Associations between satisfaction with diabetes care, diabetic control and psychological variables in adolescents with type I insulin dependent diabetes mellitus

by

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This thesis is dedicated to my late father, 'Prof' Kevin John Roberts.

Declaration

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

Signed_ Clare Louise Roberts

Contents

ABSTRACT

Insulin Dependent Diabetes Mellitus (IDDM) is a life-long condition, which is the third most common chronic illness in young people (Metcalfe & Baum, 1991). Management of the illness includes a daily regimen of blood testing, insulin injections and careful balancing of diet and exercise (Shillitoe, 1995). In adolescence, diabetes control often deteriorates (Brink, 1997; Jacobson, Hauser, Wolsdorf, Houlihan, Herskowitz, Wertlieb & Watt, 1987). This consequently can have a detrimental effect on future physical health (Diabetes Control & Complications Trial, 1994).

A large amount of research has sought to identify the relevant variables that are indicative of good and poor adjustment to chronic illness (for example, Eiser, 1990a). Several models have been developed, including the Risk and Resistance model (Wallander & Varni, 1998), which was used to guide this study. It is hypothesised that patient satisfaction with diabetes care will act as a resilience factor and therefore be associated with better psychological well being.

Eighty-three young people between the ages of 14 and 18 attending diabetes outpatient clinics in the Lothian area were assessed, using standardised measures of patient satisfaction, quality of life, psychological well being and adaptation to diabetes. The relationships between these variables, diabetic control and the effects of age, gender and time since diagnosis were calculated.

Results are discussed in relation to the planning and evaluation of medical and psychological services for adolescents with diabetes. Finally, methodological weaknesses are highlighted and implications for future research discussed.

INTRODUCTION

The following introduction aims to set out the theoretical basis for the present research. Initially, the broad concept of chronic illness will be discussed, before focusing on the specific disorder of Insulin Dependent Diabetes Mellitus. The next section will discuss the research, which has attempted to identify the important variables associated with improved medical and psychological outcome in adolescents with Insulin Dependent Diabetes Mellitus. The concept of satisfaction will then be introduced. Finally, the basis of the present research will be summarised, providing the basis for the statement of hypotheses.

1.1 Chronic illness

1.1.1 Definitions

A number of definitions of chronic illness have been suggested (Bradford, 1997). Chronic illness can refer to disorders with a protracted course for which no cure is available (Eiser, 1990b; Tansella, 1995). Other authors have suggested that chronic illness can also be 'associated with a relatively normal life span despite impaired physical or mental functioning' (Mattsson, 1972, p.801). More recently, Wallander and Varni (1998) highlighted that a chronic condition should interfere with daily functioning.

These definitions highlight that whilst there is a general consensus regarding the components of a chronic illness, there have been differing emphases placed on the notions of 'chronicity' and 'severity' (Bradford, 1997).

The lack of agreed terminology has resulted in a wide variation in the number of young people thought to be currently living with a chronic illness. Readers can be referred to Bradford (1997) for a review of prevalence rates.

1.1.2 Disease characteristics versus non-categorical approach

There has been an increased interest in whether specific paediatric disorders differ from one another in their psychological effects (Lavigne & Faier-Routman, 1992). Two different approaches have been advocated regarding the design of research in chronic illness. One has been termed the non-categorical approach, whereby a search is made for commonalities that exist across all conditions (Pless & Pinkerton, 1975; Stein & Jessop, 1982, 1984). This assumes that regardless of the type of chronic disease, all patients share many of the same stresses and vulnerabilities (Meijer, Sinnmea, Bijstra, Mellenbergh & Wolters, 2000). Chronic illness itself has been found not to determine problem identification, thus citing evidence for the non-categorical approach (Spirito, Stark, Gil & Tyc, 1995).

The alternative approach is to research specific disorders individually (Bradley, 1994a, 1994b). Bradley, who has conducted an extensive range of research regarding people with diabetes, has advocated that it is unrealistic to seek measures of psychological outcome suitable for every patient group, when medical outcomes are different. For example, glycaemic control in diabetes cannot be appropriately compared to peak flow rates as measured in asthma (Bradley, 1994b). Furthermore the experience of pain is pertinent for a range of chronic conditions, including arthritis. However, it is not a central concern of people with, for example, diabetes, whose major fear may be of a hypoglycaemic episode.

