INVESTIGATING THE COPING PROCESS IN CHILDREN AGED 7-14 WITH TYPE I DIABETES USING THE SELF-REGULATION MODEL:

A COMPARATIVE STUDY OF ALTERNATIVE METHODS OF MANAGEMENT AT DIAGNOSIS

JULIE M. WILLIAMS

D. CLIN. PSYCHOL.

UNIVERSITY OF EDINBURGH

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EX BIBL. UNIV. EDINBURGEN

DECLARATION

This thesis has been composed by myself and the work contained herein is my own.

Julie M. Williams
31.07.98

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DEDICATION

To the children of my family - my nieces
Alice
and Sophie
(who arrived when this thesis was in progress).

ABSTRACT

Childhood onset diabetes (Type I diabetes) is a chronic condition whose symptoms may be controlled using a careful regimen of diet and insulin therapy, which must be tailored to suit the sufferer's lifestyle. The ability of a child to cope with these aspects of diabetes management has a wide range of short-term and long-term implications. In the short-term, diabetes may disrupt everyday functioning, family relationships, social roles and psychological adjustment. Deficits in cognitive functioning, psychological adjustment and physical health may occur in the long-term if coping has been suboptimal over an ongoing period. Medical treatment must clearly aim to maximise diabetic control and to minimise such negative outcomes. In order to do this, factors involved in optimising the coping process in children must be understood.

While research has shown that managing children at home on diagnosis rather than routinely admitting them to hospital has no effect on diabetic control, little research has been carried out into the possible psychological benefits of these two approaches (Howie, 1998). This study therefore investigates the coping process and compares aspects of this process between children who were routinely admitted to hospital at diagnosis (in an Aberdeen clinic) and those who were managed at home (in a Dundee clinic).

The Self-Regulation Model (Leventhal, Nerenz & Steele, 1984) was used to guide the study. This model highlights the role of patients' illness representations, coping, appraisal of coping and emotional reactions - each of which may be viewed within a developmental framework - in the progression of chronic disease. 72 children aged 7-14 attending diabetes outpatient clinics in the Dundee and Aberdeen clinics were assessed using standardised questionnaires of illness representations, coping, state anxiety and behaviour problems. The relationship between these variables and diabetic control and the effects of age, time since diagnosis and management at diagnosis on the process and outcome of coping were also assessed. The results are discussed in terms of their implications for management at diagnosis and for cognitive and behavioural methods of enhancing coping in children of different ages.

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CHAPTER 1:
TYPE I DIABETES IN CHILDREN

1.1 Introduction.

The introduction to this thesis is presented in three parts. This chapter outlines Type I diabetes in children and some important issues concerning its management, highlighting in particular the current issues regarding the most appropriate model of management at diagnosis. The second chapter discusses previous psychological research into diabetes and presents the framework and the particular model which have been selected to guide the current research: the Self-Regulation Model of coping with chronic disease. Chapter 3 ties together the previous two chapters and presents particular aims and hypotheses derived from previous research within the framework of the model.

1.2 Diabetes and its management.

Definition and pathophysiology.

Diabetes is a chronic condition characterised by a deficiency in the production and/or utilisation of insulin in the pancreas (Kaufman, 1997). Since insulin is responsible for the breakdown of glucose in the body, this leads to abnormally high blood sugar levels (known as hyperglycaemia) and eventually to the build-up of ketones in the body which may, in turn, result in the life-threatening state known as Diabetic Ketoacidosis (DKA).

Initial symptoms.

When hyperglycaemic, individuals need to pass urine frequently as the body attempts to expel the excess sugar and ketones and will thus become dehydrated and excessively thirsty. Often the first sign in children is bedwetting. Because the individual is unable to utilise sugar, weight loss may also occur. Approximately two thirds of cases are identified at this stage (Kaufman, 1997), but those who may not may go on to develop DKA, which carries additional symptoms of shortness of breath, vomiting and abdominal pain and, eventually, coma and death.

Types of diabetes.

A distinction may be made between insulin-dependent diabetes (Type I diabetes) and non insulin-dependent diabetes (Type II diabetes).

Type I diabetes is believed to be autoimmune in nature and a genetic predisposition has been identified, although the concordance rate among identical twins is only approximately 33% (Kaufman, 1997; Shillitoe, 1995). Approximately 95% of cases have their onset in childhood and adolescence and theories about triggering factors include viruses, diet and environmental toxins (Kaufman, 1997). Beardsley and Goldstein (1993) reviewed the literature and found that there was no evidence that stress or other psychological factors directly affected the onset of Type I diabetes. Approximately 25% of individuals with diabetes have Type I diabetes (Jarrett, 1986), which requires insulin injections since no natural insulin is produced at all. This thesis is concerned only with this subset of diabetes sufferers.

The other 75% of individuals with diabetes have Type II diabetes, which is genetically transmitted, with the concordance rate for identical twins nearer to 100% (Shillitoe, 1995), although obesity is the greatest risk factor for its expression. Some non-caucasians are at increased risk due to genetic factors (Kaufman, 1997) and although this form of diabetes used to be known as 'late onset diabetes', it is now acknowledged to occur in adolescents if they are sufficiently overweight. In contrast to Type I diabetes, some insulin is produced and blood sugar levels can generally be regulated through dietary control only.

Epidemiology of Type I diabetes.

Type I diabetes is the third most common chronic illness in young people (Metcalfe & Baum, 1991) and the incidence rate is rising in Scotland: between 1968 and 1976 there was reported to be an 80% increase in the annual incidence rate in Scottish children to an average annual incidence rate of 13.8 per 100,000 in children aged 0-18 years (Patterson *et al.*, 1983) and this figure is in line with the rest of the British Isles (Metcalfe & Baum, 1991). Between 1984 and 1993, the rate of increase had reduced to approximately 2% per year (Rangasami *et al.,* 1997), although the average annual incidence for Scotland remained high, at 23.9 per 100,000 children. In 1996 the total number of children under 15 years with Type I diabetes in Scotland was 1444 (Tayside Children's diabetes service, 1997). 7% of these children were aged 0-4 years, 33% aged 5-9 years and 59% aged 10-14 years.

For some time, North East Scotland has had one of the highest rates of Type I diabetes in the world (Patterson *et al.*, 1983; Tayside Children's Diabetes Service, 1997). Local figures show that between 1987 and 1997 the number of families in Tayside with diabetic children and adolescents increased from 60 to 212. On average 30 new cases are currently diagnosed each year, 25% of these being in children below 5 years of age.

Seasonal differences incidence are found for those over 5 years old (Patterson *et al.*, 1983; Tayside Children's Diabetes Service, 1997), with more diagnoses being made during the winter months than in the summer. Various hypotheses concerning these differences include the higher prevalence of viruses during these months and the decline in exercise levels in young people over the winter.

Treatment of Type I diabetes.

Initial DKA requires rehydration, correction of electrolyte disturbances and insulin infusions. Longer-term, blood sugar levels may be regulated by insulin injections, which must be carefully adjusted according to the sufferer's weight, diet, physical health and exercise levels. Self-management is thus a complicated balance of many lifestyle factors.

Following initial insulin treatment, the body may continue to produce small amounts of natural insulin and since these are naturally tailored to the body's requirements, it is generally easier to maintain good diabetic control using insulin injections during this period. However, this is known as the 'honeymoon period' as it generally ends approximately a year after diagnosis, after which naturally occurring insulin is no longer present, increased insulin doses are required and diabetic control is more difficult to maintain.

Assessing blood sugar levels and diabetic control.

Current blood sugar levels may be assessed by a simple finger prick blood test which patients are taught to do themselves at home using a small computer monitor to analyse the blood. Insulin, exercise and food intake may then be adjusted accordingly.

The mean level of blood sugar over the life of a red blood cell (approximately three months (indicated by the amount of glycosylated haemoglobin, or HbA1c) can be determined from laboratory analysis of a larger blood sample. HbA1c is used routinely in diabetes clinics as a measure of diabetic control, with levels of 4-8 indicating good control, levels above this indicating that blood sugar levels are generally too high (with a risk of hyperglycaemia and DKA) and levels below this indicating that blood sugar levels are generally too low (with a danger of hypoglycaemic episodes). Once an individual has commenced insulin treatment, the main danger is hypoglycaemia, which may occur when insulin is taken without enough food, or when too much exercise it taken without enough food. This is a particular danger when patients try to keep their blood sugar levels low by controlling their diet strictly or exercising a lot.

Consequences of poor diabetic control.

Elevated blood sugar levels on a long-term basis has now been clearly shown to be associated with later microvascular complications including damage to the eyes, kidneys, nerves, heart and blood vessels (Brink, 1997; Kaufman, 1997). Over-treatment of hyperglycaemia, on the other hand, can result in hypoglycaemia, which may result in short-term cognitive, behavioural and mood disturbances (Donaldson, 1996) and at extreme levels can lead to seizures, loss of consciousness and even death (Kaufman, 1997). Since recent evidence has shown that poor diabetic control even in the early years of diagnosis contributes to these effects, it is important that good diabetic control is encouraged in children with diabetes from the outset.

Responsibility for diabetic control.

Very young children with diabetes are cared for by their parents, who administer injections and oversee diet, and they are also generally unaware of hypoglycaemic symptoms (Brink, 1997) but with increasing cognitive abilities they tend to take over more of their own care and many are administering their own injections by the time they are 8-11 years old. However, parental influence continues to be an important factor until around adolescence, when taking responsibility for diabetes care becomes and additional task of maturation. Completely independent management of diabetes before the age of 12 has been found to be associated with poorer diabetic control (Fonagy *et al*., 1987; Skinner, 1997). Even when independent management is left until adolescence, there are particular problems of poor adherence, perhaps due to a general increase in risk taking, experimenting with diet, drugs and alcohol, changing routines, changes in body image, peer pressure and emotional problems (Brink, 1997). Physical disabilities and learning disabilities may change the relative responsibilities of children and their guardians in diabetes care at a given age.

1.3 The issue of management at diagnosis.

Children newly diagnosed with diabetes have traditionally been managed initially on an inpatient basis in order to stabilise their blood sugar levels under the close supervision of medical staff. Simell *et al.* (1995) state that this approach may have the following benefits:

1. Maximum support for the child and the family.
2. Adjustment to diabetes without the stressful responsibilities of practical care.
3. An opportunity to work through the initial crisis of diagnosis before education is begun.

However in recent years shorter admission periods have been employed in some hospitals and at times patient information and insulin treatment have begun to be given purely on an outpatient basis. The advantages of this method of management are believed to be:

1. Minimal disruption to the child's life.
2. Immediate commencement of education.
3. Diversion away from the 'sick role'.
4. An increased sense of control of the diabetes at an early stage.
5. Learning about diabetes in the setting in which it will be managed.

(Gearhart & Forbes, 1995; Walker, 1953).

Such a model of management requires a high level of resources in order that regular contact can be maintained with children and their families (Charron-

Prochownick *et al.*, 1997; Gearhart & Forbes, 1995). For example, 24-hour access to information and advice is necessary under such a model, in order to reduce the risk of hypoglycaemia and other effects of poor diabetic control. In addition, inpatient management remains the model of choice for some individuals, e.g. for medical reasons such as vomiting, dehydration, diabetic ketoacidosis, coma and additional infections or conditions and for social reasons such as impoverished or unstable home environments (Gearhart & Forbes, 1995; Kostraba *et al.*, 1992).

Although the first documented report of an outpatient model of management for children newly diagnosed with diabetes in the United Kingdom is described in some detail by Walker (1953) in Leicestershire, inpatient management remains the dominant model: in 1988, 87% of paediatricians still routinely admitted children to hospital on diagnosis and over 80% of children were stabilised on an inpatient basis (British Paediatric Association Working Party, 1990). A further study found that 96% of a sample of parents surveyed in the United Kingdom reported that their children had been admitted to hospital on diagnosis of their diabetes (Lessing *et al.*, 1992). A similar situation is found in other countries, e.g. the Netherlands, where only 10% of children are managed at home on diagnosis (Hirasing *et al.*, 1996) and Finland, where admission of up to four weeks remains routine (Simell *et al.*, 1991). Outpatient management appears to be somewhat more prevalent in the United States, at around 23% in Colorado (Kostraba *et al.*, 1992). The percentage of children managed using this model had almost quadrupled between 1978 and 1988 and some centres, e.g. the Barbara Davis Centre for Childhood Diabetes, managed up to 60% of newly diagnosed children on an outpatient basis. Kostraba *et al.* also found an increasing tendency for independent physicians to manage newly diagnosed children outside the hospital setting.

Despite these figures, home-based management is seen in a positive light by approximately 50% of consultants, who stated that they would use this model if adequate community facilities were available (British Paediatric Association Working Party, 1990). A review of retrospective studies suggests that clinical outcomes such as HbA1c are not compromised by outpatient management (Howie, 1998; Swift *et al.*, 1993), and several studies have shown that outpatient management at diagnosis results in an improvement in other outcome markers such as subsequent hospital admissions (Bingley, Thomas & Gale, 1990; Charron-Prochownick *et al.*, 1997; Lee, 1992; McNally *et al.*, 1991; Paton, Andrew & Latham, 1991; Swift *et al.*, 1993). However, Hirasing *et al.* (1996) have shown that the total number of admissions of children with diabetes in the Netherlands between 1980 and 1991 decreased despite an increase in the number of new diagnoses and a constant policy of admitting all children at diagnosis. These figures suggest that readmissions may have reduced in recent regardless of method of management of diagnosis, perhaps due to general improvements in medical care and education. If management at diagnosis does result in a reduction in subsequent admissions, however, the reasons for this are unclear but it would appear that the family's ability to cope with the condition must be altered in some way (Charron-Prochownick *et al.*, 1997.

While the psychosocial effects of a purely outpatient model of management on psychosocial factors are unstudied to date, there is some evidence that reducing the length of inpatient stay at diagnosis leads to improved psychosocial outcomes. A randomised controlled study carried out in Finland has shown that children admitted to hospital for a short period (1 week) show equally good diabetic control two years subsequently compared to those admitted for the traditional longer period of approximately 3.5 weeks (Simell *et al.*, 1991). The authors hypothesised that the level and type of support given to children and their families around the time of diagnosis is an important factor in determining non-medical factors such as the family's attitudes towards diabetes and thus the subsequent success of the care of the child's diabetes. An extension to the original study supported this hypothesis by demonstrating that families whose child spent less time in hospital at diagnosis showed a tendency to become confident at coping with the diabetes more quickly and to show better psychosocial adaptation at a two year follow-up (Simell, Simell & Sintonen, 1993; Simell *et al.*, 1995). In both studies, the same amount of education and support was given although in the short-stay group a proportion of this was carried out at home following discharge. It therefore seems that reduced lengths of hospitalisation at diagnosis results in psychosocial benefits while having no detrimental effect on diabetic control and an extrapolation of this result may suggest that total outpatient management may be even more beneficial. However there is no parallel research comparing the psychological benefits of short lengths of hospital stay (i.e. generally less than one week) such as those used in Britain to a purely outpatient model of management, to date.

In Dundee, an outpatient model of management at diagnosis was introduced in 1989, whereby children attend the hospital only on an outpatient basis immediately following diagnosis, to obtain insulin supplies and self-management is then facilitated at home by regular visits from a diabetes liaison nurse. These visits are initially daily and reduce in frequency as the child and his or her family become increasingly confident in coping with the diabetes and adequate diabetic control is achieved. At the same time, regular visits to the outpatient clinic are made for review by the consultant and a 24-hour telephone service is offered. 90% of new cases are managed in this way and although it is believed to enhance patient understanding and ability to cope emotionally with the diagnosis, this has never been formally assessed in the clinic. Reasons for the admissions to hospital which have occurred to date include severe hyperglycaemia, diabetic ketoacidosis, complicating factors (e.g. unstable epilepsy) and communication problems with a family of ethnic minority. These reasons are comparable to those given by Paton, Andrew and Latham (1991). The central figure to the system is the diabetes liaison nurse, but the team also includes a dietitian and a Clinical Psychologist, as recommended by the recent large-scale Diabetes Control and Complications Trial which studied approximately 1500 children with diabetes over a period of 6.5 years (DCCT; Brink, 1997). Since 1989 there have been several diabetes liaison nurses in the clinic, the current nurse having been there since 1996.

1.4 Summary.

Type I diabetes, which is on the increase in Scotland and is particularly prevalent in the North East, is a chronic condition requiring a finely tuned balance of insulin injections, exercise and diet in order to optimise blood glucose levels. Good diabetic control from the outset is required in order to minimise long-term health problems and responsibility for this control is a developmental process for children. Traditionally management at diagnosis has been carried out on an inpatient basis and there is some evidence that minimising hospital stay results in improved coping and psychosocial adjustment within families. Although there is evidence that the short lengths of inpatient management generally used in the U.K. and outpatient management do not lead to differences in diabetic control, there is no research comparing the psychosocial effects of each method. In addition there is no research on the specific effects of management at diagnosis on the child him/herself.

Since outpatient management has been employed in Dundee since 1989, this thesis aims to investigate the psychosocial impact of this method of management on the child's ability to cope with diabetes by comparison with a group who are still routinely hospitalised at diagnosis. Chapter 2 will introduce the framework which has been selected as the theoretical basis for this investigation.

CHAPTER 2:
PSYCHOLOGICAL APPROACHES TO DIABETES

2.1 Introduction.

While Chapter 1 has highlighted some of the issues in Type I diabetes, this chapter will discuss previous research on psychological approaches to diabetes, focusing particularly on the literature concerning coping with chronic disease and introducing the Self-Regulation Model as the framework for the empirical study. A review of previous research within the Self-Regulation framework with children with chronic illness, and in particular diabetes, follows.

2.2 Previous research.

There has been increasing acknowledgement of the role of psychological factors in diabetes management and outcomes over the past 15-20 years. Indeed Davis, Hess & Hiss (1988) found that psychosocial factors predicted mortality from diabetes more accurately than many clinical and medical variables. Such factors include social functioning, effects on the family, quality of life, self-esteem, Locus of Control, emotional adjustment, adherence issues, the role of stress in diabetic control and neuropsychology - for a fuller review see Donaldson (1996) and Bennett-Johnson (1995). Early interventions focused on improving knowledge in children with diabetes (e.g. Dunn *et al.*, 1984) but more recently it has been acknowledged that knowledge alone is not predictive of outcome and research has focused on mediating factors such as problem-solving and self-esteem skills (Donaldson, 1996; Howells, 1998; La Greca & Styler, 1994).

2.3 Coping with chronic disease.

A more recent approach is to view chronic diseases such as diabetes as a source of stress for the sufferer and his/her family and to investigate various aspects of the coping process which occurs in response to that stressor. The concepts of *stress* and *coping,* originally identified and defined by Lazarus (1966) and built upon by Sarafino (1990) are central to this approach, namely:

Stress: "The condition that results when an individual perceives a discrepancy between the demands of a situation and his or her own biological, psychological or social resources." Hence the stress caused by a situation depends on the balance between (a) the individual's resources and (b) his/her perceptions of the situation, therefore a situation which causes one individual great stress may not be viewed as a stressor by another individual who perceives him/herself more equipped to cope with it.

Stressor: "The stimulus which causes stress." With respect to chronic conditions, the most common stressors are diagnosis, the condition itself, symptoms of the condition and the treatment regimen. Taylor & Aspinwall (1990) list dealing with adverse emotional reactions to the condition (e.g. depression or anxiety), managing the impact of the condition on one's social network, coping with work or leisure-related losses or limitations and managing threats to self esteem as additional stressors associated with chronic disease. Stressor are generally perceived as more stressful the more ambiguous, undesirable, unpredictable or uncontrollable they are perceived to be. Since diabetes is an often unpredictable condition with a complex, variable treatment regimen, it may be expected to be a considerable source of stress for sufferers.

Strain: "The individuals' physiological and psychological response to a stressor." This is what lay people generally refer to when they report that they 'feel stressed'.

Coping: "Any process by which the individual tries to manage the perceived discrepancy between the demands and resources they perceive in a stressful situation." Thus the term 'coping' refers to any response which the individual carries out in an attempt to reduce stress, and Lazarus and Folkman (1984) state that such responses may be cognitive or behavioural in nature. In the early coping literature coping tended to be classified as 'adaptive' or 'non-adaptive' (e.g. Weisman & Sobell, 1979) but Lazarus and Folkman (1984) state that *"No a priori assumptions are made about what is good or bad coping"*. Folkman and Lazarus (1980) instead made a distinction between coping with objective stressors ('problem-focused coping') and with the emotional response to these stressors ('emotion-focused coping'). Both forms of coping may be achieved by cognitive or behavioural means, or by some combination of the two.

2.4 The Self-Regulation Model of coping with chronic disease.

The Self-Regulation Model (Leventhal, Nerenz & Steele, 1984) is based on the above definitions, preserves the distinction between problem-focused and emotion-focused coping and is perhaps the most comprehensive and extensively researched model in the field of coping with chronic disease to date. A schematic representation of the model can be seen in Figure 2.1 (p.14).

The Self-Regulation Model views coping as an active process which involves several stages, aimed at both the individual's perceptions of the objective features of the condition and the individual's emotional reactions to that condition. The model postulates that the individual forms a cognitive model, or *illness representation* based on his/her perceptions of a given medical condition, then uses this model to plan the appropriate coping responses, the results of which are then evaluated and the process amended and repeated to take into account the new state of affairs. Simultaneously, the individual becomes aware of his/her emotional reactions to the condition and plans and executes coping strategies to deal with this reaction, then, as in the objective case, evaluates the impact of this coping and re-assesses the situation.

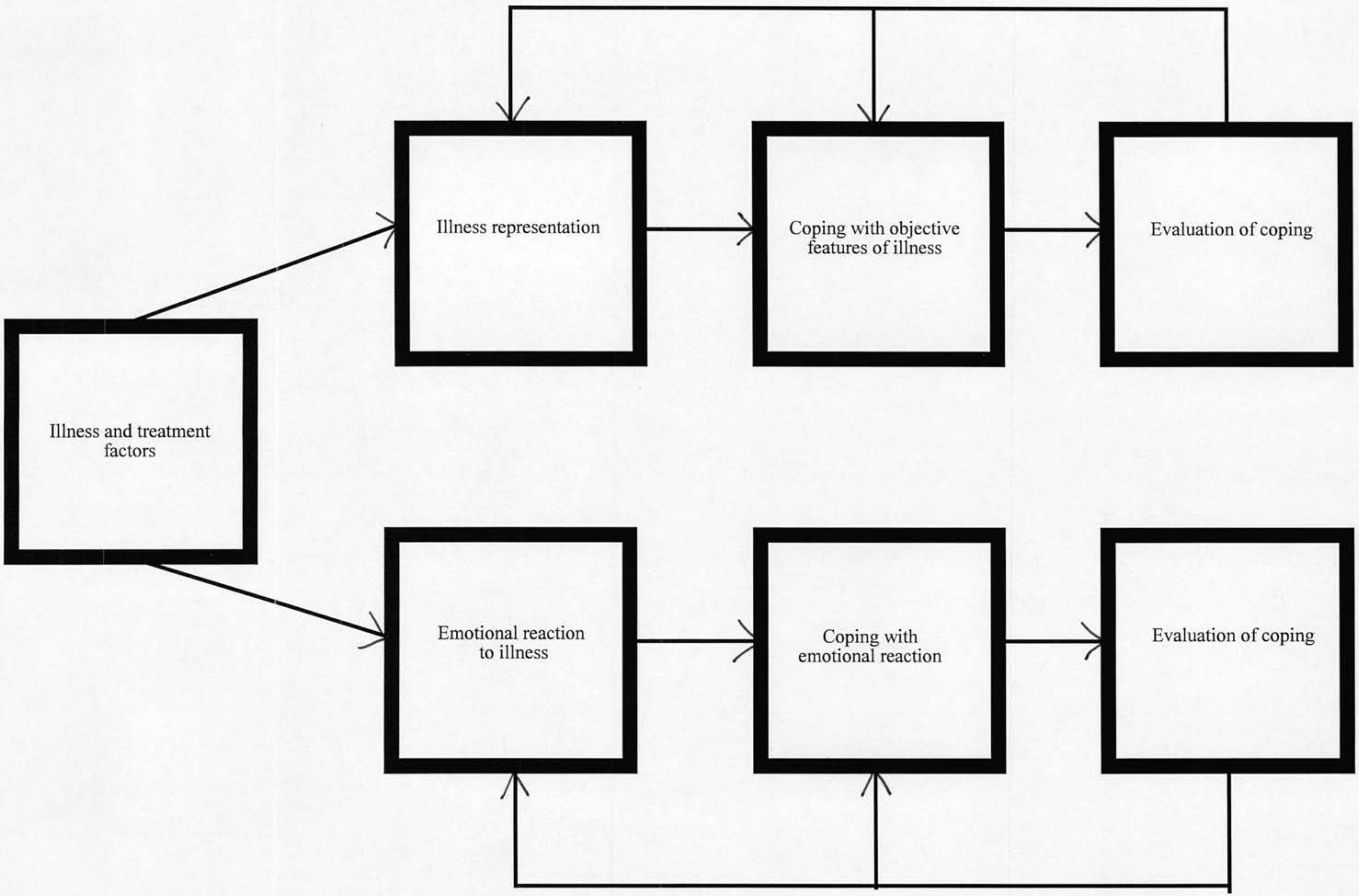


Figure 2.1: The Self-Regulation Model (Leventhal, Nerenz & Steele, 1984).

