et al., 2002; Varni, Seid, Knight, Uzark, & Szer, 2002). However, by comparing healthy and ill children the PedsQL 4.0 does not provide any information about variations in QoL within paediatric patient populations i.e. why do certain children with the same medical condition perceive their QoL as more positive than other children? Identifying both factors that affect QoL negatively and protective factors that affect QoL positively will enable researchers and health professionals to develop interventions for children in need.

This led Varni et al. (2003) adjusting the PedsQL 4.0 Generic Core Scales for use with diabetic children by integrating disease-specific HRQOL modules specifically tailored for paediatric diabetes. The Paediatric Quality of Life 3.0

Diabetes Module was developed, which measures disease-specific HRQOL for children with IDDM. The PedsQL 3.0 Type 1 Diabetes Module measure assesses the following five scales: diabetes symptoms (11 items), treatment barriers (4 items), treatment adherence (7 items), worry (3 items), and communication (3 items). It was developed on the basis of a literature review, patient and parent focus groups and individual focus interviews, item generation, cognitive interviewing, pre-testing, and subsequent field testing. The format, instructions, response scale and scoring are identical to the PedsQL 4.0 Generic Core Scales. Varni et al. (2003) explored the measurement properties of the PedsQL Generic Core Scales in type 1 and type 2 diabetes and of the Diabetes Module in type 1 diabetes. Both scales were administered to 300 children with type 1 or type 2 diabetes between the ages of 5 to 18 years and to 308 parents of children with type 1 or type 2 diabetes between 2 and 18 years of age. Half of the sample (154) came from white/non-Hispanic socio-cultural backgrounds, 83 from Hispanic/Latino backgrounds and the remainder was Black, Asian, American Indian and other. The data of the healthy sample for comparison was taken from a previous study (Varni et al., 2001) and was younger (mean age 12.2 versus 14.2 years) and represented fewer African-Americans and Asians and more Hispanics.

The PedsQL Generic Core Total Scale for both child and parent revealed internal consistency reliability with all scales exceeding α-coefficient standard of .70 (α = .88 for child self-report, 0.89 for parent proxy-report). Most PedsQL 3.0 Diabetes Module Scales also exceeded the minimum α-coefficient standard of .70 (average α = .71 for child self-report, .77 for parent proxy-report). Construct validity analysis of the PedsQL 4.0 Generic Core Scales showed that for child self-reports there was a significant difference between healthy children and diabetic children for all scales apart from physical- and social functioning. Parent proxy-report of healthy- and diabetic children differed significantly on all scales. Further analyses showed that children with type 1 diabetes reported significantly lower HRQOL than healthy children for all scales with the exception of physical- and social functioning. Children with type 2 diabetes demonstrated significantly lower HRQOL than healthy children for all scales but physical functioning. Parent proxy-reports of children with type 1 or type 2 diabetes reported significantly lower HRQOL than parents of healthy children with no significant difference between parents of children with type 1 or type 2 diabetes. Construct validity was also explored by analyzing inter-correlations between the PedsQL Generic Core Scales and the PedsQL 3.0 Diabetes Module Scales, which were in the medium to large effect size range. Finally it was investigated if HbA1C levels (index of average blood glucose levels, which is the most widely accepted measure of diabetes control) were related to HRQOL and correlations between the child self-report as well as the parents proxy-report generic core and diabetes scales and HbA1C levels showed small to medium effect sizes.

In the type 2 diabetes sample no significant difference was found between HbA1C and PedsQL for either child self-report or parent proxy-report.

Thus, overall it was found that the PedsQL Diabetes Module showed reliability and validity when applied as a child self-report and parent proxy-report assessment to measure HRQOL in diabetes.

However, when examining the content of the 28 items that make up the scale it becomes apparent that 21 of the items revolve around the treatment of the child. Eleven items assess diabetes symptoms, 7 items measure treatment adherence, and 3 of the 4 evaluate treatment barriers. Only one of the treatment barriers (whether child is being embarrassed about having diabetes), 3 items about worry and 3 items about communication problems actually assess the child's feelings and adjustment. Thus, the 21 treatment items constitute only an objective assessment of QoL by focusing what the patient is able to do, while only six items actually subjectively assess the patient's awareness or appraisal of QoL. However, when exploring a child's QoL or adjustment to the disease it is essential to determine/verify to which extent the disease and its medical treatment compromises the child's QoL. To illustrate this point further one should consider the following example. There are some diabetic children who love to eat sweets. These children feel very restricted and upset not being able to eat any sweets or only very little and consequently feel that the disease compromise their QoL in a negative way. Other diabetic children on the other hand might not like sweets that much and as a result would not feel that the disease affects their QoL. "Differences in appraisal account for the fact that individuals with the same objective health status can report very different subjective QoL" and therefore it is not enough to only assess objective factors.

2.4.1.2.2 Asthma

The Childhood Asthma Questionnaires (CAQs, Christie, French, Sowden, & West, 1993) is a disease specific QoL self-report measure for asthmatic children and consists of three versions to suit children of different ages. Form A is for use with children between 4 and 7 years, form B for 8 to 11 year-olds, and form C for 12 to 16-year-olds. The Scale comprises items assessing emotions (termed Distress) and activities (termed Active Quality of Living). In form B and C children also are assessed about symptoms (severity). The child is asked to rate the frequency of a particular activity or symptom on a four-point ordinal scale and then to rate how they feel on a five-point smiley scale to represent a very sad, through a neutral to a very happy face. Item content was derived through extensive focus group work with children and their parents and the subscale structure derived through factor analysis. Internal consistency is reported for each of the three forms separately and coefficients are normally in the acceptable range. Reproducibility is in the range of 0.68 to 0.84 in forms B and C but drops to 0.6 in form A (French, 2001).

Yet another measure is the Paediatric Asthma Quality of Life Questionnaire (PAQLQ, Juniper et al., 1996b), a self-report measure consisting of 23 items which assess a broad range of symptoms, emotions and activities. Juniper et al. (1997) reported satisfactory psychometric characteristics across a 7 to 17 years age range. However, the PAQLQ has been criticized on the grounds that it does not assess social domains and other psychosocial issues. Also, there is a lack of domains relevant for a particular target population as well as that it only covers the domains important to all age groups (Rutishauser, Sawyer, & Bowes, 1998). Even though the PAQLQ is a self-report measure, there are so far only reports when administered by a trained interviewer (French, 2001).

Only briefly mentioned here is The Life Activities Questionnaire for Childhood Asthma (Creer et al., 1993) as it assesses functioning in only one domain of QoL which is daily functioning.

The PedsQL 4.0 Generic Core Scales were also adjusted for use with asthmatic children by developing the Paediatric Quality of Life 3.0 Asthma Module (Varni, Burwinkle, Rapoff, Kamps, & Olson, 2004). The scale consists of 28 multidimensional items consisting of the following scales: asthma symptoms (11 items), treatment problems (11 items), worry (3 items), and communication (3 items). The Asthma Symptoms and Treatment Problems Scales were designed on the basis of focus groups, cognitive interviews, pre-testing, and field testing measurement development protocols (Varni, Seid, & Rode, 1999; Varni, Seid, & Kurtin, 2001). The Worry and Communication Scales were adapted from previous PedsQL disease-specific modules (Varni, Burwinkle, Katz, Meeske, & Dickinson, 2002a; Varni et al., 2002; Varni et al., 2003). The format, instructions, response scale and scoring are once again the same as for the PedsQL 4.0 Generic core Scales. Varni et al. (2004) conducted a study exploring the reliability, validity, and initial responsiveness of the newly developed scale and the PedsQL 4.0 Generic Core Scales. The following four hypotheses were raised: 1) that the PedsQL Generic Core Scales would be able to differentiate between healthy and asthmatic children, 2) that higher asthma disease-specific symptoms or difficulties would be associated with lower Generic Core Total Scale Scores i.e. worse/poorer HRQOL, 3) that the PedsQL 3.0 Asthma Module would significantly correlate with the Pediatric Asthma Quality of Life Questionnaire, which is a formerly standardized asthma disease-specific instrument, and 4) that the PedsQL would reveal initial responsiveness through patient transformation over time in a pilot intervention study. The sample consisted of 404 asthmatic children between 5 and 16 years of age and 526 parents of children, who completed the PedsQL 4.0 Generic Core Scales, the PedsQL 3.0 Asthma Module and the Pediatric Asthma Quality of Life Questionnaire (PAQOL). The data of the healthy sample were taken from a previous study (Varni et al., 2001) and 699 children were matched by age to the asthma sample and who only completed the PedsQL 4.0 Generic Core Scales. The authors stated that both the sample of children with asthma and the healthy sample were heterogeneous with respect to race/ethnicity but no detailed information was provided. Scale internal consistency reliability was established by calculating Cronbach's coefficient alpha. The self-report and proxy-report scales of the PedsQL 4.0 Generic Core Scales exceeded the minimum reliability standard of 0.70 except for the School Functioning Scales for children in the 2-7 year age group. It also approached or reached across ages an alpha of 0.90, which is recommended for individual patient analysis. The internal consistency reliability of the PedsQL 3.0 Asthma Module Scales exceeded the minimum alpha coefficient standard of 0.70 for the self-report in the 8-12 year age group for three of the four scales and all four scales of the proxy-report in the same age group. Construct validity for the PedsQL 4.0 Generic Core Scales was measured again by means of the known-groups method. It was found that for every comparison there was a difference that reached statistical significance between healthy and asthmatic children. Thus, the hypothesis was confirmed as healthy children demonstrated higher PedsQL 4.0 Generic Core Scales than asthmatic children. Construct validity for the PedsQL 3.0 Asthma Module was looked at by analyzing inter-correlations between the PedsQL 4.0 Generic Core Scales Score and the PedsQL 3.0 Asthma Module and it was found that they were in the medium to large effect size range. Construct validity was also tested through a modified multitrait-multimethod matrix by testing convergent validity. Convergent validity was explored through an analysis of the inter-correlations between the PedsQL Asthma Module Scales and the Pediatric Asthma Quality of Life Questionnaire subscales. The results showed that the PedsQL Asthma Symptom Scale correlated positively with the PAQOL Symptom Scale with a large effect size. Further, there was a positive correlation between the PedsQL Treatment Problems Scale and the PAQOL Symptom Scale also with a large effect size. Finally, there was also a positive correlation with a large effect between the PedsQL Worry Scale and the PAQOL Emotions Scale. The initial responsiveness of the PedsQL was determined through individual patient changes through time by means of a longitudinal analysis. The results showed that the Physical- and Psychological Health Summary Score of the PedsQL 4.0 Generic Core Scales for the self- and proxy-report revealed small to medium effect sizes. The Asthma Symptom Scale of the PedsQL 3.0 Asthma Module showed a medium effect size for the self-report and a small effect size for the proxy-report.

However, as with the Paediatric Quality of Life 3.0 Diabetes Module when examining the content of the 28 items that form the Paediatric Quality of Life 3.0 Asthma Module, it becomes apparent that 19 of the items revolve around the treatment of the child. Eleven items assess asthma symptoms and 8 of the 11 measure treatment problems. Only 3 of the 11 treatment problems items, 3 items about worry, and 3 items about communication problems actually assess the child's feelings and adjustment.

Thus, the same criticism applies namely that the majority of items make up an objective assessment of QoL while only a minority actually assess the patient's awareness or appraisal of QoL. To illustrate this point in the case of asthmatic children one should consider the following example. There are some asthmatic children who would love to run around endlessly. These children feel very restricted and upset not being able to be that physically active and consequently feel that the disease compromises their QoL in a negative way. Other children with asthma on the other hand might not want to be so active and as a result would feel that the disease affects their QoL to a lesser extent.

Lastly, Le Coq, Colland, Boeke, Bezemer and van Eijk (2000) developed the How Are You? (HAY) a self-report QoL questionnaire for eight-to-twelve-year-old children with asthma. The questionnaire contains both a generic and a disease-specific section. The generic section consists of 32 items covering four dimensions (1) physical activities, (2) cognitive activities, (3) social activities, and (4) physical complaints. Questions were asked about frequency of activities, quality of performance, and related feelings about experienced limitations. The disease-specific section comprises of 40 items and also includes four dimensions (1) asthma symptoms, (2) emotions related to asthma, (3) self-concept, and (4) self-management. In the context of the dimensions of asthma symptoms, self-management, and physical complaints, the child was asked about frequency of each item and the related feelings and for emotions and self-concept only frequency was assessed. The aim of their study was to validate the HAY and to assess the reproducibility and responsiveness. A sample of 228 children with asthma completed the HAY as well as the Child Attitude Toward Illness Scale (CATIS, Austin & Huberty, 1993), which assesses the attitude of children toward their asthma. Eighty of these children were assessed three times in order to determine reproducibility and responsiveness. A healthy sample of 296 children completed the generic section of the HAY. There was no information on the race/ethnicity of either sample (diabetic versus healthy). Construct validity of the HAY was assessed on the basis of a correlational analysis between scores of the HAY and CATIS which proved to be significant except for social functioning. Construct validity was further assessed by comparing the generic dimensions of children with asthma with those of the healthy sample. Children with asthma scored lower in the physical activities (p=0.0), social activities (p=0.0) and physical complaints domain (p=.06) but there was no difference in the cognitive activities domain between the two groups. Lastly construct validity was assessed by comparing the scores on all scales of asthmatic children between children with and without asthma symptoms. It was found that children without symptoms scored better on all dimensions than children with asthma symptoms. Responsiveness was demonstrated by significant score changes for all dimensions except for frequency of cognitive activities and self-management indicating that QoL scores changed when clinical status either improved or deteriorated. Finally, it was found that reproducibility was adequate.

2.4.1.3 Conclusion

There is a growing body of literature concerned with developing instruments to assess QoL in chronically ill children. It can be concluded however that all measures have certain limitations. As Eiser and Morse (2001) pointed out in their methodological review of QoL measures that are currently available there is much more research needed in this area. This is due to the psychological concept of QoL being a far more complex domain to measure than physical concepts such as height. They raised amongst others the issue that researchers focused on establishing the psychometric properties of a measure but have given much less attention to issues of content and face validity. In this context a central and crucial concern should be what children directly report about how they perceive the limitations imposed by the illness on their QoL and how they react to them. It will be important to identify variables concerning why some children react better than others i.e. which coping strategies help and which do not. Yet, their perceptions and direct reports are rarely taken into consideration. In this context Ravens-Sieberer and Bullinger (1998) stressed that a person's account about the patient's perception cannot be taken as a proxy, or equivalent information. It should be solely utilised as a separate source of information about the patient's well-being.

A study highlighting the importance of parental proxy reports was conducted by Anthony et al. (2003). In particular they explored the degree to which parental perceptions of child vulnerability predict school and social adjustment in children with rheumatologic and pulmonary diseases. They found that increased parental perceptions of child vulnerability were related to enhanced social anxiety in children. Thus, parental beliefs are an important source of information when assessing chronically ill children's adjustment.

Therefore, it is important that QoL assessments include parallel ratings by the child himself/herself and a proxy (e.g. parent) as information obtained from both will provide a more comprehensive picture.

Moreover, existing measures lack child-centred approaches to measure QoL as they generally rely on paper-and-pencil measures. Subsequently, there is a need to develop more effective methods for obtaining reliable information from children by making measures more attractive for them. The majority of children enjoy working with computers thus one future avenue of administering an assessment (e.g. questionnaire) could be by means of utilizing a lap-top and making the completion of an assessment like a game. In this context it is worth mentioning that assessments should have different developmentally appropriate forms so that both content and format are adjusted to suit children of different ages. For instance in very young children graphics of smiley or sad faces will aid understanding.

Lastly, Eiser and Morse (2001) also emphasized the importance of developing a brief assessment of QoL that can be completed during an outpatient clinic visit. Central to this idea should be that this measure is simple to administer and requires minimal training or expertise in order to recruit large samples of chronically ill children in a short time of space. Also the more concise the measure i.e. the quicker it takes to complete it, the less burden it will be for the children and caregivers.

A limitation of the studies reviewed in the area of children with chronic illness was that most studies did not analyse the impact of factors such as social class and racial composition on the results: many did not provide information on social class and ethnicity and those that did report these sample characteristics did not seek to control for these factors in the comparisons between groups. In some studies were samples of ill children were matched with samples of healthy children, the groups were not equally matched by race and age. For example in the study by Varni et al. (2003) in which The Paediatric Quality of Life 3.0 Diabetes Module was developed the healthy sample was younger than the sample of children with diabetes and there were numerous race/ethnic differences, which might have influenced the outcome. One study demonstrated race as a significant moderator between white and black children following traumatic brain injury (TBI) (Yeates, Taylor, Woodrome, Wade, Stancin & Drotar, 2002). Parent and family functioning was assessed after injury (baseline) and follow-ups were conducted 6- and 12- months later. For parents of black children the negative consequences of TBI were less prominent at baseline than for parents of white children but became more pronounced at the two follow-ups.

Thus, as socio-cultural factors associated with race moderated the effects of parents with children with TBI, there is a possibility that socio-cultural factors might also affect children's adjustment to chronic illnesses like asthma or diabetes.

In a meta-analysis of comparisons on overall adjustment between chronically ill children and healthy children, Lavigne and Faier-Routman (1992) reported that the type of control group used had an impact on the effect size. In the studies that used age, sex, SES and race as controls, means still differed significantly but the effect sizes where considerably smaller than in those studies which had not used SES and race as controls.

It is clear that the impact of SES and race in comparisons between ill and healthy children needs addressing in future research.

2.5 Treatment Adherence

In the paediatric literature the terms "compliance" and "adherence" are used interchangeably (e.g. Johnson, 1991, Roberts, 2003) and in essence have the same meaning. *The American Heritage Dictionary of the English Language* (Morris, 1982) defines adherence as "to follow without deviation". The most cited definition of medical compliance is "the extent to which a person's behaviour (in terms of taking medication, following diets, or executing life-style changes) coincides with medical or health advice" (Haynes, 1979, pp, 2-3). This definition identifies the physician's medical advice as the standard to which the patient's behaviour is compared. However, medical advice specified might be unclear, which makes it difficult for the patient to understand what constitutes compliant behaviour and even more difficult for health professionals to decide whether a patient is compliant or not (Johnson, 1991).

In childhood chronic illness, measuring adherence behaviours is even more difficult due to the complex treatment management regimes. For instance in childhood diabetes, the treatment regimen requires numerous daily behaviours in the area of insulin injections, glucose testing, diet, meal times, and exercise. The treatment regimen is made even more complex due to the relationship between regimen behaviours, such as the insulin injections which must be timed in relationship to meals. Not surprisingly, as mentioned previously this frequently leads to inadequate compliance with treatment regimens, which is a major problem in the management of paediatric chronic disease and can have serious consequences for the health of patients. Furthermore, since most research only takes account of paediatric patients who are actively involved in medical care (at least to the degree of requesting medical treatment), and are enthusiastic to participate in studies, rates of treatment compliance may not reflect the true scope of the problem (La Greca, 1988).

It is commonly assumed in the literature that chronically ill children's psychosocial functioning affects their disease management (Roberts, 2003). Research supporting this hypothesis showed that children who were highly compliant with their treatment regimen also showed higher levels of self-esteem (Littlefield et al., 1992), lower levels of anxiety and depression (Brownbridge & Fielding, 1994), and better individual coping assessed on the basis of three measures: locus of control, ratings of ego defence mechanisms, and ratings of adaptive strengths (Jacobson et al., 1990). Hence, positive adjustment was associated with better treatment compliance or vice versa. Equally the reverse pattern was found i.e. children who had difficulties in socio-emotional functioning also had problems with treatment adherence. Pretzlik (1997) found that children with cancer who were distressed during medical procedures (e.g., a blood test) also tended to avoid them. Lustman, Griffith, and Clouse (1996) found that depression in children with diabetes might hinder treatment adherence and treating it lowered blood sugar levels. Thus, children's quality of life is affected by how they cope with illness-related stressors and poor adherence is also, in some illnesses, related to high levels of stress. This section includes a review of the literature on research conducted in the area of developing instruments that measure treatment adherence in children with chronic illnesses.

2.5.1 Measures of Treatment Adherence

Czajkowski and Koocher (1986) developed the Medical Compliance Incomplete Stories Test (M-CIST), which is an assessment tool predicting medical compliance. It is based on a competency/coping skills model. It consists of five incomplete stories where the main character is confronted with a dilemma that involves a decision as to whether or not to follow specific medical advice. The child's task is to complete the story and hereby foretell the end for the main character in each story. Czajkowski and Koocher (1986) administered this test to a sample consisting of 40 cystic fibrosis (CF) inpatients between the ages of 13 and 23 years of age, who were about to undergo pulmonary clean-out, a routine treatment lasting 14 to 21 days. These data were then compared to objective measures of treatment compliance (assessing cooperation in daily participation in chest physical therapy, adhering to the recommended diet, taking all the prescribed daily oral medications and vitamins, recording daily inputs and outputs, and cooperative participation in recommended medical tests), which were obtained from medical staff members in charge for these patients. They were asked to pinpoint behaviours for which hospitalised CF patients tend to show non-compliance. From their replies, the authors selected those behaviours that the medical staff could reliably monitor on a daily basis. The results showed that the M-CIST was positively correlated with the objective assessment measure (multiple $R = .72$, $p < .01$) and also distinguished compliant from non-compliant patients.

In a further attempt to evaluate the usefulness of the M-CIST, Czajkowski and Koocher (1987) developed another two competency questionnaires, one for the patient and one for the medical staff, measuring the following coping behaviours. The patient questionnaire measured their own level of medical compliance and optimism, the severity of the illness, future goals, involvement in school or work, openness with peers about the illness, and the role they assumed in their own medical care. The staff questionnaire asked for an appraisal of the patient's compliance and optimism during current hospitalisation, and for an assessment of the severity of the patient's illness. A sample of 40 patients (ranging from 13 to 23 years of age) were administered the M-CIST and the patient questionnaire and the primary medical caregiver completed the staff questionnaire. All patients' data were again compared to an objective measure of treatment compliance. The findings once again showed that the M-CIST positively correlated with the objective compliance measures and significantly differentiated between compliant and non-compliant patients. Even though the coping behaviour assessments distinguished between compliant and non-compliant patients, it did not yield any additional power when used in combination with the M-CIST.

As previously the M-CIST had only been applied to a sample of adolescents with cystic fibrosis, D'Angelo, Woolf, Bessette, Rappaport, and Ciborowski (1992) administered it to 29 boys with haemophilia (mean age 14.2 years) aiming at exploring its predictive capabilities. In particular, the purpose of the study was to investigate possible associations between participants" M-CIST scores and ratings of medical adherence obtained from primary health care providers. These were based on the family compliance and functional status information published by the National Haemophilia Foundation (1981) and included health care provider's ratings from 1 to 4 (higher scores indicate better compliance) about the child's disease severity (number of bleeding episodes, the child's physical response to treatment, and the extent of orthopaedic impairment), child's attitude toward treatment to a bleeding episode, cooperation in learning about haemophilia, participation with medical tests, and compliance with preventive measures to minimise the incidence of bleeding episodes. In order to be able to evaluate possible influences on compliance ratings as well as M-CIST scores, patients also completed the Intellectual Achievement Responsibility Questionnaire (IARQ; Crandall, Katkovsky, Crandall, 1965), which is considered to be one of the best measures of child locus of control for assessing perceived self-responsibility for a performance-related outcome such as medical compliance (Phares, 1976). Mothers completed the Child Behavioural Checklist (CBCL; Achenbach, 1978), measuring of the child's overall behavioural functioning and social competence, and the Family Crisis Oriented Personal Scales (F-COPES; Mc Cubbin, 1981), assessing family coping attitudes toward crisis. Significant associations were found between the compliance sub-score of the M-CIST and the health care specialists' ratings of how well the children responded to bleeding episodes, accounting for 17.71% of the variance. This is a very important category of compliance, as a child's failure to seek medical help can be life-threatening. The remaining three sub-scores of the M-CIST (health optimism, self-efficacy, and total M-CIST score) did not correlate significantly with health care specialists' ratings. The authors concluded that the M-CIST is a promising assessment tool for measuring compliance among children with haemophilia. However, it has to be tested with other illness groups in order to show its potential usefulness in clinical practice.

Another adherence assessment is the Frazier Non-Compliance Inventory (FNI), which was developed by Frazier, Davis-Ali, and Dahl (1994). It consists of 11 items rated on a 5-point Likert scale (1 = very often to 5 = never) designed to assess how often patients do not take their medication for the following reasons: being away from home, misplacing medication bottles, feeling healthy, being busy with other things, running out of medication, believing that the medication is doing no good, simply forgetting, having too many pills to take, not having the money to buy medication, experiencing unpleasant side-effects from the medication, and being just plain sick of taking pills. The internal consistency has been reported to be good with an alpha coefficient of .90. However, the FNI has only been used in adult samples.

The only study applying the FNI with children was conducted by Tucker et al. (2001). Their aim was to predict medical compliance among ethnically different paediatric children and adolescents (26 African American and 42 Caucasian) with renal transplants in a sample of 6 to 20 year olds. They implemented multiple medication compliance measures due to the inconsistency found in adherence measures and adherence rates reported in the literature. The compliance measures included the Frazier Non-compliance Inventory (FNI), a self-report measure of overall medication adherence. The Primary Nephrologist's Adherence Rating Form (PNARF) was administered to the patient's nephrologist to rate the patient's level of overall medication compliance. Furthermore, the Pill Count/Refill History Form was administered, to find out and record patient' medication compliance based on the number of tablets, the Cyclosporine Level Rating Form, to record patient's most recent cyclosporine level, and the Self-Regulation of Medication Adherence Battery (SRMAAB), which is a self-regulation theory-based assessment battery for patients and consists of medication adherence motivation-, perceived control of medication adherence-, and perceived caregiver support of medication adherence questions; there is no psychometric data on that test. There were group differences in the significant predictors of medication adherence. For the African American group, motivation and perceived control questions that focused on self-efficacy significantly predicted medical compliance as rated by their primary nephrologists. For the Caucasian group, only one motivation question concerning how often they forget to take their medication predicted by the self-ratings of the FNI predicted medical compliance.

Even though the FNI predicted medical compliance in the Caucasian group, much more research is needed, especially with other chronically ill paediatric patient groups in order to determine the FNI capability to measure medical compliance, i.e. to assess how often patients do not take their medication.

Yet another treatment adherence measure was developed by Johnson, Silverstein, Rosenbloom, Carter, and Cunningham (1986). They modified the 24-hour recall interview, which is a self-report standard dietary assessment technique (Marquis, Ware, & Relles, 1979) in order to collect information on all diabetes management activities i.e. to assess general treatment adherence in diabetic children and adolescents. Participants were told that the purpose of the study was to obtain information about what patients and families normally do to manage diabetes. They interviewed 168 mother-patient pairs about the patient's diabetes management during the course of the previous day by reporting in chronological order. However, only behaviours that were related to the child's medical regimen were recorded. Each child and one parent were interviewed three times over a 2-week period. They assessed both child and mother separately, as information which was forgotten by one respondent might have been remembered by the other and combined these data as an adherence estimate. By using multiple informants, a reduction of memory errors was achieved, normally a primary error associated with this method. Parent – child agreement was used as an index of the reliability and validity of the technique.

On the basis of the participants' replies, 13 adherence behaviours were quantified, which included four injection measures (injection regularity, injection interval, injection-meal timing, regularity of injection-meal timing), five dietary measures (calories consumed, percentage of calories from fat, percentage of calories from carbohydrates, concentrated sweets, eating frequency), three exercise measures (exercise duration, exercise type, exercise frequency), and a glucose testing frequency measure. Each was constructed allowing a range of scores, higher scores indicating relative non-adherence and scores close to zero indicating relative adherence.

The results showed that all of the correlations between parent and child reports reached statistical significance ($p<.0001$), ranging from $r_s= .42$ to $r_s= .78$. Additionally, age played a significant role in daily diabetes management, with older children and adolescents (12-19 years) being significantly less compliant than their younger counterparts on 8 of the 13 adherence measures.

The authors postulated that adherence is generally perceived as a unitary trait, patients are labelled as compliant or non-compliant as if they are behaviourally consistent or inconsistent across all aspects of the treatment regimen. However, given the number and variety of treatment behaviours required, a multidimensional conceptualisation of compliance seems to be more appropriate. To explore this, the 13 different compliance behaviours were subjected to a principal component factor analysis. If adherence was indeed a unitary trait, this analysis should come up with a single factor. However, it resulted in a five-factor solution, accounting for over 70 % of the variance. The first factor consisted of all three exercise measures, and the second of all four injection measures. However, the dietary behaviours did not load on a single factor, but diet type (comprising of percent of calories consumed of carbohydrates and fat) made up the third factor, frequency of food consumption constituted the fourth factor, and calories consumed the fifth. On the basis of this finding the authors suggested a multivariate conceptualisation of compliance as more appropriate, specifically in the case of childhood diabetes.

Validity studies of the 24 hour recall telephone technique include a confirmatory factor analysis of the 13 adherence measures (Johnson, Tomer, Cunningham & Henretta; 1990), an examination of the relationship between diabetes adherence behaviours and various indices of diabetes control (Johnson, Freund, Silverstein, Hansen, & Malone, 1990; Spevack, Johnson, Riley, & Silverstein, 1991), a comparison of behavioural observations with 24 hour recall interview data (Reynolds, Johnson, & Silverstein; 1990), and an examination of the stability of adherence behaviours over a three month period using the 24 hour recall technique (Freund, Johnson, Silverstein, & Thomas; 1991).

In summary, the 24-hour recall interview when conducted with multiple informants on multiple occasions was shown to be a reliable method of assessing a wide range of diabetes adherence behaviours. The method attempted to minimise errors of memory, which is closely associated with recall interviews in two ways. Firstly, investigators emphasised recall of recent behaviours, that is yesterday, rather than behaviours that occurred a week ago or longer. Secondly, unlike in the usual recall interview procedure where data is obtained from a single informant, investigators interviewed both the child and mother.

The authors also suggest that even though the findings are most pertinent for children with IDDM, the 24-hour recall interview methodology could be adapted readily for use with children suffering from other chronic diseases.

2.5.2 Conclusion

One of the most difficult questions confronting paediatric researchers is how to measure treatment adherence in paediatric populations (La Greca, 1990), as measures are diverse and each has its advantages and limitations.

For instance, in the case of the 24-hour recall interview it showed good psychometric properties but has a major drawback, the labour-intensive nature of data collection and scoring. In addition, the 24-hour recall interview mainly assesses dietary behaviours of the child and does not include items about behavioural factors such as 1) if the child recognizes symptoms of hypo- or hyperglycaemia and knows how to react 2) if the child needs constant reminding by a parent to measure his/her blood sugar levels and administer his/her insulin injections or if s/he remembers by himself/herself 3) if the child when s/he has the opportunity (e.g. birthday party where parent is not present) eats big amounts of sweet foods 4) if the child hides sweet foods or lies about having done a blood test while s/he has not. Thus, treatment regimens that entail multiple, complex behaviours as it is in the case of asthma and diabetes, require a comprehensive assessment which covers all treatment management requirements.

The same criticism applied to the FNI as this measure only assessed one aspect of the treatment regimen, which was how often patients did not take their medication. Also, there was only one study that used the FNI with children with renal transplants and subsequently much more research is needed to determine the scale's ability to measure medical adherence in paediatric patient populations. Lastly, future research is needed to investigate if the FNI can be adapted for use with children with other chronic medical conditions.

The M-CIST on the other hand could be administered very quickly and also showed good psychometric properties. However, in the M-CIST the child was asked to complete a story where the main character was confronted with a medical dilemma by deciding whether or not to follow specific medical advice. Thus, the child's reply was based on a hypothetical situation and being a hypothetical character. It is therefore possible that a child would behave differently when he or she would encounter these medical dilemmas in real life.

Lastly, La Greca (1990) raised a more general criticism by stating that from a methodological standpoint, the use of non-standardised cut-offs for classifying patients as compliant limits the ability to make comparisons across studies, or even across different aspects of a particular treatment regimen. Therefore, one has to move towards the development of objective measures that can be replicated across studies, and that demonstrate consistent relationships with treatment outcome. This is essential for the progress of the field (La Greca, 1990).

2.6 Overall Conclusion

The findings from clinic-based studies in which groups of chronically ill children were compared to groups of healthy children or existing normative data allowed for exploring possible differences in adjustment between both groups. However, this type of study did not provide any information on within-group differences i.e. variations in adjustment among children with asthma or diabetes.

Results from meta-analyses (Lavigne & Faier-Routman, 1993; Thompson & Gustafson, 1996) showed that there were many potential variables that might correlate with adjustment but demonstrated inconsistencies in findings. This reinforces the conclusion that future research is needed in order to identify those factors that increase psychopathology as well as protective factors that contribute to the adjustment of children with chronic illness.

Research then shifted from utilising traditional outcome measures to evaluate psychosocial functioning to focusing on Quality of Life measures to assess children's adjustment to chronic illness.

However also in this area as Eiser and Morse (2001) have pointed out existing measures have certain limitations.

They raised the criticism that research has not given enough notice to issues of content and face validity. In this context a central and crucial concern should be what children <u>directly</u> report about how they perceive the limitations imposed by the illness on their QoL and how they react to them. It will be important to identify variables concerning why some children react better than others i.e. which coping strategies help and which do not. Also, it is important that QoL assessments include parallel ratings by the child himself/herself as well as a proxy (e.g. parent) as information obtained from both will provide a more comprehensive picture.

Moreover, existing measures lack child-centred approaches to measure QoL as they generally rely on paper-and-pencil measures. One future avenue to making measures more attractive would be by means of administering a questionnaire on a lap-top and consequently making the completion of an assessment like a game.

Lastly, assessments of QoL should be brief so that they can be completed during an outpatient clinic visit and easy to administer. They should require minimal training or expertise in order to recruit large samples of chronically ill children in a short time of space and simultaneously will be less of a burden for the children and caregivers to complete.

The literature review also showed that all existing treatment adherence measures have major limitations. The M-CIST assesses treatment adherence in a hypothetical situation and one cannot generalise that a child would behave in the same way when encountering these medical dilemmas in real life.

The 24-hour recall interview and the FNI only assess one aspect of the treatment regimen. However, chronic illnesses like asthma and diabetes require complex treatment regimens comprising of multiple behaviours. In order to assess those adequately a comprehensive assessment which covers all treatment management requirements is needed.

CHAPTER 3

RATIONALE AND RESEARCH STRATEGY

3.1 Background

The aim of this thesis was to develop assessments in the form of questionnaires to measure children's socio-emotional adjustment to asthma and diabetes, which represented a major aspect of the quality of life for these children. Patients and their parents are responsible for a very complex treatment regimen due to the fact that in asthma and diabetes the essence of treatment is self-care. Therefore, these specifically developed questionnaires also tapped these areas by identifying stressors that these children and families were facing, how they successfully cope with these stressors and where future interventions were needed. Overall, these questionnaires will represent a more economical way of assessing child adjustment, whereas presently the instruments available depend on longer clinical interviews (e.g. Ungar, Mirabelli, Cousins, & Boydell, 2006). As a result, these newly constructed instruments represent an important first step in the development of tools that could be used in the future to help health professionals to identify children who are at risk for developing adjustment problems. The development of any new instrument is a multi-step process, which cannot be completed in one study.

The second aim was to use these new measures to test the hypothesis of an association between children's socio-emotional adjustment to their illness and treatment adherence. Previous research has found a connection between socio-emotional functioning and treatment adherence (e.g. Pretzlik, 1997) and this study was designed to investigate this relationship further.

The study used both an illness-specific and an illness-generic approach.

The study was disease-specific in that it included the development of separate questionnaires for the two disease groups. This was considered important as each disease was known to be associated with different stressors and responses, required diverse treatment regimens and thus might have affected adjustment in different ways.

The study was generic in that it examined more than one type of chronic illness in children (asthma and diabetes) and aimed to discover commonly shared experiences across the two disease groups and how these related to the children's adjustment.

3.2 Research Strategy of Study 1 and Study 3 - Interviews

Study 1 involved interviewing a group of children with asthma and their parents about the children's experiences and feelings about having a chronic illness. Study 3 was a parallel study to study 1 and therefore had the same aim and methods but this time explored the experiences of a sample of children with diabetes rather than asthma and their parents. Even though both studies had the same aim and methods and were conducted concurrently it was decided to keep the reports separate as the children's illness differed across the studies.

The interview questions were generated by the author with a focus on the children's experiences and feelings towards the illness and how they reacted emotionally to illness-related stressors. Additionally, as emphasised in the literature it was imperative to understand paediatric patients within their social environments, thus incorporating their involvement with peers, school, and the health care professionals (e.g. Roberts, 2003). Hence the interview schedule also considered the child's adjustment in the family, in medical environments and at school.

All the interview data from children and parents were then transcribed into separate Microsoft Word documents. The researcher did not attempt to transcribe the children's dialect variety and used punctuation as indicated by grammar and intonation. This method of transcribing was used with the children's and parents' responses in order not to alter their intended answers. The children's and parents' interviews were analysed by using grounded theory methodology (Charmaz, 2003) and this analysis led to the generation of statements to be included in the questionnaires. The core ideas of grounded theory "consist of systematic inductive guidelines for collecting and analyzing data to build middle-range theoretical frameworks that explain the collected data. Throughout the research process, grounded theorists develop analytic interpretations of their data to focus further data collection, which they use in turn to inform and refine their developing theoretical analyses" (Charmaz, 2003, p. 509). Specifically, six cycles of analysis were applied for this qualitative analysis. The first three cycles were based on grounded theory methods.

3.2.1 First Step: Process of Coding the Interviews

This included categories that were defined and reflected issues that were expected to be encountered and interview data was coded under these categories. These categories reflected as much as possible emerging ideas rather than simply describing topics. This enabled the researcher to analyze data rather than remaining at the stage of ethnographic description and lead to unforeseen directions. Initial coding started by utilizing line-by-line coding, in addition to building ideas inductively, which enabled the researcher to be neutral i.e. not to impose extant theories or the beliefs of the researcher on the data, which might have had little connection to the data. Initial codes that appeared repeatedly were then utilized to do selective or focused coding i.e. analyze large quantities of data. In grounded theory, ideas represented as categories and codes were constantly refined to make them more definitive and useful, a process called theoretical sampling (Charmaz, 2003).

3.2.2 Second Step: Creation of New Categories

Thus, even though the researcher started out with a number of categories, she was aware that other issues might come up in the interviews, which did not fall under the initial categories or that existing categories might need to be renamed in order to reflect the content of a particular category more accurately.

3.2.3 Third Step: Searching for Double-Coded Data Passages

There was a chance that certain data passages of an interview were double coded with the same text being coded under two separate categories. The categories that a researcher starts with may not reflect the participants' experiences and feeling. If the researcher finds that the same passages are being coded under two categories initially conceived as distinct, it is necessary to consider whether they are distinct in the participants' experience. Double coding of the same passage will be used as an indicator that the children (or parents) do not make the distinctions that the researcher made at the start.

3.2.4 Fourth Step: Analysis of Children's and Parents' Reports and assessing the face-validity of the categories

To analyze children's and parents' reports, each theme (category) was presented in the children's and parents' own voices and a summary of the variations observed in their responses. Samples from the children's interviews were printed in separate pieces of paper without their category coding. Two judges were given these samples and the categories and asked to fit the children's and parents' statements into the categories that had been developed so far. This procedure, which was inspired by the Q-sort method, was carried out to establish the face validity of the categories used by the researcher before moving on to the development of the questionnaire items. Step four, five, and six were not based on grounded theory.

3.2.5 Fifth Step: Development of a Scoring System for the Categories

A scoring system was developed for each of the child and parent categories. This allowed for 1) testing the concordance between children's and parents' reports in the interviews by means of a correlational analysis, 2) validation of the newly developed questionnaires by conducting a correlational analysis between interview and questionnaire data to test if both types of assessment produced converging information (study 2).

In order to score interviews, Guilford (1971) recommended the construction of definitions and cues for anchoring the different points on a scale. He emphasized the importance of labelling the extremes of a scale adequately to support appropriate observation. This allowed for other observers who used the categories to attach the same meaning to these different points. Thus, categories for children and parents were created on the basis of what children and parents had said in the interviews and clearly defined anchoring points were developed. Then all the information relevant to each category in each interview was grouped and a score between 1 and 5 (with 1 the least positive and 5 the most positive) was attributed whenever possible. According to Guilford if there were too few steps a scale became too coarse and a great extent of the discriminative powers of raters were lost, whereas if a scale was too finely graded it was beyond the raters' limited powers of discrimination. Some empirical evidence addressing the issue of the right number of steps was found by Conklin (1923, cited in Guilford, 1971, p289). He carried out an analysis of 23,000 rating scales and concluded that the number of steps that was best handled by untrained researchers was five. However, for trained observers (i.e. the average inter-rater correlations were in the region of .55 to .60) a seven-point scale was seen as optimal. On the basis of this finding a 5-point scale was used in the judgement of the categories because the researcher was working with interview ratings that had not been used previously. However, it was expected that a 5-point scale classification might not be always possible for all the categories. This could happen if the information available from the interviews would not allow for such a fine discrimination and hence a 3-point scale would be more suitable.

3.2.6 Sixth Step: Checking Inter-Rater Agreement

As it is recognized that this method of scoring categories was based on the judgement of a single researcher, independent scorings were also obtained from a second researcher to obtain inter-rater agreement. Thus, the second researcher scored the reports of ten randomly selected interviewees, five taken from the asthma and five from the diabetes sample for each scale by using the anchoring points developed by the first researcher. To check inter-rater agreement, the percentage of agreement between both researchers was calculated.

Finally, the concordance between children's and parents' reports was examined. Using the scorings, a correlational analysis was conducted between the children's categories and the corresponding parents' categories.

3.3 Research Strategy of Study 2 and Study 4 - Questionnaires

Study 2 involved developing separate questionnaires for children with asthma and their parents assessing the child's adjustment and adherence with the treatment regimen. Study 4 was a parallel study to study 2 and hence had the same aim and methods but this time included a sample of children with diabetes rather than asthma and their parents. Thus, the aim of study 4 was to develop separate questionnaires for children with diabetes and their parents assessing the child's adjustment and adherence with the treatment regimen. In study 2 a paediatric asthma nurse and in study 4 a paediatric diabetes nurse were interviewed about the children's adjustment in order to gain crucial information from the perspective of health professionals, namely how the illness affects the children's lives and factors that may affect treatment adherence. On the basis of children's, parents', and nurses' replies in the interviews, child and parent questionnaires were developed by using grounded theory (Charmaz, 2003) to generate statements to be included in the questionnaires. These questionnaires were then administered to a larger number of children (N=60) and their parents to determine the reliability and validity of the new instrument.

The first step was to assess the reliability, defined in terms of internal consistency, of the items. According to Cronbach (1990), one type of scrutiny concerns reliability of a scale, which assesses the degree to which the items of each subscale measure the same construct. Analysis of reliability involved determining the internal consistency of the children's and parents' version of the asthma and diabetes questionnaires by calculating Cronbach's coefficient alpha (Cronbach, 1951) for all the items in each scale. As the child and parent questionnaires included a large sample of items, items with low reliability could be discarded. Thus, those items that were identified as lowering the internal consistency were eliminated. Alpha levels reached an acceptable reliability threshold when they were at least .7 (Nunnally and Bernstein, 1994).

The content validity of the questionnaires was initially based on the children's and parents' reports. It was further analysed on the basis of a panel of five experts who evaluated the content and relevance of the items for each child and parent scale. Items that were not considered relevant by four out of the five experts (i.e. did not reach the "four out of five criteria" or 80% agreement) were removed from the questionnaires.

Thirdly, in order to be able to add up the scales and obtain an overall score, the overall internal consistency of each of the questionnaires, the child's and the parent's was determined.

Fourthly, in order to examine whether both types of assessment i.e. interview and questionnaire produce converging information, a correlational analysis was conducted between the children's and the parents' data of both types of assessments.

Fifthly, the literature is assuming an association between severity of an illness and adverse psychological effects (e.g. Eiser, 1990). Thus, with the help of the paediatric asthma nurse, each child of the asthmatic sample was classified into one of five asthma severity groups (mild, mild-moderate, moderate, moderately severe, and severe) and a correlational analysis was conducted between children's adjustment and the severity rating of their asthma.

Lastly, the main hypothesis of an association between children's overall adjustment and treatment adherence was tested by means of a correlational analysis. In order to carry out this analysis a child's total adjustment had to be determined by combining the average of the following categories: "Child's perception of normality", "Child's feelings about the disease", and "Child's openness about the illness". This total child adjustment score was then correlated with the "Child's treatment adherence" category.

3.4 Research Strategy of Study 5

The aim of study 5 was to combine the results from study 1 to 4 to explore whether there were commonalities in the experiences of children with asthma and children with diabetes that allow for a more general statement regarding the lives of children with a chronic illness. Although the specific stressors and reactions to these are bound to vary between the two illnesses, it is possible that the children's experiences still show some similarities at a more abstract level.

Firstly, the results from the children's and parents' content categories from the interviews of the two disease groups were combined to compare the experiences of children with asthma and diabetes and to compare the experiences of parents of children with asthma or diabetes. A comparison between the two illnesses would allow for looking at whether one illness caused more physical discomfort than the other or more restrictions to the child's life. Also, comparing the parents of both illness groups would allow for exploring whether they experienced one illness as more serious than the other and consequently took more precautions.

Secondly, the results from the questionnaires from children with asthma and diabetes, and those of their parents, were combined to investigate the experiences of children of the two disease groups generically.

This combined analysis included a larger number of cases and allowed for investigating construct validity by means of a factor analysis. Thus, it was investigated whether child adjustment data consisted of a single underlying factor or multiple factors. The same analysis was carried out on the parents' perceptions of the children's adjustment.

The factor analysis carried out here was not viewed as exploratory but confirmatory. The hypothesis was that child adjustment involves different aspects of the child's life but they all measure the same phenomenon. Treatment adherence, however, is seen as a different construct, which is nevertheless related to the child's adjustment. In a way, this is similar to measuring the height and weight of children and studying their relation. If these measures were put together into a factor analysis, we could be led to believe that they measure the same factor because they are highly correlated. However, because they are conceptually distinct, one would not place them in the same factor analysis.

To test this hypothesis, a factor analysis of each of the questionnaires, child and parent, was conducted. Due to the fact that adjustment and treatment adherence were two different constructs the latter was not included in the factor analysis. The factor analysis combined both illness groups (asthma and diabetes).

Thirdly, the results from the factor analyses were used to form scores for each respondent (i.e. children and parents) on each of the factors found by using the regression method. These new child and parent factors were then correlated to explore if children's and parents' reports produced converging results. Additionally, the main hypothesis of an association between child adjustment and treatment adherence was tested.

Fourthly, it was tested if there was a difference in the overall adjustment and treatment adherence between children with asthma and children with diabetes. Also, it was examined if there was a difference in parents' reports of children's treatment adherence between the two disease groups.

Lastly, the role of parental style on children's treatment adherence (combining children's and parents' reports) was explored by means of regression analyses.

3.5 Methods

3.5.1 Ethics and Gaining Access to the Hospital

The researcher was trained by the Code of Practice of Brookes University for academic integrity and ethical approval for conducting the study was gained from Oxford Brookes Ethics Committee (Appendix 3.1).

Ethical approval for carrying out the study 1 and 3 was also sought directly from Guy's Research Ethics Committee, the collaborating establishment, and their approval was granted (Appendix 3.2). Additionally, access to the children and parents was sought and obtained through the collaboration with Dr. Dipak Kanabar, a paediatric consultant at Guy's and St. Thomas' Hospital who gave consent to oversee the study (Appendix 3.3).

Parents were informed via an information sheet (Appendix 3.4) detailing the purpose and methods used in the study and their written consent (Appendix 3.5) was sought. The information sheet also included written assurance that all the information collected would be kept confidentially and that the respondents would remain unidentified, and this assurance was repeated by the investigator verbally at the time of the interview. Lastly, parents were informed that this research was independent from the treatment the children received and the medical team and that they could withdraw at any time without giving a reason.

The children were also asked via an information sheet (Appendix 3.6 for asthma and 3.7 for diabetes) for their consent (Appendix 3.8 for asthma and 3.9 for diabetes) and were informed that the information collected would be kept confidentially. Furthermore, they were informed that they could stop at any time and would not need to finish the interview. If children appeared distressed at any time during the interview, the interviewer would interrupt the interview and was trained to deal with this situation. Debriefing was carried out in the form of written feedback at the end of the project.

Lastly, the asthma and diabetes paediatric nurses were asked via an information sheet (Appendix 3.10) for their consent (Appendix 3.12).

Once the questionnaires for children and parents were developed Ethical approval for carrying out study 2 and 4 of the study was again sought from Guy's Research Ethics Committee as they requested to see the new instruments before commencing phase two (Appendix 3.11). Parents were again informed via an information sheet (Appendix 3.13) detailing the purpose and methods used in the study and their written consent (Appendix 3.14) was sought. The new information sheet again included written assurance that all the information collected would be kept confidentially and that the respondents would remain unidentified, and would be repeated by the investigator verbally. Lastly, parents were once more informed that this research was independent from the treatment the children received and the medical team and that they could withdraw at any time without giving a reason.

The children were also once more asked via an information sheet (Appendix 3.15 for asthma and 3.16 for diabetes) for their consent (Appendix 3.17 for asthma and 3.18 for diabetes) and were informed that the information collected would be kept confidentially. Furthermore, it was emphasized that if children became distressed during the study they could stop at any time and would not need to finish the interview or questionnaire. Debriefing was carried out in the form of written feedback at the end of the project.