> Thus when designing measures specifically for people with diabetes we can focus on those issues which are especially important for them and avoid irrelevancies that will cloud the picture. In this way we can produce diabetes-specific measures that have greater sensitivity than generic measures
>
> (Bradley, 1994b, p. 3)

The present study aims to follow this second approach, namely investigating the disorder of Insulin Dependent Diabetes Mellitus using specific scales.

1.1.3 Psychological effects of chronic illness in childhood and adolescence

Several reasons for an assumed increased level of psychological difficulties in young people with chronic illness have been proposed. Adolescents in particular already face constant challenges inherent in their developmental stage. This can be made more difficult by the presence of a disorder that significantly alters physical and mental functioning with, for example, painful symptoms and treatment procedures. School life and academic performance may also be disrupted. As children grow older, they face an additional task of fostering independence from not only their parents, but healthcare professionals as well. In some conditions, young people must cope with an uncertain future and restrictions on opportunities.

Furthermore, a chronic illness disrupts normal family life. The demands of frequently attending hospital appointments and care-giving tasks result in a potential for family life to revolve around the child with illness, possibly at the expense of other family members (Bradford, 1997).

It is therefore understandable why a large amount of research effort has been undertaken to increase knowledge of the relevant prevalence, processes and variability in psychological distress. Early studies, emphasising a pathology model, found that chronically ill children show higher rates of emotional maladjustment when compared to their healthy peers (Parsons & Fox, 1952; Pless, Roghmann & Haggerty, 1972). This type of research has been criticised for being largely anecdotal and employing subjective evaluations (Bradford, 1997). More recent research has continued to compare young people suffering from a chronic illness with 'healthy' community samples, often reporting conflicting results. Several researchers have shown that the majority of children and their families adapt successfully to chronic illness, although acknowledging an increased vulnerability for some families (Garrison & McQuiston, 1989; Lavigne & Faier-Routman, 1992; Spirito *et al*, 1995; Wallander, Varni, Babani, Banis, DeHaan & Wilcox, 1989). Eiser concluded that 'the weight of scientific evidence continues to point to increased vulnerability in terms of emotional and behavioural development' (Eiser, 1990a, p.85) but emphasised that 'families with chronically ill children are normal families forced to cope with extraordinary circumstances' (Eiser, 1994, p. 1375).

It is important to remember that, within these studies, there will be great variation in the reactions of individual children and families. Indeed, some studies have found positive consequences following the onset of a chronic illness in a child (Hanson, Rodrigue, Henggler, Harris, Kleges & Carle, 1990). For example, in a study of children with diabetes, it was found that families tended to show more 'enabling behaviours', for example, acceptance, empathy and problem-solving activities (Hauser, Jacobson, Wertlieb, Weiss-Parry, Follansbee, Wolsdorf, Herskowitz, Houlihan & Rajapark, 1986).

Studies that continue to follow a pathology model, with an inherent focus on difficulties and deviations from the normal, are necessarily pessimistic. Furthermore, they are unable to account for findings emphasising that psychological outcomes in chronic illness are not necessarily negative (Hauser *et al*, 1986).

1.2 Theories of chronic childhood illness

Three generations of psychosocial research regarding the condition of Insulin Dependent Diabetes Mellitus in young people have been identified and are demonstrated in Table 1.1 below (Hanson, DeGuire, Schinkel & Kolterman, 1995). As highlighted above, early work in the field of chronic illness followed a deficit-centred, or pathology model (Eiser, 1990b). More recently, several theories or models have been proposed to explain the variability in coping and adjustment among young people and their families. The Risk and Resistance model (Wallander & Varni, 1998) has been advocated as one way of identifying those young people and families more at risk for poor adaptation to a chronic illness.