Illness representations.

The most researched component unique to the Self-Regulation Model, to date, has been that of *illness representations.* Leventhal and his colleagues have studied a wide range of clinical populations and identified four basic components of individual's representations of disease (Leventhal, Meyer & Nerenz, 1980; Nerenz, Leventhal & Love, 1982; Nerenz *et* al., 1984; see also Leventhal & Nerenz, 1985, for a full summary). These were:

Identity: The perceived symptoms of the illness plus the label given to it. The labelling of illness has been shown to be particularly important during the initial onset of a condition, before a medical diagnosis has been give, during which time individuals will be seeking to label their condition based on its symptoms and also in 'diagnosed' conditions which are less tightly medically defined, e.g. chronic fatigue syndrome. Perception of the symptoms of illness are particularly important in guiding coping with chronic conditions which may have acute symptomatic episodes, such as diabetes, epilepsy and asthma.

Cause: Hypotheses concerning the origins of the condition. In the case of diabetes, this may include the possible causes of the onset of the condition as well as causes of symptoms such as those associated with hypoglycaemia. Cognitions regarding the cause of illness have, in recent years, become of interest to researchers in their own right and have become know as *causal attributions.* A full review of the literature on causal attributions is beyond the scope of this thesis, but the interested reader is referred to Gudmundsdottir (1995) for a review.

Consequences: Ideas concerning the long-term and short-term consequences of the condition are important in guiding coping, e.g. an individual who believes that no sweets are permitted at all, ever, with diabetes and that injections must always disrupt one's lifestyle, may be expected to use different coping strategies than an individual holding the opposite views.

Timeline: Ideas concerning the onset, course and prognosis of the condition, including whether it is acute, chronic or cyclic. This can be particularly interesting in diabetes since although it is a chronic condition, it may be asymptomatic for periods of time, particularly in the 'honeymoon period' which often follows diagnosis.

The research of Lau and his colleagues (Lau & Hartman, 1983; Lau, Bernard & Hartman, 1989) has supported these findings with the addition of a fifth component of the illness representation and Goldman *et al.* (1991) has confirmed this finding:

Control/cure: Ideas concerning the potential of the condition for cure, or for controlling of symptoms e.g. by the use of insulin and diet in diabetes or inhalers in asthma.

These components of the illness representation are not independent, but interrelated (e.g. Croft, 1996; Weinman *et al.*, 1996; Williams, 1995) and are a developed and amended on the basis of bodily experience, illness experience (both personal and through others' experiences), information, cultural experience and interaction and discussion with others. For example Marteau (1985) found that parents' perceptions of the seriousness of various chronic conditions (asthma, epilepsy and diabetes) was reduced for whichever condition their own child suffered from compared to conditions with which they had no experience. A further study by Johnston *et al.* (1990) showed that illness representations varied according to experience (indexed by length of time since diagnosis) in a cross-sectional study of 130 parents of 65 children with chronic illnesses.

Coping strategies.

A large body of research and theory also exists on coping strategies used in response to various stressors. Coping strategies have been classified into those serving approach and avoidance functions (e.g. Holahon & Moos, 1985; Ray, Lindop & Gibson, 1982). These refer to:

"Cognitive and emotional activity that is oriented either toward or away from threat."

(Roth & Cohen, 1986).

Approach and avoidance strategies thus fall at either end of a continuum, along which all methods of coping lie. Such a conceptualisation of coping corresponds to the blunting-monitoring continuum (Miller & Mangan, 1983), the attention-avoidance continuum (Holmes & Stevenson, 1990) and the repression-sensitisation continuum (Bell & Byrne, 1978; Gudjonsson, 1981). In general, studies concerning coping with chronic disease have found avoidant coping to be associated with poorer adjustment (e.g. Felton & Revenson, 1984) although the nature of the stressor may influence the relative effectiveness of these two types of function. Suls & Fletcher (1985) compared avoidant and non-avoidant (rather than 'approach') coping strategies in a meta-analysis of 43 previous studies and their results suggested that avoidant coping strategies were more effective when used to cope with short-term stressors while enduring stressors were best coped with using non-avoidant strategies.

There are many possible strategies by which approach and avoidance coping may be carried out to fulfil both problem-focused and emotion-focused functions and thus previous research has identified some common strategies (summarised by Sarafino, 1990). These include direct action, seeking information, turning to others/seeking social support, resigned acceptance, venting emotions and cognitive reappraisal. Although individuals may have a typical coping style, preferring one type of coping strategy to others, individuals are generally flexible in their use of coping strategies for use in response to a variety of stressors.

Emotional reactions to illness.

Emotional reactions to illness form the second, parallel, influence on coping, according to the Self-Regulation Model. In adults these reactions would generally be defined as 'internalising' responses such as anxiety and depression; however, there is evidence that in children emotional reactions may alternatively be expressed as 'externalising' behaviours such as non-compliance, aggression, tantrums and oppositional-defiant behaviours (Webster-Stratton & Herbert, 1995).

Appraisal of coping.

There is little specifically focusing on individuals' evaluations of their coping, to date.

Critique of the Self-Regulation Model.

The Self-Regulation Model is useful for guiding research in that it views coping as a dynamic, multifactorial process and thus highlights the possibility of intervention in the coping process at either cognitive, behavioural or emotional levels. Although its current status is as a model, rather than a theory, since it has never been fully evaluated as a whole, there is substantial research and experimental evidence supporting the relationships between variables which it postulates (for a full review, see Williams, 1995). However, on the whole this research has been cross-sectional, rather than longitudinal, so little is still known about the coping process on an ongoing basis. In addition, although the original form of the model considered cognitive and emotional coping processes to be independent, and was thus known as the *Parallel processing model*, more recent versions acknowledge that there are interactions between each of the elements, i.e. the relationships are not so clear as was initially thought. Despite this, the Self-Regulation Model remains a useful model for guiding research and is beginning to be used to guide research into paediatric problems (Croft, 1996; Curson, 1998; Skinner, 1998). It was thus chosen as the basis for this investigation of the coping process in children with Type I diabetes.

2.5 Application of the Self-Regulation Model to children.

Diabetes may be considered a challenging condition to cope with, among the many associated stressors being the 'loss' of healthy functioning, demands of daily management, constraints on everyday life and one's sense of freedom, the symptoms of the illness itself, hospitalisation and medical complications (Kovacs *et* al., 1990). However, in his review of the literature Compas (1987) highlights the resilience of children in coping with stressful situations and states that

> *".....Clearly, children and adolescents' efforts at coping can have a powerful effect in moderating the impact of stress.....both problem- and emotion-focused coping are important in successful adaptation to stress."*

However, since basic features of cognitive and social development influence children's cognitive representations of stressful situations and how they cope with these (Compas, 1987; Maccoby, 1983; Wysocki *et al.*, 1989), any attempt to apply the Self-Regulation Model to children must take such developmental factors into account. For example, limited cognitive abilities in very young children will influence (a) their illness representations and (b) the type of coping strategies available to them (being more biased towards behavioural, rather than cognitive, strategies). In addition, the range of coping strategies available will increase with age and experience, as will the ability to express emotion appropriately. Reid, Dubow and Carey (1995) state that diabetes, with its associated stressors, is an 'ideal' illness to consider in examining developmental differences in the coping process.

There is a wide literature on the coping process in adults, both with and without chronic disease, which is beyond the scope of this thesis, but see Williams (1995) for a comprehensive summary. Similarly, there is a growing body of research on general coping in children but the resets of this research differ so markedly to those found in paediatric research that the following review will focus on literature on the coping process in paediatric populations in general and more specifically in children with diabetes. Some of the assessment tools mentioned in the review are described more fully in Chapter 4.

Research with children with diabetes and other chronic conditions.

Illness representations - general: It has long been acknowledged that children's illness representations follow a fairly predictable developmental progression (Garrison & McQuiston, 1989). As children grow older, the level of sophistication of their understanding of the basic concepts regarding illness changes in line with their general cognitive development (Perrin & Perrin, 1983). These authors also report that

> "*illness representations progress through a systematic, predictable sequence from prelogical and magical notions of causality in the preoperational child to coherent descriptions of complex and inter-relating physiological mechanisms in the formal operational child.*"

Thus Edwards and Davis (1997) state that children initially make sense of their condition from their general knowledge of how bodies work, what illness in general means to them and their beliefs about illness causality and treatment. Initially this understanding will be based on very concrete, observable facts, such as external wounds and a simple knowledge of those internal body parts with which information has been acquired through experiences such as headache or stomach ache. Their cognitive representation of illness and treatment may also be very concrete: for example, illness may be viewed as the body 'breaking' and treatment as 'mending' it again. When a child has a specific medical condition, their cognitive representation of the relevant body parts and systems may exceed their general knowledge of the body, health and illness. With increasing cognitive sophistication, further information is acquired from both accurate sources such as books or doctors but also from inaccurate sources such as television programmes, magazines, school friends or adults. This information, whether accurate or not, is assimilated into the existing cognitive structure to form a more complex illness representations. It is important that health professionals tailor their explanations to a child's existing cognitive framework in order to promote optimal adjustment to the condition.

Bibace and Walsh (1980) studied 4 year-olds, 7 year-olds and 11 year-olds, corresponding to Piaget's stages of preoperational, operational and formal logical development respectively. They found that preoperational children did indeed tend to understand illness in terms of observable phenomena (e.g. 'you get colds from the sun') and magical thinking ('you get colds when someone stands near you'). Concrete operational children used more complex contamination explanations (e.g. 'you get colds from going out in winter without a hat') and internalisation explanations (e.g. 'people get colds by breathing in bacteria'). Children in the formal logical stage used the most complex physiological explanations (e.g. 'you get colds when a virus gets into your bloodstream') and psychophysiological explanations (e.g. 'you get a heart attack from tension and too much worrying'). Similarly, Brewster (1982) studied 50 children with diabetes, asthma, sickle cell anaemia, orthopaedic conditions and multiple congenital abnormalities and found that their perceptions of illness were positively correlated with cognitive developmental level as in the Bibace and Walsh study. As may be predicted, it is not simply chronological age which has an effect on illness representations: in a study of beliefs about the causes of illness in 64 children aged 4-16 with cancer, diabetes, sickle cell anaemia, juvenile rheumatoid arthritis, spina bifida and asthma, both chronological age and cognitive developmental age (as indexed by IQ) were significantly associated with the complexity of illness representations but time since diagnosis was not (Kury & Rodrigue, 1995).

However, Schmidt and Weishaupt (1990) showed that developmental effects are more pronounced for some aspects of illness representations than others, and that this differed between illnesses with different medical attributes, in their study of 40 children aged 4-9 years. For example, the perceived symptoms and treatment of a cold were well understood even by very young children, while perceptions of cause showed an even more marked developmental effect than the results of Bibace and

Walsh had suggested. However, the results were very different for the less common condition of measles, for which all children had fewer causal attributions and less well developed perceptions of the cure.

Importantly, Perrin and Perrin (1983) found that often healthcare providers were unfamiliar with this developmental view of illness representations and suggested that they needed to be educated in this area if they were to communicate more effectively with the children under their care. Certainly the results of the Kury and Rodrigue (1995) suggest that prior experience with illness should not be overemphasised in assessing children's illness representations. These two studies highlight the importance of assessing illness representations carefully and systematically in children with chronic conditions in order to guide clinical practise.

Illness representations - diabetes: Although some research has been done on children's perceptions of their diabetes (Eiser, Paterson & Town, 1985; Johnson, 1984; Johnson *et al.*, 1982), very little research has systematically studied this topic more recently.

Tennen *et al.* (1981) carried out a study in the framework of learned helplessness (Seligman, 1975) and found that children aged 7-14 who attributed their diabetes to their own behaviour (i.e. internal causal attribution) had better diabetic control than those who believed that the causes of their diabetes were outwith themselves. This supports the hypothesis that internal attributions may lead to more effective coping efforts and thus influence medical outcome.

Perhaps the best study is that of Allen *et al.* (1984), who interviewed 34 children with diabetes aged 8-17 years using a semi-structured interview and classified their responses in the following way:

1. Explanations of the disease in terms of management requirements or gross symptoms only (e.g. 'you can't eat sugar'; 'you get all weak and dizzy').

2. Expression of one set of a system of related elements (e.g. 'We have too much sugar in our blood so we have to avoid eating sweets').
3. Two or more systems of related elements as in (2).
4. Reciprocal elements in the system are mentioned, with at least one set including more than two elements taken at a time (e.g. observes that is urine sugar is high, one must exercise more, watch diet carefully or adjust insulin doses).

The results showed that older children tended to express more advanced disease concepts, which were, in turn, associated with higher levels of anxiety.

There is evidence that illness representations do indeed evolve over time: in a longitudinal study Skinner (1998) found that in 12-18 year olds with Type I diabetes, perceived seriousness of diabetes increased over a six-month period as did perceived controllability. In addition, illness representations were associated with psychological and medical outcomes, with perceived consequences being predictive of the emotional reactions anxiety and depression six months later as well as the coping behaviour dietary adherence.

Coping - general: Most of the research to date has been carried out with children undergoing medical procedures (Eiser, 1990). Miller and Green (1984) found that distraction and reframing were effective coping strategies for children coping with such situations. In a study by Spirito *et al.* (1995) of 177 children aged 7-18 with sickle cell disease, diabetes, cancer, migraine, congenital orthopaedic problems, cystic fibrosis or ulcerative colitis, age differences in coping with a stressful event concerning their condition (as assessed by the KIDCOPE) were found. Adolescents were more likely to use the coping strategies resignation or blaming others than younger children were. In addition, boys reported using cognitive restructuring and self-blame more than girls, who showed increased use of emotional regulation and social support instead.

Coping - diabetes: Reid, Dubow and Carey (1995), in their review of the literature, found that older age was associated with a wider repertoire of coping strategies and generally higher levels of avoidance coping strategies. They postulate that this may be because diabetes is more difficult to control during adolescence, due to physiological changes and therefore adolescents learn that approach strategies are fruitless on many occasions. In particular, adolescents tend to use cognitive avoidance strategies, presumably since such strategies require advanced cognitive functioning, reasoning skills and self-control. Their own study of 56 children aged 8-18 (Reid, Dubow and Carey, 1995) confirmed that approach-type strategies were more commonly used than avoidance-type strategies in response to three diabetes-related stressors (social, diet and fingerprick) but that younger children used approach-type strategies more frequently than adolescents. Coping strategies were highly correlated across situations and accounted for a significant amount of the variance in emotional reaction (depression). Grey *et al.* (1997) also found that coping by avoidance at the time of diagnosis was associated with both older age and poorer diabetic control one year later (particularly in boys) in a longitudinal study of 89 8-14 year-olds in the first year after diagnosis. In addition, coping strategies were stable across this time period. A study by Band (1990) which assessed coping in a sample of 64 children using structured interview gave similar results, with younger (preoperational) children more likely to cope by trying to change the stressor while older (formal operational) children tended to accept the stressor and use cognitive coping strategies to deal with it. In this study, both coping strategies and level of cognitive development accounted for significant proportions of the variance in diabetic control, with approach coping and preoperational cognitive functioning being associated with better diabetic control.

Delamater *et al.* (1987) studied self- reported coping strategies in 27 adolescents with diabetes using the Ways of Coping Questionnaire (Folkman & Lazarus, 1980). The results showed that individuals with poor diabetic control were more likely to report coping by the avoidant strategies of wishful thinking and avoidance/help seeking than those with good diabetic control. A subsequent study with a larger sample of 47 adolescents confirmed these results, and in addition self-blame and keeping things to oneself were found to be more prevalent in individuals with poor diabetic control. It should be noted that in these studies, general rather than diabetes-specific coping strategies were assessed. With regard to diabetes-specific coping strategies in particular, Band and Weisz (1990) confirmed that the Delamater results held for adolescents but not for younger, cognitively less sophisticated children yet Reid *et al.* (1994) found the opposite in their sample of 27 children and 29 adolescents: coping strategies accounted for 8-15% of the variance in diabetic control over and above demographic factors (including age), with avoidance coping being associated with poorer diabetic control. A study by Boland and Grey (1996) found a similar percentage of the variance in diabetic control to be accounted for by coping strategies. In this study, cognitive approach coping strategies were associated with better diabetic control. Frenzel *et al.* (1988), however, found that both approach and avoidance coping were related to poor metabolic control and suggested that such strategies were more likely to be a *response* to poor diabetic control than a *cause* of it.

However, the results regarding coping are not clear-cut. For example, Weist *et al.* (1993) found no differences in coping (assessed using the KIDCOPE) between older and younger children or between those in good and poor diabetic control, in a sample of 56 children aged 8-19 who had had diabetes for more than one year. Similarly, Hanson *et al.* (1989) found no relationship between coping strategies (assessed using the Adolescent Coping Questionnaire for Problem Experiences - Patterson & McCubbin, 1987) and diabetic control in a group of 135 adolescents. Again, general rather than diabetes-specific coping strategies were assessed in this study. Such differences are likely to be due to the age groups studied and to the length of time since diagnosis.

Milousheva, Kobayashi and Matsui (1996) highlighted gender differences in coping as assessed using an interpretative drawing method in 43 children and adolescents attending a diabetic camp. The main differences were that adolescent boys were more likely to cope by avoidance coping and distraction while adolescent girls tended to seek social support by talking to their peers etc. However it should be noted that the sample size used for this analysis was very small (n=26).

Emotional reactions: Wysocki *et al.* (1989) found that pre-school children with diabetes showed higher levels of internalising behaviour problems than the norm when their mothers rated them on the Child Behaviour Checklist. Symptoms of anxiety, depressed mood and feelings of inadequacy are the most common emotional reactions displayed in older children (Gath, Smith & Baum, 1980).

Initial reactions following diagnosis have been found to be associated with more long-term diabetic control: Thernlund *et al.* (1996), in their study of 76 children aged 0-15, found that higher initial anxiety levels were associated with poorer metabolic control over the following year. However, longitudinal studies suggest that these initial emotional reactions vary with time since diagnosis. Kovacs *et al.* (1985; 1996) found that symptoms of anxiety and depression were common in 8-13 year olds within the first year after diagnosis but that these reactions decline significantly over the first six months of the illness. A similar reduction in emotional reactions by one year post-diagnosis was reflected in the findings of Hagglof *et al.* (1994). The results of longer-term studies (Grey *et al.,* 1995; Kovacs *et al.*, 1990) further confirm this finding and further demonstrate that emotional reactions increase once more during the second year post-diagnosis, perhaps due to the honeymoon effect.

Rovet, Ehrlich and Hoppe (1987) found an increased incidence of internalising and externalising behaviour problems (assessed using the Child Behaviour Checklist) in children with diabetes compared to healthy controls. Furthermore, boys who had developed diabetes after the age of four showed higher levels of behaviour problems than girls and younger boys, suggesting that age at diagnosis is an important factor and sex differences in emotional responses exist. However, behaviour problems were not found to be related to diabetic control (as assessed by HbA1c) in the sample as a whole. Conversely, Kovacs *et al.* (1992) reports that girls are more likely to display internalising symptoms such as depression and La Greca *et al.* (1995) found that such reactions were related to poor metabolic control. Current age may be a further important factor, since adolescents showed higher levels of anxiety and depression symptoms than younger children in a study by Grey *et al.* (1991). Again, these reactions were found to be associated with poorer diabetic control. However, Weist *et al.* (1993) found no age differences in anxiety (assessed using the STAI-C) or behaviour problems (assessed using the Child Behaviour Checklist) in their study.

The above studies assessed sub-clinical levels of emotional reactions, on the whole. Higher (clinically significant) levels of emotional reaction have they been found to be associated with poor diabetic control (Fonagy *et al.*, 1987) and such levels are not more commonly found in children with diabetes than in a control group (Hagglof *et al.*, 1994). Children who do display such high levels of emotional reaction were found to come from families where the parents also displayed significant levels of psychological disturbance (Fonagy *et al.*, 1987), i.e. they form a very specific subsample.

2.6 Summary.

The symptoms, management and effects of diabetes may be viewed as sources of stress for the sufferer and thus it is appropriate to investigate this condition within a stress and coping framework. A particularly useful model in this respect is the Self-Regulation Model, which highlights the roles of illness representations, coping strategies and emotional reactions in determining the outcome of chronic conditions. To date this model has not been applied in its entirety to children, but previous research on selected variables highlights the need to view each of these three variables within a developmental framework. Relationships between the variables have been identified in children with chronic conditions, and in particular those with diabetes. This model was therefore chosen as the basis for the current investigation into psychological factors which may be influenced by method of management at diagnosis, as highlighted in Chapter 1.

CHAPTER 3:

SUMMARY, AIMS AND HYPOTHESES

3.1 Summary.

Type I diabetes is a childhood-onset chronic condition requiring an individually tailored regimen of insulin injections, exercise and diet in order to stabilise blood glucose levels. Its prevalence is increasing in Scotland and is particularly high in the North East. Good diabetic control must be established early if long-term health problems are to be avoided and the child takes increasing responsibility for this with age. Management at diagnosis has traditionally been carried out on an inpatient basis and there is some evidence that minimising the length of this initial stay results in improved coping and psychosocial adjustment for the family. Although there is evidence that outpatient management at diagnosis, such as that employed in the Dundee clinic since 1989, does not lead to compromised diabetic control compared to the short lengths of inpatient generally used in the U.K., there is no research to date comparing the relative psychological benefits of each method of management. In addition, there is no research focused on the specific effects of management at diagnosis on the child him/herself.