3.5.2 The Hospital Environment

The study was carried out at Guy's and St' Thomas Hospital in London. The data collection of study 1 and 3 took place between June 2003 and August 2004. The participants were paediatric patients from the outpatient clinic of both hospitals (Guy's and St. Thomas'). During these asthma or diabetes outpatient clinics parents and their children were asked if they would be interested to learn more about a research study. When parents agreed, the researcher asked about the child's illness (as sometimes several different clinics were running at the same time) and age. If the child met the criteria of the illness and age range, both parent(s) and child were given an information sheet to read. After the parent and child had read the information sheets they were asked if they were still interested in participating and if they had further questions or concerns regarding the research. If the parent and child agreed to take part in the study, they were taken by the researcher to either one of the consulting offices (when available) or to a quiet part of the waiting area.

The researcher offered in all cases that if parents were in a rush after their visit to the clinic or felt more comfortable being interviewed at home to arrange another convenient time to visit them there.

The data collection of study 2 and 4 took place between November 2004 and August 2006. Collecting data started out at Guy's and St. Thomas Hospital in London but all children's clinics were moved to the newly developed Evelina Children's Hospital which opened in October 2005. The participants were again paediatric patients from the outpatient clinic of both hospitals (Guy's and St. Thomas'). The recruitment procedure was identical to study 1 and 3.

Investigating clinical samples involves overcoming major barriers. Firstly, ethical approval had to be sought directly from Guy's Research Ethics Committee for carrying out both stages of the study. Also at both stages when the Ethics committee required changes to the study procedure the Ethics committee application had to be resubmitted until approval was granted. As the Ethics Committee only met every six weeks, this process was lengthy. Secondly, the relatively long period for recruiting a sample of 30 children in study 1 and 3 and 60 children in study 2 and 4 was due to the fact that there were only two asthma and two diabetes clinics a month, with each of the clinics running for only two hours. Thirdly, the majority of parents and their children preferred to be assessed in their homes, which required organising a meeting with the family via telephone followed by a home visit for the actual assessment. Fourthly, as in every type of research a number of participants declined to take part. In this study of all the children with asthma and their parents the researcher approached, four declined to take part. Reasons other than having a developmental disorder were that one parent did not speak English and in another case the parent was happy to take part but the child was too shy to talk. Of all the children with diabetes and their parents the researcher approached, nobody declined to take part.

3.5.3 Organisation of the Thesis

The results were divided into five chapters (chapter 4, 5, 6, 7 and 8). Chapter 4 described study 1, which comprised of interviewing a group of children with asthma. Chapter 5 illustrated study 2, which included developing questionnaires for children with asthma and their parents and administering them to a larger sample. Chapter 6 described study 3, which was a parallel study to study 1 except for this time included children with diabetes. Chapter 7 then continued with study 4, which was a parallel study to study 3 but this time investigated a sample of children with diabetes. Chapter 8 was a general chapter combining the results of study 1 and study 3 as well as combining the results of study 2 and study 4 to examine whether there were commonalities in the experiences of children with asthma and children with diabetes that allow for a more general statement regarding the lives of children with a chronic illness as children's experiences could show some similarities at a more abstract level.

Lastly, chapter 9 presents a discussion and overall conclusion of the study, the contributions of this thesis to the literature and ends with outlining the limitations of the thesis and suggestions for future studies.

CHAPTER 4

STUDY 1 – USING INTERVIEWS TO UNDERSTAND CHILDREN WITH ASTHMA

4.1 Aim

The aim of this study was to describe the children's experiences with having asthma, focusing on the stressors that are added to their lives, how they cope with them, and the socio-emotional impact on their lives from their own perspective. Parents' participation offered an added description of their children's experiences as perceived by the parents and therefore from a different perspective.

4.2 Introduction and Background

The aim of the thesis was the development of questionnaires to measure the adjustment of children with (a) asthma, and (b) diabetes to the illness and their treatment adherence.

In order to develop these questionnaires the procedures for scale construction as described by Oppenheim (1992) were followed. Interviews were chosen as a method for eliciting information about the children's experiences with asthma and how they coped with the stressors associated with it. In order to obtain different perspectives, the children themselves and one of the parents, usually the mother, were interviewed. Thus, in this study semi-structured interviews were conducted with 15 children with asthma and one of their parents to elicit information about the children's experiences and later in study 3 interviews were conducted with 15 children with diabetes. The interview questions were generated by the author to assess the children and parents about the children's experiences and feelings towards the illness and how they reacted emotionally to illness-related stressors. Additionally, as emphasized in the literature it was imperative to understand paediatric patients within their social environments, thus incorporating their involvement with peers, school, and the health care professionals (e.g. Roberts, 2003). Hence the interview schedule also assessed the child's adjustment in the family, in medical environments and at school. Two different interview schedules were developed, one for the children and one for their parents.

Both, the child and the parent interview schedule assessed the range of responses in the following domains of the ill child's experience: (a) adjustment to medical environments (hospital and clinic), (b) distress during medical procedures, (c) adjustment in the family, (d) adjustment in school, including academic and social aspects, (e) coping with special routines, and (f) coping with specific stressors (symptoms and side-effects of medication).

The data analysis of this study involved firstly carrying out a content analysis using grounded theory methodology (Charmaz, 2003) of all the interview data from children and parents to describe the different experiences i.e. the variation in adjustment to the illness within the sample. Children's and parents' responses were coded under descriptive categories which permitted the researcher to analyse and compare what children and parents had reported about a particular theme.

Secondly, in order to utilize the interview data from children and parents more systematically a scoring system for all the child and parent categories (scales) was developed. These scorings were utilized to explore concordance between children's and parents' reports by correlating each child scale with the corresponding parent scale. Lastly, these scorings were utilized to select two case studies of two extreme cases (one well adjusted child and one poorly adjusted child) to illustrate the differences in children's adjustment to asthma.

Overall, it was expected that the content analysis of the child interviews would allow for an identification of stressors children with asthma had to cope with whereas the parent interviews would provide further information on the same issues but from a different perspective. Furthermore, it was anticipated that the correlational analysis between children's and parents' reports would reveal differences between children's and parents' perceptions about the children's experiences with the illness.

The children's and parents' responses in these interviews were utilized in the next study to design separate questionnaires for children with asthma and their parents (study 2). Specifically, the scales (categories) created in this study with their codings were utilized to generate items that were included in the newly developed questionnaires for children with asthma (study 2) and their parents.

4.3 Methods

4.3.1 The Sample

The sample consisted of 15 children with asthma (4 girls and 11 boys) with ages ranging from 7 years to 12 years and their parents. With the help of the paediatric asthma nurse, children with autism, ADHD, and Down-Syndrome were excluded from the recruitment process. The sample was heterogeneous and consisted of 12 Caucasian, one Black, and three Indian children.

Of all the parents and children the researcher approached, four declined to take part. Reasons other than having a developmental disorder were that one parent did not speak English and in another case the parent was happy to take part but the child was too shy to talk.

With the aid of the paediatric asthma nurse each child of this sample was classified into one of five asthma severity groups (mild, mild-moderate, moderate, moderately severe, and severe). This classification was based on the British Thoracic Society's Summary of Stepwise Management in Children Aged Five to Twelve (www.brit-thoracic.org.uk). Asthma severity was defined in terms of 1) level and type of medication used to minimize the symptoms of asthma, 2) if children took medication all year around, 3) the number of asthma attacks the child had in the last two years, 4) how many of these required hospitalization, and 5) if the child had any allergies. However, the nurse raised issues with classifying the severity of a child's asthma by describing the following example and posing the following question: Has a child who has constant mild asthma symptoms all year around more or less severe asthma compared to a child who has no asthma symptoms for a few years and suddenly has a very severe asthma attack and is almost dying? She explained that this example illustrated the difficulty with classifying i.e. labelling children's asthma severity. For this reason medical health professionals at the hospital did not classify children's asthma severity in their medical files to ensure that all children who were admitted to hospital with asthma attacks or symptoms received the same level of treatment i.e. with maximum care and precaution. Despite these issues, the asthma nurse classified the children's asthma severity for this study on the basis of the above criteria. Of the 15 asthmatic children one was classified as mild, six were classified as mild-moderate, five were classified as moderate, three were classified as moderately severe, and none as severe (see Table 4.1). This information was utilized in the results to explore if asthma severity had an effect on the child's adjustment.

Table 4.1 Severity of Asthma in the Sample (n=15)

Asthma Severity Category	Number of children
Mild	1
Mild-moderate	6
Moderate	5
Moderately-severe	3
Severe	0
Total	15

4.3.2 Development of the Interview Schedule

The interview questions were generated by the author to assess the children's experiences and feelings towards the illness and how they reacted emotionally to illness-related stressors; this was assessed from the children's and the parents' perspectives. Additionally, as emphasized in the literature it was imperative to understand paediatric patients within their social environments, thus incorporating their involvement with peers, school, and the health care professionals (e.g. Roberts, 2003). Hence the interview schedule also assessed the child's adjustment in the family, in medical environments and at school. Two different interview schedules were developed, one for the children and one for their parents.

Both, the child and the parent interview schedule assessed the range of responses in the following domains of the ill child's experience: (a) adjustment to medical environments (hospital and clinic), (b) distress during medical procedures, (c) adjustment in the family, (d) adjustment in school, including academic and social aspects, (e) coping with special routines, and (f) coping with specific stressors (symptoms and side-effects of medication).

The different schedules for the semi-structured interviews for children with asthma and their parents are included in Appendix 4.1 and 4.2.

4.3.3 Procedure of the Interview

Once the parent and child gave their consent to being interviewed the researcher asked who would like to start. In most cases the parent and child chose for the parent to be interviewed first. Although it stated on the information sheets for both children and parents that the interviews would be sound recorded the researcher checked with the parent and child again to ascertain that they were comfortable with this procedure. All the children went back to the play area, whilst the researcher commenced to sound record the interview with the parent and called the child when ready. Six of the parents were present when their children were interviewed, whereas the remainder would talk to other mothers, get something to eat or drink, or re-park their cars. From the six parents who were present during the interview with the child three made comments during the interview. Two of them corrected their children's answer, whereas one mother reminded the child of the answer when he was not sure.

However, when the researcher politely asked those three parents not to interfere and let their children answer, any kind of interference stopped.

The researcher was systematic in that each participant answered all the questions. Thus, if a participant did not answer a question the researcher rephrased the question. However, there was variation in how far the researcher was willing to pursue answers. For example, one of the questions which fell under the theme "Child's perception of normality" was "Do you think that a child with asthma is different from a child who does not have asthma?" If the child answered that s/he thought that there was a difference, the researcher asked what that difference was and if there were any more differences. However, if the child replied that there was no difference, the researcher would not pursue this question any more. Thus, the researcher would not ask why there was no difference to avoid a child becoming aware or promoting to think about possible differences and consequently perhaps becoming upset.

4.4 Results

A content analysis of the interview data from children and parents was carried out in which children's and parents' responses were coded under descriptive content categories (first, second, and third step). These content categories were then utilized to analyze what children and parents in their own voices had reported under each theme as well as a summary of the variations observed in their responses (fourth step). The concordance between children's and parents' reports was investigated. In order to carry out this analysis, children's and parents' reports had to be scored (fifth step). Thus, the same content categories were utilized and cues were developed for anchoring the different points on a scale. Then all the information relevant to each category in each interview was grouped and a score between 1 and 5 (with 1 the least positive and 5 the most positive outcome) was attributed whenever possible. Independent scorings using the same anchoring points were also obtained from a second researcher to achieve inter-subjective agreement (sixth step). Lastly, a correlational analysis was conducted using the scores between the four children categories and the corresponding four parent categories.

4.4.1 Content Analysis of the Interviews

A content analysis using grounded theory methodology (Charmaz, 2003) of all the interview data from children and parents was carried out in order to exemplify the different experiences. The analysis was conducted by coding children's and parents' responses under descriptive content categories. Consequently, having separate categories for each theme enabled the researcher to analyze and compare what children and parents had reported about a particular topic (first, second and third step).

In order to code children's and parents' responses, the interviews were transcribed in separate documents and then imported as individual interviews into NVivo – NUD*IST Vivo Software for Qualitative Research. NVivo facilitated coding children's and parents' data into content categories based on the initial six themes of the ill children's experiences to identify issues that were expected to be encountered (1) adjustment to medical environments (hospital and clinic); (2) distress during medical procedures; (3) adjustment in the family; (4) adjustment in school, including academic and social aspects; (5) coping with special routines; and (6) coping with specific stressors (symptoms and side-effects of medication). Thus, the first step included coding relevant interview data passages under these content categories. However, as is stated in grounded theory, during the process of carrying out this analysis the researcher realized that the existing number of categories was not sufficient. Children and parents reported themes that had not been anticipated and consequently could not be coded under these initial six categories. For instance children and parents reported many issues regarding the child's openness about the disease. Therefore additional descriptive categories were created under which the remaining data could be coded. Also, the initial six categories had to be renamed in order to describe more accurately the data coded at them. Open coding continued until all the information (interview data) produced no change to the existing categories, i.e. until theoretical saturation was achieved. The following content categories covered all the children's data: (1) the child's perception of being normal, (2) the child's perception of being treated normally by the parents, (3) the child's knowledge about the treatment and precautions, (4) the child's openness about the illness, (5) the child's level of adherence to the medical regimen, (6) the child's knowledge about how to correctly react to symptoms, (7) the child's general feelings about having the illness, (8) the child's perception of effects of the illness on the child's life.

The new parent content categories included the parent's perception of: (1) the child's perception of being normal, (2) the child's perception of being treated normally by the parents, (3) the child's knowledge about the treatment and precautions, (4) the child's openness about the illness, (5) the child's level of adherence to the medical regimen, (6) the child's knowledge about how to correctly react to symptoms, (7) the child's general feelings about having the illness, (8) the effects of the illness on the child's life and (9) the impact of the child's illness on the family and the child's adjustment at school including academic and social aspects.

In total, there were eight child and nine parent categories. The codings of these categories were then printed in random order and re-classified by two other researchers. This technique in principle assessed whether the codings had been placed in categories that seemed appropriate when considered by other researchers. It draws on the notion of face validity. All the codings were classified by the other two researchers under the correct category i.e. under the category the first researcher had coded them at, thus showing that codings had been placed in categories that seemed sensible when considered by other researchers.

Once the process of coding all the data under the above categories had been completed, it became apparent, as expected in grounded theory, that certain data passages were coded under two separate categories and that the interviewees found it difficult to speak about these experiences separately. For example, the child's treatment adherence could not be treated separately from the child's knowledge about disease, and symptoms, and the child's reaction to the symptoms. These were originally separate categories. However, it became apparent that these two categories were intertwined because part of a child's adherence with the treatment is the child's knowledge about symptoms and how to react to symptoms. Another example was that the child's feelings about the disease and the effects of the disease on the child's life were initially coded as two separate categories. However, these two categories were also tangled as the effects of the disease on the child's life affected the child's feelings about the disease and vice versa. Lastly, the child's perception of being normal and the child's perception of being treated normally were intertwined: It became clear that the child's perception was influenced by the way he or she was being treated.

In view of the fact that the same text was coded under two categories initially conceived as different, it was concluded that these categories should be merged in the analysis, as they seemed to be intertwined in the participants' experiences.

The tables 4.2 and 4.3 contain only those child and parent categories that were merged with extracts from the actual interviews for illustration.

Table 4.2 Merged Child Categories

(1) Child's perception of being normal and Child's perception of being treated normally *I: Do you think that a child with asthma is different from a child that hasn't got asthma?* *C: No not really because a child with asthma is the same as a child without asthma, they just have to take pumps and all of that.* *I: Do you think that sometimes your parents are too careful with what you want to do?* *C: Not really because my mum just lets me get on with what I want to do the same as my dad.* *I: Do you think that your parents treat you differently from your brothers and your sister because you have asthma?* *C: No not really because we all get treated the same if my mother goes out and buys my brother something she will buy everyone something.*
(2) Child's feelings about the disease and The effects of the disease on the child's life *I: What do you think now about having asthma?* *C: I hate having asthma.* *I: We all know that it is not nice having asthma, but is there anything nice about it?* *C: No.*

I: Tell me all the things you don't like about it.
C: I want to run around in football. When I have played a whole round in the field I feel a bit chesty.

(3) Child's adherence with the treatment, Child's reaction to symptoms, <u>and</u> Treatment and precautions

I: Can you tell me what you have to do everyday? How much medicine you have to take and which little tests you have to do?
C: Well with my pumps Flexitide and Serofine the one together, I have to take that twice.
I: In the morning and evening?
C: Yes.
I: Anything else?
C: My peak flow in the morning and then I take it again before I go to bed.
I: Is that what you have to do everyday?
C: Yes.
I: Did you do it yesterday, the day before yesterday, three days ago?
C: Yes.
I: You do it every, every day?
C: Yes. Except for sometimes when I forget.
I: So you do forget sometimes?
C: Hmm.
I: And what do you get when you have signs of asthma?
C: I get breathless and sometimes you can't breathe.
I: And wheezy probably?
C: Yes.
I: Do you know what to do then?
C: When I get asthma and I am at school because I am allowed to take my pumps to school I have to leave them at the office. I tell one of my friends that I need my pumps and they will go and ask for them and the teacher will give them to them and they will give them to me.
I: Can you take your pumps by yourself or do you need help?
C: Well I can take my pumps by myself but sometimes my friends will have to stay with me.
I: Is there anything you have to do that you do not like at all?
C: Yes I don't like the peak flow if you have to do it over and over again.
I: Do you still do it?
C: Yes.
I: And the pumps? Do you like taking them?
C: Yes I don't mind them.

Table 4.3 Merged Parent Categories

(1) Parent's perception of the child's perception of being treated normally <u>and</u> Parent's perception of treating child normally *I: Do you think that sometimes you are being too careful with him?* *M: Yes, when he goes to school I always have to make sure that he has his inhaler and all that. At sports day in school I always have to make sure that he is feeling OK. If I think he has got a slight cold I wouldn't let him go swimming and things like that.* *I: Does he think you are being too careful with him?* *M: Yeah, if I say he can't go swimming because he has got a cold then he would say all my friends are going and why can't I. Then I have to say you're not well and what happens if you have an attack. The teacher can't look after him he has too many children and if you tell them they try to look after him but you never know.*
(2) Parent's perception of the child's feelings about the disease <u>and</u> The effects of the disease on the child's life *I: How does he generally feel about having asthma?* *M: I think he hates it. He wants to run around with the other kids but with his asthma, he doesn't get breathless, he just starts coughing. Sometimes it drives him crazy having to sit down and…* *I: Would you say overall he copes well?* *M: Yeah, he copes well. He is very good, he does it all, he is a good boy.* *I: Does he get upset about having asthma? Does he for example think it prevents him from doing things?* *M: Yeah, we went to a Halloween party last week and he started coughing, it sounded like barking, so I had to take him away from the party and get him to calm down and take his inhaler…so yeah, it does annoy him 'cause all he wants to do is to play with the other children.*
(3) Parent's perception of the child's treatment adherence <u>and</u> Knowledge about disease, symptoms, and reaction *I: How much can he do himself and take responsibility? You said that he can take the inhaler himself but you supervise him?* *M: Yeah, he can take it himself but I do supervise him because sometimes he can muck about. If it is not me it is my husband or my mother in law. They will check that the does it properly. He knows he has to do it 5 times and that it has to be kept clean so…I do trust him with it; it is just that I prefer to watch.* *I: How much does he understand about asthma and the treatment? Does he understand what is wrong with him?* *M: I don't know. I haven't explained the full medical terms to him. I think it is about time to take him to hospital and have it all explained to him properly.* *I: But he knows what the treatment is for?* *M: He knows it's to help him with his chest.* *I: Does he know what to do when he has symptoms?* *M: Yes, sit down and calm down. Whether he actually does it the amount of*

times I'd like him to is a different story.
I: He gets his inhaler then or is it enough for him to sit down and calm down?
M: A lot of the times it's enough for him just to sit down. The only thing is he gets a cold quite easily. Also, the blue inhaler makes shim very very hyper.
I: Why is that?
M: I don't know, I have only just started to notice it.
I: Are there bits in the treatment he finds hard to follow?
M: No, apart from the hyper-activeness.
I: How do you handle the hyper-activeness?
M: Usually I just shout at him and he will sit down.

The tables 4.4 and 4.5 list the final sets of child and parent categories separately.

Table 4.4 Child Categories

(1) Child's perception of normality (Child's perception of being normal and being treated normally)
(2) Child's feelings about the disease (Child's feelings about the disease and the effects of the disease on the child's life)
(3) Child's openness about the illness
(4) Child's treatment adherence (Child's adherence with the treatment, child's reaction to symptoms, and treatment and precautions)

Table 4.5 Parent Categories

(1) Parent's perception about the child's normality (Parent's perception of the child's perception of being treated normally and parent's perception of treating child normally)
(2) Parent's perception of the child's feelings (Parent's perception of the child's feelings about the disease and the effects of the disease on the child's life)
(3) Parent's perception of the impact of the illness (Parent's perception of the impact of the illness on the family, the child's friendships, and the child's school performance)
(4) Parent's perception of the child's openness about the illness
(5) Parent's attitude about the treatment and precautions
(6) Parent's perception of the child's treatment adherence (Parent's perception of the child's treatment adherence and knowledge about disease, symptoms, and reaction)

Note. Throughout this thesis the abbreviated category name was used

In the subsequent section, each of the themes discussed by the children was analyzed. Each theme is presented with examples of children's own voices, and a summary of the variations observed in the children's attitudes was described. These variations were used later on for a more systematic and quantitative analysis of the interview data.

4.4.1.1 Child's Perception of Normality

Two themes could be distinguished with respect to the child's perception of being normal: the child's own perception and the child's perception of how he/she was treated by the parents.

Five children with asthma replied that there was no difference between children with asthma and children who did not have asthma. For example one child said "I don't think it should affect... well it does affect when it's really bad. I don't think it should affect your life that much, the asthma. I don't think it's hugely different". Another child said "no, not really because a child with asthma is the same as a child without asthma, they just have to take pumps and all of that".

The remainder (10 children) on the other hand stated that there was a difference. One child explained "because normal children don't get out of breath like us. They can do any activity longer than us". Another child described "because they are sick and the other person is not". A further child expressed "it's different because the other children don't have asthma". Yet another child felt that there was a difference because "they (healthy children) can run around a lot longer than me because I get chesty and they don't" whereas another child thought "they will get tired more quickly than other people". Lastly one child spelled out that "they (healthy children) can do more running and stuff like that".

Fourteen children reported that their parents treated them normally and, in the case where there were siblings, treated them the same as their siblings. One child explained "No, not really because we all get treated the same. If my mother goes out and buys my brother something she will buy everyone something". Another child expressed "Not really because my mum just lets me get on with what I want to do the same as my dad". Only one girl who had no siblings reported that sometimes her mother was too careful with her and said "Yes sometimes I say that's not fair I want to do that".

4.4.1.2 Child's Feelings About the Disease

Two types of themes emerged when the children were discussing their feelings about the illness: whether they disliked it or not, and how it affected their lives. Children's reports concerning their feelings about having asthma were very diverse ranging from "I hate it" and "I am bothered by it" to "it's not too bad if it is controlled" and "I am fine having it". One child reported that he hated having asthma. Seven children said that they were bothered by having asthma or did not like it. The remaining seven children stated that they were okay with having asthma.

Similarly, concerning the effects asthma had on the children's lives the responses were very varied. Some children replied that there was nothing positive about the illness which was reflected for example in the statement "it's all just bad, bad, and bad". Other negative replies were treatment and symptom related like "I always have to take my pump. I don't like it", "I don't like it because it is making me cough", "when I cough it hurts my throat", "it is stopping me from playing football", "at school when I run about everyone calls me a slow coach", and "I cough all the time". Whereas other children had accepted the illness by saying "I am okay with it" and "it doesn't really bother me because I can get on with the things I want to do, but if I run around a lot I will have to take my pump". Some children even perceived that there was something positive about having asthma “I like it because I get days off school” or “you have to come here (clinic) and then you get out of school”.

4.4.1.3 Child’s Treatment Adherence

There were two types of comments regarding treatment adherence: whether the treatment was stressful in any way and whether the children actually followed it. Six children reported illness and treatment related problems. One boy explained “I don’t like drinking my medicine. (Long pause). When I play football I have to stop and I don’t like stopping.” When asked if there was anything else he did not like he replied “Running. When I am running, having a rest”. Another boy replied that he does not like “going to hospital”. One girl did not like taking her inhaler and explained “If I take all three it does make me dizzy sometimes”. Another girl did not mind the inhalers but said “I don’t like the peak flow if you have to do it over and over again”. Yet another girl found “taking the pumps is boring”, whereas another boy did not like at all “(using) the inhaler”.

Children’s treatment adherence was assessed through the following six criteria which derived from the interviews: (1) child was familiar with his/her treatment regimen i.e. knew how often and what time to take which medication; (2) took their medication as the doctor prescribed (therefore some children had to take medication everyday whereas other children only needed to take medication in hay fever season) ; (3) was aware about the symptoms of asthma; (4) was acquainted with what to do if symptoms started to show (e.g. when short of breath or coughing the child knew to use the inhaler and to relax); (5) was able to administer the inhaler on their own without needing help; and (6) treatment responsibilities the child disliked was still followed diligently. Seven children met all of the above criteria, another seven children met at least four of the six criteria and one child only met one.

4.4.1.4 Child's Openness About the Illness

It had been expected that the child's openness about the illness might be part of treatment adherence: if a child does not want the peers to know that s/he has asthma, then this child will not use the pump in public. However, this emerged as an independent theme, which did appear to have different aspects. There was no direct association between children's treatment adherence and their openness about the disease as it was not always the case that children who were more open about the illness also adhered more with their treatment regimen. Thus, there were some children who were open about the illness but did not adhere with the treatment very well whereas other children were not open about the disease actually followed their treatment regimen very diligently.

Eleven children did not mind people asking or talking about their asthma and preferred not to keep it to themselves. Examples of why children did not mind talking about their asthma were "I don't really mind because it does not really bother me" or "it doesn't really come in to my mind. If someone asks I tell them but I am not going to go out and shouting about it". Two children reported that only sometimes did they mind people asking or talking about it and rather kept having the illness for themselves. One of the two children explained "yes, sometimes I do mind and sometimes I like talking about it". The other child said "sometimes I keep it to myself". When asked "when do you keep it to yourself?" he replied "at school". Two children never liked being asked about their asthma or talking about it and also kept it to themselves. In these two cases the researcher did not pursue any explanations why they did not like being asked about their asthma to avoid the possibility of them becoming upset.

In the subsequent section, each of the themes discussed by the parents was analysed. This time, each theme is presented with examples of parents' own voices, and a summary of the variations observed by the parents in the children's attitudes was described. Again, these variations were used later on for a more systematic and quantitative analysis of the interview data.

4.4.1.5 Parent's Perception of the Child's Normality

Parallel to the corresponding child category, there were two sides to the question: what the parents thought and what the parents believed that their children thought.

The analysis revealed that seven parents reported that they were sometimes too careful with their children. Examples were "Yes, a lot of cotton wool around him. I've wrapped him up too much. With the little one I am a lot more relaxed" or "yes, when he goes to school I always have to make sure that he has his inhaler. On sports-day in school I always have to make sure that he is feeling OK. If I think he has got a slight cold I wouldn't let him go swimming." The remaining eight parents stated that they did not perceive themselves as being too careful with their children. Exemplars of their replies were "no, not really. Sometimes I forget he has got it", "no, we have been conscious not to be, we have tried, because there is a lot of children in my house, so we try not to be and he just gets on with it", "not really, because sometimes I have not been careful and it ended up in hospital, sometimes, if I have been a bit relaxed too much" or "no, not really. No, because his asthma is not under control, so I don't think I am being too careful because he gets asthma attacks all the time".

The majority of parents (12) reported that they thought that their children did not perceive them as too careful with them. Only three parents thought that their children perceived them as being too careful with them. Illustrations were "yes, if I say he can't go swimming because he has got a cold then he would say all my friends are going why can't I" or "yes, I think sometimes I drive him crazy".

4.4.1.6 Parent's Perception of the Child's Feelings

Two types of themes emerged when the parents were discussing their children's feelings towards the disease: whether the children disliked it or not, and the impact the disease had on their lives.

Parents' reports regarding their children's feelings towards the illness were very diverse. Ten parents described their children's feelings as positive and in a way that they had accepted the illness as part of their lives, which was reflected in statements such as "I think he is fine", "fine, he just gets on with it", "she copes with it. She is very, very well, she has never known different", "alright because he is used to it ...he has always had it so he is used to it", and "he doesn't know anything different. So he is quite OK with it, it's normal". The remaining five parents on the other hand reported that their children had negative feelings towards their asthma revealing itself in the following statements "he would like not to have it", "he gets a bit anxious sometimes", "I think she is upset", "she doesn't like it", or even "he hates it".

Similarly concerning the effects asthma had on the children's lives parents' responses were very varied. Six parents reported that the disease did not prevent the child from doing anything. This was reflected in the statements such as “nothing stops him. He does not moan or anything”, “he doesn’t moan. He gets on with it if he does get a cold or a cough”, “he can do everything. It isn’t holding him back at all”, and “it does not stop him from doing things, he might cough a lot”.

However, nine parents did report negative effects on their children’s lives which were treatment and symptom related like “he gets annoyed because he can’t do certain things because he gets breathless”, “he feels embarrassed of using his inhalers in public”, “he is not happy with it because he likes playing football and he can’t do it all the time, because he gets wheezy. He wishes it will go away one day”, or “I think he has had enough of hospitals”.

4.4.1.7 Parent’s Perception of the Child’s Treatment Adherence

There were two types of comments regarding treatment adherence: to which extent parents thought that their children were following it and difficulties with it. Parent’s perception of the child’s treatment adherence was assessed through the following five criteria which derived from the interviews: 1) knew what asthma was and what the treatment was for, 2) knew what to do when he had symptoms, 3) was able to do the treatment by himself (administer the inhaler and peak flow) and did not need supervising or help, 4) did not need reminding when to take medication, and 5) had no problems/difficulties regarding the treatment regimen. One parent reported that her child met all of the above criteria, seven parents reported their children met four of the above five criteria, two parents reported that their children met three, four parents reported that their children met two and one parent reported that her child only met one.

With reference to difficulties with the treatment regimen parents reported “when she is coming round (hospital) she does get frustrated, because whenever she had to come to hospital with her chesty things she had to rely on oxygen ... that does get her down and she gets more aware". Two parents mentioned the problem of calming their children down. One explained "calming (the child) down sometimes (is a problem). Sometimes he's got to be told off that he's got to sit down." The other parent explained "the hyper-activeness. Usually I just shout at him and he will sit down". One mother described "he used to hate taking the nebuliser. He used to scream and fight me not to have the asthma pumps. But now as he has grown old he is used to having them". Another parent reported that "taking the steroid tablets" was a problem. Lastly, one mother brought up "she has this terrible cough and we cannot get rid of it".

One parent also described a more serious instance "when he has an (asthma) attack I have to take him to the clinic to get nebulised because the pumps don't work".

4.4.1.8 Parent's Perception of the Child's Openness About the Disease

As in the case of the children themselves, the parent's perception of the child's openness about the disease emerged as an independent theme.

Twelve parents reported that their children were open about their asthma and did not mind being asked about it or reminded of it whereas one parent reported that the child got very upset talking about it. Two parents were not sure and explained "it depends, sometimes she talks about it and sometimes if they are talking about things like that she says I don't want to listen. So it depends on what sort of mood she is in, sometimes you can talk about anything with her and she will be fine and other times she says no I don't want to listen", and " he's a bit embarrassed in front of his friends".

4.4.1.9 Parent's Attitude About the Treatment and Precautions

Under this theme parents reported which precautions they took to manage their children's disease.

All parents reported that they had notified the school about the child's asthma. The majority of parents (12) ensured that the child had an inhaler at school and/or the teachers knew what to do when the child had symptoms. Additionally most children were carrying their inhaler with them all the time.

Parents reported the following extra precautions concerning their children's treatment 1) taking the child regularly to the asthma clinic as recommended by health professionals, 2) avoiding the child to be in contact with furry animals, 3) not letting the child sleep-over at a friend's house in case the child became unwell (asthma symptoms) because the other parents would not know how to react, and 4) not letting the child go to birthday parties or sports-days on their own. Parents' attitudes regarding these precautions were very varied. While one mother said "even if he's not poorly I still take him regularly every couple of months (to the asthma clinic) and make sure everything is alright". Another mother replied "we tend to only go when his asthma is not very good; we are not very good attenders".

Furthermore, most children were not allowed to go near furry animals as these could trigger an asthma attack. Due to these restrictions of the treatment regimen some parents tried to find alternatives. For instance one mother said "he is desperate for a dog... we got the fish" or "we have got tropical fish, which she has chosen herself and we have said we will have a tortoise".

Most parents when asked if their child was allowed to sleep-over at a friend's house would reply "I don't let him sleep over at anybody's house" or "he hasn't had any stay-overs with friends, just with family, and they all know how to use the asthma pump and his nebuliser". Most parents would let their children go to birthday parties and sports-day by themselves and just notified the parents or the teachers of the child's asthma. The only precaution they would take is "when he goes swimming or sports or anything he has to take his asthma pump with him". One of those few parents who would accompany her child replied "birthday parties I go with her, I think a lot of mums tend to not wanting me to leave, they always want me to stay, they don't want me to leave her."

Some parents had additional worries concerning the child's asthma when other people (e.g. teachers) were in charge of the child's care. One mother explained "we had a recent incident whereby he was being brought to another school to swim in a gala and they could not find his inhalers, but they were in the sports bag and he became very breathless, he was panicking ... so that's been a worry that that sort of thing can happen so quickly and a sports teacher does not understand not to go with somebody wheezing" or "I do get a bit concerned sometimes if he feels really unwell and I go and pick him up and I feel concerned that maybe the teacher wasn't told. To make him sit in class when he is really unwell. I can understand the school's point of view because they are worried about him being behind but then your health comes first".

4.4.1.10 Parent's Perception of the Impact of the Illness

Three aspects emerged under this theme: the impact of the child's illness on the family life, on the child's school performance, and on the child's friendships.

Three parents reported that the child's asthma had no negative impact on the family life and that after diagnosis of the child no changes within the family were needed. Nine parents stated that the asthma had an impact on the family life and changes had to be made but that these did not cause any stress or problems. Only three parents reported that the child's asthma has had an impact on the family life and that the necessary changes caused problems. One problem a mother described was that she was constantly scared of her child having an asthma attack and tried to avoid anything (e.g. pets, painting work, smoke of the cars, pollution) that might trigger an asthma attack. Another mother reported that they had to get rid of their pets.

Regarding the child's school performance, 11 parents reported that they were happy with the progress and four revealed that their children were behind in school. Twelve parents reported that they thought their children were happy with how they were doing at school academically. Three parents thought that their children were not happy with their school performance and reported "he reached a stage where he says 'mom I can't read and mom I can't spell' so he is a bit anxious", "she is very much a worrier...subjects she is not enjoying so much she worries about, like spelling or reading she does get frustrated there", and "he does get a bit upset about it".

All parents reported that their children did not have any problems regarding friendships i.e. they had many friends and best friends.

4.4.1.11 Conclusion of the Content Analysis

The content analysis of the child and parent interviews allowed for an identification of stressors children with asthma had to cope with. Children reported treatment related stressors which included using inhalers, having to do the peak flow meter over and over, having to drink medicine, and having to go to hospital. Other stressors were symptom related and included not being able to run for longer periods, not being able to do certain sports (e.g. play football), and coughing all the time. However, some children mentioned positive aspects of having asthma which were getting days of school because of the asthma.

Parents mentioned the same treatment and symptoms related stressors but brought up further stressors that children had not talked about.

These included treatment related stressors which were the child being embarrassed of using the inhaler in public and calming the child down. Parents also reported a symptom related stressor in having to go to hospital for every asthma attack as the inhalers were not able control and stop the symptoms.

Overall, the combined reports of children and parents gave an insight into how these children coped with these additional stressors of having asthma and to which extent their lives were affected by them as well as their general feelings towards the illness. The analysis revealed that there were commonalities in stressors across children but differences in adjustment i.e. variability in how children perceived the limitations imposed by the illness.

The content analysis also revealed which parts of the treatment regimen children found difficult to adhere to which aspects were easy to follow. In this context it was found that there were differences in the extent to which children perceived the treatment regimen is interfering with their lives, which resulted in varying levels of treatment adherence.

Furthermore, children provided information on the extent they felt normal and were treated normally by their parents. They provided information on how open they were about having the illness, if they liked talking about it with everyone, or only with specific people or not at all.

The parents' interviews provided further information on the same issues but from a different perspective.

4.4.2 Development of a Scoring Scheme to Quantify Children's and Parents' Responses

Analyses of interviews by theme as implemented so far provided a picture of children's and parents' impressions about the child's illness, which was valuable for understanding their situation. In order to use the interview data more systematically, though, it was necessary to develop a scheme to score the categories containing all the children's and parents' responses for each theme.

To develop a scoring system for the existing child and parent categories, Guilford (1971) recommended the construction of definitions and cues i.e. to develop cues for anchoring the different points on a scale. He emphasized the importance of labelling the extremes of a scale adequately to support appropriate observation. This would allow for other observers who used the categories to attach the same meaning to these different points. Thus, utilizing the previously created content categories for children and parents anchoring points were developed which were clearly defined. NVivo assisted in this process by providing an output by theme i.e. a summary of what each person reported under a theme (category), which was printed out for each category. Scoring was achieved by grouping all the information relevant to each category in each interview and attributing a score between 1 and 5 (with 1 the least positive and 5 the most positive outcome) whenever possible. According to Guilford (1971) if there were too few steps a scale would become too coarse and a great extent of the discriminative powers of raters would be lost, whereas if a scale was too finely graded it would be beyond the raters' limited powers of discrimination.

Some empirical evidence addressing the issue of the right number of steps in a scale was found by Conklin (1923, cited in Guilford, 1971, p289). He carried out an analysis of 23,000 rating scales and concluded that the number of steps that was best handled by untrained researchers was five. However, for trained observers (i.e. the average inter-rater correlations were in the region of .55 to .60) a seven-point scale was seen as optimal. On the basis of this finding a 5-point scale was used in the judgment of the categories because the researcher was working with interview ratings that had not been used until that time. However, for the categories “Child’s openness about the illness” and “Parent’s perception of the child’s openness about the disease” a 3-point scale was used because the information available did not allow for finer discriminations.

As it was recognized that this method was based on the judgment of a single researcher, independent scorings were also obtained from a second researcher and the percentage of agreement between both researchers was examined. Therefore, another copy of all the outputs by theme was printed out for the second researcher to score by using the anchoring points developed by the first researcher. The first researcher rated all children’s and parents’ categories whereas the second researcher independently scored five randomly selected children and parents for each category. As the second researcher scored five of the four children categories and five of the six parent categories she made a total of 50 judgments. The percentage of agreement was calculated for the scorings of both researchers and if disagreement occurred it was explored if the scorings were adjacent. For nine judgments there was disagreement between the two researchers but in all cases the scores were adjacent. Thus there was an 82% percentage of agreement between the two researchers.

Listed below are, as recommended by Guilford (1978), the descriptions of the anchoring points for each category that were developed in order make these judgments with each of them being followed by a table showing the frequencies for each of the five ratings.

1. "Child's perception of normality" was judged on a five-point scale with 5 being the most positive outcome i.e. the child felt very normal. The highest rating 5 was given when 1) the child felt that there was no difference between a child with asthma and a child without the disease; 2) the child felt that parents were not too careful with the child; 3) child felt that parents treated the child the same as they treated the other sibling(s) or other parents treated their children. Rating 4 was given if one of the above three criteria did not apply. Rating 3 was given if one of the criteria did not apply as well as one of the others sometimes. Rating 2 was given when two of the criteria did not apply for the child and rating 1 if none of them applied.

Table 4.6 Frequencies of each rating for "Child's perception of normality"

Rating 1	Rating 2	Rating 3	Rating 4	Rating 5
0	5	2	6	2

2. "Parent's perception of the child's normality" was also judged on a five-point scale with again 5 being the most positive outcome. Rating 5 was given when 1) the parent never thought that s/he is being too careful with the child; 2) parent felt that child did not think that parent treated him differently to other children or was being too careful. Rating 4 was applied when parent reported that 1 or 2

applied sometimes. Rating 3 was given when parent reported 1 or 2 and rating 2 when parent reported 1 or 2 together with 1 or 2 sometimes. Rating 1 was given when both 1 and 2 did not apply.

Table 4.7 Frequencies of each rating for "Parent's perception of the child's normality"

Rating 1	Rating 2	Rating 3	Rating 4	Rating 5
3	0	3	2	7

3. <u>"Child's feelings about the disease"</u> was again assessed on a five-point scale with rating 5 being given when 1) child felt positive about the illness now; 2) child thought that there was something nice about the illness; 3) there was nothing the child did not like about the illness; and 4) child thought there was nothing s/he was not allowed because of the illness. Rating 4 was attained when any 3 aspects were met, rating 3 when 2 aspects were met, rating 2 when only one aspect applied, and rating 1 when none of the 4 aspects applied.

Table 4.8 Frequencies of each rating for "Child's feelings about the disease"

Rating 1	Rating 2	Rating 3	Rating 4	Rating 5
3	2	3	6	1

4. <u>"Parent's perception of the child's feelings"</u> was also judged on a five-point scale. This category was judged on the basis of the following: 1) parent thought that child felt positive about the illness and coped well; 2) parent thought that

child did not perceive the illness as preventing him/her from anything; 3) parent found alternatives when child was not allowed to do or to have something because of the illness; and 4) there were no problems with or bad feelings about the treatment. Rating 5 was given when all 5 aspects were met and rating 4 when 3 of the 4 aspects were met. Rating 3 was given when parents reported that 3 of the 4 applied jointly with 1 of the other 3 only sometimes. Rating 2 was given when only 2 of the 4 applied and rating 1 when 1 or none applied to the parent.

Table 4.9 Frequencies of each rating for "Parent's perception of the child's feelings"

Rating 1	Rating 2	Rating 3	Rating 4	Rating 5
2	6	1	3	3

5. <u>"Child's treatment adherence"</u> was again judged on a five-point scale with 5 being the most positive outcome i.e. the child was very compliant with the treatment. The highest rating (i.e. 5) was given when 1) the child knew which medication to take and when; 2) child took the medication everyday or when needed everyday e.g. hay fever season; 3) child knew symptoms; 4) child knew how to react upon symptoms but needed help from a caregiver; 5) child knew how to react upon symptoms (e.g. take inhaler) without any external help from a caregiver; and 6) child did not like some aspects of the treatment but still adhered to them. Rating 4 was given when 5 of the 6 applied to the child, rating 3 when 4 applied, rating 2 when 3 applied and rating 1 when 2 or less applied to the child.

Table 4.10 Frequencies of each rating for "Child's treatment adherence"

Rating 1	Rating 2	Rating 3	Rating 4	Rating 5
2	0	2	3	8

6. "Parent's perception of the child's treatment adherence" was assessed through the following five judgments: 1) parent reports that child did not need reminding when to take medication or do a medical test (peak flow meter); 2) parent reports that child knew what the treatment was for; 3) there were no problems with the treatment; 4) parent reports that the child knew what to do when s/he had symptoms; and 5) child was capable to do the treatment by himself/herself and did not need supervising. Rating 5 applied when all 5 criteria were met, rating 4 when 4 of the 5 were met, rating 3 when 3 were met, rating 2 when 2 were met and rating 1 when only 1 were met.

Table 4.11 Frequencies of each rating for "Parent's perception of the child's treatment adherence"

Rating 1	Rating 2	Rating 3	Rating 4	Rating 5
1	4	2	7	1

7. "Child's openness about the illness" was judged on a 3-point-scale even though it is recognized that three steps might be too coarse (Guilford 1971). However, the information available did not allow for finer discriminations: Rating 3 indicated that the child never minded talking about diabetes and did not keep

it to himself/herself; Rating 2 indicated that the child only sometimes liked to talk about asthma and occasionally kept it to himself/herself; Rating 1 indicated that the child did not like talking about asthma and rather kept it to himself/herself.

Table 4.12 Frequencies of each rating for “Child’s openness about the illness”

Rating 1	Rating 2	Rating 3
2	3	10

8. <u>“Parent’s perception of the child’s openness about the illness”</u> was the other judgment that used a three-point scale because again the information available did not allow for finer discriminations: Rating 3 indicated that the parent thought that the child did not mind being asked or reminded about the illness at any time; Rating 2 indicated that the parent thought that the child sometimes did not like to be asked or reminded about the illness but was comfortable with it at other times; Rating 1 indicated that the parent thought that the child did not like to be asked or reminded about the illness.

Table 4.13 Frequencies of each rating for “Parent’s perception of the child’s openness about the illness”

Rating 1	Rating 2	Rating 3
1	3	11

9. <u>“Parent’s attitude about the treatment and precautions”</u> was assessed on the basis of the following six judgments: 1) school (teacher and/or friends) were

informed about the illness; 2) child had medication at school or school knew what to do when child had symptoms; 3) parent had no worries; 4) child always carried medication with him/her <u>or</u> had medication before leaving home; 5) additional precautions were taken (e.g. child regularly attended the asthma clinic, child was not allowed pets; 6) child was not allowed to sleep-over at a friend's house <u>or</u> to go to sports-day on his/her own <u>or</u> to go to a friend's birthday party on his/her own. Rating 5 applied when all 6 criteria were met, rating 4 when 5 of the 6 were met, rating 3 when 4 were met, rating 2 when 3 were met and rating 1 when only 2 or less were met.

Table 4.14 Frequencies of each rating for "Parent's attitude about the treatment and precautions"

Rating 1	Rating 2	Rating 3	Rating 4	Rating 5
2	6	3	1	3

10. <u>"Parent's perception of the impact of the illness"</u> was assessed through the following five judgments: 1) parents were happy with the child's school progress and child was not academically behind in school; 2) child was happy with his/her school progress; 3) child had no problems with friendships; 4) child's illness had an impact on the family life and there were changes but these did not cause stress or problems; and 5) the child's illness had no impact on the family life and there were no changes because of the illness. Rating 5 was given when all 5 criteria applied, rating 4 when 4 of the 5 applied, rating 3 when 3 of the 5 applied, rating 2 when 2 applied , and rating 1 when 1 or none pertained.

Table 4.15 Frequencies of each rating for “Parent’s perception of the impact of the illness”

Rating 1	Rating 2	Rating 3	Rating 4	Rating 5
1	2	2	8	2

4.4.3 Concordance Between Child and Parent Reports in the Interviews

As the literature repeatedly stressed the importance (e.g. Eiser and Morse, 2001) of asking paediatric patients directly about how they perceive the limitations imposed by the illness on their QoL rather than only relying on their parents’ reports, this study interviewed children directly about their views. In this context, Ravens-Sieberer and Bullinger (2001) emphasized that another individual’s impression concerning a patient can neither be taken as a proxy nor as equivalent information, but rather as a separate source of information about the patient’s QoL. Thus, the parents of these children were interviewed to provide information from a different perspective. The aim was to include both parallel ratings by the children themselves and a proxy (parent) to compare both responses.

In order to investigate concordance between both perspectives, the scorings above of children’s and parents’ categories were utilized to conduct a correlational analysis between children’s and parents’ reports. Spearman’s correlation coefficient (2-tailed) was used as the data was ordinal and ranked. As there were only four children scales, they were correlated with the corresponding four parent scales and the two additional parent scales had to be excluded from this analysis.

Table 4.16 Correlations between parents' and children's interview scales

Parent Scale (n=15)	Child Scale (n=15)	Correlation
Parent's perception of the child's openness about the disease	Child's openness about the disease	0.712*
Parent's perception of the child's life feelings	Child's feelings about the disease	0.608*
Parent's perception about the child's normality	Child's perception of normality	Not significant
Parent's perception of the child's treatment adherence	Child's treatment adherence	Not significant

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

As can be gathered from table 4.14, parents' account about how open their children were about the illness and their children's feelings about the disease converged with the children's own account. The finding that children's and parents' reports converged for children's openness about the disease could be explained in terms of these domains being behaviour-related and therefore easier for parents to evaluate. For example a child who was not open about his/her asthma would be embarrassed to use the inhaler in public or would try to avoid answering questions about the illness.

Surprisingly, children's and parents' reports converged for the children's feelings about the illness even though this domain reflected the children's emotion. One interpretation of this finding could be that children with asthma share their feelings about the illness with their parents. However, children's and parents' reports differed regarding the children's treatment adherence and to which extent children felt normal and being treated normally. One explanation for why children's and parents' reports diverged for the children's treatment adherence might have been the fact that the children of this sample had varying levels of asthma severity ranging from mild and/or seasonal asthma to moderately severe asthma but no cases of severe asthma. Therefore, parents of children with milder forms of asthma might not have been too involved in the daily treatment regimen as minor non-adherence (e.g. omitting the use of the preventative inhaler) of the child was unlikely to have caused serious medical consequences. One explanation for why children's and parents' reports diverged for the children's perception of normality might have been the fact that this category fell under a domain that reflected the children's feelings and emotions and hence might have been more difficult for parents to appraise. Thus, parents' reports might have been biased by their life perspective, demonstrating that proxy ratings in the form of parent ratings did not provide a comprehensive picture about their children's treatment adherence and in how far they felt normal and being treated normally.

4.4.4 Comparison Between the Adjustment of a Well Adjusted and a Poorly Adjusted Child

In the subsequent section two case studies were presented to illustrate the differences in children's adjustment to asthma. Two extreme cases were chosen which included one case in which the child was very well adjusted to the illness and another case in which the child was very poorly adjusted. In order to carry out this comparison one child with high scores in each of the scales and one child with low scores in each of the scales of the interview were selected.