Table 1.1 Illustrations of the three generations of psychosocial research in IDDM, Hanson et al, 1995

	Type of study	**Type of measurement**	**Analytic approach**	**Expected findings**	**Probable conclusions**
First generation	- compare healthy and chronically ill groups	- single variables measured	- search for main effects (ANOVA)	- absence of consistent findings	- no link between chronic illness and pathology
Second generation	- examine risk factors within chronically ill population	- multiple variables measured	- interaction term models (regression)	- clusters of risk factors identified	- some suffer, identify who is at risk
Third generation	-prospective studies	- multiple measures - frequent assessment	- structural equation models - time series analyses	- sequence of effects specified	- cause and effect models

1.2.1 Risk and Resistance model (Wallander & Varni, 1998)

The Risk and Resistance model fits into the 'second generation' of research (Hanson *et al*, 1995). It is intended to be generic and therefore potentially applicable to a wide range of chronic paediatric physical disorders. This model of adaptation integrates

the early conceptual models proposed by Pless and Pinkerton (1975), Moos and Schaefer (1984) as well as Lazarus and Folkman (1984).

Varni and Wallander (1988) suggest that the reason families with a chronically sick child may be at greater risk for maladjustment relates to the increased number of stressful situations to which they are exposed. However, it is not proposed that the presence of a chronically sick child necessarily represents an adverse event for the family (Blankfield & Holahan, 1996). Emphasis is therefore placed upon the role of stressors and the individual's competence. Furthermore, adaptation is thus seen as a function of interactions among the following domains.

Risk variables

1. Disease and disability (for example, severity and visibility)

2. Level of functional independence

3. Psychosocial stressors (including life events and daily hassles)

Resistance variables

1. Personal factors (temperament, competence, problem-solving ability)

2. Socio-ecologic factors (family environment, social support, family members' adaptation)

3. Stress processing (cognitive appraisal, coping strategies)

Figure 1.1 gives a diagrammatic representation of the Risk and Resistance model.