Since the symptoms, management and effects of diabetes may be viewed as sources of stress for the sufferer, a stress and coping framework was chosen to examine the possible effects of method of management at diagnosis on the coping process in children. More specifically, the Self-Regulation Model, which highlights the roles of illness representations, coping strategies and emotional reactions in determining the outcome of chronic illness, was chosen to guide the current study. This model has received substantial support from research with adults but has only recently begun to be applied to children.

The current research thus aims to use the Self-Regulation Model to guide an investigation into the coping process in children with Type I diabetes, with a particular focus on any developmental effects and the possible psychological effects of management at diagnosis. The results would be expected to lead to suggestions concerning the clinical management of children with diabetes, both at diagnosis and on an ongoing basis, in order to maximise diabetic control and psychological outcomes.

3.2 Aims.

a. To assess children's illness representations of their diabetes, the stressors they encounter in connection with their diabetes, their coping strategies in response to these stressors and their emotional reactions to their diabetes.

b. To identify particular cognitions and behaviours which are associated with good emotional adaptation and diabetic control and which may be targeted by the clinical team during management.

c. To identify the effects of age, age at diagnosis, duration of diabetes, sex and management at diagnosis on each element of the coping process.

3.3 Hypotheses.

The following hypotheses regarding children's coping with Type I diabetes were derived from the Self-Regulation Model and the results of previous research discussed above.

a. Illness representations and coping strategies will be associated with (i) emotional reactions and (ii) diabetic control.

b. Emotional reactions will be associated with diabetic control.

c. Developmental effects will be seen, with illness representations, coping, emotional reactions and diabetic control being influenced by age, age at diagnosis and duration of diabetes.

d. There will be gender differences in illness representations, coping and emotional reactions.

e. There will be no difference in diabetic control between children attending a clinic using an outpatient model of management at diagnosis and those attending a clinic using an inpatient model.

f. There will be differences in illness representations, coping and emotional reactions between children attending a clinic using an outpatient model of management at diagnosis and those attending a clinic using an inpatient model.

CHAPTER 4:
METHOD

4.1 Design.

A cross-sectional study was carried out with two groups of children:

a. Those attending the Dundee clinic, where management at diagnosis is carried out on an outpatient basis, except in exceptional cases.
b. Those attending the children's diabetes clinic in Aberdeen, where hospitalisation at diagnosis remains automatic.

4.2 The two clinics.

The Dundee clinic covers the city of Dundee and surrounding towns in Tayside and North East Fife (excluding most of Angus and Perth, where separate clinics are held). Details of the outpatient method of management at diagnosis used in the clinic have been detailed in Chapter 2 (p.9). Children move to the young adult clinic at around 16 years old or as soon after this as they are deemed ready, taking into account their diabetic control and other factors such as learning difficulties, ability to adapt to a new clinic setting and staff etc. Demographic details of the clinic may be seen in Table 4.1 (p.33).

The Aberdeen clinic covers a large catchment area including the city of Aberdeen and surrounding towns, some of northern Tayside and the highlands and islands (excluding Moray, where a separate clinic is held) - a vast and varied geographical area (Smail, 1998). Children move to the adult clinic at around 14 years old. The geographical spread of this area has led to the maintenance of an inpatient model of management at diagnosis since to manage patients such large distances away at home would require very high levels of resources. At diagnosis children are automatically admitted to the ward for stabilisation, with attempts being made to minimise the length of admission. Follow-up home visits are carried out by a diabetes health visitor and children attend the outpatient clinic approximately every 3 months. A dietitian forms part of the clinic team, but at present there is no dedicated Clinical Psychology service to the clinic. Details of the demography of the clinic are shown in Table 4.1.

Table 4.1: Demographic details of the two clinics.

	DUNDEE CLINIC	ABERDEEN CLINIC
Catchment population [a]	393,600	531,200
Catchment population <15 years [a]	71,840	83,460
Total No. of children attending clinic [b]	113	127
Mean age (years)	11.5	9.6
Age range	2.6-19.9	2.0-14.5
Mean age at diagnosis	[c]	6.1
Mean duration of diabetes	4.3	3.5

Note: [a] Information & Statistics Division, 1997 (figures are for whole Health Board area; more specific details not available).
[b] Current attenders (from clinic databases).
[c] Information not available from clinic database.

The above data show that the Aberdeen clinic was larger, and covered a larger catchment area than the Dundee clinic. The children attending the Dundee clinic were older and had a slightly longer average duration of diabetes, probably due to the fact that they moved on to the young adult clinic at a later age than the Aberdeen children moved onto the adult clinic.

4.3 Participants.

Children aged 7-14 who had been diagnosed for at least one month were selected as the target sample for the following clinical and practical reasons:

a. These are the years where, on the whole, diabetes care is becoming increasingly shared between guardian and child yet before the specific problems of adolescence emerge fully.

b. A wide age range was of interest so that developmental trends could be examined.

c. Children above this age are generally being prepared to move onto the young adult clinic in Dundee.

d. Suitable questionnaires were available which were standardised for this age range.

e. A separate intervention study of adolescents aged fifteen and over was already taking place in the Dundee clinic.

f. Although the time around diagnosis is particularly important in terms of stress and coping, it was thought inappropriate to include newly diagnosed individuals who may still be struggling to cope with the initial stressors.

An additional criterion of diagnosis since 1989, when outpatient model of care was introduced in Dundee, was also used.

All eligible children attending the Dundee and Aberdeen outpatient clinics were sent a letter introducing the study (see Appendix A) and an information sheet (see Appendix B) by post. Starting two weeks later, ten of the weekly outpatient clinics were attended at each site and as many of the eligible children and their guardians as possible were approached with further details of the study and given an opportunity to ask questions, before informed consent was sought from both child and guardian (see Appendices C & D). As many as possible of the individuals who were missed in the clinic or who did not attend during the study period were telephoned and a home visit arranged. Some individuals indicated that they would be happy to take part in the study but did not have time to complete the questionnaires during their clinic visit and did not wish a home visit. Although this was discouraged, particularly with younger children, persistent individuals were given explanations of the questionnaires and allowed to take them home and return them in a prepaid envelope. Such individuals were always supplied with a contact telephone number should they have any queries concerning the questionnaires.

Efforts were made to recruit individuals who were newly diagnosed during the study period, in order to include as wide a range of children as possible. Clinic staff were consulted as to whether this was appropriate in each case: if individuals were considered to be through the immediate crisis of diagnosis after one month then they were approached in the clinic and given the information sheet. At their next clinic visit they were approached as per the above protocol to recruit them into the study.

4.4 Measures.

The measures used are summarised in Table 4.2 and described in further detail below.

Table 4.2: Measures used in the study.

VARIABLE	MEASURES	REFERENCE
Illness representations	Illness Perceptions Questionnaire	Weinman *et al.*, 1996
Coping behaviour	KIDCOPE	Spirito, Stark & Williams, 1988
Emotional reactions	State Anxiety Inventory	Spielberger, 1973
Behaviour problems	Child Behaviour Checklist	Achenbach, 1991
Diabetic control	Mean standardised HbA1c	DIABAUD study

The Illness Perceptions Questionnaire (IPQ).

Although other qualitative measures of illness representations do exist (e.g. Lacroix, 1991; Leventhal & Nerenz, 1985; Prohaska *et al.*, 1985; Skinner, 1998; Turk, Rudy & Salovey, 1986) and illness representations may also be assessed using structured interview (e.g. Hampson, Glasgow & Toobert, 1990; Hampson, Glasgow & Foster, 1995) the IPQ is the only tool to date which assesses illness representations within the Self-Regulation Model framework described above. The IPQ thus comprises scales which assess perceived cause (10 items; high scores indicate a belief in many causes for diabetes), timeline (3 items; higher scores indicate a chronic timeline), consequences (7 items; higher scores indicate more serious perceived consequences) and controllability/cureability (6 items; higher scores indicate a greater belief in controllability/cureability) of any illness, whether one suffers from that illness personally or not. In addition there is a symptoms list which is intended for adaptation according to the particular condition of interest.

The IPQ was developed using a heterogeneous combined sample of 143 hospitalised M.I. patients, 195 discharged M.I. patients, 115 chronic fatigue syndrome sufferers, 22 rheumatoid arthritis sufferers, 88 diabetes sufferers, 60 individuals with chronic pain, 32 renal patients and 193 adult asthma sufferers. Table 4.3 shows that the internal reliability of the scales is high and on the whole test-retest reliability was satisfactory (note that internal reliability was not calculated for the symptoms scale since the items on this scale were intended to be independent). The decreasing test-retest reliabilities at 3 and 6 months were considered to be due to the dynamic nature of illness representations over time discussed earlier, particularly in acute conditions such as M.I. which comprised a large proportion of this sample. In addition the scales were shown to have reasonable concurrent validity (by comparison to other medical and psychological indices in the M.I. sample) and discriminant validity since they were able to distinguish illness representations between different patient groups.

Table 4.3: Reliability of the IPQ (Weinman *et al.*, 1996).

IPQ SCALE	**CRONBACH'S ALPHA**	**TEST-RETEST RELIABILITY**		
		1 MONTH	**3 MONTHS**	**6 MONTHS**
Identity	0.82	0.84^{**}	0.34^{**}	0.06
Timeline	0.73	0.49^{*}	0.51^{**}	0.36^{**}
Consequences	0.82	0.68^{**}	0.55^{**}	0.55^{**}
Control/Cure	0.73	0.68^{**}	0.54^{**}	0.46^{**}

Note: $^{*}p<0.01$ $^{**}p<0.001$

In the original form of the IPQ, respondents rate the frequency with which they experience each symptom on a four point scale (always/frequently/ occasionally/never) and the cause, timeline, consequences and control/cure items are rated on a 5-point scale (strongly agree/agree/neither agree nor disagree/disagree/ strongly disagree). The score for the symptom scale is obtained by summing the number of items rated 'occasionally' or more and the totals for the other scales are obtained by summing the scores (with some items being reverse scored) and dividing by the number of items.

At present, the IPQ has not been standardised for use with children. However, Croft (1997) has modified the items and response format for use with children with asthma and Curson (1998) has used similar modifications for children with diabetes. These authors made the following adaptations:

a. The symptoms list was made specific to diabetes and phrased in simple words, e.g. 'I get thinner' rather than 'weight loss'. 23 items were included.

b. The wording of the items was made more 'child-friendly' and items were all phrased as questions, e.g. 'diet played a major role in causing my illness' became 'do you think that some types of food made you get diabetes?'.

c. Some items were changed to items thought to be more relevant to children, e.g., 'My illness is largely due to my own behaviour' became 'Do you think you got diabetes because you did not look after yourself properly?'.

d. The response options for the symptoms scale were change to 'never/a little bit/quite a lot/always' and the response options for the cause, timeline, consequences and control/cure items were altered so that children could respond 'definitely yes/maybe yes/not sure/maybe no/definitely no'.

e. A visual scale for responding was created whereby children simply had to point to their answer on a brightly coloured piece of card. This had been found to be particularly useful for younger children.

Scoring remained the same as the adult version and scale scores were obtained in the same way. It was decided to use this modified version of the IPQ for the current study (see Appendix E) and it is intended to carry out a further study combining the current data with that of the previous two studies at a later date, in order to investigate the psychometric properties of this children's version of the IPQ. One further addition was made for the current study: children were given the opportunity to add their own symptoms to the symptoms list and to rate the frequency with which they experienced them; however, any additions were not used in the total symptoms score.

The KIDCOPE.

The KIDCOPE was developed as a brief coping checklist for children and adolescents and particularly for paediatric populations suffering from chronic disease. Two forms are available (one for 7-12 year olds and one for 12 years and above) and the questionnaires may be used to assess coping in response to general or specific stressors. The younger version was employed in the current study since it was considered most appropriate to the age group of the sample studied and coping with diabetes-related stressors was assessed (see Appendix F).

Children were asked to choose a situation concerning their diabetes which they had found themselves in during the previous month which was 'difficult or annoying' for them to deal with. In accordance with the instructions for this questionnaire, if they could not think of any thing then a prompt was given (in the form of examples of common stressors) and if this still did not elicit a stressor then the example of taking an injection was suggested, even if the child did not consider it 'difficult or annoying to deal with'. The child was then asked to state which of a list of coping strategies was used to deal with the stressor. Some coping strategies comprise two items and are taken to be used if either item is scored; responses for each coping strategy are thus coded dichotomously. The coping strategies included are based on previous coping literature and may be combined into approach and avoidance scales (see Table 4.4).

Table 4.4: Coping strategies assessed by the KIDCOPE.

COPING STRATEGY	**APPROACH SCALE**	**AVOIDANCE SCALE**
Cognitive restructuring (1 item)	*	
Problem-solving (2 items)	*	
Seeking social support (1 item)	*	
Emotional regulation (2 items)	*	
Distraction (2 items)		*
Blaming others (1 item)		*
Wishful thinking (2 items)		*
Resignation (1 item)		*
Social withdrawal (2 items)		
Self criticism (1 item)		

Test-retest reliability of this scale has been shown to be moderate in the short-term (0.56-0.75 over 3 days) but more variable over a longer time period (0.07-0.83 over 1 week), again perhaps due to the dynamic nature of the coping process. Concurrent validity was demonstrated by favourable comparison with two longer, unpublished coping assessments: the Coping Strategies Inventory (Tobin, Holroyd & Reynolds, 1984) and the Adolescent Coping Orientation for Problem Experiences scale (Patterson & McCubbin, 1983). Although the KIDCOPE has not been extensively researched, it was considered the most appropriate brief questionnaire for this study.

The State Anxiety Inventory for Children (STAI-C).

The STAI-C is an adaptation of the widely used STAI for adults and the State Anxiety Inventory is the version which assessed anxiety in specific situations, rather than in general. It comprises 20 items whose internal consistency ranges from 0.78 to 0.85 (Grey *et al.*, 1995) and test-retest reliability has been assessed at 0.39 over 8 weeks (Roberts, Vargo & Ferguson, 1989), which is adequate given that state anxiety, by definition, changes over time. The instructions for the STAI were changed to read 'When I feel bad because of my diabetes, I feel.......' (see Appendix G).

The Child Behaviour Checklist (CBCL).

The CBCL is a parent-rated measure of children's behavioural adjustment. Separate scales exist for 2-3 year olds and 4-18 year olds and the older version, which contains separate norms for boys and girls aged 4-11 and 12-18, was used for this study. This includes 20 social competence items and 118 behaviour problem items which the parent must rate for the previous six months, but only the behaviour problem items will be reported for the purposes of this thesis. These items form 8 scales, several of which may be combined to give scores for internalising, externalising and overall behaviour problems (see Table 4.5). The CBCL has been shown to discriminate children referred to psychological services from those who are not and has good inter-rater reliability between parents (r = 0.98) and good test-retest reliability (r = 0.84; Webster-Stratton & Herbert, 1995). A copy of the CBCL may be seen in Appendix H.

Table 4.5: Scales of the CBCL.

SCALE	INCLUDED IN INTERNALISING SCORE	INCLUDED IN EXTERNALISING SCORE
Withdrawal	*	
Somatic complaints	*	
Anxiety/depression	*	
Social problems		
Thought problems		
Attention problems		
Delinquent behaviour		*
Aggressive behaviour		*

Mean standardised HbA1c.

Although HbA1c is a reliable measure of diabetic control within individual clinics, it has been acknowledged that it is not a particularly reliable index between different assessment clinics (e.g. Lernmark *et* al., 1996; Thernlund *et al*., 1996). A Scottish study (DIABAUD) is therefore currently underway which routinely collects bloods and HbA1c readings from each clinic and reanalyses the bloods centrally, using a standardised method, in order to determine a 'correction factor' for each clinic so that HbA1c readings may be reliably compared for research purposes. These corrected HbA1c values were obtained from the DIABAUD study for use in this study. Since the DIABAUD study had records for approximately 1 year, the mean of each individual's corrected HbA1c results over this period was calculated and used in analysis.

Unfortunately, standardised HbA1c readings were only available for 57 of the children in the sample, since some children would have declined to take part in the study, others may not have visited the clinic since the start of the study and for others the blood analysis results may not have been available yet. However, it was assumed that any systematic differences between individuals with and without readings would be identical between the Dundee and the Aberdeen clinics.

Demographic and medical details.

Details of age, age at diagnosis, duration of diabetes, length of hospitalisation at diagnosis were all obtained from patients and verified using medical notes. Where there was a discrepancy, data from the medical notes was used.

4.5 Procedure.

Prior to commencing the study, ethical approval was sought and obtained from both Tayside Committee on Medical Research Ethics and Grampian Health Board / University of Aberdeen Joint Ethical Committee.

The procedure for recruiting children into the study is described in Section 4.3. Once informed consent was obtained, children and their guardians were taken into a quiet room in the clinic (Dundee) or a relatively quiet area off the waiting room (Aberdeen) to complete the questionnaires. Guardians completed the CBCL while children completed their questionnaires under the supervision of the researcher.

Children were given the choice of whether to answer the questions using the standard response format, with or without help from the researcher, or using the visual response format. The questionnaires were always introduced sequentially to avoid confusion over the slightly different format of each one and in all cases the instructions were given verbally as well as in written format. It was stressed that there were no right or wrong answers, that it was acceptable not to know the answer to any question and that only the child's opinion was sought, regardless of what he or she believed others to think.

Where home visits were carried out, attempts were made wherever possible to interview the children and guardians in a quiet room, although this was not always possible. If possible and acceptable, guardians were encouraged to complete the CBCL in a separate room, especially for older children. For practical reasons, it was much easier for the researcher to carry out home visits in Dundee; hence the discrepancy in home visit rates, and thus in overall samples sizes, between the two clinics.

When individuals requested to take the questionnaires home to complete them, attempts were made to go through the instructions for each questionnaire separately and to ensure that guardians understood that they could telephone the researcher should they have any queries or difficulties.

Demographic and medical data were obtained from clinic notes and HbA1c readings obtained via the DIABAUD study following completion of the questionnaires.

4.6 Data analysis.

Data were analysed using SPSS Version 6.1 for Windows. Frequency distribution charts were used to check the accuracy of data input and all incorrectly entered values corrected. Since there were very few instances of missing data, due to the supervision of completion of the questionnaires, missing data was not pro-rated, but remained missing. All variables were checked for assumptions of normality by examining (a) frequency distribution charts, (b) boxplots and (c) the results of Kolmogorov-Smirnov goodness of fit tests and appropriate statistical tests were selected accordingly. Correlation and stepwise multiple regression techniques (with probability levels set at 0.05 for entering a variable and 0.10 for removing it from the equation) were used to address relationships between the variables in the sample as a whole. Since Howell (1989) states that when one variable is normally distributed and one categorical, Pearson's r is equivalent to point biserial correlation, Pearson's correlations were used except in instances where both variables were categorical, when Phi was used instead. T-tests, chi-squared and ANOVAs were used to compare variables between children of different age, sex, duration of diabetes and age at diagnosis as well as children attending each of the two clinics. Where the variance of a variable in the two groups was unequal, t values and degrees of freedom were adjusted accordingly and adjusted values are reported.

Where multiple statistics were being used for a single group of variables (e.g. illness representations or coping variables), the significance levels were adjusted using a Bonferroni correction. In practise this meant that a significance level of 0.01

was used for t-tests on the five illness representation variables, 0.005 was used for chi-squared analyses on the 10 coping variables, 0.02 was used for t-tests on the three CBCL variables and 0.017 was used for post-hoc tests following on from ANOVAs with the variables age at diagnosis and duration of diabetes, each of which comprised three groups (Bryman & Cramer, 1990).

To carry out the above statistics a power calculation based on Cohen (1992) indicated that a sample size of between 64 and 84 would be desirable in order to detect medium-sized effects at the 0.05 level with a power of 0.80.

CHAPTER 5:

RESULTS

5.1 Participants recruited.

A summary of the number of patients contacted, approached and recruited at each clinic is shown in Table 5.1.

Table 5.1: Summary of participants.

	DUNDEE (GROUP 1)	ABERDEEN (GROUP 2)
Eligible patients (sent letter)	65	95
New patients given information during study period	5	1
TOTAL CONTACTS	70	96
TOTAL APPROACHES (in clinic or by telephone)	51 (73%)	38 (40%)
Declined to participate	8 (16%)	8 (21%)
Completed study in clinic	23	25*
Completed study during home visit	20	1
Returned questionnaires by post	0	3
Took questionnaires and did not return them	0	1
TOTAL COMPLETERS	43 (84%)	29* (76%)
% OF ELIGIBLE THAT COMPLETED STUDY	61%	30%

Notes: 1. All percentages are of previous category, unless otherwise stated.

2. * 1 participant did not complete all of questionnaires, due to time constraints.

5.2 Demographic data.

Summary statistics of age, age at diagnosis, duration of diabetes (all in months) and sex ratio of the children in each group are shown in Table 5.2. Each of the continuous variables was normally distributed both within groups and in the total sample. There were no significant differences in any of these variables between the

Dundee and Aberdeen groups, indicating that it was appropriate to combine them into a whole sample for some of the analysis, as planned. Standard deviations were very large for all these variables, confirming that the attempts to recruit a demographically heterogeneous sample had succeeded.

Table 5.2: Demographic data.

	DUNDEE	ABERDEEN	STATISTIC	TOTAL SAMPLE
N	43	29		72
Sex ratio (M:F)	18:25	13:16	$X^2_1 = 0.06$, ns	31:41
Mean age (s.d)	134.2 (28.2)	128.6 (23.7)	$t_{70} = 0.87$, ns	131.9 (26.5)
Age range	87-180	94-171		87-180
Mean age at diagnosis (s.d.)	92.2 (44.3)	79.6 (34.4)	$t_{70} = 1.3$, ns	87.1 (40.8)
Mean duration of diabetes (s.d.)	42.0 (34.9)	49.0 (31.0)	$t_{70} = 0.88$, ns	44.8 (33.3)

5.3 Medical data.

Summaries of the number of children in each group, and in the total sample, who were hospitalised at diagnosis and length of hospitalisation are shown in Table 5.3 (p.47). This table also shows the proportion of children in each group for whom a mean standardised HbA1c reading was available from the DIABAUD database and the mean mean HbA1c for each group.

The Aberdeen group had all been hospitalised at diagnosis, which as expected was a significantly higher proportion than in the Dundee group ($X^2_1 = 24.3$, $p<0.01$), although 44% of the latter group had still been hospitalised, either because of complications (e.g. severe hyperglycaemia, DKA, co-occurring illness or unstable family environment) or because they had received their diagnosis while under the care of a different clinic. However, there was no reason to believe that the proportion of individuals experiencing such complications would differ systematically between the two groups and since the study was designed to investigate alternative models of management at diagnosis within a clinic, this finding was treated as unavoidable natural variation.