R. was 10-years-old when she was interviewed and suffered from moderate asthma. She had high scores for all four scales.

Regarding her perception of being normal she was asked if a child with asthma was different to other children. She replied "no, not really because a child with asthma is the same as a child without asthma, they just have to take pumps and all of that". When asked if she thought that her parents were too careful with her, she replied "not really because my mum just lets me get on with what I want to do the same as my dad". To the question if her parents treated her differently to her siblings she answered "no not really because we all get treated the same. If my mother goes out and buys my brother something she will buy everyone something".

Concerning her feelings towards asthma she had accepted the illness by saying "well, it doesn't really bother me because I can get on with things I want to do, but if I run around a lot I will have to take my pump, so it's quite okay with me. At first it is very upsetting that you have got asthma but then you learn that this is something you have got and you got to live with it". When asked if there was anything positive about having asthma she answered "there is because you have to come here and then you get out of school". When asked to list all the negative aspects of having asthma she described "well, waking up with a bad taste, having to take time off school, having to come here and take a peak flow and keep up my weight and my height measured".

With reference to treatment adherence, she explained "well with my pumps Flexitide and Serofine the one together I have to take twice, in the morning and evening. My peak flow in the morning and then I take it again before I go to bed". When asked if she followed her treatment regimen everyday she answered "yes, except for sometimes I forget". When asked about symptoms of asthma she said "I get breathless and sometimes you can't breathe. I get wheezy". When asked what she did when she had symptoms of asthma she answered "when I get asthma and I am at school because I am allowed to take my pumps to school I have to leave them at the office. I tell one of my friends that I need my pumps and they will go and ask for them and the teacher will give them to them and they will give them to me". When asked if she can take the inhaler by herself without any help from a caregiver she replied "well I can take my pumps by myself but sometimes my friends will have to stay with me". When she was asked if there was anything she had to do that she did not like she said "I don't like the peak flow if you have to do it over and over again. The pumps I don't mind". When asked if she still did the peak flow even though she did not like it she replied "yes". When she was asked if she takes any precautions when she goes somewhere she answered "yes take my pumps everywhere with me".

Regarding openness about the illness she answered "I don't really mind because it doesn't really bother me". When she was asked if she rather kept it to herself she replied "no, all my mates in school know that I have got asthma because some of my mates have got it as well so it's easy for us to talk".

A. was nine-years-old when he was interviewed and suffered from moderately-severe asthma. He had low scores for all four scales.
Regarding his perception of being normal he was asked if a child with asthma was different to other children. He replied "yes, children with asthma will get tired more quickly than the other people". When asked if he thought that his parents were too careful with him or treated him differently to his siblings, he replied "no".

Concerning his feelings towards asthma he had not accepted the illness and said "I am bothered by it. I don't like it". When asked if there was anything positive about having asthma he answered "no there is nothing nice because it starts making me cough and I am not allowed to go to school". When asked to list all the negative aspects of having asthma he described "it makes me cough and it's stopping me from playing football and all my sports".

With reference to treatment adherence, he explained "I have to use my asthma pump twice a day and I have to take a medicine each night". When asked if he followed his treatment regimen everyday he answered "yes". When asked about symptoms of asthma he said "I feel like my neck is clogging up and I start breathing faster. That's it". When asked what he did when he had symptoms of asthma he answered "I use my asthma pump and try to relax". When asked if he can take the inhaler by herself without any help from a caregiver he replied "I can do it by myself". When he was asked if there was anything he had to do that he did not like he said "I don't like drinking my medicine. When I play football I have to stop and I don't like stopping. Running. I don't like that when I am running having a rest". When asked if he still took his medicine every night even though he did not like it he replied “yes”. When asked if he took any precautions when he went somewhere he answered “yes I have to remember to take my asthma pumps and I have to remember not to run too fast”.

Regarding openness about the illness he answered “I don’t like talking about it”. When he was asked if he rather kept it to himself he replied “yes”.

4.5 Overall Conclusion

The content analysis of the child and parent interviews provided an insight into how children with asthma coped with the added stressors the illness inflicted on their lives and to which level their lives were affected by it along with their general feelings towards the illness. The analysis showed that there were commonalities in these stressors across children but differences in adjustment that is variability in how children perceived the limitations imposed by the illness. Children reported treatment related stressors which included using inhalers, having to do the peak flow meter over and over, having to drink medicine, and having to go to hospital. Other stressors were symptom related and included not being able to run for longer periods, not being able to do certain sports (e.g. play football), and coughing all the time. Parents mentioned the same treatment and symptoms related stressors but brought up further stressors that children had not talked about. These included treatment related stressors which were the child being embarrassed of using the inhaler in public and calming the child down. Parents also reported a symptom related stressor which was having to go to hospital for every attack as the inhalers were not able control and stop the symptoms.

Furthermore, there were some children who perceived a positive aspect of having asthma which were getting days of school because of the asthma.

The content analysis further revealed that there were differences in the extent children perceived the treatment regimen was interfering with their lives, which resulted in varying levels of treatment adherence.

Last of all children reported in how far they felt normal and were treated normally by their parents. They provided information on how open they were about having the illness, if they liked talking about it with everyone, with specific people or not at all.

Overall, the parents' interviews provided further information on the same issues but from a different perspective.

These content categories were then scored by a researcher and as it was recognized that this method was based on the judgment of a single researcher, independent scorings for five child and five parent categories were also obtained from a second researcher. The percentage of agreement between both researchers was examined and came to 82%.

Due to the high percentage of agreement between the two researchers, the scorings could then be used for the correlational analysis between children's and parents' reports.

The correlational analysis between parents' and children's reports showed that parents' account about how open their children were about the illness and their children's feelings towards the disease converged with the children's own account.

However, children's and parents' reports diverged regarding the children's treatment adherence and to which extent children felt normal and being treated normally. Thus, parents' reports were biased by their life perspective, demonstrating that proxy ratings (parent ratings) did not at all times provide a truthful description. Thus, even though parental beliefs were generally an important source of information when assessing chronically ill children's adjustment, this finding emphasized the importance of also taking into consideration children's own reports, as information obtained from both provided a more comprehensive picture.

The two case studies comparing the adjustment of a well adjusted and a poorly adjusted child illustrated once more the differences in children's adjustment to asthma.

The aim of the next study was to develop separate questionnaires for children with asthma and their parents. In order to develop these questionnaires, the children's and parents' content categories with their codings of this study were utilized to form statements to be included in the questionnaires.

Furthermore, the scorings of the content categories of this study were then used to validate the newly developed questionnaires once they have been administered to a larger sample of children with diabetes and their parents.

CHAPTER 5

STUDY 2 – DEVELOPMENT OF THE "CHILDREN'S ADJUSTMENT TO ASTHMA QUESTIONNAIRE"

5.1 Aim

The aim of this study was firstly to develop separate questionnaires for children with asthma and their parents to assess children's adjustment to the illness and their treatment adherence.

The second aim was to test the hypothesis of an association between children's adjustment to the illness and their treatment adherence, once the questionnaire has been analyzed and considered reliable.

5.2 Background

Paediatricians and health professionals who work with chronically ill children spend considerable amounts of time treating and monitoring the children's health.

It was argued in the introduction that contemporary definitions of health consider the child's well-being in a broad way i.e. they are not only restricted to physical but also to mental and social well-being. This bio-psychological approach to health has strongly influenced the development of the construct of Quality of Life of children (Wallander, 2001). Thus, in the case of children with asthma it has become very important to monitor their adjustment to the illness as high levels of stress can actually contribute to a child's physical symptoms. The treatment of asthma management is not only restricted to the administration of medication: it is to a large extent dependent on the behaviour of the paediatric patients and their families. They have to follow a very complex treatment regimen which involves taking medication on a regular basis, identifying and managing exacerbations and symptoms which can result in a serious asthma attack, and taking precautions to prevent asthma attacks by identifying and avoiding triggers. Thus, children with asthma are subjected to a large number of potential stressors and learning how to cope with these every day situations is crucial to the successful maintenance of the children's health and mental well-being.

The interviews with children and families reported in Chapter 4 (study 1) allowed for the identification of stressors introduced in the lives of these families and the ways the coped with them. The analysis also showed that there was variation in how children coped with these stressors and their perception of treatment adherence. This chapter describes how these results were used to design a measure to assess children's adjustment and treatment adherence.

5.3 Brief Overview of the Research Strategy

Separate questionnaires for children with asthma and their parents were developed on the basis of 1) an interview with a paediatric asthma nurse and 2) utilizing grounded theory on the children's and parents' replies to the interviews. The data from the children and parent questionnaires were subjected to a quantitative data analysis. Analysis of psychometric properties of the questionnaires included firstly, checking reliability by determining the internal consistency of each scale of the questionnaires as well as the internal consistency of the entire questionnaires.

Secondly, content validity, another psychometric property of a questionnaire was investigated by a panel of experts who evaluated the content and relevancy of the items for each child and parent scale. Those items that were not rated by four out of five experts as relevant were dropped from the questionnaire.

Thirdly, the concordance between the results from the interviews and the questionnaires was explored. The questionnaires for children and parents were designed on the basis of the same scales as were used to analyze the interviews. This allowed for an illness-specific approach in this chapter but also an illness-generic analysis later on.

Fourthly, the association between children's adjustment and illness severity, and the relationship between children's chronological ages and their overall adjustment was explored.

Lastly, an investigation of the relation between children's socio-emotional functioning and treatment adherence was conducted.

5.4 Method

5.4.1 The Sample

The clinical sample consisted of a total of 30 children with asthma and their parents. It included 8 girls and 22 boys with ages ranging from 7 years 1 month to 13 years 1 month and an average age of 10 years 1 month and their parents. The researcher used the term children to describe the total sample, but recognized that 13-year olds should be referred to as teenagers and not children anymore.

The researcher aimed at following up the 15 children that participated in study 1 by either approaching them when they attended a clinic at the hospital or contacting them by telephone. The researcher was able to follow-up 11 out of the 15 asthmatic children from study 1 and recruited 19 new asthmatic children in order to complete the total sample. As in phase one, with the help of the paediatric asthma nurse, children with autism, ADHD, and Down-Syndrome were excluded from the recruitment process. The sample was heterogeneous and consisted of 22 Caucasian, five Black and two Indian children and one Other (Chinese) child.

Once again with the help of the paediatric asthma nurse each child was classified into one of five asthma severity groups (mild, mild-moderate, moderate, moderately severe, and severe).

Table 5.1 Severity of Asthma in the Sample (*n*=30)

Mild	**Mild-Moderate**	**Moderate**	**Moderately-Severe**	**Severe**	**Total**
2	10	11	6	1	30

Table 5.2 Mothers' Education Levels, Occupations and Fathers' Occupations (*n*=30)

Mother's Education	**n**	**Mother's Occupation**	**n**	**Father**	**N**
GCSE or lower	18	Housewife	17	Class 1 (e.g. builder, delivery driver)	21
A-levels	6	Student	1	Class 2 engineer, IT consultant	3

Higher National Diploma	4	Class1 (e.g. shop assistant,	7	Student	0
Bachelor degree	2	Class2 (e.g. accountant, nurse)	5	Passed away	0
Master's Degree or higher	0	Class3 (e.g. lecturer)	0	No information	6

Parental Education levels and occupations are commonly used as an indicator of the families' socioeconomic status (e.g. Hollingshead, 1975). There are to the knowledge of the author no statistics to compare the proportion of families' SES of this study to the proportion of families' SES in the asthma population.

Parents' information on their SES (i.e. mothers' and fathers' education) was utilized to investigate whether it was associated with child adjustment, child treatment adherence, and parents' perception of the child's adherence. Spearman's non-parametric correlation (2-tailed) was applied since the responses were measured at the ordinal level and were ranked. There was no significant association between SES and child adjustment, child treatment adherence, and parents' perception of the child's adherence. It can be concluded that parents' SES did not have an effect on any of the three variables. Lastly, it was explored whether there was an association between SES and children's asthma severity. The literature suggests (e.g. Mielck, Retmeir, & Wjst, 1996) that prevalence of severe asthma is significantly higher in lower SES groups compared to higher SES groups. However, in this study using Spearman's non-parametric correlation (2-tailed) no significant relation was found between families' SES and children's asthma severity.

5.4.2 Development of the Questionnaires

The separate questionnaires for children and parents were developed on the basis of 1) information obtained from an interview with a paediatric asthma nurse and 2) using grounded theory (Charmaz, 2003) statements to be included in the questionnaire were generated on the basis of the replies of children and parents in the interviews.

The paediatric asthma nurse's interview schedule was generated by the author based on the literature and evaluated the children's experience of having asthma (Appendix 5.1). Specifically, the nurse's interview provided information from the professional's perspective and assessed the following domains in relation to the range of general responses they observed in medical environments: (1) the children's adjustment to medical environments (hospital and clinic), (2) distress during medical procedures, (3) children's coping with the treatment regimen and problems/issues, and (4) the children's coping with symptoms. For each theme the interview schedule included different questions around the same topic to ensure that responses were consistent.

On the basis of children's, parents', and nurses' replies in the interviews, child and parent questionnaires were developed by using grounded theory (Charmaz, 2003) to generate statements to be included in the questionnaires. "Essentially grounded theory methods consist of systematic inductive guidelines for collecting and analyzing data to build middle-range theoretical frameworks that explain the collected data. Throughout the research process, grounded theorists develop analytic interpretations of their data to focus further data collection, which they use in turn to inform and refine their developing theoretical analyses" (Charmaz, 2003, p. 509). In practice this meant that the researcher started through the process of coding to define and categorize data by creating codes. These codes and categories reflected as much as possible emerging ideas rather than simply describing topics. This enabled the researcher to analyze data rather than remain at the stage of ethnographic description. Initial coding started by utilizing line-by-line coding, in addition to building ideas inductively, which enabled the researcher to be neutral i.e. not to impose extant theories or the beliefs of the researcher on the data, which might have had little connection to the data. Initial codes that appeared repeatedly were then utilized to do selective or focused coding i.e. analyze large quantities of data. In grounded theory, ideas i.e. categories and codes are constantly refined to make them more definitive and useful, a process called theoretical sampling (Charmaz, 2003). In this thesis once the process of creating categories and coding references at them was finished the researcher browsed through each of these categories and compared the responses of children and parents. These experiences were used to form statements to be included in the questionnaires. Some adjustments were needed to ensure that statements were generally applicable and not too narrowly specified. Thus, statements that were too restricted and may not have applied to many children were changed to more general statements, to which all children could react genuinely. For example, a child said that his asthma restricts him from playing rugby and he felt angry about it. The word 'rugby' was replaced with 'sports', so that it is possible to assess how children react to feeling restricted in their participation in sports.

Additionally, it was ensured that the statements were phrased in a way that children and parents with a particular way of adjusting to the illness would agree with half of the statements and disagree with the other half. For example, a child who feels negatively about missing out in sports would agree with the statement "It is annoying that I have to stop playing or running when I get breathless" and disagree with the statement "I don't mind that I cannot run as much as other children". Also, it was ensured that each questionnaire item referred to just one issue in order to avoid situations where the respondent might agree with one part and disagree with the other. Finally, all statements that were taken from the original interviews and were in past tense were changed to present tense.

Additionally, in the parent questionnaire 10 items were added to assess parental style from the Parental Authority Questionnaire (PAQ; Buri, 1991). Bourque and Fielder (1995) recommend that, when a researcher wishes to design a new questionnaire, the best approach initially is to adopt items that are relevant and have already been tested by other researchers and adapt items when necessary. The literature already contains a questionnaire for investigating parental authority, which was subjected to content validation by an expert panel, has good-test retest reliability, shows some construct validity and does not appear to be subject to social desirability responding (Buri, 1991). This scale was assessed with high school and college students so it was necessary to adapt it for use with children. Some adaptation was also required because the scale refers to parental authority in general and the aim in this study was to explore the possibility of developing a scale to assess parental style with respect to illness management.

The PAQ is a self-report scale designed to measure Baumrind's typology of permissive, authoritarian, and authoritative parenting style for both mothers and fathers. It is a reliable 30-item, 5-point Likert scale, with 10 items per style. Buri demonstrated construct validity by testing the prediction that participants who agree with items that describe authoritarian parents would not agree with those items that describe authoritative parenting. The correlation between the authoritarian and authoritative items was r=-.48, which was significant at .005 level. Thus, these parents can be placed at different ends of the communication and warmth dimension: both take responsibility for the children's decision but authoritative parents encourage communication and authoritarian parents do not. In the adapted questionnaire, the items will be treated together so that a low score will indicate an authoritative parenting style and a high score will indicate an authoritarian parenting style.

Five items that assess authoritarian and five items that assess authoritative parenting style were adapted by the researcher for use of parents of children with asthma. The authoritarian items taken from the PAQ were 1) "Whenever my mother told me to do something as I was growing up, she expected me to do it immediately without asking any questions" which was changed into "I know what is good for him so when I tell him to do something that is part of his treatment, I expect him to do it immediately without asking any questions", 2) As I was growing up my mother let me know what behaviour she expected of me, and if I didn't meet those expectations, she punished me" was changed into "When I tell him to calm down because of his asthma and he does not, I punish him", 3) "As I was growing up my would get very upset if I tried to disagree with her" was changed into "I get very upset if he tries to disagree with me and starts a whole discussion", 4) "As I was growing up I knew what my mother expected of me in the family and she insisted that I conform to those expectations simply out of respect for her authority" was changed into "I expect from my child that he conforms to my decisions out of respect for my authority", and 5) "My mother has always felt that most problems in society would be solved if we could get parents to strictly and forcibly deal with their children when they don't do what they are supposed to as they are growing up" was changed into "All problems would be solved between mother and child if parents were strict with their children when they don't do what they are supposed to do". The authoritative items taken from the PAQ were 1) "My mother has always encouraged verbal give-and-take whenever I have felt that the family rules and restrictions were unreasonable" was changed into "I try and encourage verbal give-and-take whenever I feel that the treatment regimen and restrictions are too demanding", 2) "As I was growing up, once family policy had been established, my mother discussed the reasoning behind the policy with the children in the family" was changed into "When he wants to go somewhere where he should not because of his asthma, I discuss with him the reasons behind it", 3) "As I was growing up I knew what my mother expected of me in my family, but I also felt free to discuss those expectations with my mother when I felt that they were unreasonable" was changed into "I let my child feel free to discuss my decisions if he feels that they are unreasonable", 4) "As I was growing up, my mother seldom gave me expectations and guidelines for my behaviour" was changed into "I try not to have too high expectations of him, I just encourage him to do his best", and 5) "As I was growing up, if my mother made a decision in the family that hurt me, she was willing to discuss that decision with me and to admit it if she had made a mistake" was changed into "If I make a decision, I am willing to discuss it with him and admit if I made a mistake".

These statements were inserted randomly into the questionnaire and participants indicated their level of agreement on a 5-point scale ranging from 'strongly disagree' to 'strongly agree'. A 5-point scale was again chosen given Guilford's (1971) recommendation that the maximum number of steps for untrained raters should be five for a single (unipolar) scale. It can be assumed that the children in this sample were definitely untrained raters and most if not all parents too.

The parent's questionnaire consisted of 93 items; the items from the seven scales were randomly ordered in the questionnaire. These included 18 items from the "Parent's perception of the child's normality" scale, 17 items form the "Parent's perception of the child's treatment adherence" scale, 13 items from the "Parent's perception of the child's feelings" scale, 5 items from the "Parent's perception of the child's openness about the disease" scale, 19 items from the "Parent's perception of the impact of the illness" scale, 11 items from the "Parent's attitude about the treatment and precautions" scale, and 10 "Parental style" items. The parent version was administered using pen and paper format and there were two versions: one for parents of girls and one for parents of boys (Appendix 5.2 for parents of girls and 5.3 for parents of boys).

In addition, to the information provided by the questionnaire, parents were also asked to complete questions about demographic information (the father's and mother's occupation, and the mother's schooling in order to determine the SES of the family), the type of medication the child was on, whether the child used medication all year around, the number of asthma attacks the child had in the last two years and how many of these required hospitalization, and whether the child suffered from other diseases or allergies.

The child questionnaire contained 50 items, which were randomly ordered from the four scales. These included 11 items from the "Child's perception of normality" scale, 21 items from the "Child's treatment adherence" scale, 13 items from the "Child's feelings about the disease" scale, and 5 items from the "Child's openness about the disease" scale.

The items were developed through the qualitative analyses of the interviews, as described earlier on, and were subsequently analysed from a theoretical perspective. This theoretical analysis was important for the interpretation of the results but also for later use, when the items were presented to the expert panel. A fuller theoretical analysis is presented here. An abbreviated version was presented to the expert panel (see Appendix 5.6).

Listed below are the conceptual definitions of the child and parent scales.

"Child's Perception of Normality"

The World Health Organization (1980) makes a distinction between the definition of impairments, disabilities, and handicaps. Impairments refer to any loss or abnormality of psychological, physiological or anatomical structure or function whereas a disability is defined as the "consequence of an impairment". Handicaps relate to the "social disadvantage of a disability" and restrict or prevent the individual of the achievement of normal roles (Liptak, 1987). In the context of children with chronic illness a practical example would be to consider a child with a tumour in the leg. This child would need surgery to amputate the leg which would result in a visible disability. The literature suggests that the implication of this handicap i.e. the individual's deviation from the norm is defined by the social and physical environment and hence is a product of the society. Thus, this child could over time either become isolated from healthy peers or integrated with other children with comparable life circumstances (Eiser, 1993). Also the role of parents is important as they might limit the freedom of a child with a chronic illness to go out alone or discourage certain activities which they perceive to be associated with the potential for injury or accidents. Thus, the aim of this scale was to assess the child's notion of normality i.e. whether the child felt different because of the disease or the same to other children. The scale included statements that reflected 1) the child's own perception of being normal or different to other children and 2) whether or not the child felt that s/he was treated normally by the mother/parent (e.g. mother is or is not too careful when the child wants to do normal everyday activities).

"Parent's perception of the child's normality"

The concept of this scale was the same as for the "Child's Perception of Normality" but this time assessed from the parent's perception of the child's feelings. Items used in one previously developed instrument are presented below.

"Child's Openness about the Disease"

The aim of this scale was to assess a child's disclosure about the illness. The scale included statements about whether the child liked or disliked talking about his/her disease i.e. whether the child was open about it or rather the fact that s/he had the disease to himself/herself. There were also indirect statements that implied disclosure e.g. whether the child informed or allowed others to be informed (e.g. friends, school) about the illness.

"Parent's perception of the child's openness about the disease"

The concept of this scale was the same as for the "Child's Openness about the Disease" but this time assessed from the parent's perspective of the child's willingness to disclose the illness.

"Parent's perception of the impact of the illness"

The aim of scale was to assess the parent's views of the impact of the illness on the child's social environment, rather than on the child him/herself. This theme was raised by parents in the interviews.

"Parent's attitude about the treatment and precautions"

The aim of this scale was to assess whether parents perceived themselves as playing a role in the children's treatment and how they thought this role should be played. This theme was raised by parents in the interviews.

"Child's Feelings about the Disease"

QoL is defined as "a multidimensional concept that includes the broad areas of functional status, psychological and social well-being, health perceptions, and disease - and treatment-related symptoms" and also includes "non-medical related aspects of a person's life such as the influence of jobs, family, friends, and other living circumstances" (Koot & Wallander, 2001, pp. 5-6). QoL includes objective as well as subjective perspectives. Socio-emotional adjustment represents a major psychological aspect of quality of life in chronically ill children and is an essential component of the definition of health. Socio-emotional adjustment focuses on the child's subjective perception of and feelings about his/her circumstances rather than an objective standard. Thus, in the context of chronic illness, adjustment refers to the child's perception of the extent to which the illness and the treatment interfere with his/her life i.e. the child's general feelings about the illness.

The scale included statements that reflected 1) whether the child had accepted the illness or not (i.e. had the child positive or negative feelings towards the illness) 2) how the illness affected the child's life and the child's feelings about these changes (e.g. having to follow a strict treatment regimen) 3) The child's feelings about situations when the child had difficulties following the treatment regimen.

"Parent's perception of the child's feelings" The concept of this scale was the same as for the "Child's Feelings About the Disease" but this time assessed from the parent's perspective of the child's feelings towards the illness.

"Child's Treatment Adherence"

According to La Greca and Schuman (1995), the most widely cited definition of compliance is Hayne's (1979): the extent to which a person's behaviour coincides with medical or health advice. However, La Greca and Schuman point out that most measures do not actually measure a person's behaviour in relation to a prescribed regimen. In complex treatment regimens, such as those for asthma and diabetes, measures that are appropriate for short term treatment regimens, such as counting the number of pills taken, cannot be used.

In light of the above the scale assessed the extent to which the child perceived specific treatment adherence behaviours as intrusive i.e. the child's actual behaviours in relation to the prescribed regimen. For example, children with asthma have a potentially lower stamina and get out of breath quicker when they run for long periods of time. A child who likes doing sports (e.g. participating on sports-day) would feel that the disease is restricting him/her to a much larger extent than a child who does not like running and sports very much and would consequently perceive the illness as much more intrusive. Children with diabetes on the other hand are only allowed very small quantities of food containing sugar. Thus, a child who likes eating sweets and chocolates would feel that the disease is restricting him/her more than a child who does not like sweets and chocolates very much and would consequently perceive the illness and its restrictions as much more intrusive. Consequently, the scale assessed the child's feelings regarding specific aspects of the treatment regimen in contrast to the scale "Child's Feelings about the Disease" which assessed the child's general feelings about the illness and the restrictions.

The scale included statements that reflected 1) whether the child followed his/her treatment regimen (did the child know the precise treatment regimen i.e. which medication to take and how often, did the child know the symptoms of the disease and how to react to them or needed help from someone, was the child honest to the parent about following the treatment regimen) and 2) situations where the illness, the treatment, or the symptoms caused stressful situations and the child's feelings about them e.g. because of symptoms or because of treatment restrictions.

"Parent's perception of the child's treatment adherence"

The concept of this scale was the same as for the "Child's Treatment Adherence" but this time assessed from the parent's perspective of the child's treatment adherence.

All the child and parent scales were then evaluated by a focus group consisting of a group of developmental psychology research students. Focus groups are one step in a process of qualitative item development and review prior to quantitative item testing (Walsh, Irwin, Meier, Varni, & DeWalt, 2008). Each focus group member was sent the scales including the questionnaire items by e-mail and they were asked to evaluate 1) the phrasing i.e. the clarity of the items 2) the item content i.e. the relevancy of each item and 3) the comprehensiveness i.e. whether each scale was sufficient to represent the entire content domain or whether it was necessary to add or delete items. Then a meeting was organised in which the researcher met with all the focus group members and each item of the scales was discussed and possibly changed in the light of the above three criteria.

The child questionnaire was administered in a computerized format, showing one statement at a time on colourful backgrounds with two break images to allow the children a little gap (Appendix 5.4). The option of having a laptop computer-delivered questionnaire over of a pen-and-paper version was chosen to try and avoid children being overwhelmed by the relatively high number of statements. As most children engage well with computers, it was thought that this would make taking part more interesting, instead of the usual procedure of simply marking their replies on paper. An additional benefit of this computerized method of data collection is that children's responses are automatically scored and saved.

In order to check if each questionnaire item was easy and clear to understand for children between seven and twelve years of age, a pilot study was conducted administering the child questionnaires to two healthy children (one boy aged seven, and a girl aged ten) separately. Throughout completing the questionnaire each child was gently invited to ask questions when something was not clear to him/her, or if there were any other queries. Neither of the two children had difficulty understanding any of the questionnaire items and consequently no changes were made to the initial wording.

The child asthma questionnaires were developed on the basis of interviews with children with asthma between the ages of seven and twelve years, so the newly developed questionnaires were designed for the same age range. They would only be appropriate for this age group because in different age categories different aspects of daily life are relevant. Also, the understanding of questionnaire items and the cognitive development of children differ according to age group. Thus, within this limited age range of seven to twelve years, daily activities belonging to this particular age group can be defined explicitly and do not diverge to a large extent because of developmental similarity.

The child and parent scales were utilized later in the data analysis of this chapter to check 1) the reliability of the questionnaire by determining the internal consistency, 2) the content validity of the questionnaires via an expert panel, 3) the concordance between interview and questionnaire data, 4) the association between children's adjustment and asthma severity, 5) the association between children's adjustment and their chronological age, and 6) the main hypothesis of an association between children's adjustment and treatment adherence.

5.4.3 Procedure of the Questionnaire

The process of recruitment was identical to the previous study. After parents and children gave their consent to take part the researcher administered the questionnaire to the parent first. This was done because the parent questionnaire was more time consuming than the child questionnaire and once parents understood the instructions regarding how to respond to items they could complete it independently. This also enabled the researcher to give the child her undivided attention. Additionally, and most importantly this procedure avoided any influence of the parent on the child's responses or vice versa and hence clearly separated the report from the child from the report of the parent.

The questionnaire contained instructions about how to complete it but, to ensure maximum care in the responses, the researcher also explained verbally to the parent to read each of the statements and select a response that best applies to them on a 5-point-Likert Scale ranging from entirely agree (1) to strongly disagree (5). Lastly, the researcher explained to the parent that if s/he is not sure about any statements to leave them unanswered and continue to the next statement and that the researcher would clarify those statements with him/her after she had helped the child completing the questionnaire. The researcher then attended to the child and asked him/her to take a seat in front of the computer screen and the researcher sat along side them. The child was asked to read the instructions on how to complete the questionnaire, which were presented on the screen. The researcher repeated the instructions verbally by telling the child that s/he would see a sentence appear on the screen and that his/her task was to press any of the five coloured buttons on the keyboard that applied to him/her the most. The researcher explained to the child that s/he should press the dark green button when s/he entirely agreed with the sentence, the light green button when s/he agreed with the sentence, the half green/half red button when s/he sometimes agreed and sometimes did not agree with the sentence, the red button when s/he did not agree with the sentence and the dark red button when s/he strongly disagreed with the sentence. This was followed by a practice example: "I like going to the cinema" and the child was asked to choose a response. The researcher also explained to the child that if s/he did not understand a statement to feel free to ask at any time. After that the researcher asked the child if s/he was ready to begin or if s/he had any further questions and if not the actual questionnaire started. Even though the computer automatically saved the child's responses the researcher made a note of the child's response after each statement to have a back up of the data in case there might be a problem with the data saving process.

5.5 Results

5.5.1 Statistical Analyses

The analysis of the child and parent questionnaires followed six steps:

- The child and parent questionnaires included a large sample of items so that items with low reliability could be discarded. Analysis of reliability involved determining the internal consistency of the children and parent questionnaires separately by calculating Cronbach's coefficient alpha (Cronbach, 1951) for all the items in each scale. Alpha levels reached an acceptable reliability threshold when they were at least .7 (Nunnally and Bernstein, 1994). Thus, those items that were identified as lowering the internal consistency were eliminated.
- In order to attain content validity of the new child and parent questionnaires a panel of five experts was consulted, who evaluated the content and relevancy of each item.
- In order to be able to add up the scales and obtain an overall score, the overall internal consistency of the child and parent questionnaire was determined by calculating Cronbach's coefficient alpha for the entire questionnaire.
- In order to examine whether both types of assessment i.e. interview and questionnaire produce converging information, a correlational analysis was conducted.
- In order to explore the assumed association between severity of an illness and adverse psychological effects reported in the literature (e.g. Eiser, 1990) a correlational analysis was conducted between children's

adjustment and their asthma severity (classified into one of five asthma severity groups).

- Lastly, the main hypothesis of an association between children's overall adjustment and treatment adherence was tested by means of a correlational analysis. A significant correlation between both variables would confirm the connection between children's adjustment and their adherence with the treatment.

Since the responses to the questionnaires were measured at the ordinal level and were ranked, Spearman's non-parametric correlation (2-tailed) was applied for all the above correlational analyses.

5.5.2 Reliability

As was reported in the qualitative data analysis for study 1 the researcher created categories on the basis of children's and parents' responses in the interviews and on the basis of the content of these categories statements were generated to be included in the questionnaires. However, these categories were hypothetical and as the newly developed asthma questionnaires for children and parents were based on these categories the questionnaires needed to be scrutinized for reliability and validity. One way of checking whether a measure is reliable is by analyzing its internal consistency. This assesses how well a measure determines a single construct or characteristic. As the newly developed instruments in this study comprised of multiple scales of functioning across different domains, the internal consistency of each subscale was assessed separately, as well as for the entire instrument. Thus, validation of the questionnaires was carried out by the method of internal consistency, which was determined by calculating Cronbach's coefficient alpha (Cronbach, 1951) for all the items in each scale as well as the entire questionnaire. This was done because it was reasonable to assume that each item involved a certain amount of error and that the best measure of each scale was obtained by the combination of all the items. Thus, it was possible to apply psychometric theory to the analysis of such combined ratings. Alpha levels reached an acceptable reliability threshold to describe a population when they were at least .70 (Nunnally and Bernstein, 1994).

Analysis of the internal consistency of the questionnaires involved grouping the questionnaire items by themes that came out previously in the interview analysis and providing information on the reliability of the scales as assessed by alpha levels. The process included running separate reliability analyses for each scale and dropping gradually items that were identified as lowering the internal consistency of each scale until a reliability of a minimum of .70 was reached.
The results of each scale are presented separately below. In each analysis it has been reported which items were dropped to increase reliability of the scale, followed by a table of those items that were retained in the final questionnaires.

5.5.3 Reliability: Internal Consistency of Each Scale of the Child Questionnaire

1) “Child’s perception of normality”. This scale consisted of eleven items and had a coefficient of .66. Dropping item 27, which involved siblings, and item 35 enhanced reliability of that scale to .75.

Table 5.3 Items retained in the scale “Child’s perception of normality”

2. A child with asthma is different from a child who hasn’t asthma because having an illness makes you different

3. I don’t mind that whenever I run my mum tells me to stop because she gets worried that I will run out of breath

10. I don’t think that there is a difference between a child with asthma and a child who has not asthma

11. My mum lets me get on with what I want to do

18. Children with asthma and without are the same because asthma does not change your life that much

19. My mum rather has me at home always than that I go somewhere

26. Children with asthma get out of breath more easily than other children

34. A child with asthma is the same as a child without asthma except that a child with asthma needs inhalers

41. My mum treats me exactly the same as other mums treat their children except that I am not allowed things that might trigger my asthma

2) “Child’s openness about the disease”. This scale only contained five items even though the aim was to create more. However, it was not possible for this scale. The scale had a coefficient of .73 and therefore met the minimum reliability standard of .70. Subsequently, due to the low number of items in that scale no items were dropped.

Table 5.4 Items retained in the scale “Child’s openness about the disease”

5. My friends did not know anything about asthma before they met me
13. I showed my friends my inhalers and told them how they work
21. I don’t like using my inhalers in front of my friends
29. I don’t mind when people ask me about my asthma
37. I’d rather keep it for myself that I have asthma

3) “Child’s feelings about the disease”. This scale comprised of 13 items and had a coefficient of .65. Excluding items one, 25, and 33 increased alpha reliability to .77.

Table 5.5 Items retained in the scale “Child’s feelings about the disease”

8. It does not bother when other children pick on me because of my asthma
9. It really bothers me that I have to use my inhalers and take medicine
16. I never worry about my asthma
17. I like that I get days off school or can leave school earlier because of my asthma
24. It is better to have asthma that I can control than some other illness that

you cannot control

32. I hate the fact that I have asthma

40. There is nothing nice about having asthma

44. Having asthma is not too bad if you have it controlled

47. When I do something that could trigger asthma in me I really worry what will happen to me

50. I wish I could have a furry pet like other children

4) "Child's treatment adherence". This scale included 21 items and had a coefficient of .78. Eliminating items 6, 14, and 45 strengthened alpha reliability further to .80.

Table 5.6 Items retained in the scale "Child's treatment adherence"

4. It makes me really upset that on sports day I am not allowed to try as hard as I could so I can win

7. It makes me really afraid when I take my inhaler and the symptoms don't go away

12. I don't mind that because of my asthma I am not allowed to sleep over at a friend's house

15. I get really upset when I cannot breathe and sleep in the middle of the night

20. It is hard for me when I go to a birthday party because I have to stop myself from running around while my friends are all running around

22. I sometimes tell my mum that I have taken my medication or inhaler even though I have not

23. When I am breathless I feel helpless because I need someone to help me taking my inhaler

28. It does not bother me when I sleep over at a friend's place that I have to check that there is nothing that might trigger my asthma like a pet or smoking

30. I don't know when and how often I have to take my medication and my inhaler

31. When I feel wheezy or out of breath I take my inhaler and relax

36. It is easy for me to always remember when I go somewhere to take my inhalers with me

38. I use my inhaler and peak flow meter as often as the doctor or nurse told me

39. When my chest gets tight I don't panic

42. I wish someone would help me to take my medicine to avoid the attacks

43. I never need reminding when to take my inhalers

46. Even if my mum would not check on me I would take my medication

48. It is hard for me when I exercise not to overdo it and get short of breath

49. I know that certain things are not good for my asthma but I don't try to avoid them

5.5.4 Reliability: Internal Consistency of Each Scale of the Parent Questionnaire

1) “Parent’s perception of the child’s normality”. This scale consisted of 18 items and had a coefficient of .37. As this is considered low the negatively correlated questionnaire items 1, 28, 48, 53, 59, and 90 were dropped. Item 6 involved siblings and seven out of 30 children in this sample did not have any siblings, so there was a large proportion of missing data it was decided to drop that item too. These changes resulted in an improved alpha reliability of .70.

Table 5.7 Items retained in the scale “Parent’s perception of the child’s normality” after the reliability analysis

12. If I stop him from going somewhere he always complains that I have a long list of do and don’ts

18. Because he cannot have things that might trigger his asthma makes him realize that I treat him differently from the way other children are treated

23. He thinks that I am too strict because I constantly remind him of his inhaler and medication

33. Some parents of children with asthma are too careful but I don’t think it is necessary

38. I am not cautious with him because he has to learn to treat his asthma himself

43. I am very careful with him because of the fact that he has got asthma

65. As children with asthma get bigger and stronger it is possible to relax completely

70. I think all children should be treated the same regardless if they have asthma or not

76. Every time I was not cautious enough, it ended up in a crisis or an attack

81. I am not too careful with him sometimes I even forget that he has got asthma

86. His asthma is not under control that is why I must be very alert all the time

2) “Parental Style”. This scale contained ten items and had a coefficient of .88. Excluding any items did not enhance alpha reliability of the questionnaire further and consequently all items were retained.

Table 5.8 Items retained in the scale “Parental Style”

11. All problems would be solved between mother and child if parents were strict with their children when they don’t do what they are supposed to do

17. I expect from my child that he conforms to my decisions out of respect for my authority

58. I try and encourage verbal give-and-take whenever I feel that the treatment regimen and restrictions are too demanding

64. I let my child feel free to discuss my decisions if he feels that they are unreasonable

73. When I tell him to calm down because of his asthma and he does not, I punish him

75. I try not to have too high expectations of him, I just encourage him to do his best

79. When he wants to go somewhere where he should not because of his asthma, I discuss with him the reasons behind it

84. I know what is good for him so when I tell him to do something that is part of his treatment, I expect him to do it immediately without asking any questions

88. I get very upset if he tries to disagree with me and starts a whole discussion (e.g. why he is not allowed to have a pet)

91. If I make a decision, I am willing to discuss it with him and admit if I made a mistake

3) "Parent's perception of the child's feelings". This scale included 13 items and had a coefficient of .79. Item 9 was excluded as it correlated negatively with the scale total, which enhanced alpha reliability to .82.

Table 5.9 Items retained in the scale "Parent's perception of the child's feelings"

4. He gets upset on sports-day because due to his asthma he cannot participate as much as other children

15. He does not think that his asthma prevents him from doing anything

21. He does not get upset when he has to come to the clinic and is missing out on something

26. He gets upset because we constantly have to tell him to slow down and calm down

31. He gets frustrated when he has breathing difficulties

36. He hates having asthma because he just wants to be like a healthy child

41. He is getting used to the fact that he has got asthma and more and more accepts it as part of his life

46. He worries about his asthma and keeps on saying that he does not want to be asthmatic

51. He enjoys the visits to the hospital because it makes him feel special

56. He gets very angry and frustrated when his asthma restricts him from doing something

62. He is embarrassed of using his inhalers in public

68. He is not too bothered about the fact that he cannot have furry pets

4) "Parent's perception of the child's openness about the disease". This scale consisted of six items and had a coefficient of .90. As this scale exceeded the minimum reliability standard of .70 and due to the low number of items in that scale there was no need to drop any items.

Table 5.10 Items retained in the scale "Parent's perception of the child's openness about the disease"

3. I informed his school about his asthma

61. He keeps it for himself that he has got asthma and does not want me to tell anyone

67. He tells all his friends that he has got asthma that they can help him in case he has breathing difficulties

72. He gets upset when people ask about or remind him of his asthma

78. He is a bit embarrassed to talk about his asthma in front of his friends

83. He is very open about his asthma and talking about it is not a big deal for him

5) “Parent’s perception of the impact of the illness”. This scale comprised of 19 items and had a coefficient of .18. Item 10 (involving siblings), 16, 32, 42, 69, 80, and 92 were dropped as they correlated negatively with the scale total, which increased the alpha reliability to .67. Discarding item 89 strengthened alpha reliability further to .70. Even though item 5 involved siblings it was kept as it did not affect reliability negatively.

Table 5.11 Items retained in the scale “Parent’s perception of the impact of the illness”

5. I don’t allow his sibling(s) to bring anything home that might trigger asthma in him
22. When I buy toys or food that he cannot have for the others in the family I buy him something special so he does not feel he had nothing
27. Since he was diagnosed with asthma I reduced my time at work
37. We avoid visiting people who have pets because of his asthma
47. I had to change certain things in the house when he was diagnosed with asthma (buy humidifiers, take out carpet, change mattress)
52. I let people smoke while he is around because it does not make a difference
57. He has got a lot of friends because he gets on really well with other children
63. He feels that because of his asthma he is the odd one out amongst his friends
74. When he does not feel well, his friends look after him
85. I let him go to friends’ houses to spend the day there or to go on a day-trip

with them and their families

93. He is proud of how well he is doing at school

6) “Parent’s attitude about the treatment and precautions”. This scale included 10 items and had a coefficient of .62. Item 40 was dismissed which elevated alpha reliability to .71.

Table 5.12 Items retained in the scale “Parent’s attitude about the treatment and precautions”

8. I don’t let him sleep-over at a friend’s house because the parents would not know what to do if he has breathing difficulties

14. I let him sleep-over at a friend’s house because he can take the inhaler and all his other medication himself

20. I don’t find it necessary to inform the school what to do when he has breathing difficulties

25. I tend to only go to the asthma clinic when his asthma is not very good

30. I take him regularly to the asthma clinic even if he is fine to check everything is alright

35. I made sure that the school knows what to do when he has breathing difficulties

45. He wanted a pet but we found an alternative (e.g. fish, turtle) that made him happy

50. When he goes to a birthday party I make sure that there is nothing that might trigger his asthma like pets and pollen

55. I let him go to sports-day by himself because he knows not to over-do it

7) "Parent's perception of the child's treatment adherence". This scale comprised of 17 items and had a coefficient of .83. Eliminating item 60 raised reliability to .86.

Table 5.13 Items retained in the scale "Parent's perception of the child's treatment adherence"

2. He understands that to live well with asthma he has to take his medication

7. Even though he finds some parts of the treatment hard he follows them very diligently

13. We very rarely get into arguments because of him not wanting to take his medication or inhaler

19. He can do the whole treatment himself but I have to push him otherwise he would not do it

24. He very rarely forgets to take his inhalers

29. If he is too hyperactive there is nothing I can do

34. He knows I will check up on whether he has taken his inhalers because you cannot trust children with this responsibility

39. I don't mind that I constantly have to be on top of him with the inhalers because otherwise he does not take them

44. It is almost a daily routine that we have arguments about him wanting something that he cannot have because of his asthma

49. He knows he should not be too hyperactive but he does not stop even if he

is getting out of breath

54. He insists on going outside even after I tell him that it is bad for his asthma because of the high pollens or the cold air

66. When he gets breathing difficulties, I normally have to step in because he does not know what to do

71. When he has signs of asthma he knows what to do

77. He often needs to be reminded to take his inhalers especially when he is busy doing something else

82. Someone always has to supervise him and help him taking his inhaler to check he does it properly

87. He can use his inhaler perfectly by himself

In summary, the results from the analysis of the internal consistency of the parent and child questionnaires revealed which items had to be dropped to increase reliability of each scale to .7 and above.

The child questionnaire comprised 42 items and the parent questionnaire included 75 items.

Table 5.14 Mean, standard deviation, and internal reliability coefficients (Cronbach's Alpha) for the children scales (*n*=30)

Scale	**Mean**	**Standard Deviation**	**Internal Reliability**
Child's perception of normality	2.67	.74	.75
Child's openness about the disease	2.52	.97	.73
Child's feelings about the disease	2.95	.77	.77
Child's treatment adherence	2.79	.63	.80

Table 5.15 Mean, standard deviation, and internal reliability coefficients (Cronbach's Alpha) for the parents' scales (*n*=30)

Scale	**Mean**	**Standard Deviation**	**Internal Reliability**
Parent's perception of the child's normality	2.92	.56	.70
Parental Style	2.18	.72	.88
Parent's perception of the child's feelings	2.86	.70	.82

Parent's perception of the child's openness about the disease	2.35	.96	.90
Parent's perception of the impact of the illness	2.36	.54	.70
Parent's attitude about the treatment and precautions	2.50	.67	.71
Parent's perception of the child's treatment adherence	2.74	.67	.86

5.5.5 Content Validity of the Child and Parent Questionnaires

Content validity is an essential aspect in the development of a new assessment and addresses whether the items of an instrument adequately gauge the required domain of content (Grant & Davis, 1997). Lynn (1986) explained the process of content validation in two stages comprising of 1) the development of the instrument (domain identification, item generation, and instrument construction) and 2) judgement-quantification. As the first stage has been completed previously (study 1 and 3) this section focuses on the second stage i.e. the judgement-quantification, which involved requesting a specific number of experts to appraise the validity of items (DeVellis, 1991). The literature differs on the required number of content experts for a panel. Lynn (1986) states that a minimum of three experts is necessary whereas others suggest a minimum of two experts to a maximum of 20 experts for a panel (e.g. Gable & Wolf, 1993; Tilden, Nelson, & May, 1990). For the purpose of this study a panel of five experts was chosen consisting of a paediatric consultant, two clinical psychologists, a senior nurse, and a child psychologist. Firstly, the five experts were provided with a cover letter explaining the background of the study and why the expert was chosen as a content expert and the value of measuring the construct (Appendix 5.5). Secondly, they were presented with the actual child and parent scales containing the corresponding questionnaire items and a conceptual definition for each scale which allowed the expert to compare each item against the definition. Also, for each scale some examples were presented of other existing instruments that aimed to measure the same construct (Appendix 5.6). The experts were asked to rate each item by indicating how relevant they considered each item and mark their choice using a 5-point ordinal relevance or representative rating scale ranging from zero (the item is representative of a different scale) to four (the item is very representative of this scale). The communication with the experts was by e-mail and telephone and each expert completed the ratings independently from each other and on their own in order to avoid any influences in their responses. Once the researcher received all the ratings back from the experts the analysis of content validity entailed two steps. As Waltz et al. (1991) recommend, researchers have to firstly calculate the level of agreement amongst the experts before calculating a content validity index across experts. Inter-rater agreement was attained by adding up all the items that were rated 3 or 4 by the panel members for each scale and dividing this number by the total number of items of the scale multiplied by the number of experts. Levels of acceptable inter-rater agreement vary from .70 (Davis, 1992) to .80 (Selby-Harrington et al., 1994). Table 5.18 below shows each child scale and the level of agreement across experts composing the child questionnaire followed by a table with the corresponding information on the parent questionnaire.

Table 5.16 Child Scales with Levels of Interrater Agreement

(1) Child's perception of normality	.96
(2) Child's feelings about the disease	1.0
(3) Child's openness about the illness	.96
(4) Child's treatment adherence	.91

Table 5.17 Parent Scales with Levels of Interrater Agreement

(1) Parent's perception about the child's normality	.95
(2) Parent's perception of the child's feelings	.96
(3) Parent's perception of the impact of the illness	.92
(4) Parent's perception of the child's openness about the illness	.93
(5) Parent's attitude about the treatment and precautions	1.0
(6) Parent's perception of the child's treatment adherence	.96

As can be gathered from table 5.16 and table 5.17 the levels of interrater agreement across experts for all the child and parent scales exceeded the minimum .7 to .8 criteria suggested in the literature.

The second step in estimating the content validity of the child and parent questionnaires involved calculating the actual content validity index (CVI) for each scale. Content validity is established by the proportion of experts who rate items as representative with either 3 or 4. Lindsey Davis (1991) recommends finding a decision rule for combining the responses of the expert reviewers. She states that a simple decision rule for retaining individual items would be to utilise only those that are rated as 3 (representative of this scale) and 4 (very representative of this scale) by both content reviewers. As in this study there were more than two reviewers (i.e. five in total) it was decided to use a criterion of "4 out of 5" which means to use only those individual items that were rated as 3 or 4 by at least four of the five experts. To calculate the CVI for each scale, the total number of items rated 3 or 4 by at least four of the five experts was divided by the total number of items of the scale. Possible CVI scores range from 0 to 1 (i.e. 0% to 100%). Lindsey Davis (1991) recommends for a new instrument a minimum of 80% agreement amongst panel experts.

Tables 5.18 and 5.19 show the child and parent scales with their content validity indexes.