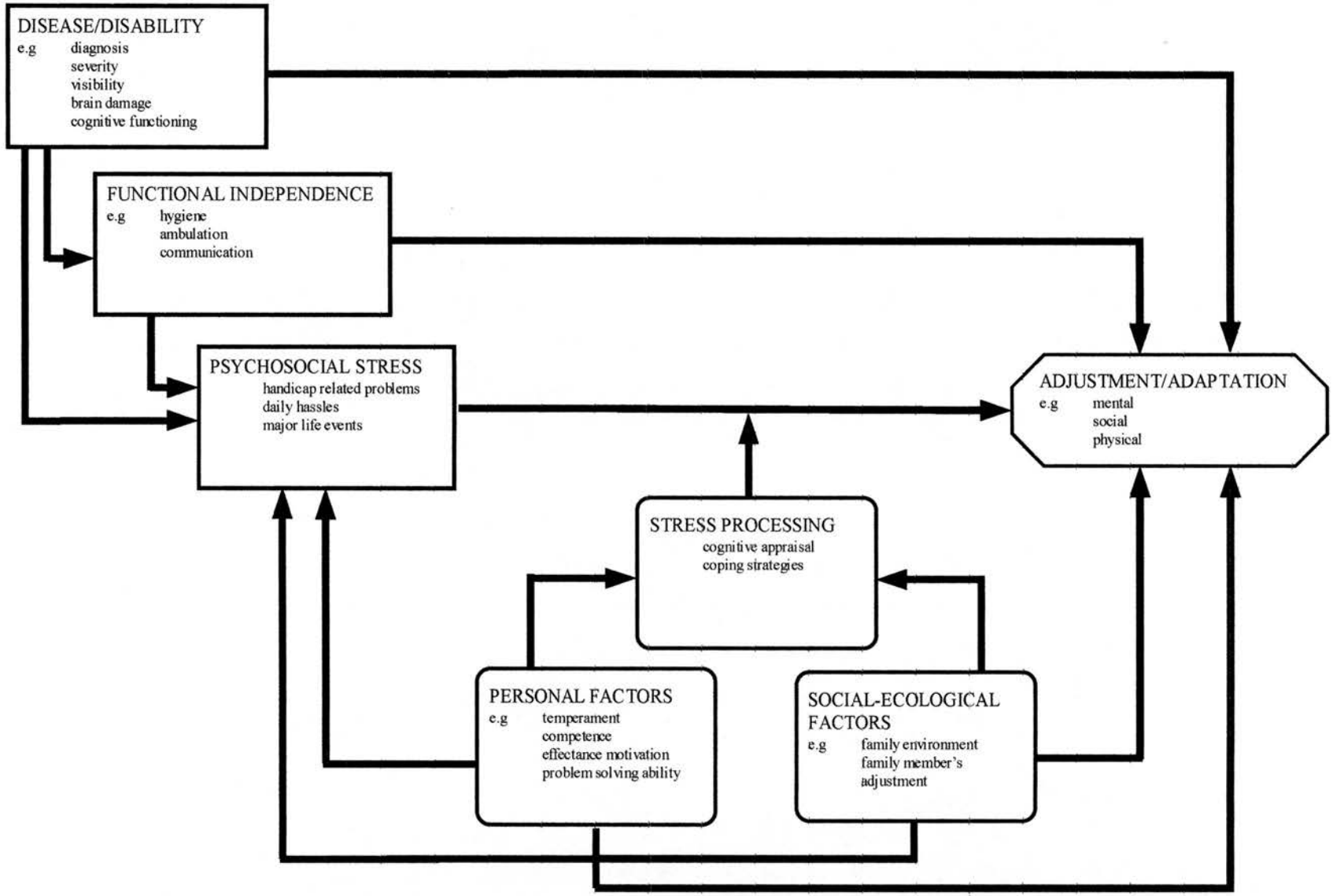


Figure 1.1 The Risk and Resistance Model

Wallander and Varni's conceptual model of child adjustment to paediatric chronic conditions. Square-corner boxes indicate risk factors; round corner boxes indicate resistance factors. Adapted from Wallander, Varni, Babani, Banis and Wilcox (1989) and reproduced from Wallander and Varni (1998).

1.2.3.Support for the model

Bradford (1997) stated that this model provides a more multi-factorial approach to the explanation of adjustment to chronic illness than previously offered by traditional models. The Risk and Resistance model may also help explain the wide variability in studies of the psychological sequelae of chronic illness.

The central tenet of the Risk and Resistance model has received empirical support. The role of family support as a resistance factor has been highlighted (Blankfeld & Holahan, 1996). Wallander and Varni (1989) reported that chronically ill children who received social support from both family and peers demonstrated fewer behavioural problems, as reported by their mothers. Additionally, among some children with Insulin Dependent Diabetes Mellitus, the relationship between stress and glycaemic control was moderated by individual differences in coping (Delamater, 1992). Wallander and Varni (1998) conclude that disease and disability are not the most significant influence on adjustment. The importance of child and parent/family characteristics is highlighted, which is consistent with other findings (Lavigne & Faier-Routman, 1992, 1993).

In order to further explore the merits of the Risk and Resistance model, it has been suggested that additional social contexts also need to be considered, such as the school and treatment environments (Wallander & Varni, 1998). Within the context of the Risk and Resistance model, it is proposed to examine the chronic condition of Insulin Dependent Diabetes Mellitus, as well as examine satisfaction with health care as a resistance factor.

1.3 Diabetes

1.3.1 The nature of diabetes

Diabetes is a severe metabolic disorder, resulting from deficiencies in either insulin production or the body's ability to use insulin effectively. Insulin is a major anabolic hormone that is required for the cellular uptake of glucose by the cells of most body tissues. Since insulin is responsible for the breakdown of glucose in the body, lowered levels leads to abnormally high levels of sugar in the blood, known as hyperglycaemia. If this disordered carbohydrate metabolism is not resolved, it can lead to the build up of ketones in the body, which may then result in the life-threatening state of Diabetic Ketoacidosis (DKA) (Bradley, 1988; Cox & Gonder-Frederick, 1992).

Symptoms of untreated diabetes include extreme tiredness, increased thirst and the passage of large amounts of urine (British Diabetic Association, 1995). Diabetes has often been labelled as 'invisible', due to its lack of external characteristics (Ceccoli, 1992).

1.3.2 Types of diabetes

It is now becoming clear that diabetes is not a single disorder, but a collection of several disorders with different underlying causes and multiple hormonal abnormalities (Bradley, 1988).

In the early 1980s, a distinction between 'Type I' and 'Type II' diabetes was made on the basis of certain immunological phenomena and genetic markers. However, the methods for measuring these characteristics are not commonly available. In practice, the terms Type I and Type II have been used synonymously with the labels Insulin Dependent Diabetes Mellitus and Non Insulin Dependent Diabetes Mellitus.