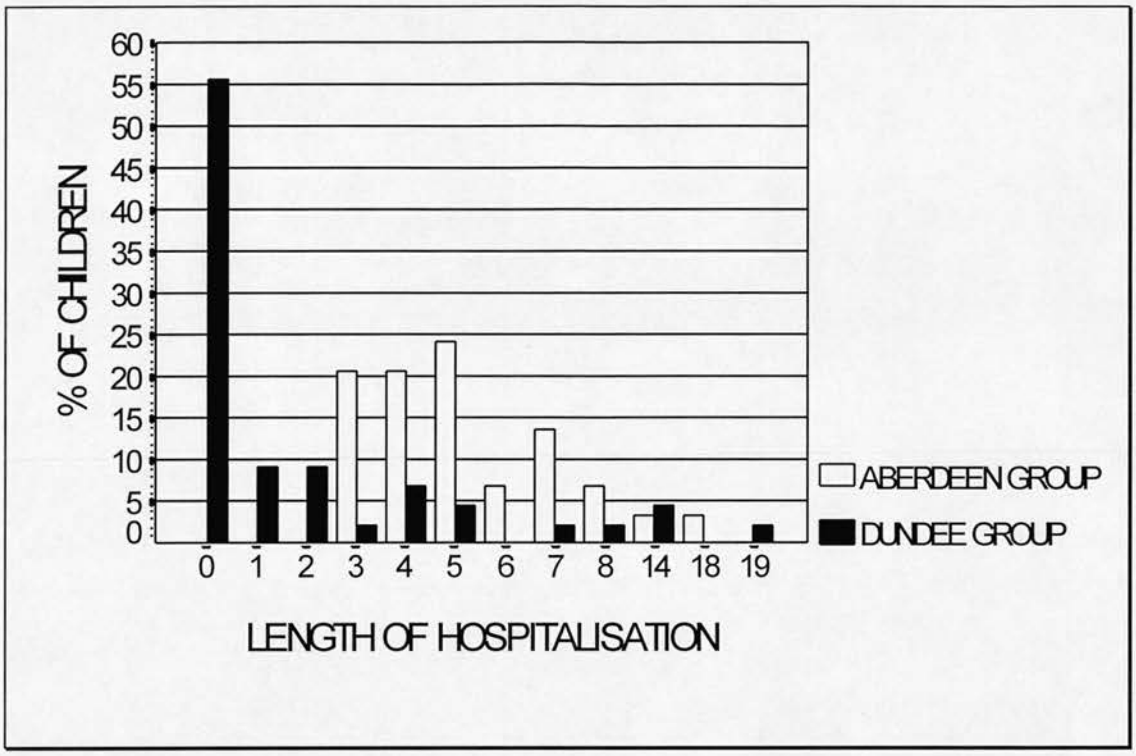
Table 5.3: Medical data.

	DUNDEE	ABERDEEN	STATISTIC	TOTAL SAMPLE
No. hospitalised	19 (44%)	29 (100%)	$X^2_1 = 24.3$, $p<0.01$	48 (67%)
Median length of hospitalisation	0	5		3
Modal length of hospitalisation (range)	0 (0-19)	5 (3-18)		0 (0-19)
No. with a M.S.H.	33 (77%)	24 (83%)	$X^2_1 = 0.10$, ns	57 (79%)
Mean M.S.H. (s.d.)	9.4 (1.1)	9.3 (1.3)	$t_{55} = 0.36$, ns	9.3 (1.2)

Note: M.S.H. = Mean standardised HbA1c.

Despite this finding, Figure 5.1 (p.48) shows that on the whole, children in the Dundee group had been managed at home while children in the Aberdeen group had been hospitalised for 3-5 days, which is comparable to the 'short-stay' group which Simell *et al.* (1991) studied (see Chapter 1). Length of hospitalisation at diagnosis was not normally distributed, either within groups or in the total sample.

Figure 5.1: Length of hospitalisation at diagnosis.



In the total sample, those who had been hospitalised were younger at diagnosis (mean age 77.2 months compared to 106.9 months; t_{70}=3.07, p<0.025) and had a longer mean duration of diabetes (53.0 months compared to 28.5 months; t_{70}=3.10, p<0.025). There were no differences in current age between those who had been hospitalised at diagnosis and those who had not (t_{70}=0.79, ns).

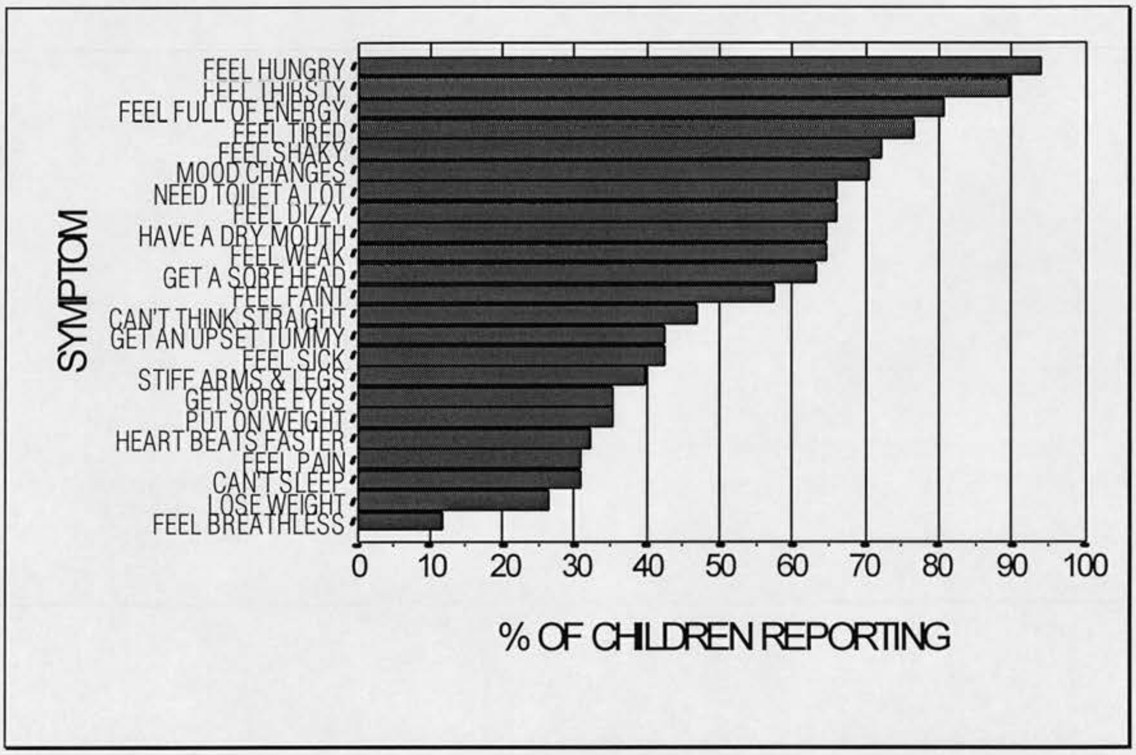
Table 5.3 also shows that similar proportions of children in each group had mean standardised HbA1c readings from the DIABAUD study, i.e. any systematic differences between those with records and those without was assumed to affect both groups equally. The variable mean standardised HbA1c was normally distributed both within groups and in the total sample and, as predicted, there were no significant differences in mean standardised HbA1c between the groups [hypothesis (e)] so again it was appropriate to combine the two groups in order to investigate psychological predictors of diabetic control.

5.4 Illness representations.

Symptoms.

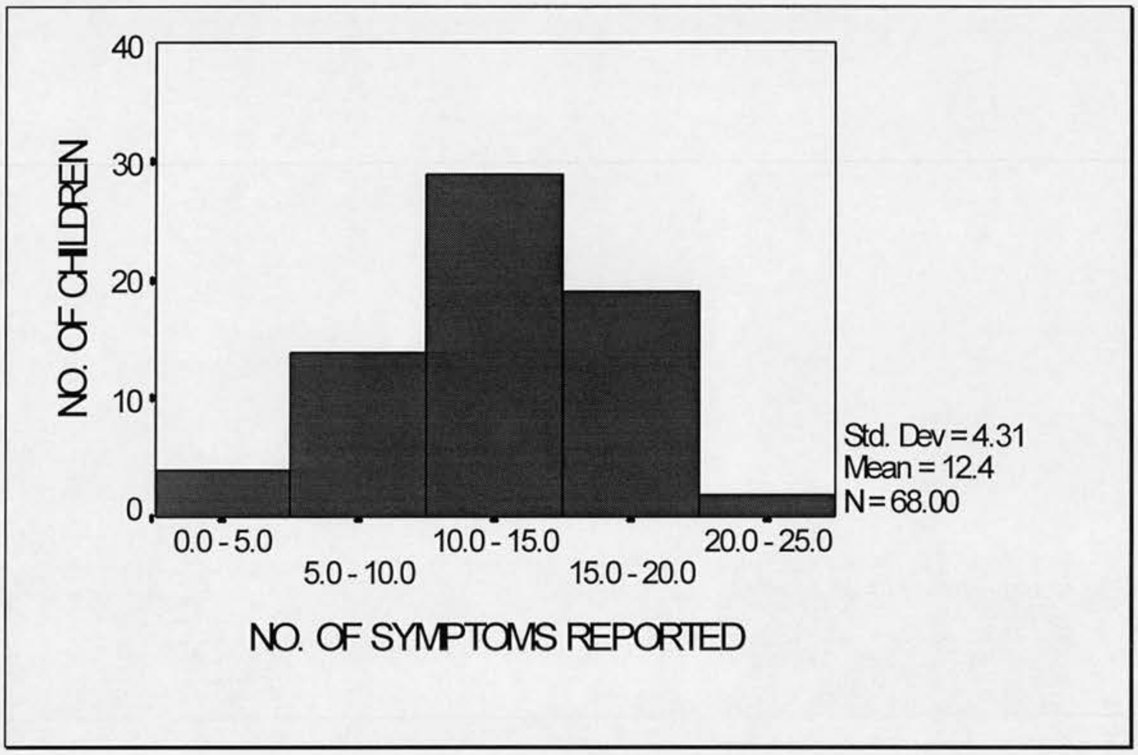
The percentage of children reporting experiencing each symptom at least occasionally due to their diabetes is shown in Figure 5.2.

Figure 5.2: Illness representations of symptoms.



Even though many of the symptoms were included only because they comprised part of the standard IPQ (e.g. stiff arms and legs; sore eyes), unexpectedly there was not one symptom which no child reported experiencing at least occasionally because of their diabetes. The most commonly experienced symptoms were hunger and thirst, hyperactivity ('feeling full of energy'), feeling tired and shaky and mood changes. The least commonly reported symptoms were breathlessness, sleep disruption, pain, rapid heartbeat and gaining or losing weight. The total number of symptoms reported at least occasionally due to diabetes was calculated as recommended by the scale's authors and used in further analyses. The distribution of this variable is shown in Figure 5.3. This variable was normally distributed both within groups and in the total sample and was thus used in further analyses as recommended by the IPQ authors.

Figure 5.3: Total number of symptoms reported.



Twelve children added symptoms to the standard list (17 symptoms in total). Eleven of these symptoms were psychological in nature (stressed, depressed, horrible, nasty, jealous, sad, upset, scared, different, embarrassed) and six were physical (sleepy, aches in legs and back, hungry in night, feel like collapsing, blurry eyes, low).

Summaries of individuals who agreed, disagreed and were not sure about each IPQ item are shown in Table 5.4 (p.51), both for younger (preoperational) children (aged 7-11) and older (formal operational) children (aged 11-14). Differences in response between these two groups of children will be discussed in

Table 5.4: Percentage of 'yes', 'no' and 'unsure' responses to IPQ scale items by children of different ages.

	% ALL AGES (N=72)			% 7-11 YEARS (N=37)			% 11-14 YEARS (N=35)		
	YES	NO	?	YES	NO	?	YES	NO	?
CAUSE									
Do you think getting diabetes happens in your family?	22	46	32	14	54	32	31	31	37
Do you think you caught diabetes from a germ?	13	47	40	18	43	49	17	51	31
Do you think you got diabetes because of bad luck?	8	19	72	5	68	27	11	77	11
Do you think you got diabetes because you didn't look after yourself properly?	6	78	17	3	78	19	9	77	14
Do you think that some types of food made you get diabetes?	6	74	21	18	70	22	3	77	20
Do you think you got diabetes because the doctor didn't look after you very well?	3	93	4	3	92	5	3	94	3
Do you think bad air caused your diabetes?	3	65	32	5	59	35	0	71	29
Do you think you got diabetes because you worried a lot about things?	1	89	10	0	92	3	3	86	11
Do you think you got diabetes because you felt very sad about things?	0	93	7	0	86	14	0	100	0
Do you think it is someone else's fault that you've got diabetes?	0	96	4	0	100	0	0	91	9
TIMELINE									
Do you think you'll always have diabetes?	69	13	18	59	16	24	80	9	11
Do you think your diabetes will get better soon?*	26	33	40	27	27	46	26	40	34
Do you think your diabetes will go away one day then come back again?	4	74	22	3	62	35	6	86	9
CONSEQUENCES									
Is your diabetes getting easier to live with?*	86	6	8	86	8	5	86	3	11
Is diabetes a serious thing to have?	65	28	21	51	35	14	51	20	29
Is your life just the same as it was before you had diabetes?*	44	33	22	49	24	27	40	43	17
Do other people treat you differently because of your diabetes?	36	57	7	41	54	5	31	60	9
Do you think of yourself as different because you have diabetes?	33	56	11	38	54	8	29	57	14
Does your diabetes stop you doing the things your friends do?	26	72	1	30	68	3	23	77	0
Is your diabetes a problem for you?	24	64	13	19	92	16	29	63	9
CONTROL/CURE									
Do you think there are things you can do to help your diabetes?	68	11	21	57	16	27	80	6	14
Do you think there are things that can be done to make your diabetes better?	57	14	40	57	8	35	57	20	23
Do you think there are things you can do to help yourself when you feel bad because of your diabetes?	50	11	39	38	19	43	63	3	34
Do you think your diabetes will get better when you are older?*	24	36	40	32	32	35	14	40	46
Do you think that if your diabetes gets worse or better is all about luck?*	14	57	40	19	41	41	9	74	17
Do you think that the medicines will make your diabetes go away?	11	67	22	16	57	27	6	77	17

Notes: (1) ? = 'unsure' response. (2) * Reverse-scored item.

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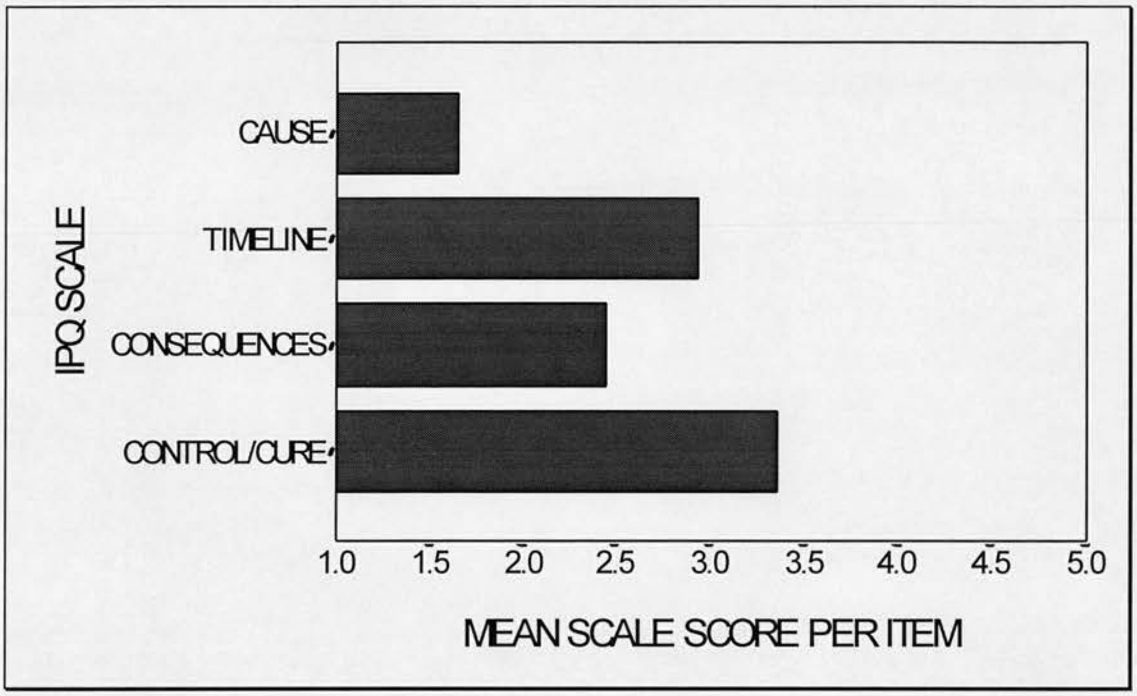
Section 5.8. In the total sample, the most commonly held beliefs concerning the cause of diabetes were that it was genetically-related, came from a germ or was due to bad luck. Very few children believed that the onset of diabetes was brought about by not looking after oneself, eating certain types of food, the doctor not looking after you correctly, bad air or worrying, although it is important to note that some children did hold such beliefs and also that there was a significant level of uncertainty regarding certain possible causes, e.g. bad luck, bad air and eating certain types of food. Most children perceived their diabetes as chronic, although a significant proportion did believe that it would improve. On the whole, the children perceived diabetes as a serious condition which was getting easier for them to live with. However, approximately one quarter of them found their diabetes to be a problem and to stop them doing the things which their friends did and approximately one third perceived themselves differently from their peers and believed that others treated them differently because of their diabetes. Between half and two-thirds of the sample believed they could do things to help control their diabetes but only one in ten believed that medication would cure their diabetes. Again, however, note that some individuals did hold such views.

Because of the significant levels of uncertainty, the total number of items which each child responded 'unsure' to was calculated and found to be normally distributed, both within groups and in the total sample. This variable was thus included in subsequent analyses, since uncertainty about one's condition may be expected to influence emotional reactions to that condition.

Although not interpretable in terms of comparing the scales to each other, and there is no previous published data with children to which these may be compared (see Chapter 2), the scale scores per item were calculated, as recommended by the IPQ authors (see Figure 5.4, p.53) and used for the main analysis. As a group, the children tended to identify few causes for their diabetes, considered it to be chronic and believed that it could be controlled/cured. Since the consequences scale had a mean value of approximately 2.5, this suggests that approximately 50% of the children believed diabetes to have relatively little effect on their life while the other 50% perceived some negative effects. All four scale scores per item were found to be normally distributed both in the two groups and in the total sample.

Figure 5.4: Mean scale scores per item for the IPQ scales.



Correlations between the five IPQ scales are shown in Table 5.5 and suggest that participants who listed many causes of diabetes were more likely to also report diabetes to have many symptoms and serious consequences.

Table 5.5: Correlations between IPQ scale scores.

	SYMPTOMS	CAUSE	TIMELINE	CONSEQUENCES
CAUSE	0.46*			
TIMELINE	0.02	0.19		
CONSEQUENCES	0.21	0.39*	0.05	
CONTROL/CURE	0.07	0.04	-0.04	0.10

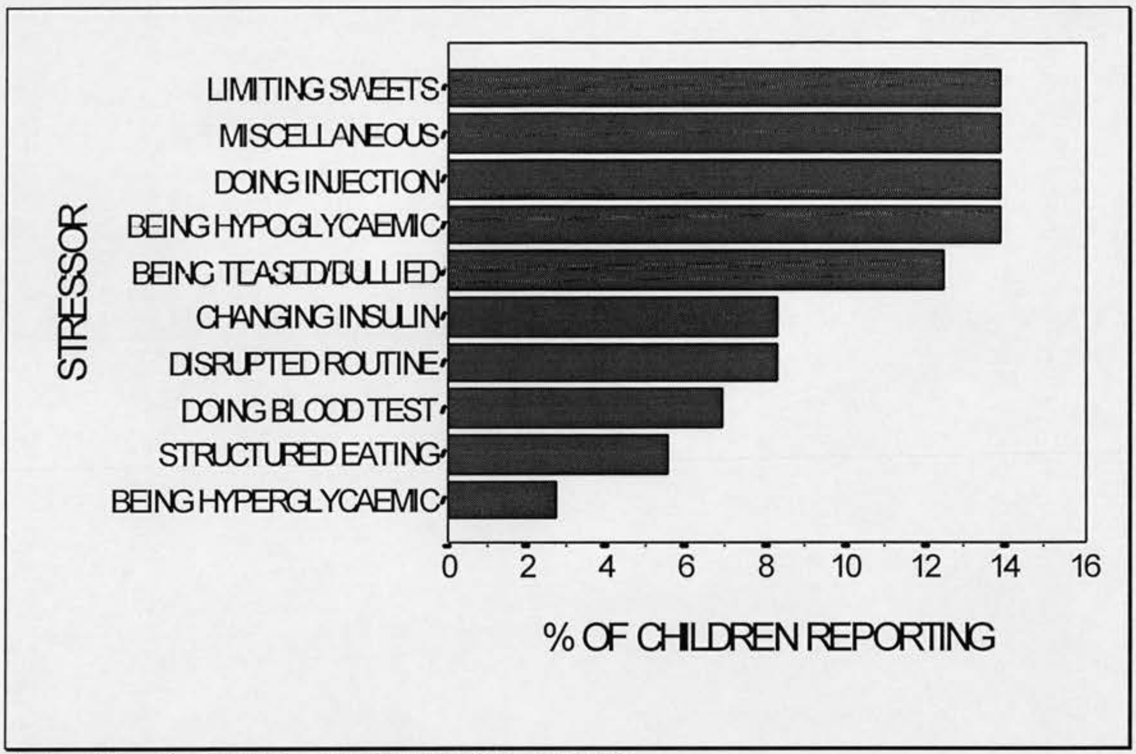
Note: * $p < 0.001$

5.5 Coping strategies.

The diabetes-related stressors which children reported were categorised into ten broad categories and the frequency with which each category was reported is displayed in Figure 5.5. The most frequently mentioned difficulties were limiting the number of sweets eaten, doing an injection (although note that this category was often chosen after prompting when the child was unable to think of any other stressor), coping with hypoglycaemia and miscellaneous items, i.e.:

Not knowing whether I could eat cake when a boy at school brought it in.
Having eye drops put in at the clinic.
Having a sore patch on my leg from my injections.
Having to go on a drip while I had some tests done.
My blood monitor broke so I had no sugar readings.
I forgot my injection because I was in a rush.
I go low in the night and have to get a fingerprick done.
My eyes got sore when I had a hypo.
I felt sick and needed the toilet a lot because I was too high.
My counts went very high then very low in an hour.

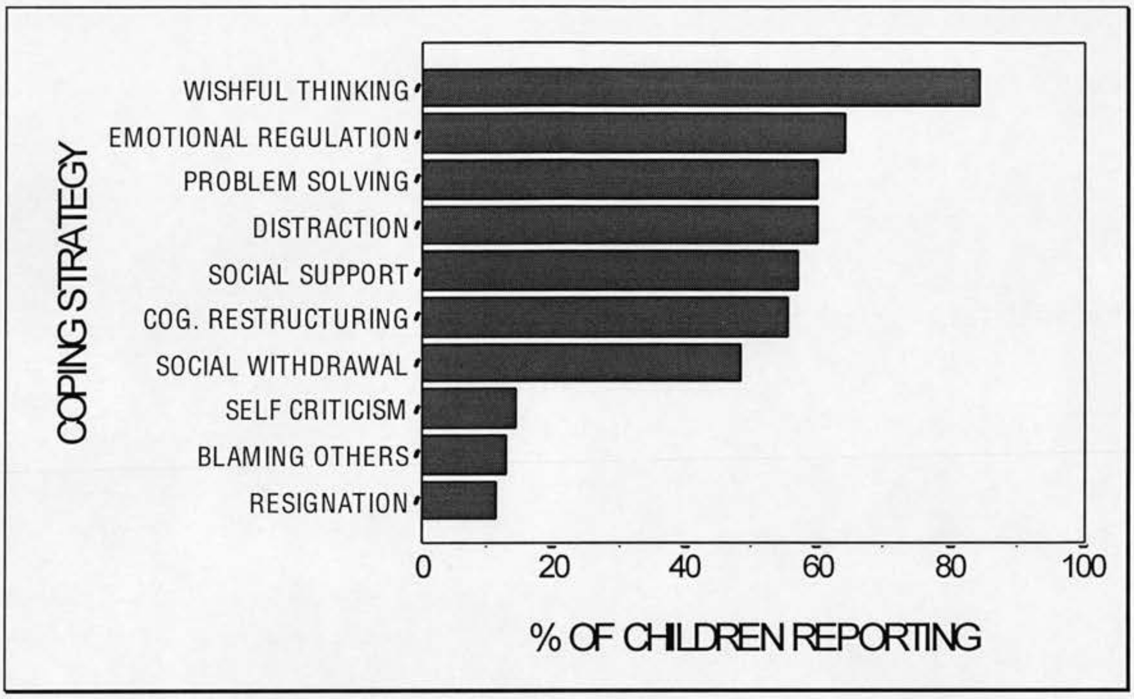
Figure 5.5: Diabetes-related stressors reported by children (KIDCOPE).