Table 5.18 Child Scales with the Corresponding Content Validity Indexes

(1) Child's perception of normality	1.0 (100%)
(2) Child's feelings about the disease	1.0 (100%)
(3) Child's openness about the illness	1.0 (100%)
(4) Child's treatment adherence	.83 (83%)

Table 5.19 Parent Scales with the Corresponding Content Validity Indexes

(1) Parent's perception about the child's normality	1.0 (100%)
(2) Parent's perception of the child's feelings	1.0 (100%)
(3) Parent's perception of the impact of the illness	1.0 (100%)
(4) Parent's perception of the child's openness about the illness	.83 (83%)
(5) Parent's attitude about the treatment and precautions	1.0 (100%)
(6) Parent's perception of the child's treatment adherence	.94 (94%)

As can be gathered from table 5.18 except for "child's treatment adherence" all other scales had a content validity index score of 100%. Table 5.19 shows that for the parent scales except for "parent's perception of the child's treatment adherence" and "parent's perception of the child's openness about the illness" all other scales had a content validity index score of 100%. All scales exceeded the minimum content validity index score of 80%. Despite this it was decided to drop those items that lowered the content validity index of the scale and to run another reliability analysis to check whether the internal consistency of the scale still exceeded the minimum threshold of .70.

For the scale "child's treatment adherence" item 15 (I get really upset when I cannot breathe and sleep in the middle of the night), item 20 (It is hard for me when I go to a birthday party because I have to stop myself from running around while my friends are all running around), and item 39 (When my chest gets tight I don't panic) were dropped; the scale still showed good reliability: alpha = .75 (it was previously equal to .80).

For the scale "parent's perception of the child's treatment adherence" item 39 (I don't mind that I constantly have to be on top of him with the inhalers because otherwise he does not take them) was dropped and showed the same reliability of .86

For the scale “parent’s perception of the child’s openness about the illness” item 3 (I informed his school about his asthma) was dropped and the alpha reliability increased from .90 to .94.

5.5.6 Reliability: Overall Internal Consistency of the Child and Parent Questionnaire

In order to be able to add up all the scales of the child and parent questionnaire the overall internal consistency of each questionnaire was determined. The overall internal consistency of the child questionnaire was .86 (previously .88) and of the parent questionnaire was .88 (previously .89) after the items were scrutinised by the expert panel. Thus, when all items of both questionnaires were used a highly reliable scale was obtained. This suggests that the items of each questionnaire could be summed up to obtain an overall score.

5.5.7 Concordance Between Interview and Questionnaire Data

The data collection for study 1 took place between June 2003 and August 2004 and for study 2 between November 2004 and August 2006. The time between the interview and the questionnaire administration was therefore up to three years in many cases. This had not been planned and resulted from delays due to seeking ethical permission for each phase of the study and relocating the participants. Given this long interval between assessments, children’s and parents’ perception of the illness might have changed between the time they were interviewed and the time they completed the questionnaire. Despite this, the results from the interviews were compared with those from the newly developed questionnaires by testing whether they produced converging information. Separate correlational analyses for the children's and parents' data were carried out between the interview and the corresponding questionnaire scales. Significant correlations would indicate that children's and parents' perceptions of the illness were stable whereas non-significant correlations would be more difficult to interpret. This is due to the long interval and the sample size (*n*=11) being very small, because only 11 out of the 15 children from the interview study could be followed up for this study. Thus, if the correlations were not significant but at least .4, this would indicate that the sample was too small. If however the correlations were lower than .4 the non significant results could not be explained in terms of the sample size being too small. In this case it would be more plausible that children's and parents' perceptions had changed.

Table 5.20 Correlations between interview scales and the corresponding questionnaire scales for children

Child Scales (*n*=11)	**Correlation**
Child's perception of normality	Not significant (.29)
Child's feelings about the disease	Not significant (.30)
Child's openness about the illness	Not significant (-.19)
Child's treatment adherence	Not significant (.15)

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

Table 5.21 Correlations between interview scales and the corresponding questionnaire scales for parents

Parent Scales (*n*=11)	**Correlation**
Parent's perception of the child's normality	Not significant (-.36)
Parent's perception of the child's feelings	Not significant (.14)
Parent's perception of the impact of the disease	Not significant (.47)
Parent's perception of the child's openness about the disease	Not significant (.23)
Parent's attitude about the treatment and precautions	Not significant (.50)
Parent's perception of the child's treatment adherence	Not significant (.46)

$^{*}p < .05$. $^{**}p < .01$.

As can be gathered from tables 5.20 and table 5.21 there was no significant association between any of the child and parent interview scales and the corresponding questionnaire scales. Furthermore there was only one scale that exceeded the value of .4 which was "Parent's attitude about treatment and precautions".

There are several possible explanations for the lack of significant correlations between interview and questionnaire data. Firstly, it is possible that children's and parents' views changed over the long period between both assessments. As explained, the request for ethical approval for the questionnaire had to be submitted after the qualitative data analysis of the interview data and extensive process of generating the questionnaire items had been completed. This long interval, which could be up to three years in some cases, led the researcher to hesitate whether it was advisable to carry out the correlational analysis between the interview ratings and the questionnaire responses. In fact, Sawyer, Reynolds, Couper, French, Kennedy, Martin, et al. (2005) report that quality of life of children with asthma and diabetes tends to improve significantly over time, and this improvement can be measured over a two-year period. It is quite reasonable to expect that the professionals would have intervened if they thought that some children's adjustment was not improving and judged them to be at risk for non-compliance or for poor adjustment to the illness. This means that predicting the questionnaire responses from the interview data would not be necessarily be possible, because effective actions by the health professionals would lead to greater changes in some children's adjustment and compliance. In spite of these reasons for caution, and as the researcher had the data, it was decided to carry out the correlational analysis, which produced negative results. Negative results under these circumstances are difficult to interpret and, as in most cases, cannot be considered as evidence. Secondly, interview data provides complex data which allows for a degree of ambiguity and tension, which is eliminated in questionnaire data. Within view of the large time gap between the measures and the small number of participants, it is very difficult to interpret the negative data. Nevertheless, these non-significant results suggest that it is necessary to seek validation of the measures in the future. One issue that must be taken into consideration is that there is now a greater awareness that parents' and children's responses do not necessarily agree (Davis, Nicolas, Waters, Cook, Gibbs, Gosch, et al., 2007). So validation through concordance across parents and children could lead to negative results, which would be difficult to interpret. However, if positive results are observed, this can provide evidence for the validity of the questionnaire. This evidence will be sought in the present study, when the children's and parents' responses are correlated, after a factor analysis is carried out. Another possible approach for further research is to seek validation through the combination of instruments that are generic (i.e. used for different illnesses: e.g. Eiser, Vance, & Seamark, 2000) and illness specific interviews, which have been developed recently for paediatric asthma patients (Ungar, Mirabelli, Cousins, & Boydell, 2006).

In the subsequent section the associations between child adjustment and demographic variables are explored. Firstly, it was investigated whether there was an association between children's adjustment and the severity of their asthma. Secondly, it was explored whether there was an affiliation between children's adjustment and their age. Lastly, the main hypothesis of the relation between children's adjustment and their adherence with the treatment was examined.

5.5.8 Children's Adjustment and Asthma Severity

Asthma shows a wide range of severity some children only suffer from occasional bouts of wheezing whereas other children suffer from severe daily and frequent attacks require strong medication and hospitalization. Due to this wide spectrum of asthma severity it was investigated if there was an association with the children's adjustment. A child's overall adjustment was determined by combining the average for "Child's perception of normality", "Child's feelings about the disease", and "Child's openness about the illness". As noted in the sample description, children's asthma severity was classified into one of five asthma severity groups (mild, mild-moderate, moderate, moderately severe, and severe). The correlational analysis to explore the relationship between children's adjustment and children's severity of asthma revealed no significant correlation between the two variables. This finding suggests that the severity of asthma had no impact on the level of children's adjustment.

5.5.9 Children's Overall Adjustment and Their Chronological Age

To investigate whether there is a connection between the children's age and their adjustment, a correlational analysis was carried out, which showed no significant correlation between children's total adjustment and their age. This finding implied that the age of the children had no impact on the level of their overall adjustment. However, when interpreting the results it should be considered that the children's age range was relatively small (7-12-year-olds) and that age therefore could have an effect if a wider age range would be included.

In the following section, the investigation of the main hypothesis between a possible association between children's adjustment and their adherence with the treatment is addressed. As children's ages and severity of asthma did not correlate with adjustment, these variables were not controlled for.

5.5.10 Children's Adjustment and Treatment Adherence

An investigation was conducted into the relation between children's overall adjustment and treatment adherence by means of a correlational analysis between both variables.

Total child adjustment was correlated with "Child's treatment adherence" showing a highly significant correlation 2-tailed (r_s = .63, p<.01, N=30). This finding confirms that children's adjustment and children's treatment adherence are domains that are connected i.e. children who were better adjusted also displayed better treatment adherence or vice versa. However, the analysis did not provide information on the direction of causality i.e. if poor adjustment causes treatment adherence difficulties or vice versa.

There was no significant correlation found between children's total adjustment and "Parent's perception of the child's treatment adherence". Thus, on the basis of parents' reports there was no association between children's adjustment and parents' perception of their children's treatment adherence. Thus, relying on exclusively proxy ratings in the form of parent reports would have concealed the significant association between children's adjustment and their adherence with the treatment once more highlighting the fact that parents were not accurate proxy raters of their children's perceptions of the illness.

5.6 Overall Conclusion

In this chapter the reliability and validity of the newly developed questionnaires for children with asthma and their parents were analyzed.

To determine reliability, the questionnaires for use with children with asthma and their parents were administered to a larger sample of 30 children and their parents. One of the most pertinent reliability assessments for adjustment measures is internal consistency of a questionnaire, which assesses how well a measure determines a single construct or characteristic. However, as the questionnaires comprised of multiple scales of functioning across different domains, the internal consistency of each subscale was assessed in addition to the internal consistency of the entire questionnaire. Internal consistency was determined by calculating Cronbach's coefficient alpha for all the items in each scale as well as of the entire child and parent questionnaire. The final questionnaires showed good internal reliability for each scale (.7 and above) and excellent internal reliability for the entire instruments (internal consistency of the child questionnaire was .86 and of the parent questionnaire was .88).

Content validity was attained via a panel of experts who rated the child and parent items for all scales for representativeness. Inter-rater agreement across experts was very high and all and the content validity indexes came to 100% except for "Child's treatment adherence" (83%), "Parent's perception of the child's treatment adherence" (94%), and "Parent's perception of the child's openness about the illness" (83%), which nevertheless exceeded the minimum of 80%. Despite this, it was decided to drop those items that were not rated 3 or 4 by at least four of the experts.

After dropping these items the child questionnaire comprised of 39 items and the parent questionnaire of 73 items.

Due to the high internal consistency for each scale as well as the entire questionnaire it can be ruled out that children were answering randomly.

To explore whether the interviews and questionnaires produced converging results a correlational analysis was conducted. It was found that none of the children's and parents' interview scales correlated significantly with the corresponding questionnaire scales. One explanation for this finding might have been that children's and parents' perceptions of the illness might have changed during the time they were interviewed and the time they completed the questionnaire. Due the large interval between the two assessments which was up to three years in some cases negative results are difficult to interpret and, as in most cases, cannot be considered as evidence. Another explanation for the result could have been due to interview data providing complex data which allows for a degree of ambiguity and tension, which is eliminated in questionnaire data.

The analysis of the relationship between children's asthma severity and their overall adjustment showed that there was no significant correlation between the two variables. Thus, children's asthma severity had no impact on their level of adjustment. It should be remembered that although the paediatric asthma nurse was consistent in her classification of children's asthma severity it would have been more reliable if children's asthma severity was rated independently by another paediatric asthma specialist using the same classification scheme and then comparing the ratings of both to check inter-rater reliability. Also, the paediatric nurse was hesitant in the first place to classify children's asthma severity and only agreed to do so for the purpose of this study. It was not standard routine of the hospital to classify children's asthma severity in their medical records to avoid "labelling" children and consequently to ensure that in the event of a child coming to A&E with asthma symptoms rapid maximum care was taken.

To conclude, the lack of an association between children's adjustment and their asthma severity drew attention to the fact that there were children who were not well adjusted at all levels of severity and therefore research should always include children with all forms of asthma severity and not limit to those with severe forms of asthma.

The results from the analysis of the children's adjustment to the illness and their age showed that age was not related to the adjustment of children with asthma. It would be unreasonable to expect that older children find it easier to deal with the illness in view of their greater level of cognitive and social maturity. The results of this analysis must be interpreted with caution: This study explored a sample of children who fell within a certain age group (7-12 year olds) and perhaps the changes in cognitive and social development are not as important within this age period as they are, for example, when 4- and 8-year olds are compared. Differences in social development might also be much more important, for example, when children and adolescents are compared. In adolescence pressures to conform to peer standards are particularly strong and teenagers might experience more strain when having to follow their treatment regimen that affects their peer relations and, consequently, could affect their adjustment. Therefore, the results cannot be generalized to children younger than the age of 7 or children who are older than the age of 12 and have entered puberty as illness-related stressors might affect children differently depending on their developmental stage.

Lastly, the main hypothesis of a relation between children's overall adjustment and treatment adherence was investigated. It was found that there was a significant correlation between children's overall adjustment and their treatment adherence: children who were better adjusted also displayed better treatment adherence or vice versa. However, this analysis cannot provide information on the direction of causality.

There was no association found between children's overall adjustment and the parent's perception of their children's treatment adherence. Consequently, if the information would have been obtained from parents only the relationship between children's adjustment and treatment adherence would have been concealed. This finding once more stressed the importance of taking into consideration children's own reports.

CHAPTER 6

STUDY 3 – USING INTERVIEWS TO UNDERSTAND CHILDREN WITH DIABETES

6.1 Aim

The aim of this study was to describe the children's experiences with having diabetes, focusing again on the stressors that are added to their lives, how they cope with them, and the socio-emotional impact on their lives from their own perspective. Parents' participation once more offered an added description of their children's experiences as perceived by the parents and therefore from a different perspective.

6.2 Introduction and Background

Study 3 was a parallel study to study 1 and therefore had the same aim and methods but this time explored the experiences of a sample of children with diabetes rather than asthma and their parents. Even though both studies had the same aim and methods and were conducted concurrently it was decided to keep the reports separate as the children's illness differed across the studies. Thus, identical to study 1, interviews were chosen as a method for eliciting information about the children's experiences with diabetes and how they coped with the stressors associated with it. In order to obtain different perspectives, the children themselves and one of the parents, usually the mother, were interviewed. The different schedules for the semi-structured interviews for children with diabetes and their parents are included in Appendix 6.1 and 6.2. Again a content analysis of all the interview data from children and parents was carried out to describe the different experiences.

The results of this analysis were then used to create scales for analyzing the interviews and, later, to design the questionnaires (study 4). Thus, in this section it was not repeated how interview schedules were developed for children with diabetes and their parents as well as the procedure of recruiting as both were identical to study 1.

6.3 Methods

6.3.1 The Sample

The sample of study 2 consisted of 15 children with Insulin-Dependent Diabetes Mellitus (IDDM) comprising of five girls and ten boys with ages ranging from seven to twelve years, their parents, and a paediatric diabetes nurse. With the help of the diabetes nurse, children with autism, ADHD, and Down-Syndrome were excluded from the recruitment process. The sample was heterogeneous and consisted of eight Caucasian children, six black children and one Indian child.

Of all the parents and children the researcher approached, nobody declined to take part.

6.3.2 Procedure of the Interview

In parallel to study 1 once the parent and child gave their consent to being interviewed the researcher asked who would like to start. Again, in most cases the parent and child chose for the parent to be interviewed first. Yet again although it stated on the information sheets for both children and parents that the interviews would be sound recorded the researcher checked with the parent and child to ascertain that they were comfortable with this procedure. All the children went back to the play area, whilst the researcher commenced to sound record the interview with the parent and called the child when ready. Seven parents were present when their children were interviewed and two of them made comments during the interview. One mother corrected her son's answer, whereas another mother reminded the child of the answer when she was not sure. However, when the researcher politely asked those parents not to interfere and let their children answer, any kind of interference stopped. Moreover, as in study 1, the researcher was systematic in that each participant had answered all the questions.

The procedure of the researcher being systematic in that each participant had answered all the questions was identical to study 1.

6.4 Results

Parallel to study 1 the results section of this study started with a content analysis of the interview data from children and parents in which children's and parents' responses were coded under different content categories (first, second, and third step). Once again, these content categories were utilized to analyze what children and parents in their own voices had reported under each theme as well as a summary of the variations observed in their responses (fourth step). Children's and parents' reports were then utilized to validate each other. In order to carry out this analysis, children's and parents' reports had to be scored (fifth step). To score these, the same content categories as well as the same anchoring points as in study 1 were utilized. Lastly, again a correlational analysis was conducted using the scores between the four children categories and the corresponding four parent categories.

6.4.1 Content Analysis of the Interviews

The procedure of the content analysis of study 2 was identical to study 1 and is not repeated here.

Tables 6.1 and 6.2 contain only those child and parent categories that were merged with actual extracts from the interviews with this time children with diabetes and their parents for illustration.

Table 6.1 Merged Child Categories

(1) Child's perception of being normal and Child' perception of being treated normally *I: Do you think that a child with diabetes is different from others?* *C: Yeah, cause children that don't have diabetes are allowed to eat and drink whatever they feel, but children who have diabetes have to watch what they eat.* *I: Do you think that sometimes your parents are too careful with what you want to do?* *C: My mom does care about me a lot so she does watch what I eat and what I do.* *I: And do you think that's too careful or are you OK with that?* *C: Actually its OK with me.* *I: Do you think your parents treat you differently than your brother and sister that don't have diabetes?* *C: No, my mom treats me actually the same. Just that I can't eat the sweets.* Everything else is the same.
(2) Child's feelings about the disease and The effects of the disease on the child's life *I: What do you think now about having diabetes?* *C: Sometimes I do not like it because I cannot eat what I like to eat and sometimes I do not really mind.* *I: We all know that it is not nice having diabetes, but is there anything nice about it?* *C: Not of what I know.* *I: What do you not like about it?*

C: Everyday having injections.

(3) Child's adherence with the treatment, Child's reaction to symptoms, <u>and</u> Treatment and precautions

I: Can you tell me what you have to do everyday? How much medicine you have to take and which little tests you have to do?

C: In the morning I wake up and I have my injection measurement nine and after that I take my injections and after I waited like five or ten minutes and then I have my breakfast. In the evening I do the same, but the measurement is eighteen.

I: And that's all you do?

C: Yes.

I: Is that what you have to do everyday?

C: Yes.

I: Did you do it yesterday, the day before yesterday, three days ago?

C: Yes.

I: So you do that everyday with no problems?

C: Yes.

I: What does the diabetes do to you?

C: It makes me weak and it makes me feel like I am going to get a sib or it makes me drowsy and thirsty.

I: Can you think about something that you feel and get when you have signs of diabetes? Yes you said you get drowsy.

I: Do you know what to do then? Do you know what to do when you feel drowsy?

C: Yes, I will have a sweet drink and I have to try and stay up to get some energy back.

I: Can you do it by yourself or do you need help?

C: I do it by myself.

I: Is there anything you have to do that you do not like at all?

C: Taking the injections because it makes me bleed.

Table 6.2 Merged Parent Categories

(1) Parent's perception of the child's perception of being treated normally <u>and</u> Parent's perception of treating child normally

I: Does he think you treat him differently because he has diabetes? Does he have siblings?

M: I treat him differently because I don't let him go. If he has got a school trip coming up…I let him go to the last one but I was so worried. And I keep telling him that he can live a normal life, but when I stop him from going places he says 'I can't go mum' and 'you won't let me go mum' and all that. So, yes he does think I treat him different (laughs).

I: Do you think that sometimes you are being too careful with Alfie?

M: I don't think I am that bad…He probably thinks I am, but I don't think that I am bad. Its just things like big trips when he has to stay away from home. That's what worries me. Other than that I don't stop him from going anywhere...he goes to his football team and that, he goes with his dad...I am not sort of that worried. When he has to stay away from home, that's what *worries me. When he has to take it all with him and do it on his own. He is quite good, he can do it on his own but I've got to push him, because I think he won't do it otherwise.*

(2) Parent's perception of the child's feelings about the disease
<u>and</u> The effects of the disease on the child's life

I: How does she generally feel about having diabetes?
P: I think she feels a little bit sad in the sense like for instance she used to like her sweets. She loves her sweets and now she has got to be restricted. I restricted a lot when she eats and when she doesn't eat and all of this and she doesn't like this because she is a big eater. There is a problem with that. And especially in this weather she tends to drink lots and lots of drinks and she has been constantly high this week all through this week so what I normally do is she gets six injections in the morning and I don't take the one in the evening at all, she doesn't take the one in the evening. She just has a normal meal.
I: But what would you say how she feels generally?
P: She is okay. Yes, she is.
I: Is she for example upset when people ask about or remind her of it because she rather keeps it for herself?
P: I think she doesn't like people feeling sorry for her, because she thinks she is still normal it's just that she has got diabetes, which she is trying to learn how to control. She thinks she is normal, she hates it when people go "ahh".
I: Does she get upset about having diabetes, does she for example think it prevents her from doing things?
P: Yes, she does sometimes. And sometimes it upset her because she thinks there are things she wants to do that she cannot do, like she love sports but obviously she cannot run very fast, she gets very tired.

(3) Parent's perception of the child's treatment adherence <u>and</u> Knowledge about disease, symptoms, and reaction

I: How much can she do herself and take responsibility? I mean I get the feeling she does a lot herself.
P: She does a lot herself, but it's mainly sweet drinks and sweets, I constantly have to watch.
I: So you only have to be careful and watch her food?
P: Yes, I suppose it has been this hot for two and a half weeks, but she has been really, really fine. But because it's been so hot I obviously had to get drinks in doors, but when she sees it she will drink it, but normally she is really fine.
I: How much does she understand about diabetes and the treatment?
P: I think she understands, because I was surprised by the article she wrote in the school newspaper. I was really shocked because she surprised me in the sense that she has got a much more in depth knowledge about it than I thought. So I think she does know the impacts.
I: Does she know what to do when she has symptoms?
P: Yes, she knows when she goes hyper and hypo. And she knows about to tell someone, when she is going high, which is very good obviously that she

speaks up.
I: Does she know what to do then straight away?
P: Yes, she knows what to do.
I: Are there bits with the treatment she finds hard to follow?
P: Yes, the blood sugar level tests.
I: The prick in the finger?
P: Ohh gosh yes we always fight over that.
I: How do you handle that?
P: Yes sometimes because I work, I was studying at the university, I just finished, and I work and it is really difficult as there are times she will do it when I am not there and when I come and she lies to me that she has taken it and then I check the meter and no she has never taken it. The injections are fine, she takes them everyday it is just the prick in the finger she does not like at all, because it hurts.

In the subsequent section, each of the themes (categories) discussed by the children was analyzed. Each theme was presented with examples of children's own quotations, and a summary of the variations observed in the children's attitudes was described. These variations were used later on for a more systematic and quantitative analysis of the interview data.

6.4.1.1 Child's Perception of Normality

Three children reported that they did not think that there was a difference between children with diabetes and children without the illness. One child explained "no I don't think so. It is just that they are the same as other people they just got something wrong with them, but it's not like they have to go to the hospital everyday, like have casts and have crutches. They are just like everybody else".

One child was not sure and explained "in a way yes and in a way no because we have got what they have got but they just haven't got the disease we have got".

All the other 12 children thought that there was a difference. One child explained "because they are allowed to eat more chocolate and all that" whereas another child said "they can eat sweets and the people that are diabetic can't". Yet another child described "because they can't have stuff that other children have and do the same things". A further explanation was "we have to have injections all the time". Lastly, another child expressed "Yes, because children that don't have diabetes are allowed to eat and drink whatever they feel like, but children who have diabetes have to watch what they eat".

Eleven children reported that their parents treated them normally and the same as their siblings. One child explained "they treat me the same". Another child felt that she was treated the same even though she was aware of a difference by saying "my mum treats me actually the same. Just that I can't eat the sweets. Everything else is the same".

One child said that his parents treated him differently to his siblings because his siblings "are allowed to do more than me like go out more". Another three children said that their parents treated them sometimes differently to their siblings. One boy explained "yes, if I go out and don't come back for lunch she (mother) gets all worried". The other two children could not give any examples why they thought that their parents are sometimes more careful with them by saying "I don't know".

6.4.1.2 Child's Feelings About the Disease

As in the case of asthma, children's reports regarding their feelings about having diabetes varied also. Six children reported that they did not like having diabetes. One child stated "I hate it really" and another child said he does not like "everything" about the illness. Three children were more positive and one child said "sometimes I do not like it because I cannot eat what I like to eat and sometimes I do not really mind". Another child explained "I am quite used to doing the stuff I am supposed to do for it but sometimes I don't get to go to some places that I want to go, so then I don't like it". Yet another child described "sometimes I do not like it because I cannot eat what I like to eat and sometimes I do not really mind".

Five children had accepted the illness which was reflected in statements like "I am ok with it" and "I am coping very well".

One child replied when he was asked about his feelings towards having diabetes that he felt "nothing".

Regarding effects of diabetes on the children's lives they reported the following negative aspects. One child explained "when my school is going on trips for like weekends I can't go with them because I have to inject myself. Sometimes I can't go on holiday, I can't go where I want to go. I can't go to a friend's house for sleep over sometimes". Another child was upset about the fact that "when I grow up I always wanted to be a tennis player, but I can't be it now". The majority of children (12) mentioned the fact that they did not like the insulin injections which was reflected in statements like "I hate getting injections" and (I don't like) "everyday having injections". Also many children (twelve) were upset about the fact that they could eat no sweets or very little by saying "the fact that

I cannot eat sweets. Lastly one child said that he did not like diabetes "when I got to eat at certain times".

Positive aspects of the illness were "you get days off school" and "I get to come early from home". One girl explained "(I like) the help that I get and how they treat me, the attention that I get from people". Another boy mentioned when asked about any nice things about diabetes "you get to watch your weight and you can go to diabetes Clubs".

In summary, negative effects of diabetes on the children's lives were treatment related (taking medicine, diet constraints) and outing restrictions whereas positive effects were getting days off school, receiving extra attention, and participating in social groups developed /invented/intended for diabetics.

Interestingly there was only one child who talked about future consequences of diabetes. It was a girl who was upset about the fact that her diabetes will prevent her from becoming a tennis player when she grows up.

6.4.1.3 Child's Treatment Adherence

Twelve children reported illness and treatment related problems. These were mainly around two aspects of the treatment regimen. One problem repeatedly mentioned were the daily insulin injections, which was reflected in a statement like "I do not like taking the injections" and the blood glucose monitoring which was reflected in a statement like "I don't like the prick in the finger". The only other treatment related problem reported was the following explanation of one child "I have to come here, because I was at my friend's house sleeping over yesterday and because I had an appointment today for diabetes I had to come so I had to leave". Only three children did not mention any illness and treatment related problems.

Children's treatment adherence was assessed through the following six criteria which derived from the interviews: (1) familiar with their treatment regimen i.e. knew how often and what time to take which medication; (2) took their medication regularly; (3) knew the symptoms of diabetes; (4) were acquainted with what to do when they had a hypo- or hyperglycaemic attack; (5) were able to administer the insulin injections and measure their blood glucose levels by themselves without needing help; and (6) treatment responsibilities they disliked were still followed diligently.

Seven children met all of the above criteria, five children met five, one child met two, and two children only met one.

6.4.1.4 Child's Openness About the Illness

Eight children did not mind being asked or talking about their diabetes and did not keep it for themselves. This was reflected in statements like "it does not bother me" or "I don't mind". Another child said "I say it (that I have diabetes)" Four children reported that only sometimes did they mind people asking or talking about it and rather kept having the illness for themselves. One child explained "I like talking about it to some people, the people that I know". Another child expressed "Sometimes (I like talking about it). I don't like when people ask 'why do you have to eat this and why do you have to eat that'. I don't like that sort of thing".

Three children never liked being asked about their diabetes or talking about it and also kept it to themselves. In these three cases the researcher did not pursue any explanations why they did not like being asked about their diabetes to avoid the possibility of them becoming upset.

In the subsequent section, each of the themes discussed by the parents was analyzed. This time, each theme was presented with examples of quotations from parents, and a summary of the variations observed by the parents in the children's attitudes was described. Again, these variations were used later on for a more systematic and quantitative analysis of the interview data.

6.4.1.5 Parent's Perception of the Child's Normality

Nine parents reported that they were sometimes too careful with their children. Illustrations of when parents perceived themselves as too careful were "when his blood sugar is very high or when the count is too low". Another parent explained "we are very concerned we look after him because his sugar level sometimes goes up and we have a reaction, like he is falling down, so I am worried about that". Another mother reported that she has to be very careful with her daughter and said "I have to be, if she could have lunch on a normal level, but I have to be here, firm on her and pushing her". Six parents perceived themselves as not being too careful with their children and for instance replied "no, I don't think so because at the end of the day she has to learn how to treat her diabetes, because I'm not always going to be there, she is ten now, she has got to get used to it and do things by herself so I was really pleased when she started to take her injections since the second day after she was diagnosed". Another mother explained "no, as a mother I don't think you are ever being too careful, you are always caring. I don't think so, I have given him freedom".

Similarly, nine parents reported that they thought that their children did not perceive them as too careful with them. One mother explained "no, I don't think (that I treat him differently to his siblings). I think they all get treated the same. I think he realizes that they don't have a drastic amount of sweets either and it's not like that he goes without". Six parents thought that their children perceived them as being too careful with them and examples were "when I stop him from going to places he says I can't go mum and you won't let me go mum and all that. So, yes he does think I treat him differently". Another parent explained that her child thought that she is too careful with him by saying "yes, when we watch him, what he takes, or when he eats sweets" whereas another mother replied "his brothers will tell you I do and he will say yes". Another mother described "he says 'mummy you are too strict on my food' and I say you know it is too dangerous. I am sorry I've got to because I want you to be healthy".

However, even though the numbers appeared to show a similarity in that the reports were both nine and six, the parents' answers did not always correspond. Seven parents reported that they thought that they were too careful with their children as well as that their children believed they were too careful with them, four of the parents reported the opposite, and the remaining four parents' reports were contradicting.

6.4.1.6 Parent's Perception of the Child's Feelings

As in the case of asthma, parents' reports regarding their children's feelings towards having diabetes were also varied. Five parents reported positive feelings towards the illness which was reflected in statements like "yes, he has accepted it now" and "okay, I think he just generally gets on with it. Sometimes he gets grumpy and asks why me and just feels sorry for himself, otherwise he is pretty much okay". Another mother described "well, she's quite a stoical sort of person, so I'd say she's a bit of a just get on with it kind of a person, this is life and it is irritating and sometimes she wishes she wasn't but mostly she just accepts it".

Four parents reported that their children's feelings towards the diabetes vary. One mother explained "sometimes he is okay and sometimes sad" and another mother said "sometimes okay and sometimes she reacts badly. She starts asking questions and I try my best". Another mother said "its ups and downs. She is alright and she is not alright sometimes. Ups and downs like". Yet, another mother described "he says 'my diabetes doesn't prevent me from doing anything' and I say 'good, great you are a good boy. You are a winner'. Something like that. But then sometimes he is upset about it and he starts to cry".

The remaining six parents were more negative and said, "sometimes he is worried and upset about it" or "she feels left out, she is the odd one out". One mother was very extreme and said "he hates it". Another mother was also very negative and said "terrible. I don't think he is coping very well with it. Not the fact that he has got it...not the insulin part. His friends can go to places, have more than one ice cream, go to McDonald's whenever they want... He can't go into a shop and buy sweeties".

Similarly, regarding the effects diabetes had on the children's lives parents' responses varied. Three parents reported positive effects of diabetes on their children's lives. This was reflected in a statement like "I don't think it prevents him from doing things. He can do anything he wants". Another mother said "he enjoys his visits to the hospital; it makes him feel quite special".

However, the majority of parents (12) reported that the illness had negative effects on the children's lives. One mother explained "he has missed that (football training session) today because ha had to come here (clinic). He was upset about doing that". Another negative effect of the illness was "it prevents her from eating things" or "I think she's upset, she gets missed out on the sweets and stuff like that, where other's can have and she can't". Yet another mother explained that the illness prevents her daughter from doing things by saying "sometimes it upsets her because she thinks there are things she wants to do that she cannot do, like she loves sports but obviously she cannot run very fast, she gets very tired".

6.4.1.7 Parent's Perception of the Child's Treatment Adherence

Parent's perception of the child's treatment adherence was assessed through the following five criteria which derived from the interviews: 1) knew what diabetes was and what the treatment was for, 2) knew what to do when s/he had symptoms, 3) were able to do the treatment by himself/herself (administer the insulin injections, measure blood sugar levels) and did not need supervising or help, 4) did not need reminding when to take medication, and 5) had no problems/difficulties regarding the treatment regimen. Two parents reported that their children met all of the above criteria, five parents reported that their children met four of the above five criteria, four parents reported that their children met three, and another four parents reported that their children met two of the criteria.

With reference to difficulties with the treatment regimen three parents reported difficulties with the diet. One parent explained "just the eating sweets part she finds hard... I get fed up. I cry. She thinks that because she ain't seen anything happen she is alright. She might have no hand, might go blind", the second parent replied "he is sad when he can't have sweets" and the third said "that he can't eat sweets is a major problem, since he was used to eat it". Two parents had problems with the insulin injections. One father explained "he really doesn't like to give insulin to himself because it hurts him really". Another parent detailed "he doesn't like doing it (the injections) in the morning, but in the afternoons and at night time he is fine with it. He doesn't like it and starts shouting and all that". Another difficulty was "the blood sugar level tests (prick in the finger) we always fight over that". One mother explained that her son confused the right insulin dosages by saying "instead of using the dose he uses in the evening he used it in the morning. Two parents described problems with eating. One mother said "just the regular eating, eating has always been a problem, because he has never enjoyed eating" whereas another mother expressed "I think the hardest bit is getting her to eat when she doesn't want to, she's not actually a big eater".

Lastly, one mother reported that "he doesn't find it (treatment regimen) hard, he just if he had a choice wouldn't do it".

Parents also described more serious instances that could have caused medical complications like "we had to cut out buying sweets and fizzy drinks because she would go behind the back and eat them. And if I am going to buy a sweet I have to count how much I bought and I might have to spot check her room to see that there are no sweets hidden in her room". One parent had problems with the blood glucose testing of her child and explained "we had that he tells you that the recording on the (blood glucose) monitor was something different because he does not want to have something to eat" and ". One mother expressed the problem of her child lying about the insulin injection and pretending he had done it and said that they overcame the problem "we made sure he was doing it in our presence or we did it for him. The problem was that he was doing it in one place, his tummy, and the tummy was going hard, the skin was going hard, so it's painful for him and the insulin was not getting into him, so we reported and they said we can do it in the neck or the bum".

Interestingly only one parent mentioned the fact of future complications due to non-adherence with the treatment regimen as a future worry. It was a mother of a girl who was very worried about her daughter becoming blind if she did not adhere with the dieting regimen.

6.4.1.8 Parent's Perception of the Child's Openness About the Disease

Nine parents reported that their children were open about their diabetes and did not mind being asked about it or reminded of it at any time which was reflected in statements like "no he is open. All his friends, when he goes to school he tells all his friends that he has got diabetes and that he can't have sweets", "he is quite open about it. All his friends know. He is not worried about that" and "no, he is fine, he is happy to talk to people, if anyone wants to listen he is happy to talk". Three parents reported that their children got very upset talking about it and one parent described "sometimes in school his friends ask him and he gets annoyed and upset". Another mother explained "he doesn't want me to tell it to other people. He says 'stop, stop, why do you tell other people about my diabetes". Yet another mother described "she keeps it for herself. Very, very much and sometimes she gets upset".

Two parents reported that it depended on the situation by saying "depends who, friends is OK, once he gets to know them" and "he is open but only with people he knows". One parent implied that it depended on the mood of the child if he got upset or not by saying "sometimes, not all the time".

6.4.1.9 Parent's Attitude About the Treatment and Precautions

As in the case of asthma, all parents reported that they had notified the school about the child's diabetes. Also, all parents had informed the teachers about the child's snack times and most of the parents had explained the signs and symptoms of hypoglycaemia (low blood sugar levels) and how to react.

Also, most parents when asked if they child was allowed to sleep-over at a friend's house would reply "he never slept over". Those few parents who allowed sleep-overs would take the following precautions "whenever she sleeps over at friends she takes a pack with her with the injections, she would take the blood sugar tester with her and glucose tablets, just in case" or "overnight, he has to eat something before he goes to bed so I would have to tell him about that if he stays out". One mother said "it is only one friend that he stays with because she has a sick child as well so she knows how to look after him". All children were allowed to go to other children's birthday parties by themselves but parents would warn the child beforehand that "he has to watch what he eats". Other precautions were "I have to check that her bag is packed properly and she has her medication and everything. And she has got her mobile phone at hand so that she can phone me and I can phone her and check up on her" or "they (the parents) all know he is diabetic and if he hasn't had any sweets that week I will allow him to eat sweets at the party". Most children were allowed to go to sports-day by themselves and parent would take the following precautions "if there is sports, he likes to play a lot of sports, he has to have a sugary treatment where he just keeps topping himself up because he is burning all his sugar up quickly, so he has to have sweets and drinks during the game".

Many parents took additional preventive measures like "my wife had to give up work to look after him", "everybody (in the family) has to eat what he eats. If he has an ice-cream then they (siblings) will have ice-cream and if they want ice-cream and he can't have it they will have to stay outside and finish it outside", and "before he goes to sleep we give him enough food ... so he doesn't get low in the morning and cause trouble, so to make sure he has had enough snacks to continue to the next morning".

When parents were asked if they buy sweets and sweet drinks for the home responses were diverse. Whereas one mother explained "everything is sugar free. The only sweets I keep at the house are glucose and that's for him just in case. If the other ones want some sweets they have to get it themselves or keep them in the room and hide them "another mother replied "there is always loads of sweets in the fridge".

Some parent had worries concerning the child's diabetes. One mother said "Birthday parties we haven't quite got the hang of yet, I tend to give her a bit more insulin and she invariably comes home with high blood sugar from birthday parties".

Another mother was very concerned about the child's school ride and said "five weeks ago he was found (on a bus stop) and his sugar level has dropped so low. One of the neighbours knew him and stopped the bus and brought him home".

6.4.1.10 Parent's Perception of the Impact of the Illness

One parent reported that the child's diabetes had no negative impact on the family life and that after diagnosis of the child no changes within the family were needed. This mother expressed "nothing changed because even with meals I still cook my meal at the same time as I used to it's just that she can have less than us. She understands that, but the others I don't deprive them because of her. Things don't change at all". Eight parents stated that the diabetes had an impact on the family life and changes had to be done but that these did not cause any stress or problems. Six parents reported that the child's diabetes had an impact on the family life and that the necessary changes caused problems. One mother said "everything changed. Everybody has to eat what he can eat". Other problems described were "my wife had to give up work to look after him", "at first I didn't buy anything sweet, cut out cakes. But as my husband said it is not fair on the others, he has got to learn to sort of adjust to it being there and not touching it", "the oldest one in the beginning was jealous (of the late snack of the diabetic child)", "the other siblings accused me that because of (name of child) they don't get sweet drinks in the morning and they like their drinks", "we used to have loads of sweet drinks (before she was diagnosed)", and "in the beginning we'd spend sometimes up to an hour persuading her to eat something before she went to bed, chasing her around the room, trying to tempt her".

Regarding the child's school performance, twelve parents reported that they were happy with the progress and three revealed that their children were academically behind in school.

All 15 parents reported that they thought that their children were happy with how they were doing at school academically. Also, all parents reported that their children did not have any problems with friendships i.e. they had many friends and best friends. However one mother described the following treatment related problem concerning her child's friendships "the only problem with friends is that if she's invited to their house the other mother has to take responsibility for her and on the whole I haven't found that people really understand quite what they're getting into. Yesterday I picked her up from a friend's house, she had had quite a big tea but she hadn't eaten any potatoes and that didn't seem to worry them, they didn't appreciate the carbohydrates component were critical ...". Another concern a father expressed was that sometimes in school "they're picking on his diabetes, you know other children".

6.4.1.11 Conclusion of the Content Analysis

The content analysis of the child and parent interviews once again allowed for an identification of stressors children with diabetes had to cope with. Children reported treatment related stressors which involved taking the insulin injections and measuring the blood sugar level, diet constraints which entailed not being able to eat sweets or only very little, and outing restrictions which included not being able to go on school weekend trips, sleeping over at a friend's house, and not being able to go on holiday. Parents also talked about the same treatment related stressors and diet constraints. However, parents brought up additional treatment-related concerns. These were that some children were eating sweets and sweet drinks behind the parents' backs or would lie about the blood glucose monitor reading to avoid having to eat something.

Even though children reported many negative aspects about having diabetes there were a number of children who perceived positive sides of having diabetes. These were getting days of school because of the diabetes, receiving extra attention, and participating in social groups for diabetics.

An interesting finding was that except for one girl and one mother of another girl, all children and parents did not mention any worries regarding future consequences or complications of diabetes. This one girl explained that she always wanted to become a tennis-player and because of her diabetes won't be able to. The one mother of another girl was very worried about her daughter becoming blind if she did not adhere with the dieting regimen.

An explanation why future complications did not come up in parents' answers might have been simply due to the fact that the interview schedule did not include specifically a question about any future worries. Another explanation might have been that parents were overwhelmed by mastering the daily demands of the illness that they did not worry as yet about the future. Yet another explanation might have been that parents' and doctors' concerns differ due to differences in the understanding of the consequences.

Overall, the combined reports of children and parents gave an insight into how these children coped with these additional stressors of having diabetes and to which extent their lives were affected by them as well as their general feelings towards the illness. The analysis revealed that there were commonalities in stressors across children but differences in adjustment that is variability in how children perceived the limitations imposed by the illness.

The content analysis also revealed which parts of the treatment regimen they found difficult to adhere to which parts were easy to follow. As in the case of children with asthma, it was found that there were differences in the extent children with diabetes perceived the treatment regimen is interfering with their lives, which again resulted in varying levels of treatment adherence.

Furthermore, children provided information on the extent they felt normal and were treated normally by their parents. They provided information on how open they were about having the illness, if they liked talking about it with everyone, or only with specific people or not at all.

The parents' interviews provided further information on the same issues but from a different perspective.

6.4.2 Development of a Scoring Scheme to Quantify Children's and Parents' Responses

Parallel to study 1 with children with asthma, analyses of interviews by theme provided a picture of children's and parents' impressions about the child's illness, which was valuable for understanding their situation. In order to use the interview data more systematically, the categories containing all the children's and parents' responses for each theme had to be scored. Thus the same categories and anchoring points as in study 1 were utilised but adjusted to suit a diabetic sample. A 5-point scale was used for all the categories except for the categories "Child's openness about the illness" and "Parent's perception of the child's openness about the disease", which as in study 1 had to be scored on a 3-point scale.

Furthermore, as in study 1 this method was based on the judgment of a single researcher and hence independent scorings had to be obtained from a second researcher and the percentage of agreement between both researchers was examined. Again the first researcher rated all children's and parents' categories whereas the second researcher independently scored five randomly selected children and parents for each category. As the second researcher scored five of the four children categories and five of the six parent categories she made a total of 50 judgments. The percentage of agreement was calculated for the scorings of both researchers and if disagreement occurred it was explored if the scorings were adjacent. For 10 judgments there was disagreement between the two researchers but in all cases the scores were adjacent. Thus there was an 80% percentage of agreement between the two researchers.

Listed below are , as recommended by Guilford (1978), the descriptions of the anchoring points for each category that were developed in order make these judgments with each of them being followed by a table showing the frequencies for each of the five ratings.

1. "Child's perception of normality" was judged on a five-point scale with 5 being the most positive outcome i.e. the child felt very normal. The highest rating 5 was given when 1) the child felt that there was no difference between a child with diabetes and a child without the disease; 2) the child felt that parents were not too careful with the child; 3) child felt that parents treated the child the same as they treated the other sibling(s). Rating 4 was given if one of the above three criteria did not apply. Rating 3 was given if one of the criteria did not apply as well as one of the others applied sometimes. Rating 2 was given when two of the criteria did not apply for the child and rating 1 if none of them applied.

Table 6.3 Frequencies of each rating for "Child's perception of normality"

Rating 1	Rating 2	Rating 3	Rating 4	Rating 5
3	3	1	4	4

2. "Parent's perception of the child's normality" was also judged on a five-point scale with again 5 being the most positive outcome. Rating 5 was given when 1) the parent never thought that s/he is being too careful with the child and 2) parent felt that child did not think that parent treated the child differently to other children or was being too careful. Rating 4 was applied when parent reported that either 1 or 2 applied sometimes. Rating 3 was given when parent reported 1 or 2. Rating 2 when parent reported 1 or 2 together with 1 or 2 sometimes. Rating 1 was given when both 1 and 2 did not apply.

Table 6.4 Frequencies of each rating for "Parent's perception of the child's normality"

Rating 1	Rating 2	Rating 3	Rating 4	Rating 5
5	1	6	0	3

3. "Child's feelings about the disease" was again assessed on a five-point scale with rating 5 being given when 1) child felt positive about the illness now; 2) child thought that there was something nice about the illness; 3) there was nothing the child did not like about the illness; and 4) child thought there was nothing s/he was not allowed because of the illness. Rating 4 was attained

when any 3 aspects were met, rating 3 when 2 aspects were met, rating 2 when only one aspect applied, and rating 1 when none of the 4 aspects applied.

Table 6.5 Frequencies of each rating for "Child's feelings about the disease"

Rating 1	Rating 2	Rating 3	Rating 4	Rating 5
3	6	3	3	0

4. "Parent's perception of the child's feelings" was also judged on a five-point scale. This category was judged on the basis of the following: 1) parent thought that child felt positive about the illness and coped well; 2) parent thought that child did not perceive the illness as preventing him/her from anything; 3) parent found alternatives when child was not allowed to do or to have something because of the illness (e.g. Diet soft drinks); and 4) there were no problems with or bad feelings about the treatment. Rating 5 was given when all 5 aspects were met and rating 4 when 3 of the 4 aspects were met. Rating 3 was given when parents reported that 3 of the 4 applied jointly with 1 of the other 3 only sometimes. Rating 2 was given when only 2 of the 4 applied and rating 1 when 1 or none applied to the parent.

Table 6.6 Frequencies of each rating for "Parent's perception of the child's feelings"

Rating 1	Rating 2	Rating 3	Rating 4	Rating 5
2	3	5	3	2

5. <u>“Child’s treatment adherence”</u> was again judged on a five-point scale with 5 being the most positive outcome i.e. the child was very compliant with the treatment. The highest rating (i.e. 5) was given when 1) the child knew which medication to take and when; 2) child took the medication everyday; 3) child knew symptoms; 4) child knew how to react upon symptoms but needed help from a caregiver; 5) child knew how to react upon symptoms (e.g. administer insulin injections, measure blood sugar levels, take a glucose tablet or eat something that contains sugar etc.) without any external help from a caregiver; and 6) child did not like some aspects of the treatment but still adhered to them. Rating 4 was given when 5 of the 6 applied to the child, rating 3 when 4 applied, rating 2 when 3 applied and rating 1 when 2 or less applied to the child.

Table 6.7 Frequencies of each rating for “Child’s treatment adherence”

Rating 1	**Rating 2**	**Rating 3**	**Rating 4**	**Rating 5**
2	1	0	5	7

6. <u>“Parent’s perception of the child’s treatment adherence”</u> was assessed through the following five judgments: 1) parent reports that child did not need reminding when to take medication (insulin injection) or do a medical test (blood sugar level test); 2) parent reports that child knew what the treatment was for; 3) there were no problems with the treatment; 4) parent reports that the child knew what to do when s/he had symptoms; and 5) child was capable to do the treatment by himself/herself and did not need supervising. Rating 5 applied when all 5 criteria were met, rating 4 when 4 of the 5 were met, rating 3 when 3 were met, rating 2 when 2 were met and rating 1 when only 1 were met.

Table 6.8 Frequencies of each rating for "Parent's perception of the child's treatment adherence"

Rating 1	Rating 2	Rating 3	Rating 4	Rating 5
0	4	4	5	2

7. <u>"Child's openness about the illness"</u> had to like in the previous study be judged on a 3-point-scale due to the information available not allowing for finer discriminations: Rating 3 indicated that the child never minded talking about diabetes and did not keep it to himself/herself; Rating 2 indicated that the child only sometimes liked to talk about diabetes and occasionally kept it to himself/herself; Rating 1 indicated that the child did not like talking about diabetes and rather kept it to himself/herself.

Table 6.9 Frequencies of each rating for "Child's openness about the illness"

Rating 1	Rating 2	Rating 3
2	6	7

8. <u>"Parent's perception of the child's openness about the disease"</u> was the other judgment that used a three-point scale because again the information available did not allow for finer discriminations: Rating 3 indicated that the parent thought that the child did not mind being asked or reminded about the illness at any time; Rating 2 indicated that the parent thought that the child sometimes did not like to be asked or reminded about the illness but was comfortable with it at

other times; Rating 1 indicated that the parent thought that the child did not like to be asked or reminded about the illness.