Insulin Dependent Diabetes Mellitus accounts for 25% of all people with diabetes. Approximately 95% of cases of Insulin Dependent Diabetes Mellitus have their onset in childhood and adolescence, with a mean age of onset of 12 years (Kaufman, 1997). It is an autoimmune process triggered off in susceptible individuals by one or more

environmental factors. Theories about these factors include diet, environmental toxins and viruses. There also appears to be a familial predisposition to developing Insulin Dependent Diabetes Mellitus.

Non Insulin Dependent Diabetes Mellitus accounts for the other 75% of people who have diabetes and has a much greater genetic transmission. Other risk factors include obesity and there is an increased incidence in certain ethnic groups. With this condition, some insulin is still produced by the body and blood sugar levels can be controlled by dietary and exercise regimes.

This thesis is concerned only with Type I diabetes, or Insulin Dependent Diabetes Mellitus. This will henceforth be referred to as diabetes.

1.3.3 Epidemiology

Diabetes is the third most common chronic illness in young people after asthma and cerebral palsy (Metcalfe & Baum, 1991). It has been estimated that in the UK there are at least 20,000 people under the age of 20 with diabetes. Almost all of these have Insulin Dependent Diabetes Mellitus (British Diabetic Association, 1996). The incidence of diabetes in the age group 0-20 years appears to be increasing (Burden, Hearnshaw, & Swift, 1989; British Diabetic Association, 1996). It has nearly doubled in recent years from 7.9 to 13.5 per 100,000 per year (Metcalfe & Baum, 1991). The United Kingdom incidence varies, with the highest rate in Scotland (Thompson, Greene & Newton, 1995). Gender distribution is nearly equal, but there is marked difference in the incidence by race, with Caucasians having the highest rates compared with African-Americans and Asians (Kaufman, 1997).

1.3.4 Diabetes as a chronic illness

In diabetes, the young person and family assume the vast majority of responsibility for the management of the condition (Daviss, Coon, Whitehead, Ryan, Burkley & McMahon, 1995). Parents will normally care for very young children with the

condition. This changes as children get older and develop cognitively (Brink, 1997). Despite the fact that diabetes impacts on virtually all aspects of everyday life, affected children and adolescents are encouraged to lead a normal life, without many of the concessions usually made to chronically ill patients (Blanz, Rensch-Riemann, Fritz-Sigmund & Schmidt, 1993).

People with diabetes face numerous daily challenges associated with their treatment; for example, dietary restrictions, insulin injections, blood testing and extra considerations for exercise. Additionally, the fear of hypoglycaemia or low blood sugar exists. Furthermore, the potential for serious long-term complications such as retinal damage, kidney problems, limb ulceration, heart disease, and stroke is a serious consideration. Life expectancy may be reduced by as much as 25% or more in some cases (Kelnar, 1994).

1.3.5 Treatment of diabetes

Medical treatment must clearly aim to maximise diabetic control and minimise negative outcomes. Blood glucose levels (glycaemic control) should be kept as close to the normal range as possible (normoglycaemia). The amount of glucose in the blood is affected by the amounts of food eaten, exercise taken and insulin level (Kaufman, 1997). Self-management of diabetes therefore involves monitoring blood glucose levels and adjusting insulin injections. This complicated balance is very difficult to achieve and sustain. Hypoglycaemia, where the blood glucose level is too low and hyperglycaemia, where the blood glucose level too high, are both dangerous.

For approximately one year following the onset of diabetes, the pancreas continues to produce small amounts of insulin. This is known as the 'honeymoon period' and diabetic control is normally easier to obtain (Kelnar, 1994). However, naturally occurring insulin does come to an end and thus insulin doses must be increased. Consequently, glycaemic control is often much more difficult to achieve after one year post-diagnosis.

The Diabetes Control and Complications Trial (1994) showed unequivocally the importance of maintaining normoglycaemia. This large-scale study carried out in 29 centres in USA and Canada, involved 1441 people with Type I diabetes. The effects of 'conventional' insulin therapy (one or two injections per day) with an intensified regimen (three or more injections per day or the use of an insulin infusion pump) were compared. Dramatic decreases of up to 76% in the occurrence of future complications were demonstrated, when normoglycaemia was achieved (DCCT, 1993,1994). The most pertinent finding was a near linear relationship between glycaemic control and risk of complications. Therefore, even moderate improvements in glycaemic control were associated with a decrease in later complications. However, intensive therapy to better achieve normoglycaemia was also associated with increased weight gain and increased frequency of hypoglycaemia.