Note: 'Changing insulin' = alterations to dose or regimen.

The number of children reporting using each coping strategy in response to the stressor they chose are shown in Figure 5.6 (p.56). Note that each of the coping variables was dichotomous in nature.

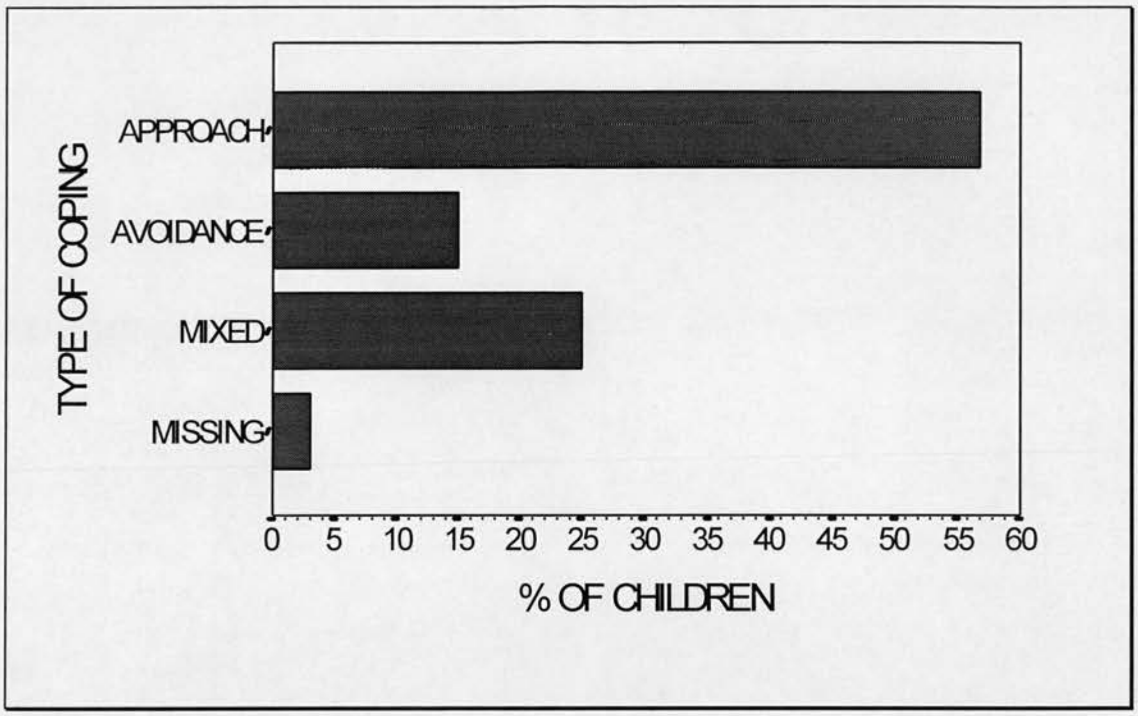
Figure 5.6: Coping strategies used in response to diabetes-related stressors.



The most common coping strategy was the avoidance strategy *wishful thinking*, which 83% of the children reported using. Following this, *emotional regulation, problem solving, distraction, social support* and cognitive *restructuring* were the most commonly reported. The least used coping strategies were the avoidance strategies *resignation, blaming others* and *self criticism*. The Phi correlations between coping strategies were all non-significant (range 0.001 to 0.41).

Total scores were obtained for approach and avoidance coping behaviours, as recommended by the scale's authors, and subjects were categorised as either predominantly using approach strategies, predominantly using avoidance strategies or using equal numbers of each (a summary of this variable appears in Figure 5.7, p.57). The majority of children (57%) used primarily approach coping strategies, while avoidance strategies predominated in only 15% of participants.

Figure 5.7: Rates of approach and avoidance coping.

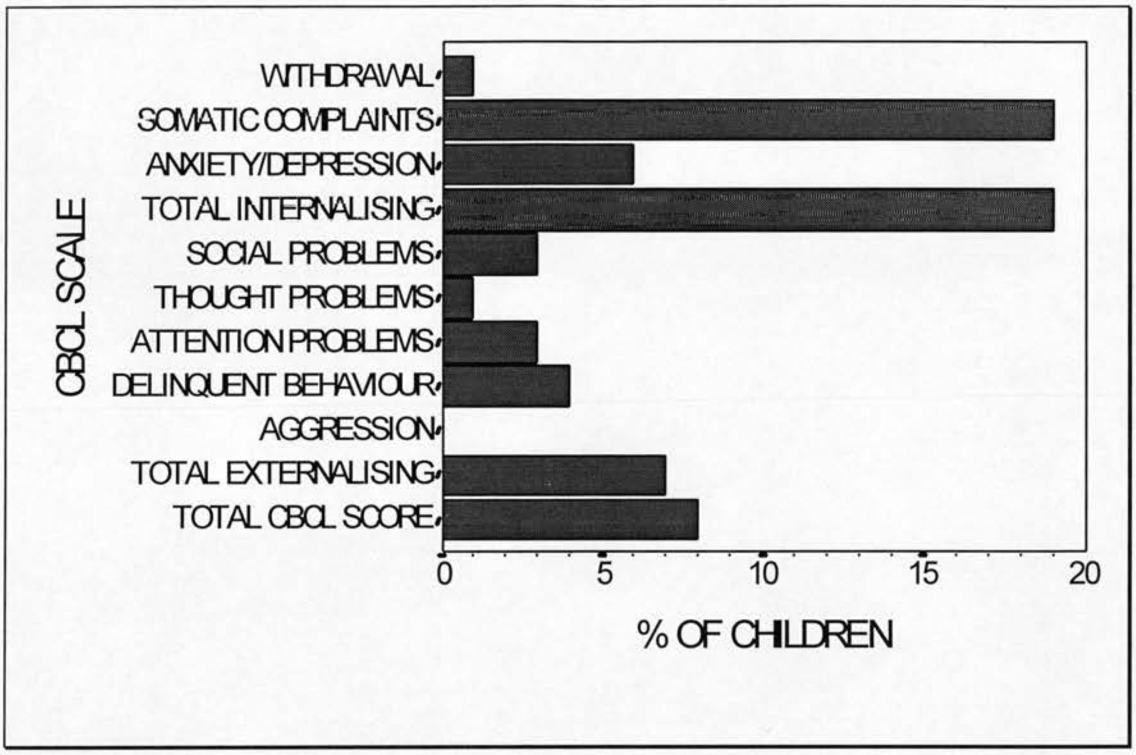


5.6 Emotional reactions.

The STAI-C results were normally distributed both within groups and in the total sample. The mean score was 30.58 (s.d. 6.9) and six individuals (8%) scored above the 95th percentile as indicated in the author's norms for this age group.

None of the individual CBCL scale scores were distributed normally although internalising, externalising and total behaviour problem scores were normally distributed, both within the two groups and in the total sample. In order to reduce the number of variables and simplify the analysis, these three variables were selected for use in the main analysis. Each child was compared to the authors' norms for his/her age and sex and the percentage in the total sample scoring above the 95th percentile are shown in Figure 5.8 (p.58).

Figure 5.8: Percentage of children scoring above the 95th percentiles on the CBCL scales.



The main finding was a significantly elevated proportion of children (19%) scoring above the 95th percentile for somatic complaints, which appeared to contribute to a similar percentage scoring above the 95th percentile for overall internalising scores. The percentage scoring above the cut-off for the other scales varied between 1% and 8% with a median of 3%, i.e. approximately the proportion which would be expected.

5.7 The relationship between illness representations, coping, emotional reactions and diabetic control [hypotheses (a) and (b)].

Pearson's correlations were obtained between IPQ variables, KIDCOPE variables and (a) STAI-C and CBCL scores and (b) mean standardised HbA1c scores (see Table 5.6, p.59). The only significant correlations were between STAI-C scores and the illness representations variables symptoms, cause and consequences

Table 5.6: Correlations between illness representations, coping and (a) emotional reactions and (b) diabetic control.

	EMOTIONAL REACTIONS				DIABETIC CONTROL
	STAI-C	CBCL			
		INTERNALISING	EXTERNALISING	TOTAL BEH. PROBLEMS	HbA1C
IPQ					
Symptoms	0.59*	0.11	-0.09	0.05	0.10
Cause	0.51*	0.003	0.16	0.12	-0.14
Timeline	0.18	0.11	0.20	0.24	-0.09
Consequences	0.36*	0.29	0.18	0.30	-0.03
Control/cure	-0.19	0.06	-0.05	-0.004	0.21
Uncertainties	0.10	0.009	0.03	0.02	-0.25
KIDCOPE					
Distraction	0.24	0.03	0.14	0.09	-0.13
Social withdrawal	0.0002	0.21	0.25	0.21	-0.15
Cognitive restructuring	0.11	0.06	-0.15	-0.14	0.08
Self criticism	0.21	0.003	0.12	0.21	0.09
Blaming others	0.41*	-0.13	0.03	0.06	0.22
Problem solving	0.33*	-0.14	-0.04	-0.05	0.03
Emotional regulation	0.30	0.003	0.08	0.08	-0.22
Wishful thinking	0.25	0.18	0.24	0.25	-0.05
Seeking social support	0.40*	-0.20	0.02	-0.06	-0.04
Resignation	-0.23	-0.20	-0.16	-0.21	-0.10
Approach coping	0.20	-0.20	-0.11	-0.17	

Note: * $p<0.005$

and the coping variables blaming others, problem solving and seeking social support. None of the illness representations or coping variables correlated significantly with either behaviour problems or diabetic control.

A stepwise multiple regression was carried out using these six illness representation and coping variables as independent variables and STAI-C scores as the dependent variable. Table 5.7 shows the unstandardised regression coefficients (B) and intercept, the standardised regression coefficients (Beta), the semipartial correlations (sr^2) and R^2, adjusted R^2 and F for the resulting equation.

Table 5.7: Multiple regression of illness representation and coping variables onto anxiety (STAI-C).

INDEPENDENT VARIABLE	**B**	**BETA**	**sr^2**
IPQ: Symptoms	0.73	0.45***	0.16
IPQ: Cause	4.06	0.23*	0.04
KIDCOPE: Blaming others	6.66	0.33***	0.10
KIDCOPE: Seeking social support	3.89	0.27**	0.07

Note: * $p<0.01$ **$p<0.001$ ***$p<0.0001$

Constant=11.72

$R^2=0.63$[1] Adjusted $R^2=0.60$

$F_{4,61}=25.62$ ($p<0.0001$)

[1] Unique variability = 0.16+0.04+0.10+0.07=0.37; Shared variability = 0.63-0.37=0.26.

R for the regression was significantly different from zero ($F_{4,61}=25.62$, $p<0.0001$). Four of the independent variables contributed significantly to the prediction of STAI-C scores: perceived symptoms alone accounted for 16% of the variance, perceived cause alone accounted for 4% of the variance, coping by blaming others alone accounted for 10% of the variance and coping by seeking social support alone accounted for 7% of the variance in diabetes-related anxiety. In combination, these four variables accounted for a further 26% in shared variability Altogether, 63% (60% when adjusted) of the variance in STAI-C scores could be predicted from the scores on these four independent variables. The variables perceived consequences and coping by problem-solving were not included in the final equation.

No significant correlations were found between diabetic control and STAI-C score ($r = 0.13$, ns), CBCL internalising scores ($r = -0.12$, ns), CBCL externalising scores ($r = -0.04$, ns) or CBCL total behaviour problem scores ($r = -0.03$, ns).

Thus there was support for hypothesis (a) (i) since illness representation and coping variables were shown to be significantly associated with anxiety concerning diabetes. However since there was no evidence that illness representations and coping variables were associated with diabetic control, hypothesis (a) (ii) was rejected. Similarly, hypothesis (b) was rejected as there was no significant relationship between emotional reactions and diabetic control.

5.8 Effects of demographic and illness variables [hypotheses (c) and (d)].

Possible effects of the variables age, age at diagnosis, duration of diabetes and sex on illness representation variables, coping strategies, emotional reactions and diabetic control were examined. However it is important to note that, using the groupings described below, the variable age at diagnosis was highly significantly correlated with both current age (Phi=0.59, $p < 0.00001$) and duration of diabetes (Phi=-0.69, $p < 0.00001$). None of the other demographic or illness variables were significantly correlated.

Age.

Children were grouped into those aged 7-11 (n=37) and those aged 11-14 (n=35), in line with previous research (e.g. Bibace and Walsh, 1980; see Chapter 2).

Illness representations: No differences were found between older and younger children in perceived symptoms ($t_{61.30}$=1.30, ns), cause (t_{70}=0.29, ns), timeline (t_{70}=0.42, ns) or consequences (t_{70}=0.44, ns) or the total number of uncertainties (t_{70}=1.65, ns). However, controllability scores were significantly higher for older children (mean=3.54; s.d.=0.51) than for younger children (mean=3.19; s.d.=0.46; t_{70}=3.05, $p<0.01$).

A comparison of the number of older and younger children's responses to individual IPQ items may be found in Table 5.4 (Section 5.4). Chi-squared analysis (with Bonferroni corrections for multiple comparisons within IPQ scales) showed that there were no significant differences between older and younger children in any of these beliefs, although there was a tendency for older children to be more certain that their diabetes was not caused by feeling sad about things (X^2_1=5.08, p=0.024) and that their diabetes was not cyclical in nature (X^2_2=7.46, p=0.024) as well as being more likely to perceive that diabetic control was not all luck (X^2_2=6.80, p=0.033), but that there were things they could do to help themselves when they felt bad because of their diabetes (X^2_2=8.36, p=0.015).

Coping: There was no significant difference in the overall number of coping strategies reported by older and younger children (t_{68}=1.68, ns). Younger and older children did not differ in their use of distraction (X^2_1=0.47, ns), social withdrawal (X^2_1=0.52, ns), cognitive restructuring (X^2_1=0.21, ns), blaming others (X^2_1=0.07, ns), self criticism (X^2_1=4.61, ns), problem solving (X^2_1=0.47, ns), wishful thinking (X^2_1=0.19, ns), seeking social support (X^2_1=1.38, ns) or resignation (X^2_1=0.01, ns). However, emotional regulation was significantly more common in younger children than in older children (X^2_1=11.71, $p<0.005$). Further analysis showed that this was due to higher levels of coping by keeping calm (X^2_1=14.76, $p<0.0002$) rather than in higher levels of venting of emotions (e.g. shouting, screaming or getting angry; X^2_1=0.01, ns). There was no significant difference in levels of approach coping in younger children compared to older children (X^2_1=5.72, ns).

Emotional reactions: There were no significant differences in either internalising behaviour ($t_{61}=0.15$, ns), externalising behaviour ($t_{66}=0.81$, ns), total behaviour problems ($t_{51.33}=0.09$, ns) or anxiety ($t_{69}=0.20$, ns).

Diabetic control: A significant difference in mean standardised HbA1c was found ($t_{39.91}=2.39$, $p<0.05$), with younger children having significantly lower levels (Mean=8.94; s.d.=0.78) than older children (Mean=9.70; s.d.=1.52).

Age at diagnosis.

Children were grouped into those aged less than 7 at diagnosis (n=35), those aged 7-11 (n=22) and those aged 11-14 (n=15), in line with the categories used to investigate age effects (above).

Illness representations: No significant differences were found between groups for perceived symptoms ($F_{2,69}=2.74$, ns), cause ($F_{2,69}=0.88$, ns), timeline ($F_{2,69}=0.27$, ns), consequences ($F_{2,69}=0.01$, ns), control/cure ($F_{2,69}=0.13$, ns) or uncertainties ($F_{2,69}=4.12$, ns).

Coping: No significant differences were found in the use of the coping strategies distraction ($X^2_2=0.49$, ns), social withdrawal ($X^2_2=2.07$, ns), cognitive restructuring ($X^2_2=1.69$, ns), self criticism ($X^2_2=2.82$, ns), blaming others ($X^2_2=0.15$, ns), problem solving ($X^2_2=0.96$, ns), emotional regulation ($X^2_2=8.78$, ns), wishful thinking ($X^2_2=0.40$, ns), seeking social support ($X^2_2=0.24$, ns) or resignation ($X^2_2=0.09$, ns) between children diagnosed at different ages. In addition, the level of approach coping used did not differ between children diagnosed at different ages ($X^2_4=3.98$, ns).

Emotional reactions: There were no significant differences between children diagnosed at different ages for internalising behaviour ($F_{2,60}=1.10$, ns), externalising behaviour ($F_{2,65}=0.27$, ns) or total behaviour problems ($F_{2,57}=0.57$, ns). Similarly, no differences in anxiety were found ($F_{2,68}=2.18$, ns).

Diabetic control: There was no significant difference in mean mean standardised HbA1c between the three groups ($F_{2,54}=0.48$, ns).

Duration of diabetes.

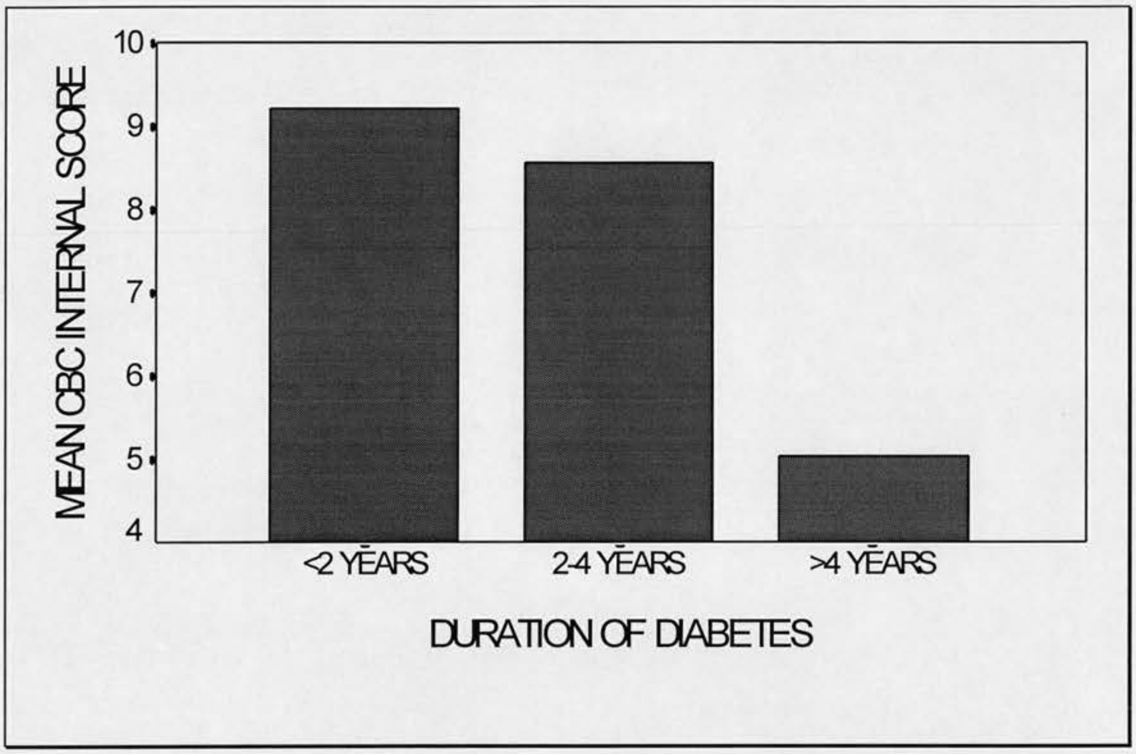
The sample was split approximately into thirds: those who had had diabetes for less than 2 years (n=24), 2-4 years (n=22) and over 4 years (n=26). These were thought to correspond roughly to the early phase and honeymoon period, mid-term and long-term adjustment.

Illness representations: There were no significant differences between individuals with different durations of diabetes in perceptions of symptoms ($F_{2,65}=0.21$, ns), cause ($F_{2,69}=0.37$, ns), timeline ($F_{2,69}=0.05$, ns), consequences ($F_{2,69}=0.67$, ns) or control/cure ($F_{2,69}=1.62$, ns). Similarly, there were no differences in the mean number of uncertainties reported ($F_{2,69}=2.39$, ns).

Coping: No significant differences were found in the levels of coping by distraction ($X^2_2=4.33$, ns), social withdrawal ($X^2_2=2.07$, ns), cognitive restructuring ($X^2_2=2.13$, ns), self criticism ($X^2_2=1.22$, ns), blaming others ($X^2_2=0.13$, ns), problem solving ($X^2_2=0.29$, ns), emotional regulation ($X^2_2=1.46$, ns), wishful thinking ($X^2_2=0.47$, ns), seeking social support ($X^2_2=1.22$, ns) or resignation ($X^2_2=3.63$, ns). In addition, there was no difference in levels of approach coping between these groups ($X^2_4=2.02$, ns).

Emotional reactions: Although there was no difference in externalising behaviour ($F_{2,65}=1.99$, ns) or total behaviour problems ($F_{2,57}=3.78$, ns), there was a significant difference in reported internalising behaviour ($F_{2,60}=4.14$, $\underline{p}<0.02$) between groups, with those diagnosed less than two years ago showing significantly higher levels than those diagnosed more than 4 years ago (see Figure 5.9). No differences in anxiety levels were found between the three groups ($F_{2,68}=0.20$, ns).

Figure 5.9: Mean levels of internalising behaviour in children with different durations of diabetes.



Diabetic control: The mean mean standardised HbA1c did not differ significantly between the three groups ($F_{2,54}=0.42$, ns).

Sex.

Illness representations: Girls and boys did not differ in scores on either the symptoms ($t_{66}=1.51$, ns), cause ($t_{70}=0.28$, ns), timeline ($t_{70}=0.08$, ns), consequences ($t_{70}=0.48$, ns) or control/cure ($t_{70}=0.28$, ns) scales or the number of uncertainties ($t_{70}=1.02$, ns).

Coping: Similar proportions of boys and girls reported coping by distraction (X^2_1=0.97, ns), social withdrawal (X^2_1=0.08, ns), cognitive restructuring (X^2_1=1.74, ns), self criticism (X^2_1=0.79, ns), blaming others (X^2_1=0.01, ns), problem solving (X^2_1=3.89, ns), emotional regulation (X^2_1=1.33, ns), wishful thinking (X^2_1=0.22, ns), seeking social support (X^2_1=1.94, ns) and resignation (X^2_1=0.11, ns). Similarly, there was no difference between the sexes in levels of approach coping (X^2_1=0.16, ns).

Emotional reactions: Externalising problems were more common in boys (mean=9.30; s.d.=5.7) than girls (mean=6.89; s.d.=4.2; $t_{52.05}$=3.13, $p<0.02$) and showed significantly higher levels of overall behaviour problems (mean=24.27, s.d.=13.4 compared to mean 16.35, s.d.=11.5; t_{58}=2.46, $p<0.02$). There were no significant differences in internalising behaviours (t_{61}=1.19, ns) or anxiety (t_{69}=0.14, ns).