Table 6.10 Frequencies of each rating for "Parent's perception of the child's openness about the illness"

Rating 1	**Rating 2**	**Rating 3**
2	5	8

9. <u>"Parent's attitude about the treatment and precautions"</u> was assessed on the basis of the following six judgments: 1) school (teacher and/or friends) were informed about the illness; 2) child had medication at school or teacher knew about snack times or school knew what to do when child had symptoms; 3) parent had no worries; 4) child always carried medication with him/her <u>or</u> had medication before leaving home <u>or</u> checked blood sugar levels before leaving home; 5) additional precautions were taken (e.g. child regularly attended the diabetes clinic, child had to eat a snack before going to sleep; 6) child was not allowed to sleep-over at a friend's house <u>or</u> to go to sports-day on his/her own <u>or</u> to go to a friend's birthday party on his/her own. Rating 5 applied when all 6 criteria were met, rating 4 when 5 of the 6 were met, rating 3 when 4 were met, rating 2 when 3 were met and rating 1 when only 2 or less were met.

Table 6.11 Frequencies of each rating for “Parent’s attitude about the treatment and precautions”

Rating 1	Rating 2	Rating 3	Rating 4	Rating 5
3	4	5	2	1

10. “Parent’s perception of the impact of the illness” was assessed through the following five judgments: 1) parents were happy with the child’s school progress and child was not academically behind in school; 2) child was happy with his/her school progress; 3) child had no problems with friendships; 4) child’s illness had an impact on the family life and there were changes but these did not cause stress or problems; and 5) the child’s illness had no impact on the family life and there were no changes because of the illness. Rating 5 was given when all 5 criteria applied, rating 4 when 4 of the 5 applied, rating 3 when 3 of the 5 applied, rating 2 when 2 applied , and rating 1 when 1 or none pertained.

Table 6.12 Frequencies of each rating for “Parent’s perception of the impact of the illness”

Rating 1	Rating 2	Rating 3	Rating 4	Rating 5
0	1	7	7	0

6.4.3 Concordance Between Child and Parent Reports in the Interviews

Identical to study 1 the above scorings were utilized to carry out a correlational analysis between children's categories and the corresponding parents' categories to investigate concordance between both perspectives.

For this analysis, Spearman's correlation coefficient (2-tailed) was used as the data was ordinal and ranked. As there were only four children scales, they were correlated with the corresponding four parent scales and the two additional parent scales had to be excluded from this analysis.

Table 6.13 Correlations between parents' and children's interview scales

Parent Scale (n=15)	**Child Scale (n=15)**	**Correlation**
Parent's perception of the child's openness about the disease	Child's openness about the disease	0.742**
Parent's perception of the child's feelings	Child's feelings about the disease	Not significant
Parent's perception about the child's normality	Child's perception of normality	Not significant
Parent's perception of the child's treatment adherence	Child's treatment adherence	0.611*

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

As can be gathered from table 6.13, parents' account about how open their children were about the illness and how much their children adhered with the treatment regimen converged with the children's own account. However, children's and parents' reports differed regarding the children's feelings towards the illness and the effects the illness had on their lives and to which extent children felt normal and being treated normally. One explanation for why children's and parents' reports converged for openness about the disease and treatment adherence could have been that these domains were behaviour-related and therefore easier for parents to evaluate. A child's openness about the illness could be inferred from a child's behaviour. For example a child who was not be open about the illness would be embarrassed of administering the insulin injections or measuring the blood sugar level in public or would try to avoid answering questions about the illness. The fact that parents' judgment about the child's treatment adherence converged with the child's account might be explained by the fact that in diabetes non-adherent behaviour with the treatment regimen causes immediate symptoms. For example, omitting an insulin injection, very quickly results in high blood sugar levels causing the child to have severe symptoms. Not adhering to the diet by eating too little results in low blood sugar levels again causing severe symptoms for the child. Thus, there is a limited frame of non-adherent behaviour (e.g. eating a limited amount of sweets) by the child that does not cause immediate severe symptoms (however can still cause severe long-term complications). Perhaps because of these immediate consequences when the treatment was not followed as required parents had a more accurate indication of their children's treatment adherence compared to parents of children with illnesses in which non-adherence did not cause immediate consequences. For example in asthma omitting the administration of the preventative inhaler does not necessarily cause an immediate asthma attack thus leading space for children to be non-adherent.

However, children's feelings about the disease and children's perception of normality were domains that reflected the children's emotions and feelings and therefore might have been more difficult for parents to judge. An examination by comparing children's and parents' reports on the child's feelings towards diabetes revealed that the parent and child perspective often diverged. For example one father described his son's feelings towards diabetes as "it's not affecting him. He is generally fine". However, the child's report differed dramatically as he described his feelings towards diabetes as "I don't like it" and "I hate getting injections". Another mother described her son's feelings towards his diabetes as "he hates it". However, the child's feelings were in reality not that negative. He perceived the illness as having nice aspects to it by saying "you get days off school". Yet another mother expressed "sometimes he is worried and upset about it" whereas her son said "I am okay with it". One more mother described her son's feelings as "terrible. I don't think he is coping very well with it, not the fact he has got it, not the insulin part" whereas the child was more positive and said "only sometimes I get scared when I get low sugar levels, but it is okay now".

Concerning the child's normality one mother stated that her son perceived himself as being treated differently in comparison to the siblings whereas the son felt that his mother treated them all the same. Another mother reported that she thought that her daughter perceived herself as being treated the same as her sibling whereas in fact the daughter thought that her parents were treating her differently.

Thus, parents' reports might have been biased by their life perspective, demonstrating that proxy ratings i.e. parent ratings did not provide a comprehensive picture about their children's feelings towards the illness and in how far they felt normal and being treated normally.

6.4.4 Comparison Between the Adjustment of a Well Adjusted and a Poorly Adjusted Child

As in the case of asthma, in the subsequent section again two case studies were presented to illustrate the differences in children's adjustment to diabetes. Once more two extreme cases were selected which included one case in which the child was very well adjusted to the illness and another case in which the child was very poorly adjusted.

S. was nine-years-old when she was interviewed and had high scores for all four scales. Regarding her perception of being normal she was asked if a child with diabetes was different to other children. She replied "no, I don't think so. It is just that they are the same as other people they just have got something wrong with them, but it's not like they have to go to the hospital everyday, like have casts and have crutches. They are just like everybody else." When asked if she thought that her parents were too careful with her, she replied "no. I think they are being very fair". To the question if her parents treated her differently to her siblings she answered "no they treat us the same".

Concerning her feelings towards diabetes she said "I thought I was going to die, because I was very ill. All these needles were going in to me I never knew what was happening. Now I am coping very well". She perceived that there was something positive about having diabetes by saying "sometimes when I am feeling low my mum tells me I am allowed to get sweets and my sister is not allowed". When asked to list negative aspects of having diabetes she replied "when I grow up I always wanted to be a tennis player, but I can't be it now. When I am feeling low I feel sick and I don't like it".

With reference to treatment adherence she explained "in the morning when I wake up and I have my injection measurement nine (units) and after that I have taken my injection I waited like five or ten minutes and then I have my breakfast. In the evening I do the same, but the measurement is 18". When asked about symptoms of diabetes she said "it makes me weak and it makes me feel like I am going to get a sib or it makes me drowsy and thirsty". When asked what she did when she had symptoms she answered "I will have a sweet drink and I have to try and stay up to get some energy back". When asked if there was anything she had to do that she did not like she said "taking the injections because it makes me bleed. And also the prick in the finger, it's scary". When asked if she still does these things everyday even though she did not like it she replied "yes because it helps me to figure out if I am low or high so I can get help". When she was asked if she takes any precautions when she goes somewhere she answered "yes, don't put pressure on yourself too much or don't do things that you know is not right. When I went to a sleep-over there were a lot of sweets and I was going to eat them, but I thought to myself what's going to happen to me if I eat them".

Regarding openness about the illness she answered "I don't mind people asking or talking to me about my diabetes". When she was asked if she rather kept it to herself she replied "no".

K. was 10-years-old when she was interviewed and had low scores for all four scales. Concerning her perception in how far she felt normal she said "children with diabetes are different to other children because they need injections and cannot eat sweets". To the question if her mother is sometimes too careful with her she answered "yes, sometimes". She thought that her parents treated her differently compared to her sister but she could not give specific examples.

Regarding her feelings towards diabetes she had not accepted the illness by saying "I don't like it". When she was asked about any positive aspects about having diabetes she replied "there is nothing nice about having diabetes". When she was asked to tell all the aspects she did not like about the illness she said "I can't do anything". When asked what she specifically did not like she mentioned "the injections". Then she added "I cannot eat sweets" and "I can't sleep over".

With reference to treatment adherence, K. explained "I take insulin twice a day in the mornings and evenings. I measure my blood sugar twice a day". To the question if she was able to administer the insulin injections by herself she answered "no I can't take the insulin injections by myself but I can measure my blood sugar level by myself".

When she was asked about symptoms of diabetes she said "I am weak sometimes. When I am low I start to tremble". When asked what she did when she had symptoms she answered "I eat something sweet". When she asked if there was anything she had to do that she did not like she said "the insulin injections because they hurt". When she was asked if she still took the injections everyday even though she did not like them she replied "yes".

To the question if she takes any precautions when she goes somewhere she answered “no”.

Regarding openness about the illness she answered “I never like talking about my diabetes. I keep it for myself”.

6.5 Overall Conclusion

The content analysis of the interviews with children with diabetes and their parents gave an insight into how these children coped with the additional stressors of having diabetes and to which extent their lives were affected by them as well as their general feelings towards the illness. As in the case of children with asthma, the analysis of the children with diabetes of this study disclosed that there were commonalities in stressors across children but differences in adjustment. Specifically, there was variability in how children perceived the limitations imposed by the illness.

The stressors that children revealed were treatment related and involved taking the insulin injections and measuring the blood sugar level, diet constraints which entailed not being able to eat sweets or only very little, and outing restrictions which included not being able to go on school weekend trips, sleeping over at a friend’s house, and not being able to go on holiday. Parents talked about the same treatment related stressors and diet constraints but reported additional treatment-related concerns. These were that some children were eating sweets and sweet drinks behind the parents’ backs or would lie about the blood glucose monitor reading to avoid having to eat something.

Despite all these negative aspects of diabetes some children perceived positive points about having diabetes which were getting days of school, receiving extra attention, and participating in social groups for diabetics.

Interestingly there was only one girl and one mother of another girl who talked about worries regarding future consequences or complications of diabetes. This one girl explained that she always wanted to become a tennis-player and because of her diabetes won't be able to. The one mother of another girl was very worried about her daughter becoming blind if she did not adhere with the dieting regimen.

Also, similarly to the children with asthma, the children of this study showed differences in the extent to which they perceived the treatment regimen was interfering with their lives, which again resulted in varying levels of treatment adherence.

Lastly, children provided information on the extent they felt normal and were treated normally by their parents. They gave an account on how open they were about having the illness, if they liked talking about it with everyone, or only with specific people or not at all.

Overall, the parents' interviews provided further information on the same issues but from a different perspective.

These content categories were as in study 1 scored by a researcher and as this method was based on the judgment of a single researcher, independent scorings for five child and five parent categories were also obtained from a second researcher. The percentage of agreement between both researchers was examined and came to 80%. Due to the high percentage of agreement between the two researchers, the scorings could then be used for the correlational analysis between children's and parents' reports.

The correlational analysis between parents' and children's reports showed that parents' version about their children's openness about the disease and how adherent they were with their treatment regimen converged with the children's own version. However, children's and parents' reports differed regarding the children's feelings towards the illness and the effects the illness had on their lives and to which extent children felt normal and being treated normally. An explanation for this finding could have been that a child's openness about the disease and a child's treatment adherence were domains that were behaviour related and therefore easier for parents to evaluate. In contrast, children's feelings about the disease and their perception of normality were domains that fell under children's emotions and as a result might have been more difficult for parents to appraise.

Thus, as in the case of asthma, parents' reports were once again biased regarding the children's feelings towards the disease and their perception of normality by their life perspective and consequently did not provide an accurate account. This finding stressed the importance of considering children's own reports, as information obtained from both parents and children provides a more comprehensive picture.

The two case studies comparing the adjustment of a well adjusted and a poorly adjusted child illustrated once more the differences in children's adjustment to diabetes.

Parallel to study 1, the aim of the next study was to develop separate questionnaires but this time for children with diabetes and their parents. In order to develop these questionnaires, children's and parents' content categories with their codings of this study were utilized to form statements to be included in the questionnaires.

Also parallel to study 1, the scorings of these content categories were then used to validate the newly developed questionnaires once they were administered to a larger sample of children with diabetes and their parents.

CHAPTER 7

STUDY 4 – DEVELOPMENT OF THE “CHILDREN’S ADJUSTMENT TO DIABETES QUESTIONNAIRE”

7.1 Aim

The aim of this study was firstly to develop separate questionnaires for children with diabetes and their parents assessing children's adjustment to the illness and their treatment adherence.

The second aim was to test the hypothesis of an association between children’s adjustment to the illness and treatment adherence, once the questionnaire has been analyzed and considered reliable

7.2 Background, Brief Overview, and Research Strategy

Study 4 was a parallel study to study 2 and hence the background was identical and was not repeated here. Study 4 had the same aim and methods but this time included a sample of children with diabetes rather than asthma and their parents. Even though both studies had the same aim and methods and were conducted concurrently it was decided to keep the reports separate as the children’s illness differed across the studies.

Thus, parallel to study 2 separate questionnaires for children with diabetes and their parents were developed on the basis of 1) an interview with a paediatric diabetes nurse and 2) utilizing grounded theory on the children’s and parents’ replies to the interviews. As in study 2 the data from the children and parent questionnaires were subjected to a quantitative data analysis. Again, analysis of the psychometric properties of the new questionnaires involved exploring reliability by determining the internal consistency of the questionnaires. Secondly, content validity, another psychometric property of a questionnaire was investigated by a panel of experts who evaluated the content and relevancy of the items for each child and parent scale.

Thirdly, the concordance between the results from the interviews and the questionnaires was explored. The questionnaires for children and parents were designed on the basis of the same scales as were used to analyze the interviews. This allowed for an illness-specific approach in this chapter but also an illness-generic analysis later on.

Fourthly, the relationship between children's chronological ages and their overall adjustment was explored.

Lastly, an investigation of the relation between children's socio-emotional functioning and treatment adherence was conducted assessing concurrent validity.

7.3 Method

7.3.1 The Sample

The sample comprised a total of 30 children with Insulin-Dependent Diabetes Mellitus (IDDM) including 13 girls and 17 boys with ages ranging from 7 years 3 months to 13 years 8 months and an average age of 10 years 9 months and their parents. As in study 3 the sample was heterogeneous and consisted of 15 Caucasian, 12 Black and three Indian children.

The researcher aimed at following up the 15 children that participated in study 3 by either approaching them when they attended a clinic at the hospital or contacting them by telephone. The researcher was able to follow-up all 15 diabetic children from study 2 and the other half (n=15) were new children with Insulin-Dependent Diabetes Mellitus (IDDM). As in study 2, all new children selected for study 4 met the criteria of not having a mental illness (autism, ADHD, etc.).

Table 7.1 Mothers' education levels, occupations and fathers' occupations (*n*=30)

Mother's Education	**n**	**Mother's Occupation**	**N**	**Father**	**N**
GCSE or lower	20	Housewife	18	Class 1 (e.g. builder, delivery driver)	12
A-levels	4	Student	2	Class 2 engineer, IT consultant	2
Higher National Diploma		Class1 (e.g. shop assistant,	5	Student	1
Bachelor degree	4	Class2 (e.g. accountant, nurse)	3	Passed away	2
Master's Degree or higher	2	Class3 (e.g. lecturer)	2	No information	13

As previously in the case of children with asthma, there are to the knowledge of the author no statistics to compare the proportion of families' SES of this study to the proportion of families' SES in the diabetes population.

It was investigated again whether SES (i.e. mothers' and fathers' education) of the parents was associated with child adjustment, child treatment adherence, and parents' perception of the child's adherence, Spearman's non-parametric correlation (2-tailed) was applied since the responses were measured at the ordinal level and were ranked. There was no significant association between SES and child adjustment, child treatment adherence, and parents' perception of the child's adherence. Thus, parents' SES did not affect any of these three variables.

7.3.2 Development of the Questionnaires

The separate questionnaires for children and parents were developed on the basis of 1) information obtained from an interview with a paediatric diabetes nurse and 2) using grounded theory (Charmaz, 2003) statements to be included in the questionnaire were generated on the basis of the replies of children and parents in the interviews.

The paediatric diabetes nurse's interview schedule was generated by the author based on the literature and evaluated the children's experience of having diabetes (Appendix 5.1). Specifically, the nurse's interview provided information from the professional's perspective and assessed the following domains in relation to the range of general responses they observed in medical environments (1) the children's adjustment to medical environments (hospital and clinic), (2) distress during medical procedures, (3) children's coping with the treatment regimen and problems/issues, and (4) the children's coping with symptoms. The interview schedule included for each theme different questions around the same topic to ensure that responses were consistent.

On the basis of children's, parents', and nurses' replies in the interviews, child and parent questionnaires were developed by using grounded theory (Charmaz, 2003) to generate statements to be included in the questionnaires. The process for utilizing grounded theory for the development of the questionnaires was identical to study 2 (children with asthma) and therefore was not repeated in this chapter. Thus, once the process of creating categories and coding references at them was finished the researcher again browsed through each of these categories and compared children and parents' responses. These experiences were utilized to form statements to be included in the questionnaires. Statements that were too restricted and might have not applied to many children were again changed to more general statements, to which all children could react genuinely. For example, a child said that his asthma restricts him from playing rugby and he felt angry about it. The word 'rugby' was changed into 'sports', so that it is possible to assess how children react to feeling restricted in their participation in sports. Additionally, it was ensured that the statements were phrased in a way that children and parents with a particular way of adjusting to the illness would agree with half of the statements and disagree with the other half. Whereas, a parent of a diabetic child who would agree with the statement "I only buy sugar free drinks for the house so he can have the same drinks as everyone else" would not agree with the statement "I buy sweets for the house because otherwise it is not fair on the sibling(s)". Also, it was ensured that each questionnaire item contained just one statement in order to avoid that the respondent might agree with one part and disagree with the other. Finally, all statements that were taken from the original interviews and were in past tense were changed to present tense.

Parallel to study 2, in the parent questionnaire 10 items were added to assess parental style from the Parental Authority Questionnaire (Buri, 1991. Five items that assess authoritarian and five items that assess authoritative parenting style were adapted by the researcher for use of parents of children with diabetes. The authoritarian items taken from the PAQ were 1) "Whenever my mother told me to do something as I was growing up, she expected me to do it immediately without asking any questions" which was changed into "I know what is good for him so when I tell him to do something that is part of his treatment, I expect him to do it immediately without asking any questions", 2) As I was growing up my mother let me know what behaviour she expected of me, and if I didn't meet those expectations, she punished me" was changed into "When I tell him not to eat something and he still eats it, I punish him", 3) "As I was growing up my would get very upset if I tried to disagree with her" was changed into "I get very upset if he tries to disagree with me and starts a whole discussion", 4) "As I was growing up I knew what my mother expected of me in the family and she insisted that I conform to those expectations simply out of respect for her authority" was changed into "I expect from my child that he conforms to my decisions out of respect for my authority", and 5) "My mother has always felt that most problems in society would be solved if we could get parents to strictly and forcibly deal with their children when they don't do what they are supposed to as they are growing up" was changed into "All problems would be solved between mother and child if parents were strict with their children when they don't do what they are supposed to do". The authoritative items taken from the PAQ were 1) "My mother has always encouraged verbal give-and-take whenever I have felt that the family rules and restrictions were unreasonable" was changed into "I try and encourage verbal give-and-take whenever I feel that the treatment regimen and restrictions are too demanding", 2) "As I was growing up, once family policy had been established, my mother discussed the reasoning behind the policy with the children in the family" was changed into "When he wants to eat something that he should not, I discuss with him the reasons behind it", 3) "As I was growing up I knew what my mother expected of me in my family, but I also felt free to discuss those expectations with my mother when I felt that they were unreasonable" was changed into "I let my child feel free to discuss my decisions if he feels that they are unreasonable", 4) "As I was growing up, my mother seldom gave me expectations and guidelines for my behaviour" was changed into "I try not to have too high expectations of him, I just encourage him to do his best", and 5) "As I was growing up, if my mother made a decision in the family that hurt me, she was willing to discuss that decision with me and to admit it if she had made a mistake" was changed into "If I make a decision, I am willing to discuss it with him and admit if I made a mistake".

These statements were inserted randomly into the questionnaire and participants indicated their level of agreement on a 5-point scale ranging from 'strongly disagree' to 'strongly agree'. These statements were again randomly mixed into the questionnaire. As in study 2, participants indicated their level of agreement on a 5-point scale ranging from 'strongly disagree' to 'strongly agree'. The parent questionnaire consisted of 95 items, the items from the seven scales were randomly ordered in the questionnaire. These included 18 items from the "Parent's perception of the child's normality" scale, 20 items form the "Parent's perception of the child's treatment adherence" scale, 12 items from the "Parent's perception of the child's feelings" scale, 5 items from the "Parent's perception of the child's openness about the disease" scale, 19 items from the "Parent's perception of the impact of the illness" scale, 11 items from the "Parent's attitude about the treatment and precautions" scale, and 10 "Parental style" items. The parent version was administered using pen and paper format (Appendix 7.2 for parents of girls and 7.3 for parents of boys).

In addition to the information provided by the questionnaire, parents were also asked to complete questions about demographic information (the father's and mother's occupation, and the mother's schooling in order to determine the SES of the family), the type of medication the child was on and his/her average blood glucose levels and the number of hospital admissions because of the child's diabetes in the last two years and whether the child suffered from other diseases.

The child questionnaire contained 50 items, which were randomly ordered from the four scales. These included 11 items from the "Child's perception of normality" scale, 21 items from the "Child's treatment adherence" scale, 13 items from the "Child's feelings about the disease" scale, and 5 items from the "Child's openness about the disease" scale. The child and parent scales were as in study 2 utilized later in the data analysis to check 1) the reliability of the questionnaire by determining its internal consistency, 2) the content validity of the questionnaires via an expert panel, 3) the concordance between interview and questionnaire data, 4) the association between children's adjustment and asthma severity, 5) the association between children's adjustment and their chronological age, and 6) the main hypothesis of an association between children's adjustment and treatment adherence.

The questionnaire was administered in a computerized format, showing one statement at a time on colourful backgrounds with two break images to allow the children a little gap (Appendix 7.4).

The child questionnaire for children with diabetes was developed on the basis of interviews with children with diabetes between the ages of 7 and 12 years and consequently it was age-specific for the same age range. This was done identical as in study 2 because in different age categories different aspects of daily life are relevant.

The procedure of administering the new questionnaires was identical to study 2 and therefore was not repeated in this study.

7.4 Results

7.4.1 Statistical Analyses

The procedure of administering the questionnaire and the analysis of the child and parent questionnaires was identical to study 2 (except that illness severity was excluded from the analysis) and followed five steps:

- The child and parent questionnaires included a large sample of items so that items with low reliability could be discarded. Analysis of reliability involved determining the internal consistency of the children and parent questionnaires separately by calculating Cronbach's coefficient alpha (Cronbach, 1951) for all the items in each scale. Alpha levels reached an acceptable reliability threshold when they were at least .7 (Nunnally and

Bernstein, 1994). Thus, those items that were identified as lowering the internal consistency were eliminated.

- Secondly, content validity was investigated by a panel of experts who evaluated the content and relevancy of the items for each child and parent scale.
- In order to be able to add up the scales and obtain an overall score, the overall internal consistency of the child and parent questionnaire was determined.
- In order to examine whether both types of assessment i.e. interview and questionnaire produce converging information, a correlational analysis was conducted.
- In order to explore the relationship between children's chronological ages and their overall adjustment, a correlational analysis was conducted.
- Lastly, the main hypothesis of an association between children's overall adjustment and treatment adherence was tested by means of a correlational analysis. A significant correlation between both variables would confirm the connection between children's adjustment and their adherence with the treatment.

Since the responses to the questionnaires were measured at the ordinal level and were ranked, Spearman's non-parametric correlation (2-tailed) was applied for all the above correlational analyses.

7.4.2 Reliability

As was reported in the qualitative data analysis for study 3 the researcher created categories on the basis of children's and parents' replies in the interviews and on the basis of the content of these categories statements were generated to be included in the questionnaires. However, these categories were hypothetical and as the newly developed diabetes questionnaires for children and parents were based on these categories the questionnaires needed to be scrutinized for reliability and validity. Parallel to study 2, validation of the questionnaires for children and parents was carried out by the method of internal consistency, which was determined by calculating Cronbach's coefficient alpha (Cronbach, 1951) for all the items in each scale as well as of the entire instrument. Alpha levels reached an acceptable reliability threshold to describe a population when they were at least .70 (Nunnally and Bernstein, 1994).

Identical to study 2 analysis of the internal consistency of the questionnaires involved grouping the questionnaire items by themes that came out previously in the interview analysis and providing information on the reliability of the scales as assessed by alpha levels. The process included running separate reliability analyses for each scale and dropping gradually items that were identified as lowering the internal consistency of each scale until a reliability of a minimum of .70 was reached.

The results of each scale are presented separately below. In each analysis it has been reported which items were dropped to increase reliability of the scale, followed by a table of those items that were retained in the final questionnaires.

7.4.3 Reliability: Internal Consistency of Each Scale of the Child Questionnaire

1) “Child’s perception of normality”. This scale consisted of 11 items and had a coefficient of .74. Dropping items 19 and 34 enhanced reliability to .80. Even though item 27 asked about siblings it was kept as it did not have a negative effect on the reliability of that scale.

Table 7.2 Items retained in the scale “Child’s perception of normality”

2. A child with diabetes is different from a child who hasn’t diabetes because having an illness makes you different

3. I don’t mind that whenever I eat sweets my mum tells me to stop because she gets too worried

10. I don’t think that there is a difference between a child with diabetes and a child who has not diabetes

11. My mum lets me get on with what I want to do

18. Children with diabetes and without are the same because diabetes does not change your life that much

26. Children with diabetes have to watch what they are eating and drinking and other children don’t

27. My mum is always too cautious with me e.g. when I want to do sports or go on a school trip than she is with my brother or sister

35. I often think that it is not fair when I am not allowed to do something just because I have diabetes

41. My mum treats me exactly the same as other mums treat their children except that I cannot eat sweets

2) “Child’s openness about the disease”. This scale only contained five items even though the aim was to create more. However, it was not possible for this scale. The scale had a coefficient of .77 and therefore met the minimum reliability standard of .70. Subsequently, due to the low number of items in that scale no items were dropped.

Table 7.3 Items retained in the scale “Child’s openness about the disease”

5. My friends did not know anything about diabetes before they met me

13. I showed my friends my injections and glucose meter and told them how it works

21. I don’t like eating my snacks in school when all the other children don’t eat

29. I don’t mind when people ask me about my diabetes

37. I’d rather keep it for myself that I have diabetes

3) “Child’s feelings about the disease”. This scale comprised of 13 items and had a coefficient of .72. Excluding items 1 and 25 increased alpha reliability to .75.

Table 7.4 Items retained in the scale “Child’s feelings about the disease”

8. It does not bother me when other children pick on me because of my diabetes

9. It does not bother me that I have to take injections every day

16. I never worry about my diabetes

17. I like that I get days off school or can leave school earlier because of my

diabetes

24. It is better to have diabetes that I can control than some other illness that you cannot control

32. I hate the fact that I have diabetes

33. It makes me very sad that I cannot eat sweets or can only have very little

40. There is nothing nice about having diabetes

44. Having diabetes is not too bad if you have it controlled

47. When I eat sweets I really worry what will happen to me

50. I wish I could eat sweets like other children

4) “Child’s treatment adherence”. This scale included 21 items and had a coefficient of .75. Eliminating items 4, 15, 20, and 23 strengthened alpha reliability further to .82.

Table 7.5 Items retained in the scale “Child’s treatment adherence”

6. When I go to a friend’s birthday party without my mum I really eat a lot of sweets

7. It makes me really afraid when my blood sugar levels are high or low and I do what the doctor told me and the symptoms don’t go away

12. I don’t mind that because of my diabetes I am not allowed to sleep over at a friend’s house

14. I always stop myself from eating sweets because it is not good for me

22. I sometimes tell my mum that I have checked my blood sugar even though I have not

28. It does not bother me when I sleep over at a friend's place that I have to check that they have the right food and drinks for me

30. I don't know how often I have to measure my blood sugar levels

31. When I am unwell I know if I am high or low in sugar levels and what to do

36. It is easy for me to always remember when I go somewhere to take my insulin and glucose meter with me

38. I do as many blood tests a day as the nurse or doctor has told me

39. When I have signs of being low or high I don't panic

42. I wish someone would help me to take my medicine to avoid that my blood sugar level goes too high or drops too low

43. I never need reminding when to take my injections

45. I always carry my blood kit with me wherever I go

46. Even if my mum would not check on me I would do the blood sugar level test

48. It is hard for me to keep my blood sugar levels steady when I exercise (topped up with sugar)

49. Because I am not allowed sweets I sometimes hide them

7.4.4 Reliability: Internal Consistency of Each Scale of the Parent Questionnaire

1) "Parent's perception of the child's normality". This scale consisted of 18 items and had a coefficient of .66. Dropping items 18, 24, 49 (involves siblings), 74, and 84 improved alpha reliability to .78. Even though item seven involved siblings and 2 out of 30 children in this sample did not have any siblings, dropping this item did not enhance alpha reliability.

Table 7.6 Items retained in the scale "Parent's perception of the child's normality"

1. He very rarely thinks that I am too cautious with him

7. He thinks I treat him exactly the same as his sibling(s)

12. If I stop him from going somewhere he always complaints that I have a long list of do and don'ts

29. He has never mentioned that I am too careful with him

34. Some parents of children with diabetes are too cautious but I don't think it is necessary

39. I am not cautious with him because he has to learn to treat his diabetes himself

44. I am very careful with him because of the fact that he has got diabetes

54. I am so vigilant with him it is as if I have wrapped him in lots of cotton wool

59. I consciously try not to treat him differently but I cannot help it

64. As children with diabetes get bigger and stronger it is possible to relax completely

69. I think all children should be treated the same regardless if they have diabetes or not

79. I am not too careful with him sometimes I even forget that he has got diabetes

88. I really cannot treat him like a healthy child

2) “Parental Style”. This scale contained ten items and had a coefficient of .60. Items 72 and 90 were dropped as they correlated negatively with the scale total, which strengthened reliability to .70.

Table 7.7 Items retained in the scale “Parental Style”

6. I expect from my child that he conforms to my decisions out of respect for my authority

17. I let my child feel free to discuss my decisions if he feels that they are unreasonable

23. I try and encourage verbal give-and-take whenever I feel that the treatment regime and restrictions I make might be unreasonable

67. When I tell him not to eat something and he still eats it, I punish him

77. I know what is good for him so when I tell him to do something that is part of his treatment, I expect him to do it immediately without asking any questions

82. I get very upset if he tries to disagree with me and starts a whole discussion (e.g. why he cannot eat something)

86. If I make a decision, I am willing to discuss it with him and admit if I did a mistake

93. All problems would be solved between mother and child if parents were strict with their children when they don’t do what they are supposed to do

3) “Parent’s perception of the child’s feelings”. This scale included 12 items and had a coefficient of .79. Excluding item 32 enhanced alpha reliability to .80.

Table 7.8 Items retained in the scale “Parent’s perception of the child’s feelings”

4. He gets upset on sports-day because due to his diabetes he cannot participate as much as other children

10. He finds sport difficult because he has to keep his blood sugar level right

15. He does not think that his diabetes prevents him from doing anything

21. He does not get upset when he has to come to the clinic and is missing out on something

27. He is sad that he won’t be able to do certain things later on in life because of his diabetes

37. He hates having diabetes because he just wants to be like a healthy child

42. He is getting used to the fact that he has got diabetes and more and more accepts it as part of his life

47. He worries about his diabetes and keeps on saying that he does not want to be diabetic

52. He enjoys the visits to the hospital because it makes him feel special

57. He gets very angry and frustrated when his diabetes restricts him from doing something

62. He is not embarrassed of using his blood glucose meter or injections in public

4) "Parent's perception of the child's openness about the disease". This scale consisted of six items and had a coefficient of .89. As this scale exceeded the minimum reliability standard of .70 and due to the low number of items in that scale there was no need to drop any items.

Table 7.9 Items retained in the scale "Parent's perception of the child's openness about the disease"

3. I informed the school about his diabetes and the snack times
61. He keeps it for himself that he has got diabetes and does not want me to tell anyone
66. He tells all his friends that he has got diabetes that they can help him in case he goes low
71. He gets upset when people ask about or remind him of his diabetes
76. He is a bit embarrassed to talk about his diabetes in front of his friends
81. He is very open about his diabetes and talking about it is not a big deal for him

5) "Parent's perception of the impact of the illness". This scale comprised of 19 items and had a coefficient of .51. Items 5, 11, 22, 28, 33, and 43 were dropped as they correlated negatively with the scale total, which strengthened alpha reliability to .69. Discarding item 53, which involved siblings, improved alpha reliability to .70. Even though item 48 involved siblings, keeping this item did not decrease reliability.

Table 7.10 Items retained in the scale "Parent's perception of the impact of the illness"

16. It is a real problem when I buy treats for the others in the family and he cannot have any

38. We all eat low sugar food that he can have so he does not feel left out at the table

48. If his sibling(s) are having sweets and he cannot, they eat them outside

58. He has got a lot of friends because he gets on really well with other children

63. He feels that because of his diabetes he is the odd one out amongst his friends

68. He sometimes gets picked on by other children because of his diabetes

73. When he does not feel well, his friends look after him

78. I let him sleep-over at a friend's house because it is good for his friendships

83. I let him go to friends' houses to spend the day there or to go on a day-trip with them and their families

87. Because of his diabetes he is behind in school, which makes him upset

91. His friends eat sweets in front of him and that makes him very upset

94. He is proud of how well he is doing at school

6) "Parent's attitude about the treatment and precautions". This scale included 10 items and had a coefficient of .41. Items 41, 46, and 51 were dismissed as

they correlated negatively with the scale total, which elevated alpha reliability to .69. Additionally, dismissing item 20 improved reliability to .71

Table 7.11 Items retained in the scale "Parent's attitude about the treatment and precautions"

9. I don't let him sleep-over at a friend's house because the parents would not know what to do if his blood sugar levels dropped or went too high

14. I let him sleep-over at a friend's house because he can do the injections and the blood tests himself

26. I tend to only go to the diabetes clinic when his diabetes is not very good

31. I take him regularly to the diabetes clinic even if he is fine to check everything is alright

36. I made sure that the school knows what to do when his blood sugar level drops

56. I let him go to sports-day by himself because he knows how to control his blood sugar level when he exercises

7) "Parent's perception of the child's treatment adherence". This scale comprised of 20 items and had a coefficient of .68. Eliminating items 35, 40, 60, 80, 89, and 95 raised alpha reliability to .80.

Table 7.12 Items retained in the scale "Parent's perception of the child's treatment adherence"

2. He understands that to live well with diabetes he has to take his medication

8. Even though he finds some parts of the treatment hard he follows them very diligently

13. We very rarely get into arguments because of him not wanting to take his medication

19. He can do the whole treatment himself but I have to push him otherwise he would not do it

25. He very rarely forgets to do his injections

30. If he drinks too many sweet drinks there is nothing I can do about

45. We very rarely have arguments about him wanting to eat too many sweets

50. He sometimes tells me that he has done the blood sugar test but when I check the meter he has not

55. When I find out that he has sweets hidden in his room and is eating them, I lose my temper

65. When he does not feel well it does not cross his mind to do a blood sugar level test

70. When he has symptoms of diabetes (blood sugar level goes high or low) he knows what to do

75. He often needs to be reminded to take his injections especially when he is busy doing something else

85. He is supposed to do the blood sugar levels test twice a day but I make him do it three times because I cannot trust him with eating sweets

92. I often have to force him to eat something before he goes to sleep that he does not go low during the night or in the morning

In summary, the results from the analysis of the internal consistency of the parent and child questionnaires revealed which items had to be dropped to increase reliability of each scale to .7 and above.

The child questionnaire comprised 42 items and the parent questionnaire included 72 items.

Table 7.13 Mean, standard deviation, and internal reliability coefficients (Cronbach's Alpha) for the children's scales (*n*=30)

Scale	**Mean**	**Standard Deviation**	**Internal Reliability**
Child's perception of normality	2.51	.74	.80
Child's openness about the disease	2.69	1.05	.77
Child's feelings about the disease	3.10	.68	.75
Child's treatment adherence	2.52	.62	.82

Table 7.14 Mean, standard deviation, and internal reliability coefficients (Cronbach's Alpha) for the parents' scales (*n*=30)

Scale	**Mean**	**Standard Deviation**	**Internal Reliability**
Parent's perception of the child's normality	2.67	.60	.78
Parental Style	2.53	.60	.88
Parent's perception of the child's feelings	2.87	.70	.80
Parent's perception of the child's openness about the disease	2.4	1.00	.89

Parent's perception of the impact of the illness	2.40	.54	.70
Parent's attitude about the treatment and precautions	2.26	.72	.71
Parent's perception of the child's treatment adherence	2.32	.59	.80

7.4.5 Content Validity of the Child and Parent Questionnaires

The procedure of the analysis of content validity was identical to study 2. It involved first calculating the level of agreement i.e. inter-rater agreement amongst the five experts before calculating a content validity index across experts.

Table 7.15 below shows each child scale and the level of agreement across experts composing the child questionnaire followed by table 7.16 with the corresponding information on the parent questionnaire.

Table 7.15 Child Categories with Levels of Interrater Agreement

(1) Child's perception of normality	.96
(2) Child's feelings about the disease	.98
(3) Child's openness about the	.96
(4) Child's treatment adherence illness	.86

Table 7.16 Parent Categories with Levels of Interrater Agreement

(1) Parent's perception about the child's normality	.91
(2) Parent's perception of the child's feelings	1.0
(3) Parent's perception of the impact of the illness	1.0
(4) Parent's perception of the child's openness about the illness	.93
(5) Parent's attitude about the treatment and precautions	.98
(6) Parent's perception of the child's treatment adherence	.90

As can be gathered from table 7.15 and table 7.16 the levels of interrater agreement across experts for all the child and parent scales exceeded the minimum .7 to .8 criteria suggested in the literature.

Parallel to study 2 the second step in estimating the content validity of the child and parent questionnaires involved calculating the actual content validity index (CVI) for each scale. Tables 7.17 and 7.18 show the child and parent scales with their content validity indexes.

Table 7.17 Child Scales with the Corresponding Content Validity Index

(1) Child's perception of normality	1.0 (100%)
(2) Child's feelings about the disease	1.0 (100%)
(3) Child's openness about the illness	1.0 (100%)
(4) Child's treatment adherence	.89 (89%)

Table 7.18 Parent Scales with the Corresponding Content Validity Index

(1) Parent's perception about the child's normality	1.0 (100%)
(2) Parent's perception of the child's feelings	1.0 (100%)
(3) Parent's perception of the impact of the illness	1.0 (100%)
(4) Parent's perception of the child's openness about the illness	.83 (83%)
(5) Parent's attitude about the treatment and precautions	1.0 (100%)
(6) Parent's perception of the child's treatment adherence	1.0 (100%)

As can be gathered from table 7.17 except for "child's treatment adherence" all other scales had a content validity index score of 100%. Table 7.18 shows that for the parent scales except for "parent's perception of the child's openness about the illness" all other scales had a content validity index score of 100%. All scales exceeded the minimum content validity index score of 80%. Despite this it was decided to drop those items that lowered the content validity index of the scale and to run another reliability analysis to check whether the internal consistency of the scale still exceeded the minimum threshold of .70.

For the scale "child's treatment adherence" items 7 (It makes me really afraid when my blood sugar levels are high or low and I do what the doctor told me and the symptoms don't go away) and item 39 (When I have signs of being low or high I don't panic) were dropped and the alpha reliability increased from .82 to .83.

For the scale "parent's perception of the child's openness about the illness" item 3 (I informed the school about his diabetes and the snack times) was dropped and the alpha reliability increased from .89 to .94.

7.4.6 Reliability: Overall Internal Consistency of the Child and Parent Questionnaire

In order to be able to add up all the scales of either the child or parent questionnaire the overall internal consistency of each questionnaire was determined. The overall internal consistency of the child questionnaire was .88 (old results .89) and of the parent questionnaire was .88 (did not change after the items were scrutinised by the expert panel). Thus, when all items of both questionnaires were used a highly reliable scale was obtained. This suggested that the items of each questionnaire could be summed up to obtain an overall score.

7.4.7 Concordance Between Interview and Questionnaire Data

As in study 2 the time interval between the interview and questionnaire administration was long i.e. up to three years in many cases. This was not planned and was a result due to delays in seeking ethical permission for each stage of the study and relocating participants. Despite this, the results from the interviews were compared with those from the newly developed questionnaires by testing if both types of assessment produced converging information. Separate correlational analyses for the children's and parents' data were carried out between the interview and the corresponding questionnaire scales.

Table 7.19 Correlation between interview scales and the corresponding questionnaire scales for children

Child Scales	**Correlation**
Child's perception of normality	Not significant

Child's feelings about the disease	Not significant (.29)
Child's openness about the illness	Not significant (.40)
Child's treatment adherence	Not significant (.19)

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

As can be gathered from table 7.19 for the children's scales there was no significant association between the interview scales and the corresponding questionnaire scales.

As discussed in the context of the parallel analysis with the sample of children with asthma, there are several possible explanations for the lack of significant correlations between interview and questionnaire data. Firstly, it is possible that children's and parents' views changed over the long period between both assessments. Secondly, interview data provides complex data which allows for a degree of ambiguity and tension, which is eliminated in questionnaire data. Under the circumstances, with a large gap between the measures and the small number of participants, it is very difficult to interpret the negative data.

Table 7.20 Correlation between interview scales and the corresponding questionnaire scales for parents

Parent Scales	**Correlation**
Parent's perception of the child's normality	Not significant (-.10)
Parent's perception of the child's feelings	0.54*
Parent's perception of the impact of the disease	Not significant (-.12)
Parent's perception of the child's openness about the disease	0.86**

Parent's attitude about the treatment and precautions	Not significant (.26)
Parent's perception of the child's treatment adherence	Not significant (-.00)

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

As can be seen from table 7.20 for the parent scales, there was only a significant association between interview scales and the corresponding questionnaire scales for "Parent's perception of the child's feelings" and for "Parent's perception of the child's openness about the disease". However, for all the other scales there was no significant correlation between the interview and questionnaire data indicating that these produced diverging information. The same points regarding the interpretation of negative results given the long interval between the interview and the questionnaire do not need to be reiterated here. What does stand out in this analysis is the significant and relatively high correlations for the two scales, parent's perceptions of the child's feelings and of the child's openness about the illness.

In the subsequent section the associations between child adjustment and a demographic variable is explored. Parallel to study 2 it was explored if there was an affiliation between children's adjustment and their age. Then the main hypothesis of the relation between children's adjustment and their adherence with the treatment was examined.

7.4.8 Children's Overall Adjustment and Their Chronological Age

To investigate whether there is a connection between the children's age and their adjustment, a correlational analysis was carried out, which showed no significant correlation between children's total adjustment and their age. This finding implied that the age of the children had no impact on the level of their overall adjustment. However, when interpreting the results it should be considered that the children's age range was relatively small (7-12-year-olds) and that age therefore could have an effect if a wider age range would be included.

7.4.9 Adjustment and Treatment Adherence

An investigation was conducted into the relation between children's overall adjustment and treatment adherence by means of a correlational analysis between both variables.

Total child adjustment was correlated with "Child's treatment adherence" showing a highly significant correlation 2-tailed ($r_s = .47$, $p<.01$, N=30). Thus, children who were better adjusted also displayed better treatment adherence or vice versa. This analysis did not provide information on the direction of causality.

However, there was no significant correlation found between children's total adjustment and "Parent's perception of the child's treatment adherence and knowledge about disease, symptoms, and reaction".

7.5 Overall Conclusion

Parallel to study 2, in this chapter the reliability and validity of the newly developed questionnaires for children with diabetes and their parents were analyzed. Once more in order to determine reliability, the questionnaires for use with children with diabetes and their parents were administered to a larger sample. Again reliability was assessed on the basis of the internal consistency of each scale as well as the entire questionnaire by calculating Cronbach's coefficient alpha. The final questionnaires showed good internal reliability for each scale (.7 and above) and excellent internal reliability for the entire instruments (internal consistency of the child questionnaire was .88 and of the parent questionnaire was .88).

Content validity as in study 2 was again attained via a panel of experts who rated the child and parent items for all scales for representativeness. Inter-rater agreement across experts was very high and all and the content validity indexes came to 100% except for "Child's treatment adherence" (89%), and "Parent's perception of the child's openness about the illness" (83%), which nevertheless exceeded the minimum of 80%. Despite this, it was decided to drop those items that were not rated 3 or 4 by at least four of the experts.

Due to the high internal consistency for each scale as well as the entire questionnaire it can be ruled out that children were answering randomly.

To explore if the interviews and questionnaires produced converging results a correlational analysis was conducted. It was found that out of the four children's interview scales except for "Child's perception of normality" none of the other scales correlated significantly with the corresponding questionnaire scales. For parents out of the six interview scales only "Parent's perception of the child's feelings" and "Parent's perception of the child's openness about the disease" correlated significantly with the corresponding questionnaire scales.

One explanation for why most of the children's and parents' interview and questionnaire scales diverged could have been due to the fact that the time interval between the two assessments was up to three years. Thus, it might have been possible that children's perceptions of the illness as well as the parents' perceptions about the children's adjustment had changed during the time they were interviewed and the time they completed the questionnaire. Due the large interval between the two assessments which was up to three years in some cases negative results are difficult to interpret and, as in most cases, cannot be considered as evidence. Another explanation for the result could have been due to interview data providing complex data which allows for a degree of ambiguity and tension, which is eliminated in questionnaire data.

The results from the analysis of the children's adjustment to the illness and their age showed that age was not related to the adjustment of children with diabetes. It would be unreasonable to expect that older children find it easier to deal with the illness in view of their greater level of cognitive and social maturity. The results of this analysis must be interpreted with caution: This study explored a sample of children who fell within a certain age group (7-12 year olds) and perhaps the changes in cognitive and social development are not as important within this age period as they are, for example, when 4- and 8-year olds are compared. Differences in social development might also be much more important, for example, when children and adolescents are compared. In adolescence pressures to conform to peer standards are particularly strong and teenagers might experience more strain when having to follow their treatment regimen that affects their peer relations and, consequently, could affect their adjustment. Therefore, the results cannot be generalized to children younger than the age of 7 or children who are older than the age of 12 and have entered puberty as illness-related stressors might affect children differently depending on their developmental stage.

Lastly, the main hypothesis of a relation between children's overall adjustment and treatment adherence was investigated. It was found that there was a significant correlation between children's overall adjustment and their treatment adherence confirming that children who were better adjusted also displayed better treatment adherence or vice versa. There was no association found between children's total adjustment and the parent's perception of their children's treatment adherence. Consequently, if the information would have been obtained from parents only the relationship between children's adjustment and treatment adherence would have been concealed. This finding once more stressed the importance of taking into consideration children's own report.

CHAPTER 8

COMMONALITIES AND DIFFERENCES IN THE EXPERIENCES OF CHILDREN WITH ASTHMA AND CHILDREN WITH DIABETES

8.1 Aim

The aims of this chapter were to explore whether there were differences and commonalities in the experiences of children with asthma and children with diabetes that allowed for a more general statement regarding the lives of children with a chronic illness and to seek evidence for construct validity of the measures through factor analysis. There are two distinct sections in this chapter. In the first section the results from the two interview studies were combined and a direct comparison was made between the results of both illnesses.

In the second section the results from the two questionnaire studies were combined utilizing in contrast to all previous studies a disease-generic approach of analysis.

In the previous chapters, the analyses were carried out at a more specific level in two senses. First, the results were treated separately for each illness. Second, each scale in the interviews and questionnaire was also analysed separately. However, the scales that were developed to measure the children's adjustment to the illness were conceived as measures of the same phenomenon, i.e. their socio-emotional adjustment. Parallel items were developed for the asthma and diabetes to allow for a single factor analysis with both sets of scales, providing a single measure of adjustment. The hypothesis is that a single factor underlies the scale that measures children's adjustment.

This was expected to apply to children's as well as to parents' questionnaires. So the second section of this chapter reports a factor analysis in which the questionnaires for children and parents of children with asthma and diabetes are treated together. Although the specific stressors and reactions to these were bound to vary between the two illnesses, it was possible that the children's experiences still showed some similarities at a more abstract level. For example, both asthma and diabetes interfere with children's social activities, although for different reasons. Do children show similar levels of concern about missing out on these social activities?

Treatment adherence is hypothesised to be a different, but related, phenomenon (see page 94-95). The scale items for adherence were thus not entered in the factor analysis of the scales for adjustment. It was not possible to run a separate factor analysis on the items for the treatment adherence scale by combining the two samples tor analysis because these could not be created as parallel items. The treatment of the two illnesses is too dissimilar for items to be considered as parallel. It was also not sensible to separate the two illness samples and run a factor analysis for each because of the small sample size in each sample (n=30). A sample size of 100 is normally expected for any Principal Component Analysis even with a relatively small number of variables as in this case (Field, 2000).

After these factor analyses are carried out, it is then possible to analyse the concordance between the children's and parents' reports regarding adjustment and adherence. It is also possible to investigate whether there is a relationship between adjustment and adherence, as hypothesised.

8.2 Results From the Interview Studies

In the subsequent section, the results from the children's and parents' content categories from the interviews of the two disease groups were combined to compare the experiences of children with asthma and diabetes and to compare the experiences of parents of children with asthma or diabetes.