These findings have resulted in the growing interest in the use of more demanding regimens of diabetes management to attain normoglycaemia. However, as treatment demands are intensified, so too are the demands made on the individuals with diabetes and their families (Bradley, Brewin, Gamsu & Moses, 1984).

1.3.6 Diabetes regime

Adherence to a diabetes regime facilitates blood glucose regulation, or glycaemic control. Well-controlled glycaemic levels are crucial in preventing later complications (DCCT, 1993, 1994). A diabetes regimen is a multifaceted construct, in which several domains have been identified as important. These include blood testing, insulin injections, dietary adherence and exercise management (Burroughs, Pontious & Santiago, 1993). Each of these components can have its set of barriers to adherence.

1.4 From adherence to empowerment

The terms used when discussing a diabetes regimen have been open to debate. Several authors have complained of the pejorative use of the terms 'compliance' and 'adherence' (Anderson, 1995; Anderson, Funnell, Butler, Arnold, Fitzgerald & Feste, 1995; Shillitoe, 1995). 'Compliance' is often regarded as a quality like a personality trait or physical characteristic, which an individual does or does not possess in sufficient measure (Shillitoe, 1988). Additionally, adherence failures are seen as the sole responsibility of the patient. Terms such as compliance and adherence are seen as the antithesis of the concept of self-regulation, which is proposed to lie at the heart of diabetes management (Shillitoe, 1995). The terms 'self-management' and 'levels of self-care' have been advocated as alternatives (Glasgow, Wilson & McCaul, 1985). These terms will be used throughout the study.

Related to the above discussion regarding the use of terms, there is a view that the medical model of care, with an emphasis on compliance, is perhaps more readily applicable to acute medical illness and therefore less appropriate for chronic disorders. A new philosophical approach has been advocated, termed the empowerment paradigm (Anderson, 1995; Anderson *et al*, 1995; Feste, 1992; Parrott, 1990). This recognizes more fully the unique role and responsibilities of the patient.

Under the empowerment paradigm, the patient is at the centre of goal setting in diabetes care and is viewed as an autonomous, equal member of the health care team. Their special expertise, that is, insight into their own values, need and goals is recognised as paramount. The balance between self-management of a medically defined regimen and quality of life is also recognised. A relationship in which medical staff are perceived as active and in control, whilst the patient is passive and acquiescent, is challenged (Anderson, 1995). In addition, the primary purpose of diabetes education is to prepare patients to make informed decisions about their self-care (Feste, 1992).

Within this paradigm, there is an underlying change in professionals' attitudes to chronically ill young people and their families (Eiser, 1990a, 1990b). The task of

professionals is to foster the acquisition of relevant coping skills within each individual young person. This will, hopefully, ultimately lead to greater independence and competence in coping with the demands of a chronic illness (Eiser, 1990a, 1990b).

The empowerment paradigm has been assessed, using a randomised controlled trial. The intervention group received a six-session empowerment education programme and showed significant gains over the waiting list control group in self-efficacy, diabetes attitudes scales and glycaemic control (Anderson *et al*, 1995).

1.4.1 Self-care in diabetes

Simonds and colleagues stated that one of the many methodological difficulties in studying diabetes management is establishing a valid measure of diabetes self-care (Simonds, Goldstein, Kilo & Hoette, 1987). The most obvious measure is simple observation. However, the complexity and pervasiveness of the diabetes regimen render this impractical. Self-reported management has also been used, but this is open to understandable concerns about accuracy and bias of self-report measures (Gordis, 1976).

Another common conceptual problem is confusing the psychosocial construct of diabetes self-care with the medical outcome measure of glycaemic control (Johnson, 1992). The empirical relationship between levels of self-care may be weaker than has been assumed (Miller-Johnson, Emery, Marvin, Clarke, Lovinger & Martin, 1995). Although glycaemic control and self-care behaviours are inextricably linked, the relationship is not a strict linear one. Level of self-management with the treatment regime, is only one of the many determinants of medical outcomes. Glycaemic control should therefore be viewed as an indirect, objective measure of self management, taking into consideration that blood glucose levels are additionally mediated by physiological factors in addition to levels of self care (Brownlee-Duffeck, Peterson, Simonds, Goldstein, Kilo & Hoette, 1987).