Diabetic control: No significant sex differences were found in mean standardised HbA1c (t_{55}=0.44, ns).

Summary.

There was some support for hypotheses (c) and (d): Some aspects of the illness representation (in particular, beliefs concerning the controllability and cureability of diabetes) were influenced by age and older individuals tended to have fewer uncertainties in some areas. The only factor which was found to influence coping was age, with younger children tending to cope more by emotional regulation (trying to stay calm) than older children did. In terms of emotional reactions, no influences on anxiety were found but internalising behaviours were more common in those most recently diagnosed and appeared to become less common with time since diagnosis while externalising behaviours and overall behaviour problems were significantly more common in boys than in girls. Age at diagnosis did not appear to influence any aspect of the coping process significantly.

5.9 Comparison of method of management at diagnosis [Hypotheses (e) and (f)].

Illness representations: There were no differences in any of the illness representations components between children attending the two clinics: symptoms (t_{70}=0.34, ns); cause (t_{70}=0.33, ns); timeline (t_{70}=0.03, ns); consequences (t_{70}=0.16, ns) and control/cure (t_{70}=1.47, ns). There were also no differences in uncertainties between the two groups (t_{70}=1.44, ns).

Coping: There were no differences in the use of distraction (X^2_1=0.16, ns), social withdrawal (X^2_1=0.003, ns), cognitive restructuring (X^2_1=0.22, ns), self criticism (X^2_1=2.26, ns), blaming others (X^2_1=3.44, ns), problem solving (X^2_1=0.81, ns), emotional regulation (X^2_1=0.11, ns), wishful thinking (X^2_1=0.03, ns), seeking social support (X^2_1=0.08, ns) or resignation (X^2_1=0.004, ns). The total level of approach coping did not differ between the two groups (X^2_1=0.86, ns).

Emotional reactions: No significant differences were found between the two groups on internalising behaviour (t_{61}=0.49, ns), externalising behaviour (t_{66}=0.26, ns) or total behaviour problems (t_{58}=0.25, ns). In addition, there were no differences in STAI-C scores between the two groups (t_{69}=1.39, ns).

Diabetic control: As mentioned earlier, there were no significant differences in mean standardised HbA1c between the two groups (t_{55}=0.36, ns).

Summary.

Hypothesis (e) was supported as there was no difference in diabetic control between children attending a clinic using an outpatient model of management at diagnosis and those attending a clinic using an inpatient model. However, there was no support for hypothesis (f) since no differences in any of the coping variables was found between these two groups of children.

CHAPTER 6:
DISCUSSION

6.1 Introduction.

This chapter opens with a summary and discussion of the results presented in Chapter 5 and goes on to consider the clinical implications of these results for the management of children with diabetes both at the time of diagnosis and on an ongoing basis. The theoretical implications and methodological strengths and weaknesses of the study are then discussed and possibilities for future research suggested.

6.2 Summary and discussion of results.

The sample.

A cross-sectional study of 72 children with Type I diabetes was carried out in order to investigate the coping process and the possible effects of illness and demographic variables on this process. Since one of the aims of the study was to investigate the possible psychological effects on the child of different models of management at diagnosis, children were recruited from two clinics, one of which managed children on an inpatient basis at diagnosis (Aberdeen) and the other, slightly smaller clinic which employed an outpatient model of management (Dundee). Although the proportion of eligible participants declining to take part in the study were similar at the two clinics, there was a difference in the proportion of eligible participants who were recruited into the study, mainly due to the fact that, for practical reasons, it was possible to carry out more home visits in Dundee than in Aberdeen. In an attempt to balance out the numbers in the two groups, some participants in Aberdeen were thus permitted to return their questionnaires by post while this method was not used in Dundee. However, only three extra participants were obtained in this way. Although no planned method of matching was employed, the two resulting clinic groups were remarkably similar in terms of age, sex, age at diagnosis, duration of diabetes and diabetic control despite the demographic differences in the clinics as a whole. Similarly, the proportions of children in the two clinics who had indices of diabetic control (mean standardised HbA1c readings) available through the DIABAUD study were similar, suggesting that any bias between those who did and those who did not was likely to affect each clinic sample equally. The two clinic samples were thus combined in order to give a larger sample in which to investigate the relationships between psychological variables and diabetic control. The mean mean standardised HbA1c for the total sample was 9.3, which is significantly higher than the target of 8.0 or less which is generally taken to indicate good diabetic control (Howells, 1998). However, there was a reasonable amount of variance in this variable, as required for the planned regression analyses.

With regard to comparing the models of management at diagnosis employed in the two clinics, it was apparent that although on the whole a greater proportion of the children in the Aberdeen clinic had been hospitalised, and for longer periods of time, 44% of the children attending the Dundee clinic had also been hospitalised at diagnosis, either because they attended a different clinic at the time or due to complicating factors such as extreme hyperglycaemia, DKA, concurrent illness or inability of the family to cope at home. This was an important observation and three points are worth highlighting in this respect. First, on a medical note, the proportion of individuals experiencing such complications would not be expected to differ systematically between the two clinics, i.e. there will be a core of children who must always be managed in hospital at diagnosis, regardless of the clinic's core model of management. This finding is therefore consistent with the observations and recommendations of Gearhart and Forbes (1995) and Kostraba *et al.*(1992). Second, on a methodological note, children and their parents were not told prior to agreement to participate in the study that one of the variables of interest was method of management at diagnosis, i.e. the sample would not be expected to be biased towards those attending the Dundee clinic who *had* been hospitalised at diagnosis, who may have felt there were more issues relevant to the time of diagnosis and therefore have been more willing to take part in the study. Finally, and most importantly, it was the *model* of management at diagnosis within a clinic which was under evaluation, rather than the actual method of management in individual cases. If a comparison had been made between individuals who had been hospitalised and those who had not, in the total sample, then the hospitalised sample would have an over-representation of children with severe hyperglycaemia, complications etc. at diagnosis, i.e. the stressors on these children, on the whole, would have been expected to vary greatly from those who were managed on an outpatient basis. Thus comparisons were made between children attending different clinics, as initially planned.

In terms of the whole sample, children who had been hospitalised at diagnosis tended to be younger at diagnosis (on average 6.5 years compared to 9.0 years) and tended to have had their diagnosis made longer ago, suggesting that on the whole, over the two clinics, there was an increasing tendency towards home-based management over recent years, presumably as the outpatient model of management at diagnosis had become progressively more consolidated in the Dundee clinic.

Meeting the aims of the study.

The aims of the study were met: namely to assess children's illness representations of their diabetes, the stressors they encounter in connection with their diabetes, their coping responses to these stressors and their emotional reactions to their diabetes, to investigate the relationship of these variables with good emotional adaptation and diabetic control and to identify the effects of demographic and medical variables (including method of management at diagnosis) on the coping process. The results pertaining to each of these aims will be discussed in turn with particular reference to the relevant specific hypotheses derived from the Self-Regulation Model and the results of previous research and to previous literature (see Chapter 3).

Illness representations.

Perhaps the most striking finding was that every symptom was reported by at least some children in connection with their diabetes, including symptoms which had only really been included because they formed part of the standard IPQ for assessing illness representations in a wide range of conditions. So, for example, some children reported sore eyes, stiff arms and legs and upset stomachs in connection with their diabetes. Although this may have been somewhat unexpected, on further questioning some reasons were given for this, e.g. 'I get sore eyes because I have to have eye drops put in at the diabetes clinic' or 'I get stiff arms and legs because of my injection sites'. This shows the importance of using qualitative, as well as quantitative data in interpreting such findings and also highlights the complexity of children's cognitive models of illness. Another interesting finding was the high level of reporting of behavioural and psychological responses to diabetes, e.g. feeling hyperactive, experiencing mood changes and being unable to think straight, each of which were reported as occurring at least occasionally in connection with their diabetes by at least 50% of participants. This is supported by the fact that the majority of additions which children made to the symptoms list voluntarily were psychological in nature, e.g. stress, depression, jealousy, fear and embarrassment. Conversely, some of the physical symptoms which one might predict would be more frequently associated with diabetes were reported with surprisingly low frequency, e.g. only 30% of the children studied reported ever feeling pain because of their diabetes, despite having to take daily insulin injections and carry out regular blood tests. These findings highlight the fact that children's beliefs and concerns about their illness may be qualitatively different than we, as adults, might predict.

The most commonly held beliefs concerning the cause of diabetes were essentially medically-based, i.e. genetics, germs and bad luck. If we assume that children do not distinguish between germs and viruses, then genetics and viruses are the two predominant hypotheses in the medical profession at present (Kaufman, 1997) and 'luck' may refer to the additional variance in aetiology which neither of these factors explains at present. Since these are also the possibilities often mentioned to families by clinic staff when children are diagnosed, the children appeared to have the models of causation of diabetes which the medical profession might endorse or encourage. It was encouraging that very few children blamed themselves for the onset of their diabetes by attributing this to factors within their control, such as not looking after themselves, eating the wrong food or worrying.

Although it was not possible to draw precise conclusions from the overall IPQ scale scores, on the whole children did hold a reasonably realistic model of their diabetes as a chronic condition although many believed it could be controlled a little better if they did additional things to help this. Anecdotally, several children believed in the possibility of new cures (including non-injectable insulin) in the future and the some of the children studied by Curson (1998) offered similar hopes. Although the majority of children did not see their diabetes as a major problem, and believed that it was getting easier to live with, over time, a significant proportion believed that both they and others saw them as different because of their diabetes. This finding should lead us to question the often quoted information in clinics and literature that 'life can be just the same as before, but you'll just have to watch what you eat and take injections for the rest of your life'. Clearly, such a model does not match up with childrens' own experience and beliefs and it may be more advisable to give them realistic expectations, based on the experience of others rather than medical optimism, from the outset.

Despite these general findings, with very few exceptions there were children who had apparent misconceptions and who were unsure about all possible causes, timelines, consequences and controllability/cure of their diabetes and the overall levels of uncertainty were significant. These observations have important clinical implications (see Section 6.3).

Illness representation components were not independent in the children studied, as has also been found in previous research with both adults and children

(Croft, 1997; Weinman *et al.*, 1996; Williams, 1995). Rather, children's ideas concerning their diabetes tended to be inter-related and again, this supports the Self-Regulation Model's postulation and the results of previous research that illness representations comprise a complex set of inter-related ideas and concepts. In the current study children who reported a wide range of possible causes for their diabetes also believed it to have more symptoms and to lead to more serious consequences. This suggests that some children have more well-developed, wide-ranging illness representations than others, on the whole, and it would be interesting to investigate whether this correlation was stronger in older, more cognitively mature, children than in youngsters. In the main previous study using the IPQ, Weinman *et al.* found additional correlations between perceived timeline and (a) control/cure and (b) consequences in a sample of 143 adults who had experienced a Myocardial Infarction. It is probable that these differences in findings are due to the age difference between the two samples and to fundamental differences between the two conditions studied. Unfortunately, a more closely matched study is not available at present for comparison of the current results although it is intended to use the study of Curson (1998), currently in preparation, as a comparator at a later date.

Coping.

The most commonly reported stressors for children were trying to limit their consumption of sweets, dealing with hypoglycaemia and doing injections, although the number reporting the latter was probably inflated by prompting from the interviewer if no other stressor had been identified. Closely behind these was being teased or bullied about their diabetes, generally by children in the school setting or by friends at home. There were also a significant number of miscellaneous stressors, all of which support the notion of diabetes as involving a wide range of stressors and challenges to the sufferer (Kovacs, 1990; Reid, Dubow & Carey, 1995). Avoiding hyperglycaemia, which is generally listed as the primary medical target for diabetes management (e.g. Kaufman, 1997) was the least commonly reported stressor, again supporting the notion that children's perceptions of diabetes, and priorities, differ markedly from those of the medical profession. It would thus be interesting to see whether medical staff were able to predict children's illness representations and concerns and any differences between these and their own concerns (see Section 6.3).

The ten coping strategies assessed using the KIDCOPE were found to be independent of each other and the most common was the avoidance strategy *wishful thinking*. With the exception of this single strategy, there was very little use of avoidance coping strategies overall and approach strategies predominated, as has been found in previous research (e.g. Reid, Dubow and Carey, 1995). It is interesting to compare the relative frequencies of reported use of each coping strategy with those found by the KIDCOPE's authors in a sample of 34 children aged 12-18 attending a diabetes camp in the United States (see Table 6.1).

Table 6.1: Frequencies of reported use of coping strategies using the KIDCOPE (Spirito, Stark & Williams, 1988).

COPING STRATEGY	**% OF CHILDREN REPORTING**	
	Spirito, Stark & Williams	Current study
Resignation	59	12
Cognitive restructuring	56	57
Wishful thinking	47	83
Emotional regulation	41	65
Problem solving	35	60
Distraction	29	60
Social support	29	58
Social withdrawal	18	49
Self criticism	9	15
Blaming others	9	13

Although the overall levels of reporting of each coping strategy were significantly higher in the current sample, the relative frequency of reporting of each strategy showed some similarity between the two samples. In fact, the order of frequency was identical, with only two exceptions: first, resignation was the most commonly reported coping strategy in the Spirito, Stark and Williams sample but the least commonly reported in the current study. However, this observation may be due to the fact that in the current study many of the younger children made little sense of this item since it was the last KIDCOPE item and asked 'did you do nothing at all about the problem, because there was nothing you could do?' when the children had just reported several things they had done in response to the other items. Several children were confused by this and asked for guidance on this item and if they had ticked other coping strategies, they were encouraged by the researcher to respond 'no', since they had clearly done *something* in an attempt to cope with the stressor. The Spirito, Stark and Williams sample were older and may not have had this problem so frequently and thus not received such guidance. The second difference between the results of the two studies was that although the absolute levels of reporting of coping by cognitive restructuring were almost identical in both samples, cognitive restructuring was the second most common coping strategy in the U.S. sample but fell approximately half way down the list in terms of frequency in the current sample. Again, this may have been due to the age difference between the two samples, since higher levels of cognitive coping have been noted in older children previously (Band, 1990; Reid, Dubow & Carey, 1995).

Emotional reactions.

The levels of diabetes-related anxiety found in this sample were no higher than would be expected for children in this age range from the norms for the STAI-C. Levels of externalising behaviour and overall behaviour problems were also within the normal range although high levels of internalising behaviour were seen in nearly four times as many children as would be expected from the norms. This effect is in line with the findings of Wysocki *et al.* (1989) concerning parental reports of pre-school children's behaviour but has so far not been documented in school-aged children. It appeared to be predominantly due to the high number of somatic complaints that the children's parents reported them to make, particularly in the two years following diagnosis (see the section below on developmental effects). Since this was a clinically identified sample, this result is not entirely surprising, particularly since many of the children themselves had reported some of these symptoms (e.g. dizziness, tiredness, aching, headaches, nausea and stomach aches) in connection with their diabetes. However, a post-hoc analysis showed that the children's reported IPQ symptom scores did not correlate significantly with parental reports of their child's somatic complaints on the CBCL (Spearman's r = 0.12, ns). One explanation for this finding may be that the when children have a chronic disease, their parents tend to be more vigilant of bodily symptoms, regardless of their origin. If this is the case then it would be interesting to assess parental anxiety levels since high levels of vigilance tend to be associated with high levels of anxiety. Another possibility is that children with diabetes do in fact have more somatic complaints, which are linked with their diabetes but they do not associate with the diabetes themselves, i.e. they do not report these on the IPQ but will complain in general to their parents. In general, however, the lack of extreme emotional reactions found in this sample of children, despite the wide range of stressors they reported having to cope with, confirms the view of Compas (1987) that children are more resilient than may be predicted in the face of chronic stress.

Influences on emotional reactions and diabetic control.

Contradictory to previous research evidence, neither diabetic control nor behaviour problems were found to be related to any of the cognitive, behavioural and emotional variables studied at all. Since the lack of a reliable relationship between coping strategies and diabetic control in children with diabetes was discussed in Chapter 2 and has been documented elsewhere (Hanson *et al.*, 1989; Skinner, 1987; Weist *et al.*, 1992), this finding is not unique to this study, although it does go against the predictions of the Self-Regulation Model. Other cross-sectional studies have found a similar lack of relationship between emotional reactions and diabetic control to the current study (e.g. Rovet, Erlich & Hoppe, 1987; Weist *et al.*, 1992), while a significant relationship between these variables has emerged mainly in longitudinal studies which have assessed emotional reactions immediately following diagnosis, rather than on an ongoing basis as in the current study (e.g. Thernlund *et* *al*., 1996). Further studies which have highlighted the relationship between emotional reactions and diabetic control have studied only adolescents, who are a unique group in terms of diabetes management anyway. Thus it seems necessary to take a more long-term, dynamic view of the relationship between coping and diabetic control than the design of the current study permits and to include a wider age range in the sample studied.

Despite this lack of relationship between cognitions, coping and behaviour problems, perhaps the most striking result of the study was that diabetes-related anxiety was strongly associated with both illness representation components and diabetes-related coping strategies. More specifically, children reporting high levels of diabetes-related anxiety were more likely to perceive many symptoms in relation to their diabetes and to attribute the onset of their condition to a wide range of causes. They were also more likely to cope by blaming others for their problem or by seeking social support from friends or family members when facing a diabetes-related stressor. Due to the cross-sectional nature of this study it is unfortunately not possible to determine the causal nature of these relationship, so several possibilities will be considered here. One explanation is that children who are highly anxious about their diabetes may be more likely to be vigilant concerning its symptoms and thus to identify more symptoms, and to seek more explanations for their condition. They may also be more likely to either seek out others when their diabetes causes them problems, rather than facing the difficulties themselves, or to blame these difficulties on others. Alternatively, it is possible that believing that diabetes has many symptoms and causes leads one to become more anxious and that blaming others and seeking social support have similar elevating effects on anxiety. In reality it is likely that the direction of causality differs for different cognitions and coping behaviours, both in general and in individual children, or that there is a reciprocal relationship between the variables, i.e. both of the above possibilities may be partially correct. It is therefore important to make a full assessment of any individual child before making any clinical decisions regarding management (see Section 6.3).

Developmental effects.

The main developmental effects seen concerned illness representations, with older children perceiving their diabetes to be more controllable than younger children, i.e. believing that their diabetes was influenced by their own behaviour, rather than simply luck as more younger children were inclined to believe. This finding is consistent with very recent results by Curson (1998), who studied 8-18 year olds using the same assessment tools, and appears to be evidence for the progressive development of an internal Locus of Control (as defined by Rotter, 1990) for the management of diabetes by children. It is important to note the contrast between holding the belief that one can *control* a condition and the causal attributions one might make concerning the *cause* of that condition (as noted earlier, the children studied tended to make external attributions for the cause of their diabetes). This hypothesis is important since internal Locus of Control has been shown to be associated with adaptive coping in general (Blanchard-Fields & Irion, 1988; Harkapaa, 1991; Parkes, 1984) and with improved health behaviour (Skinner, 1997) and metabolic control (Hagglof *et al.*, 1994) in children and adolescents with diabetes. Furthermore, this relationship has been shown to change with age, at least in an adult sample (Blanchard-Fields & Irion, 1988).

In addition there was a tendency for older children to have more clearly defined illness representations, i.e. to have less uncertainties for certain IPQ items and this was supported by adding the total number of uncertainties for all IPQ items for older and younger children: 7-11 year old children reported 30% more uncertainties than 11-14 year olds did. Again, this observation supports the Self-Regulation's notion of illness representations as one element in a dynamic process which evolves and becomes consolidated with new experiences of bodily sensations, illness experience (both personal and vicarious), information, cultural experience and interaction with others, including the medical profession (Marteau, 1985; Johnston *et al.*, 1990) which one would expect to occur with age. Within a developmental framework, this means that ideas regarding illness will become updated as cognitive development progresses and the child is able to make more complex sense of the world about him/her, including their illness and thus that the illness representation becomes more clearly defined.

There was thus some evidence to support a developmental framework for illness representations, although a number of effects which might have been predicted were not found. For example, no overall differences in perceived identity, causes, timeline or consequences of diabetes were found between children of different ages and only four of the 26 IPQ items showed even a tendency to differ between older and younger children. The contrast between this and the results of Curson (1998), who found strong developmental effects, may be due to the fact that Curson used three age ranges (8-11, 12-15 and 16-18) and studied a wider age range overall than the current study did. Previous literature has consistently highlighted the changes which occur in illness representations, coping and diabetic control in older adolescents (e.g. Brink, 1997; Skinner, 1998) and the current study would not have been able to detect these, due to the restricted age range studied. In addition, the studies which have documented developmental changes in illness representations in most detail (e.g. Bibace & Walsh, 1980; Schmidt & Weishaupt, 1990) used qualitative assessment methods and also tended to investigate children's representations of acute conditions such as colds, measles, headaches and injuries, rather than of chronic illness. The results of Schmidt and Weishaupt, in particular, highlight the fact that illness representations do differ depending on the medical attributes of the condition studied.

In contrast with the findings of some previous studies (summarised by Reid, Dubow and Carey, 1995), but in line with these Reid, Dubow and Carey's own study no difference in the total number of reported coping strategies was found between younger and older children. One more, this may be due to the fact that previous studies investigated different age groups (Reid, Dubow and Carey do not specify the ages of the children studied in the research which they summarise) while Reid, Dubow and Carey themselves used similar age ranges to the current study, with the age cut-off at 12 years. The current results did contradict some of the other results of the Reid, Dubow and Carey study, however, as well as those of Band (1990) in that no age difference in the use of approach coping was found. The only coping effect seen was that younger children were more likely to report coping with diabetes-related stressors by emotional regulation than older children were and this appeared to be due to a higher level of reported coping by keeping calm, rather than by venting emotions. Whether this was a true difference, or whether younger children simply succumbed to perceived pressure to report that they used such a coping strategy, which adults may have tended to tell them to do, more, was not certain. However, there were no other suggestions of social desirability in responses to other items which would support this possibility. The lack of a strong relationship between coping as assessed using the KIDCOPE and age has also been documented by Weist *et al.* (1992) and it is possible that other assessment tools or methods, e.g. structured interview, may be more revealing of any differences which may occur.

Demographic and illness variables were found to be unrelated to anxiety concerning diabetes, but internalising behaviour was found to be more prevalent in children who had been more recently diagnosed, and appeared to decline progressively with time since diagnosis. Since this effect appeared to be mostly due to high levels of parentally reported somatic complaints, as described earlier, it may be that parents are particularly anxious and vigilant of symptoms in the period of time immediately following diagnosis, but as they become more used to coping with diabetes, this vigilance declines and thus reported somatic complaints fall. However, this speculation would require confirmation by further research (see Section 6.7). The sex differences in internalising behaviour suggested by the results of Kovacs *et al.* (1992) were not found in the current study, but externalising behaviours and overall behaviour problems were more common in boys than in girls. This finding supports the findings of Rovet, Erlich and Hoppe (1987) who, using the CBCL, also found this to be the case in boys who had developed diabetes after the age of four, i.e. the majority of the boys participating in the current study. The lack of influence of duration of illness on other psychological variables and adjustment is not unique as it has also been documented elsewhere (Kager & Holden, 1992).