8.2.1 Child's Perception of Normality

Both children with asthma and children with diabetes had very similar perceptions in how far they felt normal. The majority i.e. 10 children with asthma and 12 children with diabetes thought that there was a difference between a child with asthma or diabetes and a child who did not have asthma/diabetes. Also, both groups of children had very similar views in how far they were treated normally. The majority i.e. 14 children with asthma and 11 children with diabetes reported that their parents treated them the same as their siblings.

Thus, most children were able to acknowledge that there was a difference between them and children who were not chronically ill but seemed to think that this did not make them into completely different children, as they were treated by their parents in the same way as their siblings.

8.2.2 Child's Feelings About the Disease

In both samples there was variability in how children felt about the disease and the extent of this variability did not differ between them. Eight children with asthma did not like the fact that they had the disease compared to six children with diabetes who did not like having diabetes and another three who only sometimes did not like having the disease. The remainder of both groups had accepted having the illness.

Equally, there were similar feelings concerning the effects the illness had on the children's lives. In both groups negative feelings expressed were treatment related or that children were restricted from doing things they wanted to do. Positive aspects of the illness in both groups were that they got days off school. To summarize, although diabetes is a more insidious disease and the treatment is more invasive, the proportion of children with asthma or diabetes who expressed negative feelings about the illness and its effects on their lives was the same. Also, in both groups the reasons children gave about positive aspects of the illness were the same.

8.2.3 Child's Openness About the Illness

Children with asthma as a whole were slightly more open about having an illness. The majority (11 children) did not mind people asking or talking about their illness compared to 8 children with diabetes. Two children with asthma only sometimes minded talking about the illness compared to four children with diabetes. Two children with asthma never liked being asked or talking about the illness compared to three children with diabetes. One speculation for why children with asthma were more open about their illness compared to children with diabetes might have been due to the fact that diabetes management requires a more invasive treatment. Children with diabetes have to have insulin injections and prick their finger to have blood readings, which they might have been embarrassed about as healthy children might be uncomfortable with the thought of needles.

8.2.4 Child's Treatment Adherence

There was a difference in how many children reported illness and treatment related problems. Whereas only six children with asthma reported treatment related problems, twice as many did so in the diabetic sample. Treatment related problems that children with asthma reported were drinking medicine, being short of breath when running, going to hospital, and not liking to take the inhaler and the peak flow meter. Children with diabetes reported problems with the treatment regimen which involved not liking the daily insulin injections, the daily blood glucose monitoring, and missing out on social activities when having to attend the diabetes clinic. The variation in treatment adherence was similar in both illness groups.

To summarize, in both samples there were children who did not like to deal with the treatment but in the diabetic sample it was twice as many children who reported treatment-related problems. However, this did not seem to influence children's treatment adherence.

In the subsequent section, parent's responses are combined and analyzed.

8.2.5 Parent's Perception of the Child's Normality

Parents of children with asthma and parents of children with diabetes had similar perceptions of how far they felt they were treating their children normally. Seven parents of asthmatic children compared to nine parents of diabetic children reported that sometimes they were too careful with their children.

Equally, both groups of parents had similar views about their children's perceptions of being treated normally. The majority, i.e. 12 parents of children with asthma and 9 parents of children with diabetes reported that they thought that their children did not perceive them as too careful with them.

To summarize, although diabetes management requires a more invasive treatment, parents in both samples had similar views in how far they were treating their children normally and in how far they thought their children perceived to be treated normally.

8.2.6 Parent's Perception of the Child's Feelings

Parents' reports regarding their children's feelings towards the illness were diverse. However, on the whole there were more parents of children with asthma who reported positive feelings towards the illness. Twice as many parents of children with asthma (10) described their children's feelings as positive and in a way that they had accepted the illness as part of their lives compared to 5 parents of children with diabetes. Four parents of children with diabetes reported that their children had mixed feelings towards the illness. Five parents of children with asthma and 6 parents of children with diabetes reported that their children had negative feelings towards the illness indicating that they had not accepted the illness as part of their lives.

Equally, concerning effects of the illness on the children's lives, parents' responses were very varied. Nine parents of asthmatic children compared to 12 parents of diabetic children reported that the illness had negative effects on the children's lives. The remainder (six parents of asthmatic children and three parents of diabetic children) reported that the illness had no negative effects on the children's lives and hence did not prevent them from doing anything.

In summary, although there was no difference between the samples in the proportion of children's own reports on their negative feelings towards the illness and the effects the illness had on their lives, there was a substantial difference between the reports of both parent samples about their children's feelings and effects of the illness on their lives. More parents of children with diabetes reported that their children had negative feelings towards the illness and perceived that the illness had negative effects on their lives. Differences in children's feelings about the illness across both illness groups were analysed in more depth later on in this chapter.

8.2.7 Parent's Perception of the Child's Openness About the Disease

Parents of children with asthma as a whole reported that their children were slightly more open about having an illness. The majority (12 parents) said that their children did not mind people asking or talking abut their illness compared to 9 parents of children with diabetes. Two parents of children with asthma and two parents of children with diabetes reported that their children only sometimes minded talking about the illness. One parent of a child with asthma reported that her child never liked being asked or talked about the illness compared to three parents of children with diabetes.

To conclude, parents' reports concurred with the between-group differences: Children with asthma seemed to be more open about their illness compared to children with diabetes.

8.2.8 Parent's Attitude about the Treatment and Precautions

Both groups of parents had informed their children's school about the illness. All parents of children with diabetes had informed the teachers about the children's snack times and most of them had explained the symptoms of diabetes. Most parents of children with asthma ensured that their children had an inhaler at school or were carrying one with them all the time and teachers were informed what to do when the child had symptoms.

Both groups of parents took many extra precautions. Parents of children with asthma as a group reported the following precautions: (a) taking the child regularly to the asthma clinic, (b) avoiding contact with furry animals, (c) not letting the child sleep-over at a friend's house, (d) accompanying the child to birthday parties and sports-day. Parents of children with diabetes reported the following precautions: (a) not letting the child sleep-over at a friend's house, (b) informing other parents about the child's diabetes before going to a birthday party, (c) all family members had to change their diet to that of the diabetic child, (d) giving the child a snack before bedtime to avoid that the child's blood sugar levels drop too much over night (e) not buying any sweets or sweet drinks for the home. However, in both groups of parents the attitudes to these precautions were very varied. Whereas some of the parents followed these precautions very diligently others were more relaxed about them or did not follow them at all.

To conclude, parents in both groups took precautions and the attitude to them varied in both groups from being very relaxed about them to following them very attentively. Thus, the level of taking precautions was not illness-specific but rather reflected diversity in parental attitudes.

8.2.9 Parent's Perception of the Impact of the Illness

There was a difference between the two illness groups concerning the parents' perception of the impact of the illness on the family. Three parents of children with asthma reported that the child's illness had no negative impact on the family and after diagnosis no changes to the family life were needed compared to one parent in the diabetes group. Nine parents of children with asthma and eight parents of children with diabetes reported that the child's illness had an impact on the family lives but that this did not cause any stress or problems. However, whereas only three parents of children with asthma reported that the child's illness had an impact on the family and that these necessary changes caused problems it was six parents of children with diabetes. Eleven parents of children with asthma were happy with their children's progress in school compared to all 15 parents of children with diabetes. Twelve parents of children with asthma perceived their children to be happy with their school progress compared to again all 15 parents of children with diabetes. Both groups of parents reported that their children had no problems with forming and maintaining friendships.

To conclude, there was a difference between parents' perception of the impact of the child's illness on the family. The proportion of parents of children with diabetes who reported that the illness had an impact on the family and that the necessary changes caused problems was almost three times higher compared to parents of children with asthma. This suggests that the treatment for managing diabetes was not only perceived to be more invasive by the patient but also by his/her family.

8.2.10 Parent's Perception of the Child's Treatment Adherence

Only 47% of parents of asthmatic children reported problems with their children's treatment compared to 80% of parents of children with diabetes.

Types of problems parents of children with asthma reported were either treatment or symptom related. Types of problems parents of children with diabetes reported were either diet or treatment-related problems.

There was variation in the level of treatment adherence parents reported, which was similar in both illness groups.

In summary, parents' reports concurred with the between-group differences: Parents of children with diabetes reported more treatment-related problems but parents' perception of their children's treatment adherence did not differ between both groups.

8.2.11 Conclusions

Combining the results from the content analyses of children with asthma and diabetes and their parents allowed for an exploration of commonalities and differences in their experiences with the illness. Both children with asthma and children with diabetes had similar perceptions in how far they felt normal and being treated normally by their parents. Furthermore, both illness groups had very diverse feelings towards their illness ranging from having accepted the illness as part of life to hating having the illness. This variation in feelings was again very similar in both groups. Regarding the openness about having the illness, children with asthma as a group were slightly more open compared to children with diabetes.

Concerning treatment adherence, the variation in both groups was once again comparable. However, children with diabetes reported twice as many treatment related problems compared to the children with asthma. Comparing the content analysis from parents of both illnesses provided further information on the same issues but from a different perspective. Parents of both illness groups had similar perceptions in how far they thought they were treating their children normally and similar views on their children's perceptions of being treated normally. Concerning parents' perceptions about their children's feelings towards the illness, parents of children with asthma reported twice as many positive feelings than parents of children with diabetes. Also, more parents of children with diabetes than parents of children with asthma reported that the illness had negative effects on the children's lives. Moreover, parents of children with asthma as a group perceived their children as more open about the illness than parents of children with diabetes. In addition, there was a variation in the extent to which parents took treatment-related precautions, which again was similar in both illness groups. Parents of children with asthma perceived the impact of the illness on the family as less intrusive compared to parents of children with diabetes.

From the parent perspective, the variation in the level of the children's treatment adherence was comparable in both illness groups. However, as the children with asthma themselves, parents of children with asthma also reported less treatment related problems compared to the other illness group.

8.2.12 Inter-Rater Reliability

As previously mentioned two researchers independently rated the interviews (study1 and study 3) in order to utilize the interview data more systematically by developing a scoring system for each scale. The first researcher scored all children's and parents' reports for each scale whereas the second researcher scored randomly selected 10 children's and parents' reports (5 from the asthma sample and 5 from the diabetes sample) for each scale. As five scorings for each study sample was too small to run a correlational analysis, the percentage of agreement was calculated for the scorings of both researchers, which came to 82% for the asthma sample and 80% in the diabetes sample.

In order to investigate inter-rater reliability of the two researchers, the five scorings for each sample were combined and Spearman's correlation coefficient was used since the responses were ordinal and not continuous.

Table 8.1 Inter-Rater Correlations of the Two Researchers for Children's and Parents' Scales

Scale	**Correlation**
Child's perception of normality	0.92**
Parent's perception of the child's perception of normality	0.96**
Child's feelings about the disease	0.91**
Parent's perception of the child's feelings	0.87**
Child's openness about the illness	1.0**
Parent's perception of the child's openness about the disease	1.0**
Parent's attitude about the treatment and precautions	0.92**
Parent's perception of the impact of the illness	0.86**
Child's treatment adherence	0.97**
Parent's perception of the child's treatment adherence	0.92**

*<p.05;** p<.01

The inter-rater correlations of the two independent researchers for all child and parent scales were all significant at the .001 level. The high and significant correlations confirmed that the first researcher's judgments (scorings) were unbiased and could be used for the correlational analysis between children's and parents' reports.

8.3 Brief Overview of the Questionnaire Studies

In the subsequent section, the results from the questionnaires from children with asthma and diabetes and their parents were combined.

The first aim was to assess construct validity of the questionnaires i.e. to examine the associations between the different components of the construct of adjustment. Thus, it was investigated whether child adjustment and the parents' perception of the child's adjustment consisted of a single underlying factor or multiple factors. Construct validity was analysed on the basis of a factor analysis of the parent questionnaire scales assessing adjustment which were 1) parent's perception of the child's normality 2) parent's perception of the child's feelings and 3) parent's perception of the child's openness about the disease. Two other scales, parent's perception of the impact of the illness and parent's attitude about the treatment and precautions, were included in the analysis because they were hypothesised to reflect a different dimension of adjustment, which was external to the child but nevertheless impacted on the child's adjustment. As the aim was to utilise an illness-generic approach the data from parents of children with asthma or diabetes were combined. Due to the fact that adjustment and treatment adherence were two different constructs the latter scale was not included in the factor analysis.

A factor analysis was also conducted for the child scales assessing adjustment which were 1) child's perception of normality 2) child's feelings about the disease and 3) child's openness about the disease again combining the data from both illness groups (children with asthma and children with diabetes).

It is noted here that it was not possible to combine the sample and run a factor analysis on the items for the treatment adherence scale because these could not be created as parallel items. The treatment of the two illnesses is too dissimilar for items to be considered as parallel. The reliability of the scale was .75 for children's reports of treatment adherence to asthma and .83 for the children's reports of treatment adherence to diabetes. For the parents' reports, the corresponding figures were .86 for asthma and .80 for diabetes, respectively. When scores are used for these scales in subsequent analyses, they will be averages for the scales rather than factor scores.

Secondly, the aim was to explore whether children's and parents' reports provided the same information. Although health professionals assume that proxy ratings in the form of parent reports can provide information about the impact of disease and treatment on the child, it is increasingly acknowledged that the child's perspective is different, but equally valid. To investigate this relationship further the results from the factor analyses were used to form scores for each respondent (i.e. children and parents) on each of the factors found by using the regression method and the new child and parent factors were then correlated to explore whether children's and parents' reports produced converging results.

Thirdly, the aim was to once more test the main hypothesis of an association between child adjustment and treatment adherence but this time disease-generically. For this analysis, the child factor from the factor analysis was correlated with child's treatment adherence as well as parents' perception of the child's treatment adherence.

Fourthly, the aim was rather than combining both illnesses to compare them. It was tested whether there were differences in the overall adjustment and treatment adherence between children with asthma and children with diabetes. Also, it was examined whether there was a difference in parents' reports of children's treatment adherence between the two disease groups (asthma and diabetes). The analysis involved using independent groups t-tests to investigate differences across the two illness groups.

Lastly, the role of parental style on children's treatment adherence (combining children's and parents' reports) was explored. As correlations do not provide any information on the predictive power of variables a regression analysis was conducted.

8.4 Results

8.4.1 Construct Validity of the Parent and Children Questionnaires

The aim of the factor analyses were twofold: a) to test construct validity of the child and parent questionnaires i.e. the construct of adjustment, and b) to once more compare parents' and children's responses in the questionnaires and test if they produced converging results.

Construct validity goes behind the content of an instrument and explores the associations between its different components with the object of consideration (Cronbach, 1990). Thus, construct validity of the questionnaires on the basis of a factor analysis identified the number of independent dimensions in the questionnaire assessing the child's adjustment. Specifically, the question was whether child adjustment and parent's perception of the child's adjustment each consisted of a single factor or multiple factors. Furthermore, the factor analyses provided information on the amount of variance explained by the different factors, and the relations between the scales. Thus, the factor analyses were utilized to test the hypotheses about which scales of the parent and child questionnaires were related.

As the aim of this study was to use a disease-generic approach of analysis, the data from children with asthma and diabetes and their parents were combined. In this context it should be mentioned that it was not possible to conduct separate factor analyses in the previous disease-specific studies due to the relatively small sample size of 30 children with asthma and their parents (study 2) and 30 children with diabetes and their parents (study 4) as the minimum sample size was not met (Field, 2000).

Therefore, in this study the data from parents of children with asthma and diabetes were combined as well as the data from children with asthma and diabetes and the assessment of construct validity was carried out through a separate factor analysis of the questionnaires of the combined data of parents and combined data of children. Despite increasing the sample size to 60 in each analysis a sample size of 100 is normally expected for any Principal Component Analysis, even with a relatively small number of variables as in this case (Field, 2000). Thus, the results have to be interpreted with caution because the number of participants was still small and the risk of these factors not being replicated in another study was therefore, large (Kinnear & Gray, 1999).

For the combined parent data, Principal Components (Varimax Rotation) extracted three factors with Eigenvalues greater than 1, and 57% of the variance was explained. All communalities were less than 1. The main results are presented in Table 8.2 below (for table of inter-correlations of factor analysis see Appendix 8.

Table 8.2 Factor Loadings for the Parent Scales

Scales	**Component 1**	**Component 2**	**Component 3**
Normality			.82
Feelings	.70		
Impact of the illness		.62	
Treatment and Precautions		.84	
Openness	.86		

Stevens (1992) recommends for a sample size of 50 a loading of .72 that can be considered as significant.

Thus, for factor 1 the significant loadings were for "Parent's perception of the child's feelings" (.70) and "Parent's perception of the child's openness about the disease" (.86) reflecting domains of the child's personal life. For factor 2, there was a significant loading for "Parent's attitude about the treatment and precautions" (.84) and high loadings for "Parent's perception of the impact of the illness on the family" (.62) reflecting domains of the child's social. For factor 3 there was only a significant loading for "Parent's perception of normality" (.82) reflecting the child's self-perception. This finding goes against the expectation that there would be a single factor underlying the parents' perception of the child's adjustment (including the parents' perspectives on the child's perception of normality, and the child's feelings and openness about the illness) and a second but related factor, assessed by the parents' views of the impact of the illness on the family and the child's social life and the parents' ways of dealing with precautions and the treatment: Three factors were extracted, suggesting that parents have a more differentiated view of the children's adjustment than it was expected.

The same analysis (see table 8.3) was carried out for the children's scales, but in this case there were only three scales as opposed to five. The Principal Components (Varimax Rotation) extracted only one factor with Eigenvalue greater than 1 which accounted for 56.2 % of the variance in the data (for table of inter-correlations of factor analysis see (Appendix 8.2).

Table 8.3 Factor Loadings for the Child Scales

Scale	Component 1
Normality	.64
Feelings	.72
Openness	.86

Factor 1 had a significant loading for "Child's feelings about the disease" (.72) and "Child's openness about the disease" (.86) and a fairly high loading almost significant for "Child's perception of normality" (.64). It is noted here that the scale on the child's perception of normality did not meet Steven's criterion of a minimal factor loading. However, because no other factor was extracted, it can be tentatively included in the first factor. In future research, the issue of whether the child's perception of normality should be seen as a separate factor must be considered. It is encouraging that the scales that meet this criterion are the same scales that were shown to form factor 1 in the analysis of the parents questionnaire. The convergence of these results of the factor analysis provides some evidence of construct validity.

As mentioned above, the results of the factor analyses were also utilized to compare parents' and children's responses to investigate whether the information obtained from parents and children about the child's adjustment and treatment adherence would be concordant.

8.4.2 Parents as Proxy Raters for Their Children

The factor scores for each respondent on each of the factors were used. The regression method was used to form the scores, which consists of pre-multiplying the factor loadings matrix with the inverse of the correlation matrix for the individual items which then provides a new matrix containing scores for each item on each factor. These item scores were then used to form scores for each respondent by forming a regression equation with the item scores as coefficients of the item values. So for example for the first factor found amongst the parents' data, the score for an individual parent would be given by:

$$\textbf{Individual score for factor 1} = \beta_1 \times X_1 + \beta_2 \times X_2$$

Where β_1 = item score for "Parents perception of the child's feelings"

β_2 = item score for "Parents perception about the child's openness about the disease"

X_1 = individuals score for "Parents perception of the child's feelings"

X_2 = individuals score for "Parents perception about the child's openness about the disease"

Similarly for the other parent factor, as well as the child factor.

This method ensures that the resulting individual factor scores have a mean of 0.

These scores were calculated automatically in SPSS.

This allowed for an investigation into the associations between all these factors by means of a correlational analysis.

To explore the association of the three parent factors and child adjustment (child factor), Spearman's rank correlation was applied as the data was ordinal and ranked (table 8.4).

Table 8.4 Correlations Between Child Adjustment and the three Parents Factors (N=60)

Factor/ Scale	**Parent Factor 1**	**Parent Factor 2**	**Parent Factor 3**
Child Adjustment	.36**	.22	-.07

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

As can be gathered from table 8.4 children's own perception of their adjustment converged with parent factor 1. The scales that had high loadings on this factor were the parents' perceptions of the child's feeling towards the illness and the child's openness about the illness. In the child questionnaire, the two corresponding scales have the highest load in the factor and meet Steven's criterion of a minimum loading of .72. This convergence in the information provided by the parents and the children is encouraging as it provides further evidence for construct validity.

The children's own perception of their adjustment did not correlate with parent factor 2, reflecting parents' reports of the disease's impact on children's social life nor with parent factor 3, reflecting parents' reports of the child's self-perception of being normal. This is expected from the results of the factor analysis: The children's scales had only one underlying factor, which correlated with the first of parent factor, and thus it was unlikely that it would correlated with the other two.

A correlational analysis was conducted between children's accounts of treatment adherence and parent's reports of the child's treatment adherence to investigate whether the information obtained from parents and children would be concordant. A highly significant correlation 2-tailed (r_s = .33, *p*<.01, N=60) was found indicating that children's own accounts of treatment adherence converged with parents' reports. This is an important result towards the validation of the treatment adherence measure: Although children and parents know different aspects of how the children implement precautionary measures and react to symptoms in implementing the treatment, there is an overall agreement in their views of how well the children adhere to treatment.

The factor analyses presented in this chapter make a distinct contribution to this study. It was found that children's adjustment was explained by a single factor, as hypothesised, but parents' perception of the children's adjustment was more differentiated. Factor 1 in the parents' questionnaire included their perceptions of the child's feelings and openness with respect to the illness and correlated significantly with the children's questionnaire responses. This provides some evidence of construct validity for the measures. However, it should be recalled that the sample in this study is considered small and that results of factor analysis with small samples may not be replicated with larger samples. Thus, this can be seen as a solid first step towards developing these measures, which can be used in further research.

8.4.3 The Association Between Child's Adjustment and Treatment Adherence

This section focused on the second main aim of this thesis which was to test the hypothesis of an association between children's adjustment to the illness and their treatment adherence on the basis of newly developed questionnaires for children and parents. In contrast to study 2 and study 4 which used an illness-specific approach, this section utilized an illness-generic approach. Child adjustment was assessed on the basis of the single child adjustment factor that came out from the previous factor analysis; the correlation between this measure and child's treatment adherence as well as parents' perception of the child's treatment adherence was investigated.

Table 8.5 Correlations Between Child Adjustment with Child Treatment Adherence and Parent Perception of Child Adherence (N=60)

Factor/ Scale	**Child's Treatment Adherence**	**Parent's Perception of Child's Treatment Adherence**
Child Adjustment	.51**	.07

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

As can be gathered from table 8.5 there was a highly significant correlation between children's adjustment and children's treatment adherence, once again confirming previous findings (study 2 and study 4) that children's adjustment and children's treatment adherence were associated. Children who were better adjusted to the illness also adhered better with the treatment regimen and vice versa. Furthermore, parallel to previous findings (study 2 and study 4) there was again no significant association between children's adjustment and parents' perception of the children's treatment adherence. This lack of correlation is puzzling because the reports by the children and the parents on the child's adjustment and on the child's treatment adherence were significantly correlated. The interpretation that can be offered is that children's knowledge of occasions in which they do not follow the treatment regimen is different from the parental knowledge, and that the children know that they do not follow the regimen exactly when they find it more disturbing of their social lives or personally more stressful. However, this interpretation is *post hoc*, and, although it is suggested on the basis of children's reports (for example, how they fail to adhere to treatment when the parent is absent), it must be treated as speculative and a motivation for further investigations.

8.4.5 Comparison of Children's Adjustment and Treatment Adherence Between Illnesses

A comparison between the adjustment and treatment adherence of the two illness groups allows for investigating whether children with one of these illnesses feel that the illness is a greater source of stress. Diabetes management seems to place more restrictions on the children's lives compared to asthma. This section explored whether there were differences in children's adjustment between the two disease groups. It also explored if children and parents experience diabetes as a more invasive illness and consequently find the treatment regimen harder to follow.

To test if there was a difference in children's overall adjustment, treatment adherence, and parents' reported treatment adherence between children with asthma and children with diabetes independent groups t-tests were conducted as the data was parametric and obtained using an independent groups design.

The analysis of differences in overall adjustment between children with asthma and children with diabetes found no significant difference in adjustment between the two disease groups. This finding indicated that even though having asthma or diabetes poses different kinds of stressors on the lives of these children, the overall effect on their lives was comparable.

The analysis of differences in children's reported treatment adherence again showed no significant difference between the two disease groups in the level of children's treatment adherence. Thus, children with asthma and children with diabetes reported similar levels of treatment adherence.

However, there was a significant difference in parents' reports of their children's treatment adherence between children with asthma and children with diabetes (t = 2.538, df = 58, p = .014, two-tailed). Parents of children with asthma reported lower treatment adherence (mean = 2.7) than parents of children with diabetes (mean = 2.3) as the scale was constructed in a way that the higher the score the lower the treatment adherence.

To summarize, based on the children's reports there was no difference found between the two disease groups in their overall adjustment and in the level of children's treatment adherence. However, there was a significant difference in parents' reports of their children's treatment adherence. According to parents, children with asthma were significantly less adherent with their treatment regimen compared to children with diabetes. An explanation for this difference could have been due to the nature of both illnesses. Diabetes management requires a much more controlled treatment regimen, which when not followed by the patient causes immediate consequences of severe symptoms. For instance omitting an insulin injection can be life-threatening. In asthma management not following the treatment regimen diligently can but does not necessarily have to result in immediate consequences. Thus, a child with asthma can get away with occasionally omitting the preventative inhalers.

8.4.6 The Role of Parental Style in Children's Treatment Adherence

The parent questionnaire included 10 items that assessed parenting style, which were adopted from the Parental Authority Questionnaire (PAQ; Buri, 1991). Five items that assess authoritarian and five items that assess authoritative parenting style were adapted by the researcher for use of parents of children with asthma or diabetes. The aim for including these items was to explore if a parenting pattern that stresses the importance of obedience to authority versus a parenting pattern that uses explanations about rules and decisions and reasoning was related to children's treatment adherence. Thus, it was tested if parents who were more controlling versus parents who were less controlling had an effect on the children's treatment adherence.

Two simple regression analyses were conducted, one for the asthma sample and one for the diabetes sample, to estimate the independent contributions of child adjustment, children's chronological ages, and parental style to children's and parents' reports of children's treatment adherence combined. A combined measure based on child and parent reports of treatment adherence was used as an exploratory analysis as none of the three independent variables above predicted children's own treatment adherence reports.

For the asthma sample using the stepwise method, a significant model emerged but the only significant factor was child adjustment: Adjusted R square =.20; $F_{1,28}$=8.0, p<.05. Significant variables are shown in table 8.6

Table 8.6 Multiple Regression Results for Prediction of Children's Treatment Adherence in the Asthma Sample

Predictor Variable	**Beta**	***P***
Child Adjustment	.52	p <.0005

Table 8.6 showed that parental style and children's chronological ages were not significant predictors in this model.

For the diabetes sample using the stepwise method, a significant model emerged, and parental style made a significant contribution to the prediction of children's treatment adherence after controlling for child adjustment: Adjusted R square =.36; $F_{2,27}$=7.5, p<.05. Significant variables shown in table 8.7.

Table 8.7 Multiple Regression Results for Prediction of Children's Treatment Adherence in the Diabetes Sample

Predictor Variable	**Beta**	***P***
Child Adjustment	.34	p <.0005
Parental Style	.45	p <.001

Table 8.7 showed that child adjustment and parental style were significant predictors of the combined reports of children and parents of the children's treatment adherence in the sample of children with diabetes. Children's chronological age was not a significant predictor.

Thus, parental style was only a predictor of treatment adherence in the sample of children with diabetes. A less controlling parental style was associated with better treatment adherence in the children. However, from this analysis causality could not be determined i.e. does a less controlling style lead to better treatment adherence in the children or does better treatment adherence lead to a less controlling parental style. Intervention studies would be necessary to assess whether improving treatment adherence allows parents to be less controlling or helping parents to decrease the amount of control they exert improves treatment adherence.

To test if this finding of parenting style effects restricted to the diabetes sample might have been due to a difference in parental style between parents of children with asthma and parents of children with diabetes a nonparametric 2 independent samples Mann-Whitney Test was conducted because the data for parental style was nonparametric. The results showed that there was a significant difference in parental style between the disease groups ($U = 273.000$, $N_1 = 30$, $N_2 = 30$, $p = .008$, two-tailed). Parents of children with asthma showed a less controlling parental style (mean 2.2) compared to parents of children with diabetes (mean 2.5).

8.5 Summary and Conclusions

The aim of this chapter in contrast to all the previous chapters (study 1 to 4) was to combine the results of children from both disease groups and their parents hence using a disease-generic approach of analysis. This allowed for exploring commonalities and differences in the experiences of being a child with asthma or diabetes and the parents' perceptions of the children's experiences.

The first part of this chapter focused on the results from the content analysis of the interviews with children with asthma or diabetes and their parents, which were combined to compare their experiences. The experiences of children with asthma or diabetes were comparable in relation to how far they felt normal and were treated normally by their parents, their feelings towards the illness, and their treatment adherence. However, there were differences between both illness groups: children with diabetes reported twice as many treatment related problems and were also on the whole less open about having the illness compared to children with asthma. Parents of children with either illness had similar perceptions in how far they were treating their children normally and in how far they thought their children felt they were being treated normally, confirming children's own reports. However, children's and parents' reports differed in terms of the children's feelings towards the illness as twice as many parents of children with asthma reported that their children had positive feelings.

Also, there were more parents of children with diabetes who reported that the illness had negative effects on their children's lives and perceived their children as less open about the disease compared to parents of children with asthma. Parallel to children's own reports, parents of children with diabetes reported more treatment related problems.

The second part of this chapter focused on the results from the questionnaire study again utilizing the disease-generic approach.

Firstly, the construct validity of the newly developed questionnaires for children and parents was assessed testing if child adjustment and parents' perception of child adjustment consisted of a single factor or multiple factors and its relation to treatment adherence. Two factor analyses were carried out, one for the adjustment scales from parents of children with asthma or diabetes questionnaires and one for the adjustment scales from children with asthma or diabetes.

The factor analysis of the parent data revealed three factors, one containing scales that reflected the child's personal life, one comprised of scales reflecting the child's social life, and one that reflected the child's self-perception of normality. It was expected to observe only one factor underlying the parents' perceptions of their children's adjustment and a second, related factor reporting on the impact of the illness on the child's social life and family and the parents' precautions and ways of dealing with the treatment.

Only one factor emerged from the factor analysis of the child data suggesting that child adjustment consisted of one underlying factor.

Secondly, as it is increasingly acknowledged that the child's perspective is different, but equally valid, children's and parents' responses were compared. It was investigated whether the same information can be obtained from the parents (proxy) about children's adjustment. For this analysis the results from the factor analyses i.e. the three parents factors reflecting child adjustment were correlated with the single child adjustment factor. It was found that one of the three parent factors reflecting child adjustment was significantly correlated with the child adjustment factor i.e. parents' accounts of the disease's impact on the child's personal life converged with children's own accounts. This convergence in the information provided by the parents and the children is encouraging as it provides further evidence for construct validity.

Also, parents' reports of child adherence were correlated with children's own reports of treatment adherence. The correlation was highly significant showing that parents' perception of the child's treatment adherence converged with children's own reports on their treatment adherence. This is an important result towards the validation of the treatment adherence measure: Although children and parents know different aspects of how the children implement precautionary measures and react to symptoms in implementing the treatment, there is an overall agreement in their views of how well the children adhere to treatment.
Thirdly, the main hypothesis of an association between children's adjustment to the illness and their treatment adherence was tested, this time combining the findings for the two diseases. As in the previous disease-specific studies, it was found that there was a relationship between child adjustment and treatment adherence once again confirming that these two domains were associated.

Fourthly, the aim was to compare the two illnesses. It was tested whether there was a difference in the overall adjustment and treatment adherence between children with asthma and children with diabetes to compare if children perceived one of the illnesses as causing a greater source of stress. Additionally, parent's perception of the children's treatment adherence between both illnesses was compared. There was no significant difference in children's own reports of adjustment and treatment adherence. However, parents of children with asthma reported their children as being less adherent with the treatment compared to parents of children with diabetes.

Lastly, the role of parenting style on children's treatment adherence was examined by means of regression analyses. It was analysed whether parental style was related to children's treatment adherence and whether there was a difference in parenting style depending on the illness (asthma versus diabetes) and the children's age. It was found that, after controlling for child adjustment, parental style only predicted treatment adherence in the sample of children with diabetes. The comparative analysis of parents' parental style in the two groups showed that parents of children with diabetes were significantly more controlling in their parental style compared to children with asthma. In children with diabetes, a more controlling parental style had a negative effect on children's treatment adherence.

CHAPTER 9

DISCUSSION AND CONCLUSION

9.1 Introduction

The aim of this study was to develop questionnaires that identify stressors faced by children with asthma or diabetes and how they are coping with these. The study represents the first steps in developing a new assessment tool but more work is required to examine its validity and reliability further. In the future, such instruments could aid health professionals in understanding the paediatric patients and could be used in research that involves these children. A valid instrument of this nature would make it easier for health professionals to consider and understand the child's perspective when analyzing the effectiveness of treatment.

Medical treatments used to be conceived of as a sequence of events under the control of a professional, who made a diagnosis and prescribed the medication. However, current definitions of health consider the well-being of patients in a wider way, not only their physical well-being. It is also recognized that medical treatments involve medication as well as the patient's behaviour, both in the use of the medication, in preventive behaviours which will affect how well the treatment works, and in stress management, as stress can often exacerbate a medical condition. This new conception of healthcare services has led to an increasing interest in the patients' voices and participation in treatment planning.

The Department of Health the UK (2000) sets out the vision that children and their families are involved in decisions about their treatment and care and play an active role in the daily management of their illness. In the area of paediatrics for the first time for many years one component of this explicit commitment is the National Service Framework (NSF) for children (Department of Health, 2004), which sets out clear standards that will have to be met in the future. The most important aim of these standards is the need to "hear children's voices" and consider the consequences of the illness on their psychosocial well-being as well as their families.

Parallel to the NSF there has been ample research into the effects of the illness on the child. Due to the demands in managing the illness and the additional stresses associated with it, an important focus of study has been the examination of chronically ill children and their families as a population at risk for the development of behaviour disorders (Hamlett, Pellegrini, & Katz, 1992). In their overview of the current literature Barlow and Ellard's (2006) concluded that chronically ill children were at an elevated risk for psychological distress even though the number of children who fall in a clinical range was relatively small. They also pointed out that there might be differences across illnesses but the shortage of studies does not allow for final conclusions.

There has been a shift in research from utilizing traditional outcome measures to evaluate psychosocial functioning, to focusing on Quality of Life measures to assess children's adjustment to chronic illness as the former were criticized for being developed for healthy children and consequently inadequate for use with chronically ill children (Kazak et al., 1995; Perrin et al., 1991). However, existing

QoL assessments have been criticized on the grounds of taking too long to complete, lacking child-centred approaches as they generally rely on paper-and-pencil measures and most importantly that they are not sufficiently based on what children directly report concerning how they perceive the limitations imposed by the illness on their QoL and how they react to them (Eiser and Morse, 2001).

As mentioned previously, due to the nature of the illness children with asthma or diabetes and their families have to follow a strict and complex treatment regimen and often experience treatment adherence challenges. In fact, treatment adherence is poor amongst chronically ill children - e.g. suffering from asthma (Baum & Creer, 1986) and diabetes (Johnson, Silverstein, Roosenbloom, Carter, & Cunningham, 1986).

Children's non-adherence with medical treatment regimens has serious consequences for their health and as a result causes a major problem for themselves, their parents, families and health professionals who work with them. However, existing treatment adherence measures have been criticized for having major limitations.

In this context, previous work has also suggested that children's adjustment and their treatment adherence are related (e.g. Pretzlik, 1997). Thus in this thesis it was hypothesized that children's adjustment is affected by how they cope with illness-related stressors and vice versa, poor adherence is related to high levels of stress thus affecting children's adjustment.

In view of the above and to contribute to the understanding of children with chronic illnesses this thesis had two main aims. The first was to make a methodological contribution, and take the first steps to develop separate questionnaires for children with asthma and children with diabetes and their parents to assess children's adjustment to the illness and treatment adherence. Criticisms highlighted in the literature were considered and addressed in the development of the new questionnaires.

The second aim was to utilize these newly developed questionnaires to test the hypothesis of an association between children's adjustment to the illness and treatment adherence.

In the thesis both an illness-specific and a generic approach were taken as the literature showed that there is no consensus about which approach is considered to give a more useful picture of the impact of the disease. Both have advantages and disadvantages when assessing complicated concepts like children's adjustment to chronic illness and treatment adherence. Thus, by combining both methods of investigation it was expected to gain a more comprehensive understanding. The study was disease-specific in that it included the development of separate questionnaires for the two disease groups. This was considered important as each disease was known to be associated with different stressors and responses, required diverse treatment regimens and thus might have affected adjustment in different ways.

The study was disease-generic in that it examined more than one type of chronic illness in children (asthma and diabetes) and aimed to discover commonly shared experiences across the two disease groups and how these related to the children's adjustment.

The chapter starts with the results from the illness-generic analysis, followed by the disease-specific analysis with both being discussed in light of the existing literature. The chapter ends with a discussion of the limitations of the study and suggestions for future work.

9.2 Findings from the Illness-Generic Analysis

9.2.1 Results from the Content Analysis of the Interviews

In order to develop the questionnaires the first stage of this investigation included identifying stressors that children and families have to face and how they coped with them. The method employed to elicit information was by means of interviewing individually a sample of children with asthma and a sample of children with diabetes and their parents about their experiences with the illness. In addition, a paediatric asthma nurse and a paediatric diabetes nurse were interviewed about children's experiences with the illness to obtain information from a health professional's perspective.

The interviews were analyzed using grounded theory methodology (Charmaz, 2003) by coding children's and parents' responses under descriptive content categories. Having separate categories for each theme enabled the researcher to analyze and compare what children and parents had reported about a particular topic.

Overall, the combined reports of children and parents gave an insight into how the children coped with these additional stressors of having asthma or diabetes and the extent to which their lives were affected by them as well as their general feelings towards the illness. The analyses revealed that there were commonalities in stressors across children but differences in adjustment i.e. variability in how children perceived the limitations imposed by the illness.

For example, one common stressor in children with asthma was the fact that they were not allowed to go near furry animals as these could trigger an asthma attack. A solution for this type of stressor was to find alternative animals that are not furry. Thus, one mother described "he is desperate for a dog... so we got the fish" whereas another mother explained "we have got tropical fish, which she has chosen herself and we have said we will have a tortoise".

Most parents of children with asthma would let their children go to birthday parties and sports-day by themselves and just notified the parents or the teachers of the child's asthma and made sure that the child had the inhaler with him/her. However, those parents who felt that their children could not go on their own and did not want them to miss out found the following alternative "birthday parties I go with her, I think a lot of mums tend to not wanting me to leave, they always want me to stay, they don't want me to leave her."

One common stressor in children with diabetes was the fact that they cannot have or can only have very small quantities of sweets. One solution for this type of stressor was for one mother was "everybody (in the family) has to eat what he eats. If he has an ice-cream then they (siblings) will have ice-cream and if they want ice-cream and he can't have it they will have to stay outside and finish it outside".

In the cases where children were not allowed any sweets or were prone to eating too much when available at home another mother's solution was that "everything is sugar free. The only sweets I keep at the house are glucose and that's for him just in case. If the other ones want some sweets they have to get it themselves or keep them in the room and hide them".

However, there were stressors as a result of the illness to which parents could not find solutions. In the case of parents of children with asthma they were worried when other people (e.g. teachers) were in charge of the child's care. One mother explained "we had a recent incident whereby he was being brought to another school to swim in a gala and they could not find his inhalers, but they were in the sports bag and he became very breathless, he was panicking ... so that's been a worry that that sort of thing can happen so quickly and a sports teacher does not understand not to go with somebody wheezing". Another mother expressed "I do get a bit concerned sometimes if he feels really unwell and I go and pick him up and I feel concerned that maybe the teacher wasn't told. To make him sit in class when he is really unwell. I can understand the school's point of view because they are worried about him being behind but then your health comes first".

In the case of parents of children with diabetes they were worried about the child having abnormally high (hyperglycaemia) or low (hypoglycaemia) blood glucose levels in the parents' absence. One mother explained "Birthday parties we haven't quite got the hang of yet, I tend to give her a bit more insulin and she invariably comes home with high blood sugar from birthday parties".

Another mother was very concerned about the child's school ride and said "five weeks ago he was found (on a bus stop) and his sugar level has dropped so low. One of the neighbours knew him and stopped the bus and brought him home".

The information obtained from the interviews with children and parents can be of help to health professionals in several ways.

1. It is clear that parents have common concerns and that these can be anticipated, as well as alternative solutions that some parents have found. These concerns focus mostly on everyday issues, which may be seen as too trivial to be discussed, but it is likely that awareness of these might help them anticipate situations and handle them more effectively when the time comes.
2. Parents are wary of times when their children are under the care of others. Parents can be made aware that this is a common experience and that, although it may not be common for parents to attend birthday parties, they can discuss this with the host, who could be indeed grateful for the help. Also, teachers at school have to be made more aware about the symptoms of the child's illness and how to take immediate actions (e.g. on school trips have the inhalers to hand at all times, inform the parents when the child is unwell at school).
3. Children diagnosed with asthma should be informed that they can keep pets but must choose them carefully (e.g. fish, tortoise) and exclude furry animals (e.g. cat and dog) as these can trigger asthma.
4. Children diagnosed with diabetes should be informed that they can have sweets but in moderation or chocolates specially formulated for diabetics. Also, usually children like soft drinks which can be replaced with the diet version (sugar free).

The content analysis also revealed which parts of the treatment regimen children found difficult to adhere to and which aspects were easier to follow. In this context it was found that there were differences in the extent to which children perceived that the treatment regimen was interfering with their lives and as a result their feelings towards the illness, which was associated with varying levels of treatment adherence.

For example, in the case of children with asthma they had very diverse feelings about the illness, ranging from "I hate it" and "I am bothered by it" to "it's not too bad if it is controlled" and "I am fine having it". Similarly in the case of children with diabetes their feelings were very varied. Whereas some children stated "I hate it really" other children were more positive and said "I am quite used to doing the stuff I am supposed to do for it but sometimes I don't get to go to some places that I want to go, so then I don't like it" or "sometimes I do not like it because I cannot eat what I like to eat and sometimes I do not really mind".

Treatment and symptom related problems that children with asthma reported were drinking medicine, being short of breath when running, going to hospital, and not liking to take the inhaler and the peak flow meter. Children with diabetes reported problems with the treatment regimen which involved not liking the daily insulin injections, the daily blood glucose monitoring, and missing out on social activities when having to attend the diabetes clinic. The variation in treatment adherence was similar in both illness groups. However, there was a difference across the illnesses in how many children reported illness and treatment related problems. Whereas only six children with asthma reported treatment related problems, twice as many did so in the diabetic sample.

Health professionals could consider the above information in the planning of the children's treatments.

9.2.2 Development of the Questionnaires

Children's and parents' responses in the interviews were then used to develop separate questionnaires for children with asthma or diabetes and their parents to assess children's adjustment to the illness and treatment adherence. Once again, grounded theory (Charmaz, 2003) was applied to generate statements from each category to be included in the questionnaires. Additionally, in both versions of the parent questionnaire (parents of children with asthma and parents of children with diabetes) ten items were added to assess parental style which were taken from the Parental Authority Questionnaire (Buri, 1991) and adapted by the researcher for use of parents of children with asthma or diabetes.

Due to Eiser and Morse (2001) highlighting the need to develop more child-centred approaches to measurement than the traditional use of paper-and-pencil assessments, a new method of obtaining information from children was developed which was more attractive and appealing to children. In this study the novel way to administer the child versions of the questionnaire was by delivering them with the aid of a computer.

The researcher believes that children enjoyed completing the questionnaires as none of the children wanted to withdraw from the study before finishing, even though they were reassured several times that they could stop at any time.

These newly developed questionnaires were administered to a sample of 30 children with asthma and 30 children with diabetes and their parents to check the validity and reliability.

Five initial steps were taken in the direction of obtaining reliability and validity information regarding the questionnaire.

First, the items were derived from the children's and parents' experiences as described in the interviews, and thus represent their voices.

Second, the items were checked in a focus group composed of psychologists and a paediatric nurse for clarity and consistency with the children's and parents' responses in the interviews.

Third, the items were rated by an expert panel with respect to their relevance to the scales they intended to measure. Those items that did not meet the criteria for inclusion in the questionnaire were excluded from further analysis.

Fourth, internal consistency of the questionnaire was determined by calculating Cronbach's coefficient alpha (Cronbach, 1951) for all the items in each scale. Alpha levels reached an acceptable reliability threshold when they reached at least .7 (Nunnally and Bernstein, 1994). Acceptable levels of internal reliability were achieved in the final scales by dropping items with low reliability.

The final questionnaire for children and parents showed good internal reliability for all the scales (.7 and above) and very good internal reliability for the entire questionnaire (.88 and above).

It can also be ruled out that children's responses were random due to the fact that the internal consistency of the subscales and the total scales were high.

Finally, factor analyses were carried out with the parents' and children's questionnaire including the scales designed to measure the children's adjustment to the illness. The results are reported in the section that uses the illness generic approach (section 9.3).

The newly constructed questionnaires for children with asthma or diabetes and their parents are still in the early phases of their development and need further investigation but could in the future aid health professionals to identify children at risk for adjustment problems and/or at risk for having difficulties following their treatment regimen.

After further work in the development of the questionnaires, children could in the future be identified as being at risk on the basis of the questionnaire assessment and be referred for further investigation (e.g. assessed by a clinical interview) to verify possible adjustment and/or treatment adherence difficulties.

One possible limitation of using children's self-reports has to be acknowledged, which concerns children's desire to please the researcher in their responses. However, the researcher had the impression that the children were honest in their responses to the questionnaire due to the fact that children in both illness groups admitted instances in which they were not adherent with the treatment regimen. For example several children with asthma agreed entirely with the statement that they run a lot at a friend's birthday party when their parent(s) were not in attendance. A parallel example for children with diabetes was that some children admitted to eating a lot of sweets when they went to a friend's birthday party without their parent(s).

However, there is reason for concern in the use of self-reports in children with a chronic illness. Phipps and Steele (2002) addressed this issue when investigating why children with cancer and other chronic illnesses do not show greater levels of anxiety than healthy controls in measure of trait anxiety: On the contrary, they show significantly lower levels of anxiety than healthy controls. Their hypothesis was that these lower anxiety scores were a consequence of defensiveness, which was measured in their study by the Children's Social Desirability Questionnaire. Their hypothesis would lead to the prediction of a significant and negative correlation between anxiety and social desirability scores; unfortunately, they do not report this correlation. Their interest was in creating groups of children with different adaptive styles. They report the identification of four groups: (1) High anxious; (2) Defensive high anxious; (3) Low anxious; (4) Repressive. The repressive group was defined by a score at or above the 75th percentile in the social desirability scale, controlling for age. There were significantly more children with a chronic illness in this group than healthy children. This result does suggest that there may be an interference of social desirability in self-reports of anxiety for chronically ill children.

It is important to remember that the finding of lower levels of anxiety in chronically ill children motivated the study by Phipps and Steele. In the introduction, it was discussed that not all measures show consistently poor outcomes for chronically ill children in comparison to healthy children; it is thus possible that Phipps and Steele were using a measure that does not work well for this group. The meta-analyses conducted, for example, by Bennett (1994), Lavigne and Faier-Routman (1992) and McQuaid, Kopel, and Nassau (2001) show that the majority of the studies indicates a poorer outcome for ill children, even if the effect size is reduced when controls for SES and race are used. Thus, the interpretation of Phipps and Steele's study is not straightforward. However, there is an important lesson to be learned from this discussion: In further studies of self-report measures of children's adjustment to the illness and treatment adherence, researchers should include a measure of social desirability. This step would contribute to the understanding of how the children approach this task and to the validation of the measures.

In the specific case of the measures considered here, the comparison with healthy controls is, of course, inappropriate: The items refer to the children's adjustment to the illness and treatment adherence, which is not relevant to healthy children.

9.2.3 Children's Adjustment and Treatment Adherence

The questionnaire data from children and parents were used to test the hypothesis of an association between children's adjustment to the illness and children's reports of their treatment adherence. In addition, the association between children's adherence and parents' reports of children's treatment adherence was explored to investigate whether proxy ratings in the form of parent reports about their children's treatment adherence would provide the same information.

The main hypothesis was confirmed as in both disease groups it was found that there was a significant relation between children's adjustment and their own reports about their treatment adherence indicating that children who were better adjusted also displayed better treatment adherence or vice versa. This connection between adjustment and treatment adherence also confirmed the usefulness of the new questionnaires as they help to identify children at risk. This finding was in line with previous research that suggested that the psychosocial functioning of children with chronic illnesses correlates with their disease management (Roberts, 2003). For instance it was shown that children who were highly compliant with their treatment regimen also showed higher levels of self-esteem (Littlefield et al., 1992), lower levels of anxiety and depression (Brownbridge & Fielding, 1994), and better individual coping and more positive adjustment (Jacobson et al., 1990). Hence in all these studies, positive adjustment was associated with better treatment adherence. Similarly the literature showed the reverse pattern i.e. children who had difficulties in socio-emotional functioning also had problems with treatment adherence. Pretzlik (1997) for example demonstrated that children with cancer who were distressed during medical procedures tended to avoid them. Lustman, Griffith, and Clouse (1996) found that depression in children with diabetes might hinder treatment adherence and treating it lowered blood sugar levels.

Interestingly, in both disease groups there was no significant relation between children's adjustment and parent's reports of the children's treatment adherence. Thus, if the analysis of the main hypothesis of an association between children's adjustment and treatment adherence had only been based on proxy reports in the form of parents' reports, the association between children's adjustment and treatment adherence would have been concealed. The issue of parents as proxy raters for their children is discussed in more detail in the next section.