It has been demonstrated that levels of self-care in one aspect of a diabetes regime are not highly correlated with those in other areas (Johnson, 1992; Orme & Binik, 1989).

For example, being motivated to do injections regularly may not necessarily mean that an individual pays the same level of attention to their diet. Measuring self-care is therefore a complex, multi-dimensional task (Bradley, 1994b). One solution is to use multiple measures of self-care for each aspect of the regimen, but this is often difficult in practice. However, given that there is no perfect or gold standard measure of self-care, multi-dimensional instruments and assessments have been advocated (Glasgow & Anderson, 1995).

Self-management of a diabetes regime is dependent on the person's attitudes and behaviour (Sensky, Meadows, Wise & Thompson, 1995). The elements of diabetes regimen most often associated with lowest levels of self-management are those that have the most impact on the individual's lifestyle (Kurtz, 1990). For example, the diet component of a diabetes regimen is perhaps the most complex and has been rated by young people as one of the most difficult aspects of diabetes (Reid, Dubow, Carey & Dura, 1994; Weissberg-Benchell, Glasgow, Tynan, Wirtz, Turek & Ward, 1995). The complex, multi-faceted regimen in diabetes makes low levels of self-care highly probable (Weissberg *et al*, 1995).

Research studies have demonstrated the importance to self-care of a range of psychological and social factors, including:

- Affective disturbance (Lustman, Griffith, Clouse & Cryer, 1986; Wrigley & Mayou, 1991)
- Health beliefs (Brownlee-Duffeck *et al*, 1987)
- Methods of coping (Sinzato, Fukino, Tamai, Isizu & Nakagawa, 1985)
- Family interactions (Rubin & Peyrot, 1992)
- Higher levels of family cohesion (Anderson, 1990; Hauser, Jacobson, Lavori, Wolsdorf, Herskowitz, Milley & Bliss, 1990)

There is no evidence of a straightforward relationship between knowledge and self-management. In simple terms, there is little linking 'what a patient knows and what a

patient does' (Shillitoe, 1988, p.193). Programmes that have sought to increase levels of knowledge through education have also found that education alone does not improve self-care levels (Glasgow & Anderson, 1995; Shillitoe, 1995). The effectiveness of education programmes can be enhanced if they are combined with supportive training in self-management (Delameter, Bubb, Davis, Smith, Schmidt, White & Santiago, 1996).

Furthermore, a common, but ineffective, approach used to improve levels of self-care centres on pleading and scaring young patients with tales of future physical complications (Nichols, 1996). This 'scared straight' method of subtly threatening patients with physical disaster is usually counterproductive (Nichols, 1996).

The most effective way of encouraging people in their self-management programmes has yet to be determined (Shillitoe, 1995). For adolescents, success has been reported using problem-solving groups (Anderson, Wolf & Burkhart, 1989) and coping skills training (Davidson, Boland & Grey, 1997; Grey, Boland, Davidson, Yu, Sullivan-Bolyai & Tamborlane, 1998). In one study, young people between the ages of 13 and 20 were randomly assigned to either a coping skills package or treatment as normal. The experimental group had lowered HbA1c levels than those in normal treatment (Grey *et al*, 1998).

1.4.2 Time and age effects on self-care

Increasing duration of illness has been associated with worsening levels of self-care (Jacobson *et al*, 1987; Kovacs, Goldston, Obrosky & Iyengar, 1992). Associated with this phenomenon, increasing age has also been associated with decreases in self-care to several aspects of the diabetic regimen (Bond, Aiken & Somerville, 1992; Johnson, Silverstein, Rosenbloom, Carter & Cunningham, 1986). When levels of self-care were studied in school-age children, it was found that lowered self-management tended to emerge in middle adolescence and was protracted (Kovacs *et al*, 1992). The authors also proposed close monitoring of newly diagnosed school age diabetics, who may display no overt difficulties, as the risk period for onset of lowered levels of self-care can often occur approximately three years after diagnosis (Kovacs *et al*, 1992).

In summary, patients with diabetes at all ages are generally only partially or inconsistently able to undertake their full self-management regimes (Kovacs *et al*, 1992).