One finding of the current study which has been well documented in previous studies is that younger children (aged 11 to 14 years) had significantly better diabetic control than their older peers (aged 7-11 years). Although the clinical significance of this finding in the current study must be questioned since the difference in scores was approximately one HbA1c unit, this result may be partially due to increasing self-care in children as they grow older (Thernlund *et al.*, 1996) combined with the beginnings of a decline in diabetic control which occurs towards adolescence (e.g. Allen *et al.*, 1992; Palta *et al.*, 1996). This decline has been shown to be partly due to physiological aspects of puberty and partly due to a decline in self-care during the teenage years (Thomas, Peterson & Goldstein, 1997; Skinner, 1998). Skinner thus highlights the important of research into the particular psychological issues faced in adolescence and their relationship to diabetic control.

Effects of method of management at diagnosis.

As predicted from previous research (see the review by Swift *et al.*, 1993), diabetic control did not differ between children attending a clinic with an outpatient model of management at diagnosis and those attending a clinic employing an inpatient model, being on average 9.3-9.4, i.e. slightly above the recommended level of 8.0 (Howells, 1998). However, contrary to the predictions made on the basis of limited previous research, no differences at all in illness representations, coping strategies or emotional reactions to diabetes were found between children attending the two clinics, either. The implications of this result are discussed in Section 6.4.

Note.

In interpreting the above results, it is important to remember that although on the whole illness representations, coping and emotional reactions were not found to be greatly influenced by each other or by demographic and illness variables, individual children did have misperceptions and uncertainties concerning diabetes, did cope in potentially maladaptive ways, did experience high levels of anxiety regarding their diabetes and did display elevated levels of both internalising and externalising behaviour problems. Thus an individual approach to diabetes management must be borne in mind and intervention in each case tailored to the specific needs of the child.

6.3 Clinical implications: Managing children in the clinic setting.

One of the clinically important findings in this study was that HbA1c levels were slightly above the recommended level of 8.0, on average and particularly in the older children (11-14 year olds). This may be partly due to the physiological effects of development towards puberty but it may also be influenced by children becoming increasingly responsible for managing their own diabetes as they become less dependent on their parents and it once again highlights the particular issues regarding management during adolescence. In this regard it may be particularly useful to have a young adult clinic, where the staff are well-educated in the issues concerning adolescent diabetes and can thus help this client group most effectively.

Since certain children appear to have misunderstandings, uncertainties, inappropriate coping strategies or high levels of emotional reactions regardless of their age, age at diagnosis or the length of time they have had diabetes, (and this finding confirms the results of Kury and Rodrigue, 1995), the most important clinical consideration is that clinic staff are aware of potential individual differences regardless of these factors and assess each case on its own merits, i.e. do not assume that older children, those who have had diabetes for longer or those who were older at diagnosis will necessarily be any more accurate or confident about their diabetes than other children. In this connection, it would be interesting to assess whether the clinic staffs' perceptions of children's illness representations, perceived stressors and preferred coping strategies were accurate when compared to the data obtained from the children themselves in this study. There is some evidence that medical staffs' perceptions of childrens' illness representations are, in fact, inaccurate in some respects: a recent study by Leung *et al.* (1997) showed that adolescents' perceptions of the severity of their diabetes was not correlated with objective assessments of this (a finding also made by Kury and Rodrigue, 1995), but that their physicians were unaware of this discrepancy and assumed that they were, i.e. there was a mis-match between adolescents' beliefs and physicians' perceptions of these. This confirms the results of previous findings with adults with physical problems, since Johnston (1982) has shown that fellow patients more accurately perceived patients' worries than nursing staff on the ward, who had many misperceptions. If such results were replicated in children with chronic illness, then there may be a role for staff education in order that they might target the genuine concerns of the children in their care, rather than simply the 'text book concerns' and diabetes management becomes a true collaboration between staff, children and their families. Koocher (1985) suggests that such education should involve increasing awareness of the effects of developmental level, specific stressors associated with the illness and the family context - some topics which the results of this study may shed some light on.

Such an individualised approach to assessment of chronic illness in children must carry over to treatment as well, in light of the finding by Curson (1998) that parental illness representations differ significantly from their diabetic child's, so that misunderstandings and uncertainties may remain if the clinical management work is carried out primarily through the parents. Such an approach to management would permit staff to take account of variation in children's cognitive abilities in giving their education, as described above, rather than simply tailoring interventions to the child's chronological age. Anecdotally, it was noted in the course of the current study that some of the clinic staff did not address education directly, particularly with some of the children whom they considered to be developmentally delayed, but always worked through the parents. This observation was confirmed by the fact that on several occasions the staff did not believe such children would be suitable for the study, implying that they did not believe they would have their own ideas and coping strategies for dealing with their diabetes. In fact, in nearly every instance the child was recruited into the study and was able to respond to the questions, albeit on a lower developmental level than others of his or her age.

The surprising salience of the psychological aspects of diabetes to the children themselves suggests that perhaps more time should be allocated to identifying and addressing such issues in the course of clinical work. In addition, it was noted that there was a considerable overlap between the symptoms children reported in connection with their diabetes on the IPQ and some of the anxiety symptoms assessed by the STAI-C. Although not a major finding of this study, it would be important to make sure that children and their parents were aware of this potential overlap, where deemed necessary, and again, some staff training in this respect may be useful. The finding that children's somatic complaints are reported by parents more often shortly after diagnosis and decline with time further highlights the importance of explaining very clearly to children and their parents what the symptoms of diabetes are and giving them realistic expectations from the beginning. This may serve to reduce anxiety if this is due to high levels of vigilance concerning symptoms, or to reduce vigilance concerning symptoms if this is due to high levels of anxiety. However, it is possible that such a stage of heightened anxiety and vigilance may be adaptive in the early stages and may even be essential for adaptive coping and long-term adjustment to diabetes, as has been found in diabetes (Hagglof, 1994) and in other chronic conditions such as asthma (Dahlem, Kinsman & Horton, 1977; Williams, 1995).

6.4 Clinical implications: Management at diagnosis.

This was an important study because no previous research had been carried out comparing the psychological effects of managing children under a model of outpatient management at diagnosis with the more traditional model of hospitalisation. The only randomised controlled study, carried out in Finland, compared long durations of hospitalisation with shorter stays such as those which are already routinely employed in the U.K. (Simell *et al.*, 1991) and was therefore not directly applicable to the U.K. context. In addition, this study was the first comparative study to investigate aspects of children's self-reported adaptation within a specific psychological framework. The results were highly consistent in suggesting that there are no long-term effects on either diabetic control or any of the variables studied here of managing children on an outpatient basis rather than by the traditional inpatient method. However, the fact that there is mounting evidence that longer-term medical outcomes such as re-hospitalisation rates are improved by outpatient management at diagnosis does suggest that some psychological or behavioural variables must be influenced by treatment in this early stage. Since the variable studied in the current study were not found to be associated with diabetic control anyway, further studies including additional child and family variables would be required in order to recommend one method of management over the other. It would also seem appropriate to study the period immediately following diagnosis, which was not included in the current study. In particular, if it were possible then a randomised controlled study with a wide range of outcomes, beginning immediately following diagnosis, would be desirable. Such a study would be difficult to organise and it would be extremely difficult, if not impossible, to keep the researcher blind as to the method of treatment of each child since interviews would be required during the first few days following diagnosis, when the child would be in hospital if randomised to this group and at home if not. An alternative method of assessing such effects would be to introduce an outpatient model of management in a clinic which had previously admitted children to hospital at diagnosis and to study the children diagnosed for the periods immediately prior to and following this change, although such a method would entail the same problems of possible researcher bias.

The child-specific variables which might be included in such a study which have been highlighted as important in previous work include self efficacy for diabetes treatment (Howells, 1988), problem-solving abilities (Donaldson, 1996; Howells, 1998) and Locus of Control for the management of diabetes, as highlighted by Hagglof *et al.* (1994) and the results of the current study. In terms of family adaptation, Thernlund *et al.* (1996) have shown that maternal reactions such as distress and anxiety concerning injections in the period immediately following diagnosis were strongly associated with similar reactions in the child at this time. In addition, diabetes-related anxiety (e.g. concerning injections) in both mothers and children at this early stage was associated with good diabetic control and psychological adjustment 10 months later, while generalised distress and anxiety in either parent or child led to far worse outcomes. In addition, paternal reactions to the diagnosis were associated with diabetic control in their adolescent offspring. This study therefore highlights the importance of addressing generalised and diabetes-related anxiety in family members soon after diagnosis in future studies and Shapiro (1983) reviews theoretical models which may be used to guide such an investigation.

For the present, however, the results of this study show that there appear to be no long-term adverse reactions on the child's illness representations, coping strategies or psychological adjustment due to management under either model at diagnosis. The model of choice in a given clinic will presumably remain dependent partly on resources, although recent evidence has suggested that outpatient management may be affordable given the decrease in cost due to a reduction in subsequent readmissions which has been identified (Bingley, Thomas & Gale, 1990; Charron-Prochownick *et al*, 1997; Lee, 1992; McNally *et al*., 1991; Paton, Andrew & Latham, 1991; Swift *et al*., 1993), particularly if hospital beds are closed as a result (Howie, 1998; Kostraba *et al.*, 1992). A further factor is geographical spread of the catchment area of the clinic, since outpatient management would be significantly more expensive in a large, rural area than in a densely populated city, given the high level of home visits by diabetes nurse specialists which are necessary in order to manage newly diagnosed children at home. Even if an outpatient model were practical given these considerations, there would be certain individuals who would still require admission, as appeared to have been the case in the Dundee sample in this study (Gearhart & Forbes, 1995; Kostraba *et al.*, 1992).

It is possible that the quality of input at diagnosis is more important in influencing the child's subsequent coping than the actual method of management at diagnosis and there was certainly a high level and quality of input in the two clinics studied. Regardless of the method of management, it is important to address children's misconceptions and uncertainties about diabetes during the early phase following diagnosis and in the subsequent period, and to encourage adaptive coping, as described in Section 6.3 (above).

6.5 Theoretical implications.

The main finding of the current study in terms of the Self-Regulation Model was that both illness representations and coping strategies were associated with diabetes-related anxiety, i.e. that the 'objective' and the 'emotional' pathways of the model are not independent as suggested in Figure 2.1 (p.14). This supports previous research findings (e.g. Allen *et al.*, 1984; Curson, 1998; Williams, 1995) and is additional evidence that the feedback loops which the model's authors have more recently added to the model are, in fact, necessary (Leventhal, Diefenbach & Leventhal, 1992). The lack of additional relationships between variables does not lend further support to the model, however. The most similar study to the current one, by Curson (1998) found different results in 8-18 year olds with Type I diabetes, where strong links between illness representations, coping and emotional reactions were demonstrated, thus providing more support for the Self-Regulation Model than the current results did. Perhaps this is due to a wider age range leading to more variation in the variables of interest in Curson's study and to the fact that she split her sample into three age groups rather than two. It would appear that the Self-Regulation Model provides a useful framework in which to investigate the psychological effects of chronic disease, but has not yet, to date, been operationalised in a standard way which would lead it towards the status of a theory, rather than a model.

Despite this, the current study did demonstrate that individual components of the Self-Regulation Model may be usefully investigated within a developmental framework and this supports the results of Croft (1996) and Curson (1998). This is essential if further work into the coping process in children is to be carried out using this model and in providing a framework for this initial study the model has made an important contribution. In order to proceed with this endeavour, perhaps more focus on individual components of the model, e.g. illness representations, is necessary and a body of knowledge requires to be built up using similar methods and measures so that results may be comparable. Only when such processes are better understood would the likelihood of combining these findings into a coherent theory be increased.

One weakness of the Self-Regulation Model is that it does not explicitly postulate how the coping process might relate to illness outcome (in this case, diabetic control). Several authors (e.g. Earll & Johnston, 1994; Johnston, 1994; Williams, 1995) have made the assumption that such outcomes are the result of coping efforts and this assumption was investigated in the current study. However, there was no evidence that any of the cognitive or behavioural variables studied related directly to diabetic control in this case. Other studies have found similar results: for example, Weist *et al.* (1989) and Hanson *et al.* (1989). Further research investigating the relationship between the coping process and illness outcome is required and perhaps the possibility of mediating variables of this relationship should also be considered.

At present, as mentioned in Chapter 2, the most neglected aspect of the Self-Regulation Model is that of the individual's evaluation of coping, which is assumed to be central to the dynamic nature of the model. The KIDCOPE does include a scale for children to evaluate how well they think that each reported coping strategy has helped them, but unfortunately the scale's authors have not investigated this aspect of the questionnaire sufficiently to provide guidelines for its use (Spirito, Stark & Williams, 1988). This scale was included in the current study but not analysed for these reasons; however an initial scan of the data suggested that younger children tended to believe that the coping strategies they employed were more effective than older children did and it is intended to analyse this data fully at a future date. If this is indeed the case then this would provide a possible explanation for the finding of previous studies (Band, 1990; Kovacs *et* al., 1992; Reid, Dubow & Carey, 1995; Weissberg-Benchall *et al*., 1995) that levels of direct coping and adherence decrease towards adolescence, as diabetic control declines due to physiological changes and the individual may perceive that their own coping strategies are no longer effective in controlling diabetes and thus reduce their use of these strategies.

Many factors must be taken into account in attempting to operationalise the Self-Regulation Model for use with children. One important consideration, highlighted by Spirito *et al.* (1995), is that it may not be the chosen methods of coping with a single stressor (as assessed in the current study) which is important in determining outcomes, but rather the resilience and flexibility of the coping repertoire. What constitutes adaptive coping in one situation, e.g. taking injections, may not be so beneficial when coping with another stressor such as being teased about diabetes. In this respect, it may be useful to use a more general measure of diabetes-specific coping, e.g. asking children to list several diabetes-related stressors within the past month and to report which coping strategies they have used to deal with *any* of these stressors, rather than just with a specific stressor as in the KIDCOPE. However, this method would bring problems of its own in terms of reliability of reporting and Reid, Dubow and Carey (1995) have in fact found that approach and avoidance-type coping strategies do tend to be used consistently in dealing with three diabetes-related stressors which were commonly mentioned by children in the current study (social problem, diet and blood test). Thus the most appropriate method of assessment of coping strategies remains under debate.

A related consideration is whether it is really appropriate to mix measures concerning a specific diabetes-related situation (e.g. the KIDCOPE), measures concerning diabetes in general (e.g. the IPQ and the STAI-C as used in this study) and general measures (e.g. the CBCL). Should one really expect coping with a single isolated incident to be related to behaviour problems in general, or to anxiety concerning the total package of wide-ranging diabetes-related stressors? At present authors tend to select whichever measure suits their means and is practical but such considerations need to be taken into account.

6.6 Methodological considerations.

One particular strength of this study was the fact that the effects on the child him/herself were of interest and thus children themselves were asked for their views on diabetes and its associated stressors. Many of the children and parents who took part in the study commented that they particularly valued this and were especially keen to take part because of this. However, Curson (1998) assessed children's and parents' illness representations of diabetes using the IPQ and found that parents tended to view diabetes more realistically, as chronic, less controllable and having greater consequences as their children, who were more optimistic in their illness models. Since this result suggests that there is no direct link between parental and child illness representations, it is possible that the illness representations of the parents of the children in the current study may have been influenced more by the method of management at diagnosis than those of the children themselves. For this reason it may have been useful to assess illness representations in the parents of the children studied as well.

Due to practical difficulties, children in the sample were recruited in different ways and completed the study in different settings. Following the initial letter introducing the study and the information sheet being sent, the majority were approached in the clinic settings, but some of the Dundee sample were telephoned and asked whether they were willing to take part. In both samples, but primarily the Dundee sample, a minority of participants completed the questionnaires during a home visit by the researcher, although every effort was made to keep to a standardised protocol in administering the questionnaires, regardless of setting. Perhaps a bigger effect may have been expected due to the fact that in the Aberdeen sample, three individuals completed the questionnaires at home, without the supervision of the researcher. Ideally, a standardised method of recruitment and completion should have been used, or comparisons made between individuals recruited and assessed in different settings, but unfortunately the numbers in each subsample did not permit this in the current study.

The sample size obtained was satisfactory for the analyses planned and the samples from the two clinics were well-matched demographically. It would have been desirable to compare an additional demographic variable between the two clinic samples: that of social class, which may have varied between the two geographical catchment areas and is widely acknowledged to influence health outcomes (e.g. Kovacs *et al.*, 1985). This could have been done from postcode analyses or from parental occupation. However, since there were no differences in coping or outcome between the groups anyway, in retrospect it is unlikely that this was a factor, or if it was that it had any significant effect on the results of the study.

No directional hypotheses were made regarding the psychological effects of management at diagnosis since there was no adequate research evidence on which to do so. Analysis of the data were thus deliberately not carried out until all data had been collected, to avoid any experimenter bias due to prior knowledge of the results and this was considered to be a further strength of the study.

Statistically, strict significance levels were employed to allow for the large number of comparisons being made and this means that any results reported were highly significant and unlikely to be spurious. With regard to the measures used, it was unfortunate that due to the relatively recent interest in applying the Self-Regulation Model to children, there was no pre-existing data with which to compare the data obtained. In addition, only standardised measures were used and although these have their merits (Spirito, Stark & Williams, 1988), much data may be missed by using these in isolation, as highlighted in the above discussion (Section 6.1). Although attempts were made to permit children to expand on their responses in the current study, some more structured qualitative questions may have revealed some important information which was missed by the questionnaire methods. Furthermore, although this study suggests that method of management at diagnosis has no effect on the coping process, emotional adaptation or diabetic control of children attending the clinic, it must be borne in mind that a narrow range of variables was studied. Thus it would be particularly important to extend the range of emotional variables studied, since the children themselves highlighted the wide range of emotional reactions which diabetes may evoke, through their responses. In particular, it may have been useful to include an appropriate measure of depression, which was omitted because the measures completed by the children in the study were all intended to be diabetes-specific and there were no depression assessment tools which were readily adaptable for this purpose.

One of the main difficulties with the study was its cross-sectional nature, which means that no causal inferences may be made concerning the results. For example, it is not possible to explain exact nature of the relationship between illness representations, coping and diabetes-related anxiety without further investigation. Longitudinal studies are always useful in this respect but unfortunately there are very few methodologically sound ones in this field, partly because of the high levels of resources required to carry out such studies. In terms of assessing developmental differences in the coping process, it would have been desirable to assess children's cognitive level formally (e.g. by assessing IQ as done by Kury and Rodrigue, 1995), rather than to imply it by age, but unfortunately this was not possible with the time and resource restraints encountered. However in retrospect it may have been possible to gain a general estimate of cognitive level by employing a relatively quick assessment of cognitive functioning involving asking children two simple questions regarding conservation of area as Band (1990) did. This would have been particularly important in the current study since at least four of the children assessed were reported to have some learning difficulties by their parents.

A further limitation of the study was that processes in the early stages of diabetes were not studied, the focus being on long-term adaptation to diabetes instead. In fact, children who were very recently diagnosed were deliberately omitted from the study until one at least one month post-diagnosis, for ethical reasons. It must therefore not be concluded that method of management at diagnosis has no effect whatsoever on the child and the family's adaptation; rather, all that can be stated is that, within the model of coping studied, no differences in long-terms adjustment were found.

6.7 Implications for future research.

This section will briefly summarise the possibilities for future research which have been highlighted in this study, some of which have already been referred to above.

First, it would be useful to study a wider age range of children, including older adolescents and to assess their level of cognitive functioning, rather than to assume this from their chronological age. A wider range of variables, particularly in the area of emotional reactions to diabetes, would be desirable, perhaps including more qualitative measures than the scale of the present study allowed.

In addition it would be useful to assess health professionals' perceptions of the coping process in children and of developmental processes involved in this. Such a study would be best done in a very practical way, focusing on management of children within the clinic and maintaining the clinical relevance at all times. There may also be a role for evaluating staff training in this area if the results of such a study were to highlight such a need.

With regard to evaluating the possible mediating role of psychological effects in the relationship between method of management at diagnosis and medical outcomes such as re-hospitalisation rates, longitudinal studies with a wider range of variables (perhaps including measures of family adjustment to diabetes) would be necessary before drawing any firm conclusions regarding the relative merits of each model of management. It may also be possible to identify individual children and families who may benefit particularly from a particular method of management over the other. This research is crucial in terms of future medical management policies.

6.8 Conclusions.

The Self-Regulation Model has provided a useful framework in which to investigate the coping process in children with Type I diabetes and has led to some interesting and clinically valuable findings, although on the whole no strong support for the model was found. With regard to identifying possible psychological effects of method of management at diagnosis, the study revealed no differences between children in a clinic using an inpatient model of management and those attending a clinic employing an outpatient model. Further research into other possible psychological effects of management at diagnosis is required, preferably via a longitudinal study beginning close to the time of diagnosis and including a wider range of psychological variables than that in the present study.

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APPENDIX A:

INTRODUCTORY LETTER

February, 1998

Dear parent or guardian,

We enclose details of a study we would like to invite your child to take part in. We would be grateful if you would take some time to read this information and consider whether or not you would be prepared for him/her to take part in the study. Dr Julie Williams will be at the diabetes clinic when you attend next and will be prepared to discuss the study with you and answer any questions you may have before asking whether or not you agree to participate.

Yours sincerely,

Dr P. Smail
Consultant Paediatric Endocrinologist

Dr Julie Williams
Trainee Clinical Psychologist

APPENDIX B:

INFORMATION SHEET

CHILDRENS' BELIEFS ABOUT, AND RESPONSES TO, THEIR DIABETES

VOLUNTEER INFORMATION SHEET

We invite your child to participate in a research project which we believe to be of potential importance. However, before you decide whether you wish your child to participate, we need to be sure you understand firstly why we are doing it and secondly what it would involve if you agreed. We are therefore providing you with the following information. Read it carefully and be sure to ask and questions you have and, if you want, to discuss it with outsiders. We will do our best to explain and to provide any further information you may ask for now or later. You do not have to make an immediate decision.

The research aims to investigate what children with diabetes think about their illness, how they cope with it and any particular worries or anxieties they may have about their diabetes and its treatment. We will use the information to adapt the way we deal with children in the clinic so that hopefully we can help them to cope with their diabetes better.

The study is being carried out by Dr Julie Williams, trainee Clinical Psychologist, in the paediatric diabetes clinic at Aberdeen Royal Children's Hospital. All children aged 7-14 who attend the diabetes outpatient clinics in Grampian and Tayside are being approached to take part in the study.

We would like your permission for your child to complete some questionnaires. This should take no more than half an hour and could be done in the waiting room when you next attend the diabetes clinic. We will also ask you to complete a short questionnaire about your child. In addition, we are asking permission to take information about your child's diabetic control from his/her medical notes. You will not receive individual feedback on your child's results and **your child's medical treatment will not be affected in any way, whether you agree for him/her to take part or not.** The name on your child's questionnaires will be used to match it to his/her medical notes only. All responses will remain confidential to the Psychologist - your child's consultant will never know your child's individual results. The only exception to this will be if there are serious concerns about your child's diabetes, in which case the consultant may be informed, but this would always be discussed with you as well. Your GP will not know that you are taking part in the study. You and your child will not be asked to do anything else as a result of your child's participation in the study.

The Joint Ethical Committee of Grampian Health Board and the University of Aberdeen that has responsibility for scrutinising all proposals for medical research on humans has examined the proposal for this study and has raised no objections to the study from the point of view of medical ethics. The committee may at any time inspect the data collected to ensure that their guidelines have been adhered to.

Participation in the study is entirely voluntary and you are free to refuse for your child to take part or to withdraw from the study at any time without having to give a reason and without this affecting your child's future medical care or your relationship with the medical staff looking after him/her.