9.2.4 Comparison of the Interview and Questionnaire Data

Although the interval between the time of the interview and the time of the completion of the questionnaires was very long (up to three years) it was still considered useful to explore whether both types of assessment produced converging results.

In the asthma sample, none of the results from the child and parent interview scales converged with the corresponding data from the questionnaire scales. In the diabetes sample, none of the results from the child scales converged with the corresponding data from the questionnaire scales. In contrast, in the diabetes parent scales two out of the six scales produced converging information. These were parents' perception of the child's feelings and parents' perception of the child's openness about the disease. One explanation for this divergence between the results of the interview and questionnaire could have been in terms of children and parents responding randomly. However, this can be ruled out because of the high internal consistency of the scales.

Another explanation could be due to the fact that interview data provides complex information which allows for a degree of ambiguity and tension, which is eliminated in questionnaire (scales) data.

Yet another explanation could be that children's and parents' perception had changed between the time of the interview and the time of the questionnaire. In this context Hamlett, Pellegrini, and Katz (1992) explained that the management of childhood chronic illness requires a lifetime of adjustment due to illness-related stressors and developmental phases and duties which cause constant changes to the child's ability to cope with the illness. The finding is also consistent with Eiser et al. (1999) and Varni et al. (2003) who stress that there are fluctuations in children's perceptions of the illness due to the fact that disease and treatment variables continuously change children's adjustment.

To conclude, under the circumstances, with a large gap between the measures and the small number of participants, it is very difficult to interpret the negative data. Future studies should keep the interval between the interview and questionnaire administration to a minimum. The large interval could not be avoided in this study: The procedures for ethical approval require that the instruments be presented to the ethics committee and the questionnaire items were developed from the analysis of the interviews. In the future, both the interview schedules and questionnaire items would be available when ethics approval is sought so the interval could be reduced considerably. It is advisable to assess the convergence of results of the two instruments once more using a shorter interval between the two.

9.2.5 Adjustment and Severity of Children's Asthma

In the asthma sample it was explored if children's asthma severity had an effect on their adjustment. A paediatric asthma nurse classified each child of this sample into one of five asthma severity groups (mild, mild-moderate, moderate, moderately-severe, and severe). It was found that severity of asthma had no impact on the level of children's adjustment. Thus, there is no evidence that having mild or severe asthma affects a child's adjustment.

This finding is in line with a study by Wamboldt et al. (1998) who found that children with severe asthma did not rate themselves as having higher levels of anxiety than those with mild or moderate asthma or than standardized norms. This finding is also in line with Kashani et al. (1988) who found that severity of asthma was neither related to mild psychological problems nor to clinical psychopathology. Kashani et al. suggested that one explanation for the inability to find a relationship between asthma severity and psychological functioning might reflect the effectiveness of the treatment regimen. Thus, children's adjustment might not be related to the severity of their asthma but rather to the extent that the symptoms could be controlled by the treatment.

Nevertheless, this finding must be interpreted with caution as other research reports a significant association (Gustafsson et al. 2002). Although the paediatric asthma nurse in this study was consistent in her classification it would have been more reliable if children's asthma severity was rated independently by another paediatric asthma specialist using the same classification scheme and then comparing the ratings of both to check inter-rater reliability. Also, it should be remembered that the paediatric nurse was hesitant to classify children's asthma severity and only agreed to do so for the purpose of this study. It was not standard routine of the hospital to classify children's asthma severity in their medical records to avoid "labelling" children and consequently to ensure that in the event of a child coming to A&E with asthma symptoms rapid maximum care was taken.

Lastly, there are children who are not well adjusted at all levels of severity and therefore research should always include children with the full range of asthma severity and not be limited only to those with severe forms of asthma. Perrin, MacLean, and Perrin (1989) found that adjustment was significantly worse among children who were rated as having "moderate" asthma by their parents compared to those who were rated as having "mild" or "severe" asthma.

9.2.6 Children's Adjustment and Their Chronological Ages

Due to the inconsistency in previous findings, the association between children's adjustment and their chronological age was investigated. Thompson and Gustafson (1996) conducted a review of studies exploring variables that were correlated with psychological adjustment in children with chronic illness. They found that children's chronological ages had neither an effect on behaviour and emotional problems nor on self-esteem.

However, there is research that has found an effect of age of onset of the disease (e.g. Mrazek, Schuman, & Klinnert, 1998; Rovet, Ehrlich, & Hoppe, 1987; Ryan & Morrow, 1986).

In this study it was found that in both samples, i.e. children with asthma and children with diabetes, there was no significant association between children's adjustment and their age. However, it should be considered that in this study children's age at disease onset was not controlled for, which might have impinged on the results. It can be concluded that the nature of the association between age and children's adjustment is complex. Further research into this area is needed which should control for age at disease onset.

Lastly, the finding of a lack of an age effect on children's adjustment cannot be generalized to children of other age groups as illness-related stressors might affect children differently depending on their developmental stage. For example, in puberty pressures to conform to peer standards are particularly tough and adolescents might experience more strain when having to follow their treatment regimen and show more adjustment problems than younger children.

Thompson and Gustafson therefore suggested that the influence of age on children's adjustment should be explored longitudinally. This would enable a developmental analysis rather than a cross sectional analysis and connections with other variables could be determined.

9.3 Findings From the Illness-Generic Analysis

9.3.1 Construct Validity of the Questionnaires

In the following section the data from children and parents is discussed from an illness-generic perspective. Thus, the data sets for the two illnesses were combined to examine whether there were commonalities in the experiences of children with asthma and children with diabetes. In this analysis the construct validity of the questionnaires was investigated. Factor analysis was employed to identify the number of independent dimensions in the questionnaire assessing the child's adjustment. Specifically, there was an examination of whether child adjustment and parent's perception of the child's adjustment each consisted of a single factor or multiple factors. For the parent scales, the factor analysis revealed three factors, with one reflecting domains of the child's personal life, one reflecting domains of the child's social life, and the third reflecting the child's self-perception. For the child scales, the factor analysis revealed only one underlying factor for child adjustment. The results suggest that parents have a more differentiated view of the children's adjustment.

Another aim of the factor analysis was to test the convergence between parents' reports and children's reports of adjustment and treatment adherence.

9.3.2 Parents as Proxy Raters for Their Children and the Association Between Children's Adjustment and Treatment Adherence

A further issue mentioned in the Introduction was the circumstance in which proxies' ratings of paediatric patients' QoL were accurate and acceptable, as this has been a topic of growing concern.

Achenbach, McConaughy, and Howell (1987) showed that the assessment of physically healthy children's adjustment based on independently derived information from child/adolescent, parent, teacher, and health care professionals has shown a lack of congruence among these reporting sources. In a meta-analysis of published studies, a mean correlation of .22 was found between children's/adolescents' self ratings and ratings by parents, teachers, and health-care professionals.

In this context Varni, Katz, Colegrove and Dolgin (1995) found that there was also lack of agreement among two or multiple informants of child/adolescent using well-standardized measures to investigate the psychological and social adjustment of children newly diagnosed with cancer. This discordance between reporters has been termed "cross-informant variance". Another study confirming the differing perspectives of multiple reporters when assessing the QoL of paediatric cancer patients was conducted by Varni et al. (1998). They once again found cross-informant variance as evidenced by the medium magnitude of correlational effect sizes among paediatric patients and parent perceptions of the patients QoL and concluded that a proxy rater's health-related Quality of Life estimates were insufficiently accurate in many cases. Furthermore, Varni et al. (2001) found low concordance between children's and parents' responses in a large sample of chronically ill, acutely ill, and healthy children (n=963) and their parents (n=1629).

Due to the literature indicating the need to be aware of possible limitations of using proxy raters to assess paediatric patients' QoL this study addressed this issue by separately assessing the parents but also the children themselves about the children's adjustment to the illness.

Thus, another hypothesis of this thesis was whether proxy ratings in the form of parents' reports could provide the same information about children's adjustment and treatment adherence as would be obtained from children themselves.

To test this hypothesis children's and parents' responses in the interviews and questionnaires were compared. The results (factor scores) from the factor analyses were used to compare parents' and children's responses to investigate whether it was possible to obtain accurate information from the parent (proxy) about the child's adjustment and treatment adherence.

It was found that children's own reports of their adjustment converged with the parent factor that reflected the disease's impact on the child's personal life (r=.36). However, children's own perception of their adjustment did not converge with the parent factor that reflected the disease's impact on children's social life and their self-perception. Lastly, children's own accounts of treatment adherence converged with parents' reports (r=.33). In both cases (i.e. for the measure of adjustment and of treatment adherence), the correlations were low, as in the previous studies.

To conclude, it was indeed found that parents and children did not have the same outlook regarding the extent to which the illness and the treatment regimen interfered with the children's lives. This finding was in line with Vance et al. (2001) who also found poor to moderate concordance between children's and parents' reports about children's QoL in a paediatric cancer population.

Vance et al. suggested questioning the intrinsic worth of considering concordance between children's and parents' reports as a requirement for new QoL assessments. According to Spranger and Aaronson (1992) the parent and child perspectives are not based on an identical data pool as they vary in their understanding of events, questions, and expectations. Thus, rather than exploring concordance between parents and children it would be better to view both perspectives as providing complementary information.

Furthermore, it was found that when comparing children's and parents' replies of both illnesses, there were differences between which aspects (scales) of the children's experiences diverged or converged with parents' accounts. Whereas almost all scales between the reports of children with diabetes and their parents converged, it was only one in the asthma sample. This suggests that the accuracy of proxy ratings (parents' reports) might be illness specific. It would be useful to find out whether other studies replicate the pattern of the current findings. Thus, more research is needed to gain a comprehensive understanding of the relationship between children and parent reports to understand when parents would be able to provide reliable proxy ratings for their children. One avenue would be to extend research to children with other chronic diseases and investigate the pattern of concordance between children's and parents' reports.

Lastly, on the basis of these new factors, the association between children's adjustment and treatment adherence was explored for a second time.

A highly significant correlation was found between children's adjustment and children's treatment adherence, once again confirming previous findings (study 2 and study 4) that the domains of children's adjustment and children's treatment adherence were associated. Children who were better adjusted to the illness also adhered better with the treatment regimen and vice versa. Furthermore, parallel to previous findings (study 2 and study 4) there was again no significant association found between children's adjustment and parents' perception of the child's treatment adherence questioning the accuracy of the proxy ratings by parents.

9.3.2 Parental Style and Children's Ages as Predictors of Treatment Adherence

The effect of authoritarian and authoritative parenting style and children's chronological age on children's treatment adherence was investigated by means of regression analysis. It was found that, after controlling for the child's adjustment, parenting style was only a predictor of treatment adherence in the sample of children with diabetes. It was also found that parents of children with diabetes showed a more controlling parenting style than parents of children with asthma. Combining both results suggest that a more controlling parenting style had a negative effect on children's treatment adherence. This finding conflicts with previous research. For instance Miller-Johnson et al. (1994) found that parental discipline was not related to children's treatment adherence but found another variable which was conflict between children and parents that placed children at increased risk for poor adherence. Therefore, future research needs to clarify the role of a controlling parental style as a predictor of treatment adherence in children with IDDM further. In this context it should be noted that one component of the three parental styles was not assessed in the questionnaires of this thesis, which was the permissive parenting style.

Consequently, future research should assess all three parenting styles and their relationship with treatment adherence.

Children's chronological age was not a predictor of treatment adherence in either disease group. This finding is in line with Miller-Johnson et al. who also did not find an association between the parent-child relationship and children's chronological ages even though the sample comprised a much wider age rage (8-18 years). However, research findings in this area are not consistent as others have found a relationship between age and non-adherence with the tendency that teens were less compliant than younger children (e.g. Kovacs et al., 1992; Johnson et al., 1986).

In this context a limitation of this thesis could have been that the children's ages and time since diagnosis (i.e. IDDM duration) could not be analysed separately. Therefore, there was a possibility that the interval between children's diagnosis and onset of non-adherence could have reflected a phase of initial adjustment to the illness that was not linked to children's chronological ages. However, this speculation needs to be addressed in future research by controlling for the variable of time of diagnosis.

9.3.3 Comparison of Adjustment and Treatment Adherence in Both Disease Groups

To verify whether one of the illnesses caused a greater source of stress than the other, it was investigated whether there was a difference in adjustment or treatment adherence between children with asthma or diabetes. On the basis of children's reports, there was no difference found between the two disease groups in their overall adjustment and in the overall level of children's treatment adherence. This finding indicates that even though having asthma or diabetes posed different kinds of stressors on the lives of these children, the overall effect on their lives was comparable.

However, according to parents' reports, children with asthma were significantly less adherent with their treatment regimen compared to children with diabetes. This finding could be explained by the fact that children with diabetes simply do not have a choice other than following most aspects of their treatment regimen as non-adherence causes immediate life-threatening consequences. In contrast, children with asthma have more leeway in their treatment adherence as non-adherence with certain regimens does not necessarily result in immediate negative consequences.

9.4 Limitations and Future Research

The results from this thesis should be viewed in the context of potential sample biases and limitations in the design of the studies, which should be carefully considered in the interpretation of the findings. First, the results were obtained with a particular sample of children with asthma or IDDM between 7 and 13 years of age at one hospital site. Thus, findings cannot be generalized to children with other chronic illnesses for example illnesses that are more visible as they might be more stigmatizing such as end-stage renal disease, cancer, or epilepsy. Also, findings cannot be generalized to children with asthma or IDDM in other age groups as illness-related stressors might affect children differently depending on their developmental stage. For example, in adolescence pressures to conform to peer standards are particularly tough and adolescents might experience more strain when having to follow their treatment regimen.

A methodological limitation of the present study was that the influences of the families' ethnic backgrounds on the children's adjustment and treatment adherence were not investigated. As was shown in the literature review this topic in general constitutes an under-researched area hence needs addressing and should be a focus of future research.

The relationship between families' socio economic status (SES) and children's adjustment and treatment adherence was investigated. The correlational analyses were not significant for either children's adjustment or treatment adherence, but the absence of a correlation between SES and children's adjustment or their treatment adherence is difficult to interpret.

It should be noted that the majority of children came from low socio-economic backgrounds and this may affected the possibility of detecting SES effects. The literature suggests that the resilience of the children and parents in this sample might have been lower compared to the rest of the population due to the presence of an additional risk factor. For example, according to Rutter (1979) SES is one factor that might increase the psychological and social disruption associated with chronic illnesses.

In this context MacLean et al. (1992) found that SES predicted psychological functioning in children with asthma. Higher SES predicted higher activity and social ability as well as more general social competence.

The studies were also limited by a relatively small sample size of 30 children with asthma and 30 children with diabetes consequently leading to low statistical power which may have hampered the detection of significant findings. Thus, testing the newly developed questionnaires using multi-centre collaboration to yield a larger sample size would enable employment of multivariate techniques to confirm the instrument and the subscales.

Another possible shortcoming of this thesis is that gender differences in connection with adjustment and treatment adherence were not explored. However, most studies have not found significant differences in parent-reported behaviour difficulties as a function of gender (Roberts, 2003).

Another limitation of this study might have been due to the fact that children and parents were offered the choice of completing the assessments (interview and questionnaire) either at the children's outpatient clinic or by the researcher visiting them at home at a convenient time to make participating more appealing to them. It was therefore possible that the clinic setting was more stressful for some children and parents, which might have inflated their adjustment scores compared to being assessed at home. It is therefore recommended for future studies to keep the place of assessment constant.

Yet another possible limitation of this thesis could have been that test-retest reliability was not conducted even though it is generally recognized that this is normally one requirement for any new scale. However, in a sample of children with chronic illness test-retest reliability should be balanced against the requirement for the questionnaire to be sensitive to short-term fluctuations in children's perceptions as external factors such as disease and treatment variables constantly change children's adjustment (Eiser et al., 1999; Varni et al., 2003).

Due to the cross-sectional design of the studies, cause and effect cannot be determined and prospective studies will be needed to expand upon the relationship between children's adjustment and treatment adherence. One direction of future research could be to explore children and their parents longitudinally and follow them up in a repeated measures design starting right at the point of diagnosis. This would allow for an exploration of the pattern of the relationship between children's adjustment and their adherence with the treatment. It is plausible to assume that adjustment to chronic illness and treatment adherence are not static but rather change over time for an individual child.

Lastly, future research should check the criterion validity of the newly developed questionnaires by examining its relationship with existing standardized measures. The main difficulty in carrying out this research is the lack of instruments that take the children's and parents' perspectives into account throughout the questions. However, this could then be examined against an instrument such as the PedsQL Asthma (Varni et al., 2004) and Diabetes (Varni et al., 2003) versions, relying mostly on the items that do take the subjective perspective.

To conclude, the questionnaires for children with asthma or diabetes and their parents developed in this study assessing adjustment and treatment adherence in a single measure proved to be reliable and valid. Future research is needed to explore whether children who were identified on the basis of the questionnaires to demonstrate poor adjustment and/or treatment adherence are in fact at risk. Another avenue for future research would be to explore whether the same method of questionnaire design could be used to develop questionnaires for children with other chronic conditions.

It is the hope of the author that the psychometric properties of the questionnaires will be further explored in future research and ultimately once proven to be reliable and valid used in clinical practice.

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Appendix 4.1 Child Asthma Interview

My name is Selin and I came to this hospital, because I would like to know more about children who have asthma and what they think about it.
I already spoke to a few children with asthma here, and they all told me different things.
I would like to know from you what it is like having asthma. Is it okay if I ask you a few questions and you just tell me what you think, and as you know there are no right or wrong answers? Do you mind if I tape record what we are saying so I can listen to it again if I want to? Let's have a go now, but if you want to stop you just let me know.

INTERVIEW WITH THE CHILD

Do you remember when you had asthma first, what were you thinking about it then?
What do you think now?

CHILD'S FEELINGS:
Okay, we all know that it is not nice to have asthma, but are there any nice things about it?
What do you not like about it?
Do you think that a child with asthma is different from others?
Do you mind when people ask or talk to you about your asthma?
Do you rather keep it for yourself?

FAMILY:
Is there anything you are not allowed at all, can you think about something?
Is your brother/sister allowed to do it?
Do you think that sometimes your parents are too careful with what you want to do?
Do you think that your parents treat you differently from your brother or sister because you have asthma?

SCHOOL:
What about school, how are you doing are you doing?
What about friends?
Do you have any special friends?
What sort of things do you do with your friends?
What about when you go to a birthday party, or sleep over at a friend, or there is sports-day in school, is there anything you have to remember?

TREATMENT:
Can you tell me what you have to do everyday? How much medicine you have to take and which little tests you have to do?
Is there anything you have to do everyday?
Did you do it yesterday, the day before yesterday, three days ago?
What does the asthma do to you?
Can you think about something that you feel and get when you have signs of asthma?
Do you know what to do then?
Can you do it by yourself or do you need help?
Is there anything you have to do that you do not like at all?
Do you still do it?

Appendix 4.2 Parent Asthma Interview

I am here with Ms/Mr … and s/he gave me permission to record the interview.
(name of child) was diagnosed with asthma when s/he was (age).

INTERVIEW WITH THE PARENT

When (name of child) was diagnosed with asthma what was your reaction?
How did you explain it to him/her?

CHILD'S FEELINGS:
How does s/he generally feel about having asthma?
Is s/he for example upset when people ask about or remind him/her of it because s/he rather keeps it for himself/herself?
Does s/he think you treat him/her differently because s/he has asthma?
Does s/he get upset about having asthma, e.g. does s/he think it prevents her from doing things?

FAMILY:
Let us now look at how s/he gets handled in the family. Did any family routines change because of him /her being diagnosed with asthma?
Can you think about something or a situation (name of child) wanted, but could not have? How did you handle it?
How do you deal with situations in which the other sibling(s) want(s) something (e.g. a pet, certain food) and you are concerned that it might trigger asthma in (name of child)?
Do you think that sometimes you are being too careful with (name of child)?
Does s/he think you are?

SCHOOL:
What about school, any worries, concerns, successes there?
How is s/he doing in school? Are you happy with his/her progress?
Is s/he happy with how s/he is doing?
Is there anything you have to inform the school about or the other children have to know about?
Are there any problems with friends, how does s/he perceive his/her friendships?
What happens for example when s/he goes to a birthday party, or sleeps over somewhere, or there is sports-day in school. Do you have to take any precautions?

TREATMENT:
Let us know talk about his/her treatment. Which medical procedure and tests does s/he have to undergo and which medication does s/he have to take?
What about his/her feelings concerning hospital appointments, taking medication, medical procedures, side-effects, is there anything s/he is worried, scared, or upset about?
How much can s/he do himself/herself and take responsibility?
How much does s/he understand about asthma and the treatment?
Does s/he know what to do when s/he has symptoms?
Are there bits with the treatment s/he finds hard to follow? How do you handle that?

Appendix 5.1 Interview Schedule for Paediatric Asthma and Diabetes Nurse

INTERVIEW WITH THE NURSE

Do you have the feeling that the children are anxious whilst attending the clinic/hospital?

How do you know that they are anxious?

Are they scared before and/or during medical procedures?

How do you know that they are scared?

Do they cry during medical procedures?

If yes, are they relieved after having undergone it?

Do they follow your instruction during medical procedures?

Do you think that having the mother in the room helps?

Do they hold on to the mother during medical procedures?

Do they seek reassurance from you or the mother during medical procedures?

Are they always fine with complying with the prescribed treatment or is there anything that disturbs or upsets them?

Do they know how to cope with symptoms of their asthma/diabetes and the correct procedure to follow? Can they for example take their medication themselves or do they need help?

Do you overall think that they have learnt to control their asthma/diabetes?

Appendix 5.2 Questionnaire for Parents of Children with Asthma - Girl Version

PARENT ASTHMA QUESTIONNAIRE

Name of child:

Age: Date of birth:

Sibling(s): gender: age:

gender: age:

Type of medication:

She takes medication all year around:

Number of asthma attacks in the last 2 years:

Number of asthma attacks in the last 2 years which ended up in hospital:

Other diseases:

Allergies:

Father's occupation:

Mother's occupation:

Mother's schooling (please tick appropriate box)

GCSE or lower ☐ A-Levels ☐ Higher National Diploma ☐

Bachelor Degree ☐ Master's Degree or higher ☐

Please fill in the questionnaire by choosing a response that says how much you agree or disagree with each of the following statements. Please choose one of the five numbers that applies to you the most. Remember that there are no right or wrong answers. Just say what is true for you. All your responses will be kept private. You have the right to withdraw at any time.

Entirely Agree	**Agree**	**Sometimes Yes Sometimes No**	**Disagree**	**Strongly Disagree**
1	**2**	**3**	**4**	**5**

1) She very rarely thinks that I am too cautious with her

2) She understands that to live well with asthma she has to take her medication

3) I informed her school about her asthma

Entirely Agree	Agree	Sometimes Yes Sometimes No	Disagree	Strongly Disagree
1	2	3	4	5

4) She gets upset on sports-day because due to her asthma she cannot participate as much as other children

5) I don't allow her sibling(s) to bring anything home that might trigger asthma in her

6) She thinks I treat her exactly the same as her sibling(s)

7) Even though she finds some parts of the treatment hard, she follows them very diligently

8) I don't let her sleep-over at a friend's house because the parents would not know what to do if she has breathing difficulties

9) It does not bother her that doing sports is difficult for her because she gets out of breath and tired easily

10) I buy cuddly toys or certain foods that she cannot have for the other sibling(s) because it is not fair on the sibling(s)

11) All problems would be solved between mother and child if parents were strict with their children when they don't do what they are supposed to do

12) If I stop her from going somewhere she always complains that I have a long list of do and don'ts

13) We very rarely get into arguments because of her not wanting to take her medication or inhaler

14) I let her sleep-over at a friend's house because she can take the inhaler and all her other medication herself

15) She does not think that her asthma prevents her from doing anything

16) It is a real problem when I buy toys or food for the others in the family and she cannot have them

17) I expect from my child that she conforms to my decisions out of respect for my authority

Entirely Agree	**Agree**	**Sometimes Yes Sometimes No**	**Disagree**	**Strongly Disagree**
1	**2**	**3**	**4**	**5**

18) Because she cannot have things that might trigger her asthma makes her realize that I treat her differently from the way other children are treated

19) She can do the whole treatment herself but I have to push her otherwise she would not do it

20) I don't find it necessary to inform the school what to do when she has breathing difficulties

21) She does not get upset when she has to come to the clinic and is missing out on something

22) When I buy toys or food that she cannot have for the others in the family, I buy her something special so she does not feel she had nothing

23) She thinks that I am too strict because I constantly remind her of her inhaler and medication

24) She very rarely forgets to take her inhalers

25) I tend to only go to the asthma clinic when her asthma is not very good

26) She gets upset because we constantly have to tell her to slow down and calm down

27) Since she was diagnosed with asthma I reduced my time at work

28) She has never mentioned that I am too careful with her

29) If she is too hyperactive there is nothing I can do

30) I take her regularly to the asthma clinic even if she is fine to check everything is alright

31) She gets frustrated when she has breathing difficulties

32) Her asthma is not a big deal in the family

33) Some parents of children with asthma are too careful but I don't think it is necessary

Entirely Agree	**Agree**	**Sometimes Yes Sometimes No**	**Disagree**	**Strongly Disagree**
1	**2**	**3**	**4**	**5**

34) She knows I will check up on whether she has taken her inhalers because you cannot trust children with this responsibility

35) I made sure that the school knows what to do when she has breathing difficulties

36) She hates having asthma because she just wants to be like a healthy child

37) We avoid visiting people who have pets because of her asthma

38) I am not cautious with her because she has to learn to treat her asthma herself

39) I don't mind that I constantly have to be on top of her with the inhalers because otherwise she does not take them

40) She wants a pet so much that we always get into arguments about it because she cannot have one

41) She is getting used to the fact that she has got asthma and more and more accepts it as part of her life

42) I do not think it is necessary to wet dust the house more often because of her asthma

43) I am very careful with her because of the fact that she has got asthma

44) It is almost a daily routine that we have arguments about her wanting something that she cannot have because of her asthma

45) She wanted a pet but we found an alternative (e.g. fish, turtle) that made her happy

46) She worries about her asthma and keeps on saying that she does not want to be asthmatic

47) I had to change certain things in the house when she was diagnosed with asthma (buy humidifiers, take out carpet, change mattress)

48) I treat her the same as her sibling(s) except that I make sure that she has her inhalers when she goes somewhere

Entirely Agree	**Agree**	**Sometimes Yes Sometimes No**	**Disagree**	**Strongly Disagree**
1	**2**	**3**	**4**	**5**

49) She knows she should not be too hyperactive but she does not stop even if she is getting out of breath

50) When she goes to a birthday party I make sure that there is nothing that might trigger her asthma like pets and pollen

51) She enjoys the visits to the hospital because it makes her feel special

52) I let people smoke while she is around because it does not make a difference

53) I am so vigilant with her it is as if I have wrapped her in lots of cotton wool

54) She insists on going outside even after I tell her that it is bad for her asthma because of the high pollens or the cold air

55) I let her go to sports-day by herself because she knows not to over-do it

56) She gets very angry and frustrated when her asthma restricts her from doing something

57) She has got a lot of friends because she gets on really well with other children

58) I try and encourage verbal give-and-take whenever I feel that the treatment regimen and restrictions are too demanding

59) I consciously try not to treat her differently but I cannot help it

60) She is always asking what asthma is and what the treatment is for

61) She keeps it for herself that she has got asthma and does not want me to tell anyone

62) She is embarrassed of using her inhalers in public

63) She feels that because of her asthma she is the odd one out amongst her friends

64) I let my child feel free to discuss my decisions if she feels that they are unreasonable

65) As children with asthma get bigger and stronger it is possible to relax completely

Entirely Agree	Agree	Sometimes Yes Sometimes No	Disagree	Strongly Disagree
1	2	3	4	5

66) When she gets breathing difficulties, I normally have to step in because she does not know what to do

67) She tells all her friends that she has got asthma that they can help her in case she has breathing difficulties

68) She is not too bothered about the fact that she cannot have furry pets

69) She sometimes gets picked on by other children because of her asthma

70) I think all children should be treated the same regardless if they have asthma or not

71) When she has signs of asthma she knows what to do

72) She gets upset when people ask about or remind her of her asthma

73) When I tell her to calm down because of her asthma and she does not, I punish her

74) When she does not feel well, her friends look after her

75) I try not to have too high expectations of her, I just encourage her to do her best

76) Every time I was not cautious enough, it ended up in a crisis or an attack

77) She often needs to be reminded to take her inhalers especially when she is busy doing something else

78) She is a bit embarrassed to talk about her asthma in front of her friends

79) When she wants to go somewhere where she should not because of her asthma, I discuss with her the reasons behind it

80) I let her sleep-over at a friend's house because it is good for her friendships

81) I am not too careful with her sometimes I even forget that she has got asthma

82) Someone always has to supervise her and help her taking her inhaler to check she does it properly

Entirely Agree	**Agree**	**Sometimes Yes Sometimes No**	**Disagree**	**Strongly Disagree**
1	**2**	**3**	**4**	**5**

83) She is very open about her asthma and talking about it is not a big deal for her

84) I know what is good for her so when I tell her to do something that is part of her treatment, I expect her to do it immediately without asking any questions

85) I let her go to friends' houses to spend the day there or to go on a day-trip with them and their families

86) Her asthma is not under control that is why I must be very alert all the time

87) She can use her inhaler perfectly by herself

88) I get very upset if she tries to disagree with me and starts a whole discussion (e.g. why she is not allowed to have a pet)

89) Because of her asthma she is behind in school, which makes her upset

90) I really cannot treat her like a healthy child

91) If I make a decision, I am willing to discuss it with her and admit if I made a mistake

92) The fact that her friends are much better at sports makes her very upset

93) She is proud of how well she is doing at school

Appendix 5.3 Questionnaire for Parents of Children with Asthma – Boy Version

PARENT ASTHMA QUESTIONNAIRE

Name of child:

Age: Date of birth:

Sibling(s): gender: age:

gender: age:

Type of medication:

He takes medication all year around:

Number of asthma attacks in the last 2 years:

Number of asthma attacks in the last 2 years which ended up in hospital:

Other diseases:

Allergies:

Father's occupation:

Mother's occupation:

Mother's schooling (please tick appropriate box)

GCSE or lower ☐ A-Levels ☐ Higher National Diploma ☐

Bachelor Degree ☐ Master's Degree or higher ☐

Please fill in the questionnaire by choosing a response that says how much you agree or disagree with each of the following statements. Please choose one of the five numbers that applies to you the most. Remember that there are no right or wrong answers. Just say what is true for you. All your responses will be kept private. You have the right to withdraw at any time.

Entirely Agree	**Agree**	**Sometimes Yes Sometimes No**	**Disagree**	**Strongly Disagree**
1	**2**	**3**	**4**	**5**

1) He very rarely thinks that I am too cautious with him

2) He understands that to live well with asthma he has to take his medication

Entirely Agree	Agree	Sometimes Yes Sometimes No	Disagree	Strongly Disagree
1	2	3	4	5

3) I informed his school about his asthma

4) He gets upset on sports-day because due to his asthma he cannot participate as much as other children

5) I don't allow his sibling(s) to bring anything home that might trigger asthma in him

6) He thinks I treat him exactly the same as his sibling(s)

7) Even though he finds some parts of the treatment hard he follows them very diligently

8) I don't let him sleep-over at a friend's house because the parents would not know what to do if he has breathing difficulties

9) It does not bother him that doing sports is difficult for him because he gets out of breath and tired easily

10) I buy cuddly toys or certain foods that he cannot have for the other sibling(s) because it is not fair on the sibling(s)

11) All problems would be solved between mother and child if parents were strict with their children when they don't do what they are supposed to do

12) If I stop him from going somewhere he always complains that I have a long list of do and don'ts

13) We very rarely get into arguments because of him not wanting to take his medication or inhaler

14) I let him sleep-over at a friend's house because he can take the inhaler and all his other medication himself

15) He does not think that his asthma prevents him from doing anything

16) It is a real problem when I buy toys or food for the others in the family and he cannot have them

17) I expect from my child that he conforms to my decisions out of respect for my authority

Entirely Agree	Agree	Sometimes Yes Sometimes No	Disagree	Strongly Disagree
1	2	3	4	5

18) Because he cannot have things that might trigger his asthma makes him realize that I treat him differently from the way other children are treated

19) He can do the whole treatment himself but I have to push him otherwise he would not do it

20) I don't find it necessary to inform the school what to do when he has breathing difficulties

21) He does not get upset when he has to come to the clinic and is missing out on something

22) When I buy toys or food that he cannot have for the others in the family I buy him something special so he does not feel he had nothing

23) He thinks that I am too strict because I constantly remind him of his inhaler and medication

24) He very rarely forgets to take his inhalers

25) I tend to only go to the asthma clinic when his asthma is not very good

26) He gets upset because we constantly have to tell him to slow down and calm down

27) Since he was diagnosed with asthma I reduced my time at work

28) He has never mentioned that I am too careful with him

29) If he is too hyperactive there is nothing I can do

30) I take him regularly to the asthma clinic even if he is fine to check everything is alright

31) He gets frustrated when he has breathing difficulties

32) His asthma is not a big deal in the family

33) Some parents of children with asthma are too careful but I don't think it is necessary

Entirely Agree	Agree	Sometimes Yes Sometimes No	Disagree	Strongly Disagree
1	2	3	4	5

34) He knows I will check up on whether he has taken his inhalers because you cannot trust children with this responsibility

35) I made sure that the school knows what to do when he has breathing difficulties

36) He hates having asthma because he just wants to be like a healthy child

37) We avoid visiting people who have pets because of his asthma

38) I am not cautious with him because he has to learn to treat his asthma himself

39) I don't mind that I constantly have to be on top of him with the inhalers because otherwise he does not take them

40) He wants a pet so much that we always get into arguments about it because he cannot have one

41) He is getting used to the fact that he has got asthma and more and more accepts it as part of his life

42) I do not think it is necessary to wet dust the house more often because of his asthma

43) I am very careful with him because of the fact that he has got asthma

44) It is almost a daily routine that we have arguments about him wanting something that he cannot have because of his asthma

45) He wanted a pet but we found an alternative (e.g. fish, turtle) that made him happy

46) He worries about his asthma and keeps on saying that he does not want to be asthmatic

47) I had to change certain things in the house when he was diagnosed with asthma (buy humidifiers, take out carpet, change mattress)

48) I treat him the same as his sibling(s) except that I make sure that he has his inhalers when he goes somewhere

Entirely Agree	Agree	Sometimes Yes Sometimes No	Disagree	Strongly Disagree
1	2	3	4	5

49) He knows he should not be too hyperactive but he does not stop even if he is getting out of breath

50) When he goes to a birthday party I make sure that there is nothing that might trigger his asthma like pets and pollen

51) He enjoys the visits to the hospital because it makes him feel special

52) I let people smoke while he is around because it does not make a difference

53) I am so vigilant with him it is as if I have wrapped him in lots of cotton wool

54) He insists on going outside even after I tell him that it is bad for his asthma because of the high pollens or the cold air

55) I let him go to sports-day by himself because he knows not to over-do it

56) He gets very angry and frustrated when his asthma restricts him from doing something

57) He has got a lot of friends because he gets on really well with other children

58) I try and encourage verbal give-and-take whenever I feel that the treatment regimen and restrictions are too demanding

59) I consciously try not to treat him differently but I cannot help it

60) He is always asking what asthma is and what the treatment is for

61) He keeps it for himself that he has got asthma and does not want me to tell anyone

62) He is embarrassed of using his inhalers in public

63) He feels that because of his asthma he is the odd one out amongst his friends

64) I let my child feel free to discuss my decisions if he feels that they are unreasonable

65) As children with asthma get bigger and stronger it is possible to relax completely

Entirely Agree	Agree	Sometimes Yes Sometimes No	Disagree	Strongly Disagree
1	2	3	4	5

66) When he gets breathing difficulties, I normally have to step in because he does not know what to do

67) He tells all his friends that he has got asthma that they can help him in case he has breathing difficulties

68) He is not too bothered about the fact that he cannot have furry pets

69) He sometimes gets picked on by other children because of his asthma

70) I think all children should be treated the same regardless if they have asthma or not

71) When he has signs of asthma he knows what to do

72) He gets upset when people ask about or remind him of his asthma

73) When I tell him to calm down because of his asthma and he does not, I punish him

74) When he does not feel well, his friends look after him

75) I try not to have too high expectations of him, I just encourage him to do his best

76) Every time I was not cautious enough, it ended up in a crisis or an attack

77) He often needs to be reminded to take his inhalers especially when he is busy doing something else

78) He is a bit embarrassed to talk about his asthma in front of his friends

79) When he wants to go somewhere where he should not because of his asthma, I discuss with him the reasons behind it

80) I let him sleep-over at a friend's house because it is good for his friendships

81) I am not too careful with him sometimes I even forget that he has got asthma

82) Someone always has to supervise him and help him taking his inhaler to check he does it properly

Entirely Agree	**Agree**	**Sometimes Yes Sometimes No**	**Disagree**	**Strongly Disagree**
1	**2**	**3**	**4**	**5**

83) He is very open about his asthma and talking about it is not a big deal for him

84) I know what is good for him so when I tell him to do something that is part of his treatment, I expect him to do it immediately without asking any questions

85) I let him go to friends' houses to spend the day there or to go on a day-trip with them and their families

86) His asthma is not under control that is why I must be very alert all the time

87) He can use his inhaler perfectly by himself

88) I get very upset if he tries to disagree with me and starts a whole discussion (e.g. why he is not allowed to have a pet)

89) Because of his asthma he is behind in school, which makes him upset

90) I really cannot treat him like a healthy child

91) If I make a decision, I am willing to discuss it with him and admit if I made a mistake

92) The fact that his friends are much better at sports makes him very upset

93) He is proud of how well he is doing at school

Appendix 5.4 Child Asthma Questionnaire

CHILD ASTHMA QUESTIONNAIRE

Name of child:
Age:

Please fill in the questionnaire by choosing a response that says how much you agree or disagree with each of the following statements. Circle one of the five numbers that applies to you the most. Remember that there are no right or wrong answers. Just say what is true for you. All your responses will be kept private. You have the right to withdraw at any time.

Entirely Agree	Agree	Sometimes yes sometimes no	Disagree	Strongly Disagree
1	2	3	4	5

1) I wish I could just be so very good that my asthma would go away

2) A child with asthma is different from a child who hasn't asthma because having an illness makes you different

3) I don't mind that whenever I run my mum tells me to stop because she gets worried that I will run out of breath

4) It makes me really upset that on sports day I am not allowed to try as hard as I could so I can win

5) My friends did not know anything about asthma before they met me

6) When I go to a friend's birthday party without my mum I really run around a lot

7) It makes me really afraid when I take my inhaler and the symptoms don't go away

8) It does not bother when other children pick on me because of my asthma

9) It really bothers me that I have to use my inhalers and take medicine

10) I don't think that there is a difference between a child with asthma and a child who has not asthma

11) My mum lets me get on with what I want to do

12) I don't mind that because of my asthma I am not allowed to sleep over at a friend's house

13) I showed my friends my inhalers and told them how they work

14) I always stop myself from running too much because it is not good for me

15) I get really upset when I cannot breathe and sleep in the middle of the night

16) I never worry about my asthma

17) I like that I get days off school or can leave school earlier because of my asthma

18) Children with asthma and without are the same because asthma does not change your life that much

19) My mum rather has me at home always than that I go somewhere

20) It is hard for me when I go to a birthday party because I have to stop myself from running around while my friends are all running around

21) I don't like using my inhalers in front of my friends

22) I sometimes tell my mum that I have taken my medication or inhaler even though I have not

23) When I am breathless I feel helpless because I need someone to help me taking my inhaler

24) It is better to have asthma that I can control than some other illness that you cannot control

25) It is annoying that I have to stop playing or running when I get breathless

26) Children with asthma get out of breath more easily than other children

27) My mum is often too cautious with me e.g. when I want to do sports or go on a school trip than she is with my brother or sister

28) It does not bother me when I sleep over at a friend's place that I have to check that there is nothing that might trigger my asthma like a pet or smoking

29) I don't mind when people ask me about my asthma

30) I don't know when and how often I have to take my medication and my inhaler

31) When I feel wheezy or out of breath I take my inhaler and relax

32) I hate the fact that I have asthma

33) I can run for much longer than other children

34) A child with asthma is the same as a child without asthma except that a child with asthma needs inhalers

35) I often think that it is not fair when I am not allowed to do something just because I have asthma

36) It is easy for me to always remember when I go somewhere to take my inhalers with me

37) I'd rather keep it for myself that I have asthma

38) I use my inhaler and peak flow meter as often as the doctor or nurse told me

39) When my chest gets tight I don't panic

40) There is nothing nice about having asthma

41) My mum treats me exactly the same as other mums treat their children except that I am not allowed things that might trigger my asthma

42) I wish someone would help me to take my medicine to avoid the attacks

43) I never need reminding when to take my inhalers

44) Having asthma is not too bad if you have it controlled

45) I always carry my inhalers with me where ever I go

46) Even if my mum would not check on me I would take my medication

47) When I do something that could trigger asthma in me I really worry what will happen to me

48) It is hard for me when I exercise not to overdo it and get short of breath

49) I know that certain things are not good for my asthma but I don't try to avoid them

50) I wish I could have a furry pet like other children

Appendix 5.5 Cover Letter to Expert Panel

Dear panel of experts,

You are being asked to participate as a content expert because of your professional background and knowledge in the area of children with chronic illnesses. Your participation in the instrument review process is valuable as this is a very important step in the development of the questionnaires. Once the new questionnaires have been validated and proven reliable they could aid health professionals in the future to identify children at risk for adjustment and treatment adherence difficulties. I realise that your time is very valuable and am truly grateful for your help.

In this letter, I explain the background of the development of the questionnaires. The attached form describes the procedure that I would like you to follow in making your judgements.

There is some evidence in the literature that children who find it difficult to adjust to a chronic illness are at risk for non-adherence to treatment. I am developing two questionnaires to be used with children with asthma or diabetes that aim to assess (1) children's socio-emotional adjustment and (2) risk for non-adherence to treatment.

Socio-emotional adjustment to the illness

According to the World Health Organization Quality of Life Group (WHOQOL), QOL[1] is an individual's perceptions of their position in life, in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad concept affected by the person's physical health, psychological state, level of independence, social relationships, their relationship to the salient features of their environment and their beliefs. In general, socio-emotional adjustment refers to a child's subjective perception of and feelings about his/her circumstances rather than to an objective standard. In the context of chronic illness, adjustment refers to the psychological component of QOL that is, to the child's perception and emotional reaction to the way the illness and the treatment are affecting his/her life.

There are some measures of QOL for children with asthma and diabetes but they focus mostly on the objective aspects of QOL, i.e. what the children are able and not able to do and symptoms, and not the children's feelings about the restrictions the illness and treatment poses on them. The Pediatric Quality of Life Asthma and Diabetes Modules include items that assess the children's perception and feelings towards symptoms, treatment and restrictions but the number of items that assess the child's feelings is small. Thus, the aim of this study is to develop a more comprehensive assessment that covers the whole range of the child's experiences with the illness.

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[1] Eiser & Mosre (2001)

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Socio-emotional adjustment to the illness

According to the World Health Organization Quality of Life Group (WHOQOL), QOL[1] is an individual's perceptions of their position in life, in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad concept affected by the person's physical health, psychological state, level of independence, social relationships, their relationship to the salient features of their environment and their beliefs. In general, socio-emotional adjustment refers to a child's subjective perception of and feelings about his/her circumstances rather than to an objective standard. In the context of chronic illness, adjustment refers to the psychological component of QOL that is, to the child's perception and emotional reaction to the way the illness and the treatment are affecting his/her life.

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[1] Eiser & Mosre (2001)

Treatment adherence

The essence of treatment in asthma and diabetes is self-care; the children have to follow a strict and complex treatment regimen. Adherence to treatment involves the ability to identify situations that should be avoided because they could trigger a reaction (avoid strenuous exercise, avoid sweets, for example) and to identify symptoms that should be treated (with inhalers, rest or insulin, for example). The challenge in identifying children at risk for non-compliance with this strict regimen is to be able to find out when the children's feelings towards avoiding situations that they often view positively (win in sports, play with animals, eat sweets) or engaging in treatment actions that they view negatively (using an inhaler publicly can be seen as embarrassing, taking blood samples can be viewed as painful) places them at risk for non-compliance with the treatment. This is the subjective aspect of compliance, which can be used to develop a questionnaire that would help identify children at risk and offer them appropriate assistance in achieving good treatment adherence. Some scales developed previously to measure treatment adherence combine objective and subjective items in the same scale.

The development of this scale

In order to develop the new questionnaires 15 children with asthma and 15 children with diabetes and their parents, were interviewed as a method to elicit information about the children's experiences with the illness. A content analysis of the interview data was carried out using grounded theory methodology to identify descriptive categories that emerged in the description of the different aspects of their experiences and the variation in children's reactions within the sample.

The analysis of the interviews with children led to the identification of three categories related to their socio-emotional adjustment:

1. Child's perception of normality
2. Child's feelings about the illness
3. Child's openness about the illness.

The analysis of the children's views of treatment adherence showed that they spoke about adherence, their reaction to symptoms and precautions necessary to avoid incidents usually in close connection with each other. So the fourth theme that emerged in the analysis of the interviews was connected to adherence, treatment and precautions, and formed the basis for the development of the second scale.

Analysis of the parents' interviews revealed that the same themes appeared, along with two additional themes; parent's own attitude towards the treatment adherence and precautions and parent's perception of the impact of the illness on the child's social environment (the family, friends, and school performance).

On the basis of the themes identified in the children's interviews, the items for the child questionnaire were developed. The items used as far as possible the children's own language; changes were made to make the item less gender biased or to obtain a balance between statements with which the children would agree or disagree. The same procedure was used to develop the parent questionnaires. The respondents (child/parent) were asked to indicate their level of agreement for each item on a 5-point scale ranging from "entirely agree" to "strongly disagree".

The importance of panel experts

Children's and parents' views are crucial to developing measures about the children's socio-emotional adjustment and difficulties in complying with treatment but they cannot replace the judgement of experts who can analyse the same issue from different perspectives. On the attached forms you will find the child and parent scales with their conceptual definitions and you are kindly requested to judge how representative each item is for each scale in your view. I am asking four other experts to go through the same procedure. This will help me look for convergence in the ratings and to make decisions regarding which items should be treated together in further analyses.

Later steps in this process will include an analysis of the reliability of the scales and a factor analysis. Future work, not anticipated to be part of this research, will focus on the validation of the scales emerging from this project with a large sample of participants.

Your participation is very much appreciated. Many thanks.

Appendix 5.6 Conceptual Definitions and Rating Scales for Expert Panel

Please find below the child and parent scales with their conceptual definitions and some examples of items used in other questionnaires that aim to measure the same construct. By using the following 5-point ordinal relevance or representative rating scale, please indicate how relevant you consider each item and mark your choice after every item. If you use 0 as a rating, please indicate under which other scale the item might be placed, or indicate N for not relevant to any of the scales.

0 = the item is representative of a different scale
1 = the item is not representative of this scale
2 = the item is marginally representative of this scale
3 = the item is representative of this scale
4 = the item is very representative of this scale

CHILD SCALES (ASTHMA AND DIABETES)

"Child's Perception of Normality". It is currently recognised that norms are personal and social constructions: some children who have diabetes or asthma may think of themselves as normal, but happen to have diabetes or asthma, and others may think of themselves as not normal, exactly because they have diabetes or asthma. The aim of this scale was to assess the child's feelings of normality i.e. whether the child feels different or the same to other children because of the illness.

Examples of items from the Perceived Illness Experience Scale (PIE)
My parents treat me like a baby
My parents use the illness to stop me doing things
My parents make a fuss of me because of my illness

Child's perception of normality (Asthma)	0: representative of a different scale 1: not representative 2: marginally representative 3: representative 4: very representative	If you think that the item is representative of a different scale, tick the scale you are thinking of, if any of these would be relevant in your view.
	0 1 2 3 4	O = Openness about illness F = Feeling about illness R = Risk for non-compliance N = Not relevant
2. A child with asthma is different from a child who hasn't asthma because having an illness makes you different		
3. I don't mind that whenever I run my mum tells me to stop because she gets worried that I will run out of breath		
10. I don't think that there is a difference between a child with asthma and a child who has not asthma		
11. My mum lets me get on with what I want to do		
18. Children with asthma and without are the same because asthma does not change your life that much		
19. My mum rather has me at home always than that I go somewhere		
26. Children with asthma get out of breath more easily than other children		
34. A child with asthma is the same as a child without asthma except that a child with asthma needs inhalers		
41. My mum treats me exactly the same as other mums treat their children except that I am not allowed things that might trigger my asthma		

Child's perception of normality (Diabetes)	0: representative of a different scale 1: not representative 2: marginally representative 3: representative 4: very representative	If you think that the item is representative of a different scale, tick the scale you are thinking of, if any of these would be relevant in your view.
	0 1 2 3 4	O = Openness about illness F = Feeling about illness R = Risk for non-compliance N = Not relevant
2. A child with diabetes is different from a child who hasn't diabetes because having an illness makes you different		
3. I don't mind that whenever I eat sweets my mum tells me to stop because she gets too worried		
10. I don't think that there is a difference between a child with diabetes and a child who has not diabetes		
11. My mum lets me get on with what I want to do		
18. Children with diabetes and without are the same because diabetes does not change your life that much		
26. Children with diabetes have to watch what they are eating and drinking and other children don't		
27. My mum is always too cautious with me e.g. when I want to do sports or go on a school trip than she is with my brother or sister		
35. I often think that it is not fair when I am not allowed to do something just because I have diabetes		
41. My mum treats me exactly the same as other mums treat their children except that I cannot eat sweets		

"Child's Feelings about the Illness". Asthma and diabetes are illnesses that affect the children's lives objectively. The aim of this scale was to assess how the children feel about the effects of the illness on their lives. Two previous scales have used items that investigate the children's feelings about their illness.

Examples from the PedsQL Asthma Module –Worry:
I worry about whether or not my medical treatments are working
I worry about my asthma

Examples from the PIE
I get cross about how much my illness spoils my life

Child's Feelings about the Illness (Asthma)	0: representative of a different scale 1: not representative 2: marginally representative 3: representative 4: very representative	If you think that the item is representative of a different scale, tick the scale you are thinking of, if any of these would be relevant in your view.
	0 1 2 3 4	O = Openness about illness P = Perception about Normality R = Risk for non-compliance N = Not relevant
8. It does not bother when other children pick on me because of my asthma		
9. It really bothers me that I have to use my inhalers and take medicine		
16. I never worry about my asthma		
17. I like that I get days off school or can leave school earlier because of my asthma		
24. It is better to have asthma that I can control than some other illness that you cannot control		
32. I hate the fact that I have asthma		
40. There is nothing nice about having asthma		
44. Having asthma is not too bad if you have it controlled		
47. When I do something that could trigger asthma in me I really worry what will happen to me		
50. I wish I could have a furry pet like other children		

Child's Feelings about the Illness (Diabetes)	0: representative of a different scale 1: not representative 2: marginally representative 3: representative 4: very representative	If you think that the item is representative of a different scale, tick the scale you are thinking of, if any of these would be relevant in your view.
	0 1 2 3 4	O = Openness about illness P = Perception about Normality R = Risk for non-compliance N = Not relevant
8. It does not bother me when other children pick on me because of my diabetes		
9. It does not bother me that I have to take injections every day		
16. I never worry about my diabetes		
17. I like that I get days off school or can leave school earlier because of my diabetes		
24. It is better to have diabetes that I can control than some other illness that you cannot control		
32. I hate the fact that I have diabetes		
33. It makes me very sad that I cannot eat sweets or can only have very little		
40. There is nothing nice about having diabetes		
44. Having diabetes is not too bad if you have it controlled		
47. When I eat sweets I really worry what will happen to me		
50. I wish I could eat sweets like other children		

"Child's Openness about the illness". The aim of this scale was to assess the degree to which a child is willing to disclose information about his/her illness. Two other scales have included items about the child's openness about the illness.

Examples from the PedsQL Asthma Module – Communication:
It is hard for me to tell the doctors and nurses how I feel
It is hard for me to explain my illness to other people

Examples from the PIE
I get cross when people ask about my illness
I only tell people about my illness if I really have to

Child's Openness about the Illness (Asthma)	0: representative of a different scale 1: not representative 2: marginally representative 3: representative 4: very representative	If you think that the item is representative of a different scale, tick the scale you are thinking of, if any of these would be relevant in your view.
	0 1 2 3 4	P = Perception about Normality F = Feeling about illness R = Risk for non-compliance N = Not relevant
5. My friends did not know anything about asthma before they met me		
13. I showed my friends my inhalers and told them how they work		
21. I don't like using my inhalers in front of my friends		
29. I don't mind when people ask me about my asthma		
37. I'd rather keep it for myself that I have asthma		

Child's Openness about the Illness (Diabetes)	0: representative of a different scale 1: not representative 2: marginally representative 3: representative 4: very representative	If you think that the item is representative of a different scale, tick the scale you are thinking of, if any of these would be relevant in your view.
	0 1 2 3 4	P = Perception about Normality F = Feeling about illness R = Risk for non-compliance N = Not relevant
5. My friends did not know anything about diabetes before they met me		
13. I showed my friends my injections and glucose meter and told them how it works		
21. I don't like eating my snacks in school when all the other children don't eat		
29. I don't mind when people ask me about my diabetes		
37. I'd rather keep it for myself that I have diabetes		

"Child's risk for non-adherence to treatment".
The scale assessed how far the child perceived the treatment adherence behaviours as intrusive or stressful, or alternatively, something with which they could live without stress. Examples of items that aimed at measuring a similar construct are presented below.

Examples from the PedsQL Asthma Module – Asthma Symptoms and Treatment Problems:
I get scared when I have asthma attacks
It is hard for me to play with pets
It is hard for me to play outside
I have trouble sleeping because of my medicines
I don't like to carry my inhaler
I forget to take my medicines
I get scared when I have to have medical treatments

Child's risk for non-adherence to treatment (Asthma)	0: representative of a different scale 1: not representative 2: marginally representative 3: representative 4: very representative	If you think that the item is representative of a different scale, tick the scale you are thinking of, if any of these would be relevant in your view.
	0 1 2 3 4	O = Openness about illness F = Feeling about illness P = Perception about Normality N = Not relevant
4. It makes me really upset that on sports day I am not allowed to try as hard as I could so I can win		
7. It makes me really afraid when I take my inhaler and the symptoms don't go away		
12. I don't mind that because of my asthma I am not allowed to sleep over at a friend's house		
15. I get really upset when I cannot breathe and sleep in the middle of the night		
20. It is hard for me when I go to a birthday party because I have to stop myself from running around while my friends are all running around		
22. I sometimes tell my mum that I have taken my medication or inhaler even though I have not		
23. When I am breathless I feel helpless because I need someone to help me taking my inhaler		
28. It does not bother me when I sleep over at a friend's place that I have to check that there is nothing that might trigger my asthma like a pet or smoking		
30. I don't know when and how often I have to take my medication and my inhaler		
31. When I feel wheezy or out of breath I take my inhaler and relax		
36. It is easy for me to always remember when I go somewhere to take my inhalers with me		
38. I use my inhaler and peak flow meter as often as the doctor or nurse told me		
39. When my chest gets tight I don't panic		
42. I wish someone would help me to take my medicine to avoid the attacks		
43. I never need reminding when to take my		

inhalers		
46. Even if my mum would not check on me I would take my medication		
48. It is hard for me when I exercise not to overdo it and get short of breath		
49. I know that certain things are not good for my asthma but I don't try to avoid them		

Child's risk for non-adherence to treatment (Diabetes)	0: representative of a different scale 1: not representative 2: marginally representative 3: representative 4: very representative	If you think that the item is representative of a different scale, tick the scale you are thinking of, if any of these would be relevant in your view.
	0 1 2 3 4	O = Openness about illness F = Feeling about illness P = Perception about Normality N = Not relevant
6. When I go to a friend's birthday party without my mum I really eat a lot of sweets		
7. It makes me really afraid when my blood sugar levels are high or low and I do what the doctor told me and the symptoms don't go away		
12. I don't mind that because of my diabetes I am not allowed to sleep over at a friend's house		
14. I always stop myself from eating sweets because it is not good for me		
22. I sometimes tell my mum that I have checked my blood sugar even though I have not		
28. It does not bother me when I sleep over at a friend's place that I have to check that they have the right food and drinks for me		
30. I don't know how often I have to measure my blood sugar levels		
31. When I am unwell I know if I am high or low in sugar levels and what to do		
36. It is easy for me to always remember when		

I go somewhere to take my insulin and glucose meter with me		
38. I do as many blood tests a day as the nurse or doctor has told me		
39. When I have signs of being low or high I don't panic		
42. I wish someone would help me to take my medicine to avoid that my blood sugar level goes too high or drops too low		
43. I never need reminding when to take my injections		
45. I always carry my blood kit with me wherever I go		
46. Even if my mum would not check on me I would do the blood sugar level test		
48. It is hard for me to keep my blood sugar levels steady when I exercise (topped up with sugar)		
49. Because I am not allowed sweets I sometimes hide them		

PARENT QUESTIONNAIRE (ASTHMA AND DIABETES)

"Parent's perception of the child's normality". The concept of this scale was the same as for the "Child's Perception of Normality" but this time assessed from the parent's perception of the child's feelings. Items used in one previously developed instrument are presented below.

Examples from the PIE

My child thinks I make a fuss of him/her because of the illness
My child thinks I treat him/her like a baby
My child thinks I use the illness to stop him/her doing things

Parent's perception of the child's normality (Asthma)	0: representative of a different scale 1: not representative 2: marginally representative 3: representative 4: very representative	If you think that the item is representative of a different scale, tick the scale you are thinking of, if any of these would be relevant in your view.
	0 1 2 3 4	O = Openness about illness F = Feeling about illness R = Risk for non-compliance T = Treatment and precautions I = Impact of the disease N = Not relevant
12. If I stop him from going somewhere he always complains that I have a long list of do and don'ts		
18. Because he cannot have things that might trigger his asthma makes him realize that I treat him differently from the way other children are treated		
23. He thinks that I am too strict because I constantly remind him of his inhaler and medication		
33. Some parents of children with asthma are too careful but I don't think it is necessary		
38. I am not cautious with him because he has to learn to treat his asthma himself		
43. I am very careful with him because of the fact that he has got asthma		
65. As children with asthma get bigger and stronger it is possible to relax completely		
70. I think all children should be treated the same regardless if they have asthma or not		
76. Every time I was not cautious enough, it ended up in a crisis or an attack		
81. I am not too careful with him sometimes I even forget that he has got asthma		
86. His asthma is not under control that is why I must be very alert all the time		

Parent's perception of the child's normality (Diabetes)	0: representative of a different scale 1: not representative 2: marginally representative 3: representative 4: very representative	If you think that the item is representative of a different scale, tick the scale you are thinking of, if any of these would be relevant in your view.
	0 1 2 3 4	O = Openness about illness F = Feeling about illness R = Risk for non-compliance T = Treatment and precautions I = Impact of the disease N = Not relevant
1. He very rarely thinks that I am too cautious with him		
7. He thinks I treat him exactly the same as his sibling(s)		
12. If I stop him from going somewhere he always complaints that I have a long list of do and don'ts		
29. He has never mentioned that I am too careful with him		
34. Some parents of children with diabetes are too cautious but I don't think it is necessary		
39. I am not cautious with him because he has to learn to treat his diabetes himself		
44. I am very careful with him because of the fact that he has got diabetes		
54. I am so vigilant with him it is as if I have wrapped him in lots of cotton wool		
59. I consciously try not to treat him differently but I cannot help it		
64. As children with diabetes get bigger and stronger it is possible to relax completely		
69. I think all children should be treated the same regardless if they have diabetes or not		
79. I am not too careful with him sometimes I even forget that he has got diabetes		
88. I really cannot treat him like a healthy child		

"Parent's perception of the child's feelings". The concept of this scale was the same as for the "Child's Feelings About the Disease" but this time assessed from the parent's perspective of the child's feelings towards the illness.

Examples from the Parent PedsQL Asthma Module –Worry:

In the past one month, how much of a problem has your child with worrying about side effects from medication
In the past one month, how much of a problem has your child with worrying about his or her asthma

Examples from the PIE
My child gets cross about how much the illness spoils his/her life

Parent's perception of the child's feelings (Asthma)	0: representative of a different scale 1: not representative 2: marginally representative 3: representative 4: very representative	If you think that the item is representative of a different scale, tick the scale you are thinking of, if any of these would be relevant in your view.
	0 1 2 3 4	O = Openness about illness P = Perception about Normality R = Risk for non-compliance T = Treatment and precautions I = Impact of the disease N = Not relevant
4. He gets upset on sports-day because due to his asthma he cannot participate as much as other children		
15. He does not think that his asthma prevents him from doing anything		
21. He does not get upset when he has to come to the clinic and is missing out on something		
26. He gets upset because we constantly have to tell him to slow down and calm down		
31. He gets frustrated when he has breathing difficulties		
36. He hates having asthma because he just wants to be like a healthy child		
41. He is getting used to the fact that he has got asthma and more and more accepts it as part of his life		
46. He worries about his asthma and keeps on saying that he does not want to be asthmatic		
51. He enjoys the visits to the hospital because it makes him feel special		
56. He gets very angry and frustrated when his asthma restricts him from doing something		
62. He is embarrassed of using his inhalers in public		
68. He is not too bothered about the fact that he cannot have furry pets		

Parent's perception of the child's feelings (Diabetes)	0: representative of a different scale 1: not representative 2: marginally representative 3: representative 4: very representative	If you think that the item is representative of a different scale, tick the scale you are thinking of, if any of these would be relevant in your view.
	0 1 2 3 4	O = Openness about illness P = Perception about Normality R = Risk for non-compliance T = Treatment and precautions I = Impact of the disease N = Not relevant
4. He gets upset on sports-day because due to his diabetes he cannot participate as much as other children		
10. He finds sport difficult because he has to keep his blood sugar level right		
15. He does not think that his diabetes prevents him from doing anything		
21. He does not get upset when he has to come to the clinic and is missing out on something		
27. He is sad that he won't be able to do certain things later on in life because of his diabetes		
37. He hates having diabetes because he just wants to be like a healthy child		
42. He is getting used to the fact that he has got diabetes and more and more accepts it as part of his life		
47. He worries about his diabetes and keeps on saying that he does not want to be diabetic		
52. He enjoys the visits to the hospital because it makes him feel special		
57. He gets very angry and frustrated when his diabetes restricts him from doing something		
62. He is not embarrassed of using his blood glucose meter or injections in public		

"Parent's perception of the child's openness about the disease". The concept of this scale was the same as for the "Child's Openness about the Disease" but this time assessed from the parent's perspective of the child's willingness to disclosure the illness.

Examples from the PedsQL Asthma Module – Communication:

In the past one month, how much of a problem has your child with explaining his or her illness to other people

Examples from the PIE

My child gets cross when people ask about the illness
My child only tells people about the illness if s/he really has to

Parent's perception of the child's openness about the disease (Asthma)	0: representative of a different scale 1: not representative 2: marginally representative 3: representative 4: very representative	If you think that the item is representative of a different scale, tick the scale you are thinking of, if any of these would be relevant in your view.
	0 1 2 3 4	P = Perception about Normality F = Feeling about illness R = Risk for non-compliance T = Treatment and precautions I = Impact of the disease N = Not relevant
3. I informed his school about his asthma		
61. He keeps it for himself that he has got asthma and does not want me to tell anyone		
67. He tells all his friends that he has got asthma that they can help him in case he has breathing difficulties		
72. He gets upset when people ask about or remind him of his asthma		
78. He is a bit embarrassed to talk about his asthma in front of his friends		
83. He is very open about his asthma and talking about it is not a big deal for him		

Parent's perception of the child's openness about the disease (Diabetes)	0: representative of a different scale 1: not representative 2: marginally representative 3: representative 4: very representative	If you think that the item is representative of a different scale, tick the scale you are thinking of, if any of these would be relevant in your view.
	0 1 2 3 4	P = Perception about Normality F = Feeling about illness R = Risk for non-compliance T = Treatment and precautions I = Impact of the disease N = Not relevant
3. I informed the school about his diabetes and the snack times		
61. He keeps it for himself that he has got diabetes and does not want me to tell anyone		
66. He tells all his friends that he has got diabetes that they can help him in case he goes low		
71. He gets upset when people ask about or remind him of his diabetes		
76. He is a bit embarrassed to talk about his diabetes in front of his friends		
81. He is very open about his diabetes and talking about it is not a big deal for him		

<u>"Parent's perception of the impact of the illness".</u> The aim of scale was to assess the parent's views of the impact of the illness on the child's social environment, rather than on the child him/herself. This theme was raised by parents in the interviews. Similar scales or items have not been identified in previous research.

Parent's perception of the impact of the illness (Asthma)	0: representative of a different scale 1: not representative 2: marginally representative 3: representative 4: very representative	If you think that the item is representative of a different scale, tick the scale you are thinking of, if any of these would be relevant in your view.
	0 1 2 3 4	P = Perception about Normality F = Feeling about illness R = Risk for non-compliance T = Treatment and precautions O = Openness about illness N = Not relevant
5. I don't allow his sibling(s) to bring anything home that might trigger asthma in him		
22. When I buy toys or food that he cannot have for the others in the family I buy him something special so he does not feel he had nothing		
27. Since he was diagnosed with asthma I reduced my time at work		
37. We avoid visiting people who have pets because of his asthma		
47. I had to change certain things in the house when he was diagnosed with asthma (buy humidifiers, take out carpet, change mattress)		
52. I let people smoke while he is around because it does not make a difference		
57. He has got a lot of friends because he gets on really well with other children		
63. He feels that because of his asthma he is the odd one out amongst his friends		
74. When he does not feel well, his friends look after him		
85. I let him go to friends' houses to spend the day there or to go on a day-trip with them and their families		
93. He is proud of how well he is doing at school		

Parent's perception of the impact of the illness (Diabetes)	0: representative of a different scale 1: not representative 2: marginally representative 3: representative 4: very representative	If you think that the item is representative of a different scale, tick the scale you are thinking of, if any of these would be relevant in your view.
	0 1 2 3 4	P = Perception about Normality F = Feeling about illness R = Risk for non-compliance T = Treatment and precautions O = Openness about illness N = Not relevant
16. It is a real problem when I buy treats for the others in the family and he cannot have any		
38. We all eat low sugar food that he can have so he does not feel left out at the table		
48. If his sibling(s) are having sweets and he cannot, they eat them outside		
58. He has got a lot of friends because he gets on really well with other children		
63. He feels that because of his diabetes he is the odd one out amongst his friends		
68. He sometimes gets picked on by other children because of his diabetes		
73. When he does not feel well, his friends look after him		
78. I let him sleep-over at a friend's house because it is good for his friendships		
83. I let him go to friends' houses to spend the day there or to go on a day-trip with them and their families		
87. Because of his diabetes he is behind in school, which makes him upset		
91. His friends eat sweets in front of him and that makes him very upset		
94. He is proud of how well he is doing at school		

"Parent's attitude about the treatment and precautions". The aim of this scale was to assess whether parents perceived themselves as playing a role in the children's treatment and how they thought this role should be played. This theme was raised by parents in the interviews. Similar scales or items have not been identified in previous research.

Parent's attitude about the treatment and precautions (Asthma)	0: representative of a different scale 1: not representative 2: marginally representative 3: representative 4: very representative	If you think that the item is representative of a different scale, tick the scale you are thinking of, if any of these would be relevant in your view.
	0 1 2 3 4	P = Perception about Normality F = Feeling about illness R = Risk for non-compliance I = Impact of the disease O = Openness about illness N = Not relevant
8. I don't let him sleep-over at a friend's house because the parents would not know what to do if he has breathing difficulties		
14. I let him sleep-over at a friend's house because he can take the inhaler and all his other medication himself		
20. I don't find it necessary to inform the school what to do when he has breathing difficulties		
25. I tend to only go to the asthma clinic when his asthma is not very good		
30. I take him regularly to the asthma clinic even if he is fine to check everything is alright		
35. I made sure that the school knows what to do when he has breathing difficulties		
45. He wanted a pet but we found an alternative (e.g. fish, turtle) that made him happy		
50. When he goes to a birthday party I make sure that there is nothing that might trigger his asthma like pets and pollen		
55. I let him go to sports-day by himself because he knows not to over-do it		

Parent's attitude about the treatment and precautions (Diabetes)	0: representative of a different scale 1: not representative 2: marginally representative 3: representative 4: very representative	If you think that the item is representative of a different scale, tick the scale you are thinking of, if any of these would be relevant in your view.
	0 1 2 3 4	P = Perception about Normality F = Feeling about illness R = Risk for non-compliance I = Impact of the disease O = Openness about illness N = Not relevant
9. I don't let him sleep-over at a friend's house because the parents would not know what to do if his blood sugar levels dropped or went too high		
14. I let him sleep-over at a friend's house because he can do the injections and the blood tests himself		
26. I tend to only go to the diabetes clinic when his diabetes is not very good		
31. I take him regularly to the diabetes clinic even if he is fine to check everything is alright		
36. I made sure that the school knows what to do when his blood sugar level drops		
56. I let him go to sports-day by himself because he knows how to control his blood sugar level when he exercises		

"Parent's perception of the child's risk for non-adherence to treatment". The concept of this scale was the same as for the "Child's Treatment Adherence" but this time assessed from the parent's perspective of the child's treatment adherence.

Examples from the PedsQL Asthma Module – Asthma Symptoms and Treatment Problems:

In the past one month, how much of a problem has your child had with getting scared while having asthma attacks

In the past one month, how much of a problem has your child had with disliking carrying his or her inhaler

In the past one month, how much of a problem has your child had with being responsible for his or her medicines

In the past one month, how much of a problem has your child had with controlling his or her asthma

In the past one month, how much of a problem has your child had with refusing to take medicines

In the past one month, how much of a problem has your child had with forgetting to take medicines

Parent's perception of the child's risk for non-adherence to treatment (Asthma)	0: representative of a different scale 1: not representative 2: marginally representative 3: representative 4: very representative	If you think that the item is representative of a different scale, tick the scale you are thinking of, if any of these would be relevant in your view.
	0 1 2 3 4	O = Openness about illness F = Feeling about illness P = Perception about Normality T = Treatment and precautions I = Impact of the disease N = Not relevant
2. He understands that to live well with asthma he has to take his medication		
7. Even though he finds some parts of the treatment hard he follows them very diligently		
13. We very rarely get into arguments because of him not wanting to take his medication or inhaler		

19. He can do the whole treatment himself but I have to push him otherwise he would not do it		
24. He very rarely forgets to take his inhalers		
29. If he is too hyperactive there is nothing I can do		
34. He knows I will check up on whether he has taken his inhalers because you cannot trust children with this responsibility		
39. I don't mind that I constantly have to be on top of him with the inhalers because otherwise he does not take them		
44. It is almost a daily routine that we have arguments about him wanting something that he cannot have because of his asthma		
49. He knows he should not be too hyperactive but he does not stop even if he is getting out of breath		
54. He insists on going outside even after I tell him that it is bad for his asthma because of the high pollens or the cold air		
66. When he gets breathing difficulties, I normally have to step in because he does not know what to do		
71. When he has signs of asthma he knows what to do		
77. He often needs to be reminded to take his inhalers especially when he is busy doing something else		
82. Someone always has to supervise him and help him taking his inhaler to check he does it properly		
87. He can use his inhaler perfectly by himself		

Parent's perception of the child's risk for non-adherence to treatment (Diabetes)	0: representative of a different scale 1: not representative 2: marginally representative 3: representative 4: very representative	If you think that the item is representative of a different scale, tick the scale you are thinking of, if any of these would be relevant in your view.
	0 1 2 3 4	O = Openness about illness F = Feeling about illness P = Perception about Normality T = Treatment and

		precautions I = Impact of the disease N = Not relevant
2. He understands that to live well with diabetes he has to take his medication		
8. Even though he finds some parts of the treatment hard he follows them very diligently		
13. We very rarely get into arguments because of him not wanting to take his medication		
19. He can do the whole treatment himself but I have to push him otherwise he would not do it		
25. He very rarely forgets to do his injections		
30. If he drinks too many sweet drinks there is nothing I can do about		
45. We very rarely have arguments about him wanting to eat too many sweets		
50. He sometimes tells me that he has done the blood sugar test but when I check the meter he has not		
55. When I find out that he has sweets hidden in his room and is eating them, I loose my temper		
65. When he does not feel well it does not cross his mind to do a blood sugar level test		
70. When he has symptoms of diabetes (blood sugar level goes high or low) he knows what to do		
75. He often needs to be reminded to take his injections especially when he is busy doing something else		
85. He is supposed to do the blood sugar levels test twice a day but I make him do it three times because I cannot trust him with eating sweets		
92. I often have to force him to eat something before he goes to sleep that he does not go low during the night or in the morning		

Appendix 6.1 Child Diabetes Interview

My name is Selin and I came to this hospital, because I would like to know more about children who have diabetes and what they think about it.
I already spoke to a few children and diabetes here, and they all told me different things.
I would like to know from you what it is like having diabetes. Is it okay if I ask you a few questions and you just tell me what you think, and as you know there are no right or wrong answers? Do you mind if I tape record what we are saying so I can listen to it again if I want to? Let's have a go now, but if you want to stop you just let me know.

INTERVIEW WITH THE CHILD

Do you remember when you had diabetes first, what were you thinking about it then?
What do you think now?

CHILD'S FEELINGS:
Okay, we all know that it is not nice to have diabetes, but are there any nice things about it?
What do you not like about it?
Do you think that a child with diabetes is different from others?
Do you mind when people ask or talk to you about your diabetes?
Do you rather keep it for yourself?

FAMILY:
Is there anything you are not allowed at all, can you think about something?
Is your brother/sister allowed to do it?
Do you think that sometimes your parents are too careful with what you want to do?
Do you think that your parents treat you differently from your brother or sister because you have diabetes?

SCHOOL:
What about school, how are you doing are you doing?
What about friends?
Do you have any special friends?
What sort of things do you do with your friends?
What about when you go to a birthday party, or sleep over at a friend, or there is sports-day in school, is there anything you have to remember?

TREATMENT:
Can you tell me what you have to do everyday? How much medicine you have to take and which little tests you have to do?
Is there anything you have to do everyday?
Did you do it yesterday, the day before yesterday, three days ago?
What does the diabetes do to you?
Can you think about something that you feel and get when you have signs of diabetes?
Do you know what to do then?
Can you do it by yourself or do you need help?
Is there anything you have to do that you do not like at all?
Do you still do it?

Appendix 6.2 Parent Diabetes Interview

I am here with Ms/Mr ... and s/he gave me permission to record the interview.
(name of child) was diagnosed with diabetes when s/he was (age).

INTERVIEW WITH THE PARENT

When (name of child) was diagnosed with diabetes what was your reaction?
How did you explain it to (name of child)?

CHILD'S FEELINGS:
How does s/he generally feel about having diabetes?
Is s/he for example upset when people ask about or remind him/her of it because s/he rather keeps it for himself/herself?
Does s/he think you treat him/her differently because s/he has diabetes?
Does s/he get upset about having diabetes, e.g. does s/he think it prevents him/her from doing things?

FAMILY:
Let us now look at how s/he gets handled in the family. Did any family routines change because of him/her being diagnosed with diabetes?
Obviously, s/he has to have meals and snacks on fixed times, has this become a routine for the other sibling(s) as well?
What about sweets and sweet drinks for the other sibling(s)? Do you buy and give them sweets or have you perhaps decided not to have anything in the house as (name of child) is not allowed to have them?
Do you think that sometimes you are being too careful with (name of child)?
Does s/he think you are?

SCHOOL:
What about school, any worries, concerns, successes there?
How is s/he doing in school? Are you happy with his/her progress?
Is s/he happy with how s/he is doing?
Is there anything you have to inform the school about or the other children have to know about?
Are there any problems with friends, how does s/he perceive his/her friendships?
What happens for example when s/he goes to a birthday party, or sleeps over somewhere, or there is sports-day in school. Do you have to take any precautions?

TREATMENT:
Let us know talk about (name of child)'s treatment. Which medical procedure and tests does s/he have to undergo and which medication does s/he have to take?
What about his/her feelings concerning hospital appointments, taking medication, medical procedures, side-effects, is there anything s/he is worried, scared, or upset about?
How much can s/he do himself/herself and take responsibility?
How much does s/he understand about diabetes and the treatment?
Does s/he know what to do when s/he has symptoms?
Are there bits with the treatment s/he finds hard to follow? How do you handle that?

Appendix 7.1 Questionnaire for Parents of Children with Diabetes - Girl Version

PARENT DIABETES QUESTIONNAIRE

Name of child:

Age: Date of birth:

Sibling(s): gender: age:

gender: age:

Type of medication:

How are the HBA1C levels:

Number of hospital admissions because of diabetes in the last 2 years:

Other diseases:

Father's occupation:

Mother's occupation:

Mother's schooling (please tick appropriate box)

GCSE or lower ☐ A-Levels ☐ Higher National Diploma ☐

Bachelor Degree ☐ Master's Degree or higher ☐

Please fill in the questionnaire by choosing a response that says how much you agree or disagree with each of the following statements. Please choose one of the five numbers that applies to you the most. Remember that there are no right or wrong answers. Just say what is true for you. All your responses will be kept private. You have the right to withdraw at any time.

Entirely Agree	**Agree**	**Sometimes Yes Sometimes No**	**Disagree**	**Strongly Disagree**
1	**2**	**3**	**4**	**5**

1) She very rarely thinks that I am too cautious with her

2) She understands that to live well with diabetes she has to take her medication

3) I informed the school about her diabetes and the snack times

Entirely Agree	**Agree**	**Sometimes Yes Sometimes No**	**Disagree**	**Strongly Disagree**
1	**2**	**3**	**4**	**5**

4) She gets upset on sports-day because due to her diabetes she cannot participate as much as other children

5) I only buy sugar free drinks for the house so she can have the same drinks as everyone else

6) I expect from my child that she conforms to my decisions out of respect for my authority

7) She thinks I treat her exactly the same as her sibling(s)

8) Even though she finds some parts of the treatment hard she follows them very diligently

9) I don't let her sleep-over at a friend's house because the parents would not know what to do if her blood sugar levels dropped or went too high

10) She finds sport difficult because she has to keep her blood sugar level right

11) I buy sweets for the house because otherwise it is not fair on the sibling(s)

12) If I stop her from going somewhere she always complains that I have a long list of do and don'ts

13) We very rarely get into arguments because of her not wanting to take her medication

14) I let her sleep-over at a friend's house because she can do the injections and the blood tests herself

15) She does not think that her diabetes prevents her from doing anything

16) It is a real problem when I buy treats for the others in the family and she cannot have any

17) I let my child feel free to discuss my decisions if she feels that they are unreasonable

18) Because she cannot always eat what other children are eating makes her realize that I treat her differently from the way other children are treated

19) She can do the whole treatment herself but I have to push her otherwise she would not do it

Entirely Agree	**Agree**	**Sometimes Yes Sometimes No**	**Disagree**	**Strongly Disagree**
1	**2**	**3**	**4**	**5**

20) I don't find it necessary to inform the school about what to do when she has problems with her blood sugar level

21) She does not get upset when she has to come to the clinic and is missing out on something

22) When I buy treats for the others in the family I buy her something special so she does not feel she had no special treats

23) I try and encourage verbal give-and-take whenever I feel that the treatment regime and restrictions I make might be unreasonable

24) She thinks that I am too strict because I constantly remind her of her injections and blood tests

25) She very rarely forgets to do her injections

26) I tend to only go to the diabetes clinic when her diabetes is not very good

27) She is sad that she won't be able to do certain things later on in life because of her diabetes

28) Since she was diagnosed with diabetes I reduced my time at work

29) She has never mentioned that I am too careful with her

30) If she drinks too many sweet drinks there is nothing I can do about

31) I take her regularly to the diabetes clinic even if she is fine to check everything is alright

32) She does not get bothered by the fact that she cannot eat anything she wants like healthy children can

33) Her diabetes is not a big deal in the family

34) Some parents of children with diabetes are too cautious but I don't think it is necessary

Entirely Agree	**Agree**	**Sometimes Yes Sometimes No**	**Disagree**	**Strongly Disagree**
1	2	3	4	5

35) She knows I will check up on whether she has done the blood sugar test because you cannot trust children with this responsibility

36) I made sure that the school knows what to do when her blood sugar level drops

37) She hates having diabetes because she just wants to be like a healthy child

38) We all eat low sugar food that she can have so she does not feel left out at the table

39) I am not cautious with her because she has to learn to treat her diabetes herself

40) I don't mind that I constantly have to be on top of her with the blood sugar level tests because otherwise she does not do them

41) She wants to eat sweets so desperately that we always get into arguments about it because she cannot have them or just very little

42) She is getting used to the fact that she has got diabetes and more and more accepts it as part of her life

43) Her siblings were jealous about her having snacks late in the evening therefore I also give them some

44) I am very careful with her because of the fact that she has got diabetes

45) We very rarely have arguments about her wanting to eat too many sweets

46) When she wants to eat something sweet and cannot have it, I try to find an alternative that makes her happy like chocolate for diabetics

47) She worries about her diabetes and keeps on saying that she does not want to be diabetic

48) If her sibling(s) are having sweets and she cannot, they eat them outside

49) I treat her the same as her sibling(s) except that I make sure that she has her blood kit when she goes somewhere

Entirely Agree	**Agree**	**Sometimes Yes Sometimes No**	**Disagree**	**Strongly Disagree**
1	**2**	**3**	**4**	**5**

50) She sometimes tells me that she has done the blood sugar test but when I check the meter she has not

51) When she goes to a birthday party she has to have had enough insulin to bring her sugar level down as she will eat some sweets there

52) She enjoys the visits to the hospital because it makes her feel special

53) I wish her siblings would not eat their sweets in front of her but they do

54) I am so vigilant with her it is as if I have wrapped her in lots of cotton wool

55) When I find out that she has sweets hidden in her room and is eating them, I loose my temper

56) I let her go to sports-day by herself because she knows how to control her blood sugar level when she exercises

57) She gets very angry and frustrated when her diabetes restricts her from doing something

58) She has got a lot of friends because she gets on really well with other children

59) I consciously try not to treat her differently but I cannot help it

60) She is always asking what diabetes is and what the treatment is for

61) She keeps it for herself that she has got diabetes and does not want me to tell anyone

62) She is not embarrassed of using her blood glucose meter or injections in public

63) She feels that because of her diabetes she is the odd one out amongst her friends

64) As children with diabetes get bigger and stronger it is possible to relax completely

65) When she does not feel well it does not cross her mind to do a blood sugar level test

Entirely Agree	**Agree**	**Sometimes Yes Sometimes No**	**Disagree**	**Strongly Disagree**
1	**2**	**3**	**4**	**5**

66) She tells all her friends that she has got diabetes that they can help her in case she goes low

67) When I tell her not to eat something and she still eats it, I punish her

68) She sometimes gets picked on by other children because of her diabetes

69) I think all children should be treated the same regardless if they have diabetes or not

70) When she has symptoms of diabetes (blood sugar level goes high or low) she knows what to do

71) She gets upset when people ask about or remind her of her diabetes

72) When she wants to eat something that she should not, I discuss with her the reasons behind it

73) When she does not feel well, her friends look after her

74) Every time I was not cautious enough, it ended up in a crisis

75) She often needs to be reminded to take her injections especially when she is busy doing something else

76) She is a bit embarrassed to talk about her diabetes in front of her friends

77) I know what is good for her so when I tell her to do something that is part of her treatment, I expect her to do it immediately without asking any questions

78) I let her sleep-over at a friend's house because it is good for her friendships

79) I am not too careful with her sometimes I even forget that she has got diabetes

80) It does not bother me that I constantly have to watch how many sweet drinks she is having because she does not know what little means

81) She is very open about her diabetes and talking about it is not a big deal for her

Entirely Agree	**Agree**	**Sometimes Yes Sometimes No**	**Disagree**	**Strongly Disagree**
1	**2**	**3**	**4**	**5**

82) I get very upset if she tries to disagree with me and starts a whole discussion (e.g. why she cannot eat something)

83) I let her go to friends' houses to spend the day there or to go on a day-trip with them and their families

84) Her diabetes is not under control that is why I must be very alert all the time

85) She is supposed to do the blood sugar levels test twice a day but I make her do it three times because I cannot trust her with eating sweets

86) If I make a decision, I am willing to discuss it with her and admit if I did a mistake

87) Because of her diabetes she is behind in school, which makes her upset

88) I really cannot treat her like a healthy child

89) She prefers to do the blood sugar level test herself

90) I try not to have too high expectations of her, I just encourage that she does her best

91) Her friends eat sweets in front of her and that makes her very upset

92) I often have to force her to eat something before she goes to sleep that she does not go low during the night or in the morning

93) All problems would be solved between mother and child if parents were strict with their children when they don't do what they are supposed to do

94) She is proud of how well she is doing at school

95) She insists that I have to administer the injections

Appendix 7.2 Questionnaire for Parents of Children with Diabetes - Boy Version

PARENT DIABETES QUESTIONNAIRE

Name of child:

Age: Date of birth:

Sibling(s): gender: age:

gender: age:

Type of medication:

How are the HBA1C levels:

Number of hospital admissions because of diabetes in the last 2 years:

Other diseases:

Father's occupation:

Mother's occupation:

Mother's schooling (please tick appropriate box)

GCSE or lower ☐ A-Levels ☐ Higher National Diploma ☐

Bachelor Degree ☐ Master's Degree or higher ☐

Please fill in the questionnaire by selecting a response that says how much you agree or disagree with each of the following statements. Please choose one of the five numbers that applies to you the most. Remember that there are no right or wrong answers. Just say what is true for you. All your responses will be kept private. You have the right to withdraw at any time.

Entirely Agree	**Agree**	**Sometimes Yes Sometimes No**	**Disagree**	**Strongly Disagree**
1	2	3	4	5

1) He very rarely thinks that I am too cautious with him

2) He understands that to live well with diabetes he has to take his medication

3) I informed the school about his diabetes and the snack times

Entirely Agree	**Agree**	**Sometimes Yes Sometimes No**	**Disagree**	**Strongly Disagree**
1	**2**	**3**	**4**	**5**

4) He gets upset on sports-day because due to his diabetes he cannot participate as much as other children

5) I only buy sugar free drinks for the house so he can have the same drinks as everyone else

6) I expect from my child that he conforms to my decisions out of respect for my authority

7) He thinks I treat him exactly the same as his sibling(s)

8) Even though he finds some parts of the treatment hard he follows them very diligently

9) I don't let him sleep-over at a friend's house because the parents would not know what to do if his blood sugar levels dropped or went too high

10) He finds sport difficult because he has to keep his blood sugar level right

11) I buy sweets for the house because otherwise it is not fair on the sibling(s)

12) If I stop him from going somewhere he always complains that I have a long list of do and don'ts

13) We very rarely get into arguments because of him not wanting to take his medication

14) I let him sleep-over at a friend's house because he can do the injections and the blood tests himself

15) He does not think that his diabetes prevents him from doing anything

16) It is a real problem when I buy treats for the others in the family and he cannot have any

17) I let my child feel free to discuss my decisions if he feels that they are unreasonable

18) Because he cannot always eat what other children are eating makes him realize that I treat him differently from the way other children are treated

19) He can do the whole treatment himself but I have to push him otherwise he would not do it

Entirely Agree	Agree	Sometimes Yes Sometimes No	Disagree	Strongly Disagree
1	2	3	4	5

20) I don't find it necessary to inform the school about what to do when he has problems with his blood sugar level

21) He does not get upset when he has to come to the clinic and is missing out on something

22) When I buy treats for the others in the family I buy him something special so he does not feel he had no special treats

23) I try and encourage verbal give-and-take whenever I feel that the treatment regime and restrictions I make might be unreasonable

24) He thinks that I am too strict because I constantly remind him of his injections and blood tests

25) He very rarely forgets to do his injections

26) I tend to only go to the diabetes clinic when his diabetes is not very good

27) He is sad that he won't be able to do certain things later on in life because of his diabetes

28) Since he was diagnosed with diabetes I reduced my time at work

29) He has never mentioned that I am too careful with him

30) If he drinks too many sweet drinks there is nothing I can do about

31) I take him regularly to the diabetes clinic even if he is fine to check everything is alright

32) He does not get bothered by the fact that he cannot eat anything he wants like healthy children can

33) His diabetes is not a big deal in the family

34) Some parents of children with diabetes are too cautious but I don't think it is necessary

Entirely Agree	Agree	Sometimes Yes Sometimes No	Disagree	Strongly Disagree
1	2	3	4	5

35) He knows I will check up on whether he has done the blood sugar test because you cannot trust children with this responsibility

36) I made sure that the school knows what to do when his blood sugar level drops

37) He hates having diabetes because he just wants to be like a healthy child

38) We all eat low sugar food that he can have so he does not feel left out at the table

39) I am not cautious with him because he has to learn to treat his diabetes himself

40) I don't mind that I constantly have to be on top of him with the blood sugar level tests because otherwise he does not do them

41) He wants to eat sweets so desperately that we always get into arguments about it because he cannot have them or just very little

42) He is getting used to the fact that he has got diabetes and more and more accepts it as part of his life

43) His siblings were jealous about him having snacks late in the evening therefore I also give them some

44) I am very careful with him because of the fact that he has got diabetes

45) We very rarely have arguments about him wanting to eat too many sweets

46) When he wants to eat something sweet and cannot have it, I try to find an alternative that makes him happy like chocolate for diabetics

47) He worries about his diabetes and keeps on saying that he does not want to be diabetic

48) If his sibling(s) are having sweets and he cannot, they eat them outside

49) I treat him the same as his sibling(s) except that I make sure that he has his blood kit when he goes somewhere

Entirely Agree	**Agree**	**Sometimes Yes Sometimes No**	**Disagree**	**Strongly Disagree**
1	**2**	**3**	**4**	**5**

50) He sometimes tells me that he has done the blood sugar test but when I check the meter he has not

51) When he goes to a birthday party he has to have had enough insulin to bring his sugar level down as he will eat some sweets there

52) He enjoys the visits to the hospital because it makes him feel special

53) I wish his siblings would not eat their sweets in front of him but they do

54) I am so vigilant with him it is as if I have wrapped him in lots of cotton wool

55) When I find out that he has sweets hidden in his room and is eating them, I loose my temper

56) I let him go to sports-day by himself because he knows how to control his blood sugar level when he exercises

57) He gets very angry and frustrated when his diabetes restricts him from doing something

58) He has got a lot of friends because he gets on really well with other children

59) I consciously try not to treat him differently but I cannot help it

60) He is always asking what diabetes is and what the treatment is for

61) He keeps it for himself that he has got diabetes and does not want me to tell anyone

62) He is not embarrassed of using his blood glucose meter or injections in public

63) He feels that because of his diabetes he is the odd one out amongst his friends

64) As children with diabetes get bigger and stronger it is possible to relax completely

65) When he does not feel well it does not cross his mind to do a blood sugar level test

Entirely Agree	**Agree**	**Sometimes Yes Sometimes No**	**Disagree**	**Strongly Disagree**
1	**2**	**3**	**4**	**5**

66) He tells all his friends that he has got diabetes that they can help him in case he goes low

67) When I tell him not to eat something and he still eats it, I punish him

68) He sometimes gets picked on by other children because of his diabetes

69) I think all children should be treated the same regardless if they have diabetes or not

70) When he has symptoms of diabetes (blood sugar level goes high or low) he knows what to do

71) He gets upset when people ask about or remind him of his diabetes

72) When he wants to eat something that he should not, I discuss with him the reasons behind it

73) When he does not feel well, his friends look after him

74) Every time I was not cautious enough, it ended up in a crisis

75) He often needs to be reminded to take his injections especially when he is busy doing something else

76) He is a bit embarrassed to talk about his diabetes in front of his friends

77) I know what is good for him so when I tell him to do something that is part of his treatment, I expect him to do it immediately without asking any questions

78) I let him sleep-over at a friend's house because it is good for his friendships

79) I am not too careful with him sometimes I even forget that he has got diabetes

80) It does not bother me that I constantly have to watch how many sweet drinks he is having because he does not know what little means

81) He is very open about his diabetes and talking about it is not a big deal for him

Entirely Agree	**Agree**	**Sometimes Yes Sometimes No**	**Disagree**	**Strongly Disagree**
1	**2**	**3**	**4**	**5**

82) I get very upset if he tries to disagree with me and starts a whole discussion (e.g. why he cannot eat something)

83) I let him go to friends' houses to spend the day there or to go on a day-trip with them and their families

84) His diabetes is not under control that is why I must be very alert all the time

85) He is supposed to do the blood sugar levels test twice a day but I make him do it three times because I cannot trust him with eating sweets

86) If I make a decision, I am willing to discuss it with him and admit if I did a mistake

87) Because of his diabetes he is behind in school, which makes him upset

88) I really cannot treat him like a healthy child

89) He prefers to do the blood sugar level test himself

90) I try not to have too high expectations of him, I just encourage that he does his best

91) His friends eat sweets in front of him and that makes him very upset

92) I often have to force him to eat something before he goes to sleep that he does not go low during the night or in the morning

93) All problems would be solved between mother and child if parents were strict with their children when they don't do what they are supposed to do

94) He is proud of how well he is doing at school

95) He insists that I have to administer the injections

Appendix 7.3 Child Diabetes Questionnaire

CHILD DIABETES QUESTIONNAIRE

Name of child:
Age:

Please fill in the questionnaire by choosing a response that says how much you agree or disagree with each of the following statements. Circle one of the five numbers that applies to you the most. Remember that there are no right or wrong answers. Just say what is true for you. All your responses will be kept private. You have the right to withdraw at any time.

Entirely Agree	Agree	Sometimes yes some times no	Disagree	Strongly Disagree
1	2	3	4	5

1) I wish I could just be so very good that my diabetes would go away

2) A child with diabetes is different from a child who hasn't diabetes because having an illness makes you different

3) I don't mind that whenever I eat sweets my mum tells me to stop because she gets too worried

4) It makes me really upset that on sports day I am not allowed to try as hard as I could so I can win

5) My friends did not know anything about diabetes before they met me

6) When I go to a friend's birthday party without my mum I really eat a lot of sweets

7) It makes me really afraid when my blood sugar levels are high or low and I do what the doctor told me and the symptoms don't go away

8) It does not bother me when other children pick on me because of my diabetes

9) It does not bother me that I have to take injections every day

10) I don't think that there is a difference between a child with diabetes and a child who has not diabetes

11) My mum lets me get on with what I want to do

12) I don't mind that because of my diabetes I am not allowed to sleep over at a friend's house

13) I showed my friends my injections and glucose meter and told them how it works

14) I always stop myself from eating sweets because it is not good for me

15) I get really upset when my blood sugar levels drop or rise in the middle of the night and I cannot sleep

16) I never worry about my diabetes

17) I like that I get days off school or can leave school earlier because of my diabetes

18) Children with diabetes and without are the same because diabetes does not change your life that much

19) My mum rather has me at home always than that I go somewhere

20) It is hard for me when I go to a birthday party because I have to stop myself from eating sweets when my friends eat them

21) I don't like eating my snacks in school when all the other children don't eat

22) I sometimes tell my mum that I have checked my blood sugar even though I have not

23) When my blood sugar levels are really low I feel helpless because I need someone to help me take my glucose tablet or something sweet

24) It is better to have diabetes that I can control than some other illness that you cannot control

25) It really upsets me when I think that my diabetes could make it hard for me to do certain things when I grow up

26) Children with diabetes have to watch what they are eating and drinking and other children don't

27) My mum is always too cautious with me e.g. when I want to do sports or go on a school trip than she is with my brother or sister

28) It does not bother me when I sleep over at a friend's place that I have to check that they have the right food and drinks for me

29) I don't mind when people ask me about my diabetes

30) I don't know how often I have to measure my blood sugar levels

31) When I am unwell I know if I am high or low in sugar levels and what to do

32) I hate the fact that I have diabetes

33) It makes me very sad that I cannot eat sweets or can only have very little

34) A child with diabetes is the same as a child without diabetes except that a child with diabetes needs injections

35) I often think that it is not fair when I am not allowed to do something just because I have diabetes

36) It is easy for me to always remember when I go somewhere to take my insulin and glucose meter with me

37) I'd rather keep it for myself that I have diabetes

38) I do as many blood tests a day as the nurse or doctor has told me

39) When I have signs of being low or high I don't panic

40) There is nothing nice about having diabetes

41) My mum treats me exactly the same as other mums treat their children except that I cannot eat sweets

42) I wish someone would help me to take my medicine to avoid that my blood sugar level goes too high or drops too low

43) I never need reminding when to take my injections

44) Having diabetes is not too bad if you have it controlled

45) I always carry my blood kit with me where ever I go

46) Even if my mum would not check on me I would do the blood sugar level test

47) When I eat sweets I really worry what will happen to me

48) It is hard for me to keep my blood sugar levels steady when I exercise (topped up with sugar)

49) Because I am not allowed sweets I sometimes hide them

50) I wish I could eat sweets like other children

Appendix 8.1 Table of Inter-Correlations of Factor Analysis of Parent Data

Factor Analysis

Communalities

	Initial	Extraction
expert parent new normality	1.000	.781
expert parent new effects	1.000	.767
expert parent new openess	1.000	.796
expert parent new impact	1.000	.707
expert parent new treatment	1.000	.782

Extraction Method: Principal Component Analysis.

Total Variance Explained

Component	Initial Eigenvalues			Extraction Sums of Squared Loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	1.598	31.961	31.961	1.598	31.961	31.961
2	1.213	24.258	56.219	1.213	24.258	56.219
3	1.022	20.432	76.651	1.022	20.432	76.651
4	.809	16.188	92.839			
5	.358	7.161	100.000			

Extraction Method: Principal Component Analysis.

Component Matrix(a)

	Component		
	1	2	3
expert parent new normality	-.317	.050	.823
expert parent new effects	.701	-.220	.476
expert parent new openess	.855	-.252	.031
expert parent new impact	.518	.621	-.229
expert parent new treatment	.075	.844	.253

Extraction Method: Principal Component Analysis.
a 3 components extracted.

Appendix 8.2 Table of Inter-Correlations of Factor Analysis of Child Data

Factor Analysis

Communalities

	Initial	Extraction
expert child new normality	1.000	.409
expert child new openess	1.000	.742
expert child new effects	1.000	.520

Extraction Method: Principal Component Analysis.

Total Variance Explained

Component	Initial Eigenvalues			Extraction Sums of Squared Loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	1.671	55.717	55.717	1.671	55.717	55.717
2	.866	28.870	84.586			
3	.462	15.414	100.000			

Extraction Method: Principal Component Analysis.

Component Matrix(a)

	Component
	1
expert child new normality	.640
expert child new openess	.861
expert child new effects	.721

Extraction Method: Principal Component Analysis.
a 1 components extracted.