APPENDIX C:

CHILDREN'S CONSENT FORM

CHILDRENS' CONSENT FORM

ABOUT YOUR DIABETES

We would like to ask you some questions about your diabetes. The questions will ask you what your diabetes is like, what you do about your diabetes and how you feel about your diabetes.

There are no right or wrong answers, only how you feel! So please be as honest as you can when you answer the questions because this will help us to help you and other children with diabetes better.

While you fill in your questionnaire, we would also like the adult who is with you today to fill in a questionnaire about you.

If you will help us with our study then please sign your name on the line below.

Thank you very much.

Do you agree to help with the study by filling in the questionnaires? (Please circle your answer)	Yes	No
Is it OK for the adult who is with you today to fill in the questionnaire?	Yes	No

Signed: ....

APPENDIX D:

PARENT'S CONSENT FORM

PARENT / GUARDIAN CONSENT FORM

CHILDRENS' BELIEFS ABOUT, AND RESPONSES TO, THEIR DIABETES

Name of parent/guardian: ....

Relationship to child: ....

Child's name: ....

Child's date of birth: ....

Principal Investigator: ....

I have read the patient/volunteer information sheet on the above study and have had the opportunity to discuss the details with .... and ask questions. The doctor has explained to me the nature and purpose of the questionnaires. I understand fully what is proposed to be done.

I have agreed for my child to take part in the study as it is has been outlined to me, but I understand that I am completely free to withdraw him/her from the study or any part of the study at any time I wish and that this will not affect my continuing medical treatment in any way.

I understand that these trials are part of a research project designed to promote medical knowledge, which has been approved by the Joint Ethical Committee, and may be of no benefit to me personally.

I hereby fully and freely consent for my child to participate in the study which has been fully explained to me.

Signature of parent/guardian: ....

Date : ....

I confirm that I have explained to the patient/volunteer named above, the nature and purpose of the questionnaires.

Signature of Investigator: ....

Date: ....

Please note: This form must be kept in Section A of the patients notes.

APPENDIX E:

THE MODIFIED VERSION OF THE IPQ
(BASED ON WEINMAN *ET AL.*, 1996)

WHAT YOUR DIABETES IS LIKE

- We would like to find out about your diabetes. Please answer the following questions.
- There are no right or wrong answers - just answer what is most like you.
- If you are not sure of an answer then please guess as well as you can - we will not mind, in fact this is better than asking someone else what they think!

Children can feel different things because of their diabetes.
How often do you feel these things *because of your diabetes*?
Please tick the box that is most like you.

	Always	**Quite a lot**	**A little bit**	**Never**
I feel thirsty				
I feel pain				
I feel faint				
I feel sick				
I find it hard to breathe				
I get thinner				
I need to go to the toilet a lot				
I feel tired				
My arms and legs get stiff				
My mood changes				
I get sore eyes				
I get hungry				
I get a dry mouth				
I am full of energy				
I feel shaky				
I get fatter				
I get a sore head				
My heart beats faster				
I get an upset tummy				
I can't sleep				
I feel dizzy				
I can't think straight				
I feel weak				

Are there any other things that you sometimes feel *because of your diabetes* that are not on the list? If so then please write the feelings here and say how often you feel them:

	Always	Quite a lot	A little bit	Never
I feel ________________				
I feel ________________				
I feel ________________				
I feel ________________				

Put a tick in the box that is how you feel about your diabetes.

1. Do you think that bad air caused your diabetes?

Definitely yes ☐ Perhaps yes ☐ Not sure ☐ Perhaps no ☐ Definitely no ☐

2. Does your diabetes stop you doing the things your friends do?

Definitely yes ☐ Perhaps yes ☐ Not sure ☐ Perhaps no ☐ Definitely no ☐

3. Do you think that if your diabetes gets worse or better is all about luck?

Definitely yes ☐ Perhaps yes ☐ Not sure ☐ Perhaps no ☐ Definitely no ☐

4. Do you think of yourself as different because you have diabetes?

Definitely yes ☐ Perhaps yes ☐ Not sure ☐ Perhaps no ☐ Definitely no ☐

5. Do you think your diabetes will get better soon?

Definitely yes ☐ Perhaps yes ☐ Not sure ☐ Perhaps no ☐ Definitely no ☐

6. Is diabetes a serious thing to have?

Definitely yes ☐ Perhaps yes ☐ Not sure ☐ Perhaps no ☐ Definitely no ☐

7. Do you think it is someone else's fault that you've got diabetes?

Definitely yes ☐ Perhaps yes ☐ Not sure ☐ Perhaps no ☐ Definitely no ☐

8. Do you think you got diabetes because your doctor didn't look after you well?

Definitely yes ☐ Perhaps yes ☐ Not sure ☐ Perhaps no ☐ Definitely no ☐

9. Is your diabetes a problem for you?

Definitely yes ☐ Perhaps yes ☐ Not sure ☐ Perhaps no ☐ Definitely no ☐

10. Do you think getting diabetes happens in your family?

Definitely yes ☐ Perhaps yes ☐ Not sure ☐ Perhaps no ☐ Definitely no ☐

11. Do you think there are things you can do to help your diabetes?

Definitely yes ☐ Perhaps yes ☐ Not sure ☐ Perhaps no ☐ Definitely no ☐

12. Do you think you got diabetes because you worried a lot about things?

Definitely yes ☐ Perhaps yes ☐ Not sure ☐ Perhaps no ☐ Definitely no ☐

13. Is your diabetes getting easier to live with?

Definitely yes ☐ Perhaps yes ☐ Not sure ☐ Perhaps no ☐ Definitely no ☐

14. Do you think that your diabetes will go away and then come back again?

Definitely yes ☐ Perhaps yes ☐ Not sure ☐ Perhaps no ☐ Definitely no ☐

15. Do you think there are things you can do to help yourself when you feel bad because of your diabetes?

Definitely yes ☐ Perhaps yes ☐ Not sure ☐ Perhaps no ☐ Definitely no ☐

16. Do you think you got diabetes because you felt very sad about things?

Definitely yes ☐ Perhaps yes ☐ Not sure ☐ Perhaps no ☐ Definitely no ☐

17. Do you think that some types of food made you get diabetes?

Definitely yes ☐ Perhaps yes ☐ Not sure ☐ Perhaps no ☐ Definitely no ☐

18. Do you think that being naughty caused your diabetes?

Definitely yes ☐ Perhaps yes ☐ Not sure ☐ Perhaps no ☐ Definitely no ☐

19. Do you think your diabetes will get better when you are older?

Definitely yes ☐ Perhaps yes ☐ Not sure ☐ Perhaps no ☐ Definitely no ☐

20. Do you think that the medicines will make your diabetes go away?

Definitely yes ☐ Perhaps yes ☐ Not sure ☐ Perhaps no ☐ Definitely no ☐

21. Do you think you got diabetes because of bad luck?

Definitely yes ☐ Perhaps yes ☐ Not sure ☐ Perhaps no ☐ Definitely no ☐

22. Do you think you got diabetes because you did not look after yourself?

Definitely yes ☐ Perhaps yes ☐ Not sure ☐ Perhaps no ☐ Definitely no ☐

23. Do you think you will always have diabetes?

Definitely yes ☐ Perhaps yes ☐ Not sure ☐ Perhaps no ☐ Definitely no ☐

24. Do you think you caught your diabetes from a germ?

Definitely yes ☐ Perhaps yes ☐ Not sure ☐ Perhaps no ☐ Definitely no ☐

25. Do other people treat you differently because of your diabetes?

Definitely yes ☐ Perhaps yes ☐ Not sure ☐ Perhaps no ☐ Definitely no ☐

26. Do you think there are things that can be done to make your diabetes better?

Definitely yes ☐ Perhaps yes ☐ Not sure ☐ Perhaps no ☐ Definitely no ☐

27. Is your life just the same as it was before you got diabetes?

Definitely yes ☐ Perhaps yes ☐ Not sure ☐ Perhaps no ☐ Definitely no ☐

APPENDIX F:

THE KIDCOPE

(SPIRITO, STARK & WILLIAMS, 1988)

WHAT YOU DO ABOUT YOUR DIABETES

We would like to find out how children deal with problems to do with their diabetes.

Please think about something to do with your diabetes that has happened to you in the past month. Please write down that situation here:

____

____

____

____

____

____

Please circle the answers:

1. Did this situation make you nervous?

Not at all   A little bit   Somewhat   Quite a lot   Very much

2. Did this situation make you sad?

Not at all   A little bit   Somewhat   Quite a lot   Very much

3. Did this situation make you angry or mad?

Not at all   A little bit   Somewhat   Quite a lot   Very much

Now please turn to the next sheet and circle whether you used any of the following ways to help deal with the problem.

YOUNGER VERSION

		Did you do this?		How much did it help?		
1.	I just tried to forget it	yes	no	Not at all	A little	A lot
2.	I did something like watch TV or played a game to forget it.	yes	no	Not at all	A little	A lot
3.	I stayed by myself.	yes	no	Not at all	A little	A lot
4.	I kept quiet about the problem.	yes	no	Not at all	A little	A lot
5.	I tried to see the good side of things.	yes	no	Not at all	A little	A lot
6.	I blamed myself for causing the problem.	yes	no	Not at all	A little	A lot
7.	I blamed someone else for causing the problem.	yes	no	Not at all	A little	A lot
8.	I tried to fix the problem by thinking of answers.	yes	no	Not at all	A little	A lot
9.	I tried to fix the problem by doing something or talking to someone.	yes	no	Not at all	A little	A lot
10.	I yelled, screamed, or got mad.	yes	no	Not at all	A little	A lot
11.	I tried to calm myself down.	yes	no	Not at all	A little	A lot
12.	I wished the problem had never happened.	yes	no	Not at all	A little	A lot
13.	I wished I could make things different.	yes	no	Not at all	A little	A lot
14.	I tried to feel better by spending time with others like family, grownups, or friends.	yes	no	Not at all	A little	A lot
15.	I didn't do anything because the problem couldn't be fixed.	yes	no	Not at all	A little	A lot

APPENDIX G:

THE STATE-TRAIT ANXIETY INVENTORY
FOR CHILDREN (STAI-C)
(SPIELBERGER, 1973)

HOW YOU FEEL ABOUT YOUR DIABETES

Here are some sentences which boys and girls use to describe themselves. Read each one and decide whether it is *hardly ever, sometimes or never* true for you *when you feel bad because of your diabetes.* Tick the box which seems to describe you best. There are no right or wrong answers. Do not spend too much time on each sentence.

Remember, choose the word which seems to best describe how you usually feel *when you feel bad because of your diabetes.*

When I feel bad because of my diabetes.......

1. I worry about making mistakes . . . . ☐ hardly-ever ☐ sometimes ☐ often
2. I feel like crying . . . . ☐ hardly-ever ☐ sometimes ☐ often
3. I feel unhappy . . . . ☐ hardly-ever ☐ sometimes ☐ often
4. I have trouble making up my mind . . . ☐ hardly-ever ☐ sometimes ☐ often
5. It is difficult for me to face my problems . ☐ hardly-ever ☐ sometimes ☐ often
6. I worry too much . . . . ☐ hardly-ever ☐ sometimes ☐ often
7. I get upset at home . . . . ☐ hardly-ever ☐ sometimes ☐ often
8. I am shy . . . . ☐ hardly-ever ☐ sometimes ☐ often
9. I feel troubled . . . . ☐ hardly-ever ☐ sometimes ☐ often
10. Unimportant thoughts run through my mind and bother me . . . . ☐ hardly-ever ☐ sometimes ☐ often
11. I worry about school . . . . ☐ hardly-ever ☐ sometimes ☐ often
12. I have trouble deciding what to do . . . ☐ hardly-ever ☐ sometimes ☐ often
13. I notice my heart beats fast . . . . . . ☐ hardly-ever ☐ sometimes ☐ often
14. I am secretly afraid . . . . ☐ hardly-ever ☐ sometimes ☐ often
15. I worry about my parents . . . . ☐ hardly-ever ☐ sometimes ☐ often
16. My hands get sweaty . . . . ☐ hardly-ever ☐ sometimes ☐ often
17. I worry about things that may happen . . ☐ hardly-ever ☐ sometimes ☐ often
18. It is hard for me to fall asleep at night . ☐ hardly-ever ☐ sometimes ☐ often
19. I get a funny feeling in my stomach . . . ☐ hardly-ever ☐ sometimes ☐ often
20. I worry about what others think of me . ☐ hardly-ever ☐ sometimes ☐ often

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APPENDIX H:

THE CHILD BEHAVIOUR CHECKLIST (CBCL)
(ACHENBACH, 1991)

CHILD BEHAVIOR CHECKLIST FOR AGES 4-18

For office use only
ID #

D'S
E

Boy ☐ Girl

AGE

ETHNIC
GROUP
OR RACE

Y'S DATE

______ Date______ Yr. ________

CHILD'S BIRTHDATE

Mo. ________ Date ________ Yr. ________

DE IN
OOL ______

ATTENDING
OOL ☐

Please fill out this form to reflect *your* view of the child's behavior even if other people might not agree. Feel free to write additional comments beside each item and in the spaces provided on page 2.

PARENTS' USUAL TYPE OF WORK, even if not working now. *(Please be specific—for example, auto mechanic, high school teacher, homemaker, laborer, lathe operator, shoe salesman, army sergeant.)*

FATHER'S
TYPE OF WORK: ____________________

MOTHER'S
TYPE OF WORK: ____________________

THIS FORM FILLED OUT BY:

☐ Mother (name): ____________________

☐ Father (name): ____________________

☐ Other—name & relationship to child: ____________________

Please list the sports your child most likes to take part in. For example: swimming, baseball, skating, skate boarding, bike riding, fishing, etc.

☐ None

	Compared to others of the same age, about how much time does he/she spend in each?				Compared to others of the same age, how well does he/she do each one?			
	Don't Know	Less Than Average	Average	More Than Average	Don't Know	Below Average	Average	Above Average
a. ________	☐	☐	☐	☐	☐	☐	☐	☐
b. ________	☐	☐	☐	☐	☐	☐	☐	☐
c. ________	☐	☐	☐	☐	☐	☐	☐	☐

Please list your child's favorite hobbies, activities, and games, other than sports. For example: stamps, dolls, books, piano, crafts, cars, singing, etc. (Do not include listening to radio or TV.)

☐ None

	Compared to others of the same age, about how much time does he/she spend in each?				Compared to others of the same age, how well does he/she do each one?			
	Don't Know	Less Than Average	Average	More Than Average	Don't Know	Below Average	Average	Above Average
a. ________	☐	☐	☐	☐	☐	☐	☐	☐
b. ________	☐	☐	☐	☐	☐	☐	☐	☐
c. ________	☐	☐	☐	☐	☐	☐	☐	☐

Please list any organizations, clubs, teams, or groups your child belongs to.

☐ None

	Compared to others of the same age, how active is he/she in each?			
	Don't Know	Less Active	Average	More Active
a. ________	☐	☐	☐	☐
b. ________	☐	☐	☐	☐
c. ________	☐	☐	☐	☐

Please list any jobs or chores your child has. For example: paper route, babysitting, making bed, working in store, etc. (Include both paid and unpaid jobs and chores.)

☐ None

	Compared to others of the same age, how well does he/she carry them out?			
	Don't Know	Below Average	Average	Above Average
a. ________	☐	☐	☐	☐
b. ________	☐	☐	☐	☐
c. ________	☐	☐	☐	☐

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1-91 Edition

1. About how many close friends does your child have? ☐ None ☐ 1 ☐ 2 or 3 ☐ 4 or more
(Do not include brothers & sisters)

2. About how many times a week does your child do things with any friends outside of regular school hours?
(Do not include brothers & sisters) ☐ Less than 1 ☐ 1 or 2 ☐ 3 or more

---

Compared to others of his/her age, how well does your child:

	Worse	About Average	Better	
a. Get along with his/her brothers & sisters?	☐	☐	☐	☐ Has no brothers or sisters
b. Get along with other kids?	☐	☐	☐	
c. Behave with his/her parents?	☐	☐	☐	
d. Play and work by himself/herself?	☐	☐	☐	

---

1. For ages 6 and older — performance in academic subjects. If child is not being taught, please give reason ______________________________

	Failing	Below average	Average	Above average
a. Reading, English, or Language Arts	☐	☐	☐	☐
b. History or Social Studies	☐	☐	☐	☐
c. Arithmetic or Math	☐	☐	☐	☐
d. Science	☐	☐	☐	☐
e. ______________	☐	☐	☐	☐
f. ______________	☐	☐	☐	☐
g. ______________	☐	☐	☐	☐

r academic
ects — for ex-
le: computer
ses, foreign
uage, busi-
. Do *not* in-
e gym, shop,
r's ed., etc.

---

2. Is your child in a special class or special school? ☐ No ☐ Yes — what kind of class or school?

---

3. Has your child repeated a grade? ☐ No ☐ Yes — grade and reason

---

4. Has your child had any academic or other problems in school? ☐ No ☐ Yes — please describe

When did these problems start?

Have these problems ended? ☐ No ☐ Yes — when?

---

s your child have any illness, physical disability, or mental handicap? ☐ No ☐ Yes — please describe

---

t concerns you most about your child?

---

se describe the best things about your child:

Below is a list of items that describe children and youth. For each item that describes your child **now or within the past 6 months**, please circle the **2** if the item is **very true** or **often true** of your child. Circle the **1** if the item is **somewhat** or **sometimes true** of your child. If the item is **not true** of your child, circle the **0**. Please answer all items as well as you can, even if some do not seem to apply to your child.

0 = Not True (as far as you know) **1 = Somewhat or Sometimes True** **2 = Very True or Often True**

1 2 1. Acts too young for his/her age
1 2 2. Allergy (describe): ______
______
1 2 3. Argues a lot
1 2 4. Asthma
1 2 5. Behaves like opposite sex
1 2 6. Bowel movements outside toilet
1 2 7. Bragging, boasting
1 2 8. Can't concentrate, can't pay attention for long
1 2 9. Can't get his/her mind off certain thoughts; obsessions (describe): ______
______
1 2 10. Can't sit still, restless, or hyperactive
1 2 11. Clings to adults or too dependent
1 2 12. Complains of loneliness
1 2 13. Confused or seems to be in a fog
1 2 14. Cries a lot
1 2 15. Cruel to animals
1 2 16. Cruelty, bullying, or meanness to others
1 2 17. Day-dreams or gets lost in his/her thoughts
1 2 18. Deliberately harms self or attempts suicide
1 2 19. Demands a lot of attention
1 2 20. Destroys his/her own things
1 2 21. Destroys things belonging to his/her family or others
1 2 22. Disobedient at home
1 2 23. Disobedient at school
1 2 24. Doesn't eat well
1 2 25. Doesn't get along with other kids
1 2 26. Doesn't seem to feel guilty after misbehaving
1 2 27. Easily jealous
1 2 28. Eats or drinks things that are not food — *don't* include sweets (describe): ______
______
1 2 29. Fears certain animals, situations, or places, other than school (describe): ______
______
1 2 30. Fears going to school

0 1 2 31. Fears he/she might think or do something bad
0 1 2 32. Feels he/she has to be perfect
0 1 2 33. Feels or complains that no one loves him/her
0 1 2 34. Feels others are out to get him/her
0 1 2 35. Feels worthless or inferior
0 1 2 36. Gets hurt a lot, accident-prone
0 1 2 37. Gets in many fights
0 1 2 38. Gets teased a lot
0 1 2 39. Hangs around with others who get in trouble
0 1 2 40. Hears sounds or voices that aren't there (describe): ______
______
0 1 2 41. Impulsive or acts without thinking
0 1 2 42. Would rather be alone than with others
0 1 2 43. Lying or cheating
0 1 2 44. Bites fingernails
0 1 2 45. Nervous, highstrung, or tense
0 1 2 46. Nervous movements or twitching (describe):
______
______
0 1 2 47. Nightmares
0 1 2 48. Not liked by other kids
0 1 2 49. Constipated, doesn't move bowels
0 1 2 50. Too fearful or anxious
0 1 2 51. Feels dizzy
0 1 2 52. Feels too guilty
0 1 2 53. Overeating
0 1 2 54. Overtired
0 1 2 55. Overweight

56. Physical problems without known medical cause:
0 1 2 a. Aches or pains (*not* headaches)
0 1 2 b. Headaches
0 1 2 c. Nausea, feels sick
0 1 2 d. Problems with eyes (describe): ______
______
0 1 2 e. Rashes or other skin problems
0 1 2 f. Stomachaches or cramps
0 1 2 g. Vomiting, throwing up
0 1 2 h. Other (describe): ______
______

Please see other side

0 = Not True (as far as you know) 1 = Somewhat or Sometimes True 2 = Very True or Often True

2 57. Physically attacks people
2 58. Picks nose, skin, or other parts of body (describe): ________

____

1 2 59. Plays with own sex parts in public
1 2 60. Plays with own sex parts too much

1 2 61. Poor school work
1 2 62. Poorly coordinated or clumsy

1 2 63. Prefers being with older kids
1 2 64. Prefers being with younger kids

1 2 65. Refuses to talk
1 2 66. Repeats certain acts over and over; compulsions (describe): ________

____

1 2 67. Runs away from home
1 2 68. Screams a lot

1 2 69. Secretive, keeps things to self
1 2 70. Sees things that aren't there (describe):

____

____

1 2 71. Self-conscious or easily embarrassed
1 2 72. Sets fires

1 2 73. Sexual problems (describe): ________

____

____

1 2 74. Showing off or clowning

1 2 75. Shy or timid
1 2 76. Sleeps less than most kids

1 2 77. Sleeps more than most kids during day and/or night (describe): ________

____

1 2 78. Smears or plays with bowel movements

1 2 79. Speech problem (describe): ________

____

1 2 80. Stares blankly

1 2 81. Steals at home
1 2 82. Steals outside the home

1 2 83. Stores up things he/she doesn't need (describe): ________

____

0 1 2 84. Strange behavior (describe): ________

____

0 1 2 85. Strange ideas (describe): ________

____

0 1 2 86. Stubborn, sullen, or irritable

0 1 2 87. Sudden changes in mood or feelings
0 1 2 88. Sulks a lot

0 1 2 89. Suspicious
0 1 2 90. Swearing or obscene language

0 1 2 91. Talks about killing self
0 1 2 92. Talks or walks in sleep (describe): ________

____

0 1 2 93. Talks too much
0 1 2 94. Teases a lot

0 1 2 95. Temper tantrums or hot temper
0 1 2 96. Thinks about sex too much

0 1 2 97. Threatens people
0 1 2 98. Thumb-sucking

0 1 2 99. Too concerned with neatness or cleanliness
0 1 2 100. Trouble sleeping (describe): ________

____

0 1 2 101. Truancy, skips school
0 1 2 102. Underactive, slow moving, or lacks energy

0 1 2 103. Unhappy, sad, or depressed
0 1 2 104. Unusually loud

0 1 2 105. Uses alcohol or drugs for nonmedical purposes (describe): ________

____

0 1 2 106. Vandalism

0 1 2 107. Wets self during the day
0 1 2 108. Wets the bed

0 1 2 109. Whining
0 1 2 110. Wishes to be of opposite sex

0 1 2 111. Withdrawn, doesn't get involved with others
0 1 2 112. Worries

113. Please write in any problems your child has that were not listed above:

0 1 2 ________

0 1 2 ________

0 1 2 ________

EASE BE SURE YOU HAVE ANSWERED ALL ITEMS.

UNDERLINE ANY YOU ARE CONCERNED ABOUT.