1.4.3 Glycaemic control

Assessment of glycaemic control is routinely checked via blood samples in two ways. Firstly, the patient takes a small sample of blood from their finger and analyses this using a hand held computer. This provides a 'current' blood glucose reading to guide day-to-day insulin management. Secondly, staff analyse a sample at each clinic visit to give a reading of glycosylated haemoglobin, commonly abbreviated to HbA1c.

HbA1c measures the average level of blood sugar during the preceding three months. The non-diabetic range for HbA1c levels is 4.1% to 5.3%. Levels of 4%-8% indicate a good degree of control and results above and below this level are indicative of poor control, signalling hyperglycaemia and hypoglycaemia respectively. HbA1c values are recognised as the most accurate measure of general glycaemic control, with higher percentages reflecting poorer control over the previous two to three months (Dunn, Cole & Soeldner, 1979; Gonen, Rochman & Rubenstein, 1979). The measure of HbA1c has been shown to have high validity and reliability (Marrero, Vandagriff, & Gibson, 1992; Pope, Apps, Page, Allen & Bodansky, 1993). However, it has also been criticised, as it does not reflect blood glucose variation, only mean blood glucose (Bradley, 1988).

A single HbA1c level is a variable reflecting short-term glycaemic control. Some researchers have also assessed glycaemic control over one year, giving a longer-range clinical profile of a patient's blood glucose control (Guttman-Bauman, Strugger, Flaherty & McEvoy, 1998).

Increasingly, it is being demonstrated that health outcomes, such as glycaemic control, are determined by multiple factors (Bradley, Gamsu, Moses, Knight, Boulton, Drury & Ward, 1987). Control is dependent upon on multi-factorial influences that differ from

teenager to teenager. In addition, each individual will be vulnerable to different influences at varying times (Carson, Walker, Kelnar & McKnight, 2000).

Grey and colleagues found that HbA1c levels were not associated with quality of life or any other psychosocial factors (Grey, Boland, Yu, Sullivan-Bolyai & Tamborlane, 1988). The only exception was in adolescents who perceived their families as providing more guidance and control. These young people had lower HbA1c levels than their peers who perceived their families as less involved. It was therefore advocated that HbA1c is not a sufficient indicator of treatment success in adolescents (Grey *et al*, 1988).

Ingersoll and Marrero (1991) also found no association between glycaemic control and quality of life in their study of adolescents. However, in a similar design, Guttman-Bauman and colleagues (1998) found that adolescents with better glycaemic control did report better quality of life, in direct contradiction to Ingersoll and Marrero (1991).

There are few consistent findings when comparing glycaemic control with psychological factors. The weight of evidence suggests that poor psychosocial adjustment is associated with poor glycaemic control, but as the majority of designs employ correlational methods, psychological problems could easily be the symptom of poor glycaemic control, rather than the cause (Johnson, 1980).

Furthermore, well-controlled diabetes is not always associated with psychological well being (Evans & Hughes, 1987). The authors investigated the associations between glycaemic control and psychological health. They suggested that their participants who had HbA1c levels in the range 10-11.9%, showed 'a good balance with reasonable diabetic control, internal locus of control and high self esteem' (Evans & Hughes, 1987, p. 372).

1.5 Effects of diabetes

1.5.1 Medical sequelae of diabetes

Short-term complications of diabetes include hypoglycaemia, which may result in corresponding cognitive, behavioural and mood disturbances (Donaldson, 1996; Parrott, 1990). If intervention does not occur, seizures, loss of consciousness and even death can be the result (Kaufman, 1997). Furthermore, hypoglycaemia is associated with a potential for accidents (Strauss, 1996).

The potential long-term complications of diabetes include damage to the microvascular and macrovascular systems. This can lead to retinopathy (eye problems), circulation difficulties, heart disease and limb ulceration. Complications following poor diabetic control are the third leading cause of death in the United States (Jordan, 1995). The occurrence of complications is so common that Bradley (1988) has commented that it is unusual for people with diabetes to be without complications after 20 years. A summary on the poor prognosis of young people with diabetes (British Paediatric Association Working Party, 1990) found that within 40 years of diagnosis:

- 60% were dead
- 30% were blind or visually impaired
- 12% had gangrene or had undergone lower limb amputation.

Ryan and colleagues evaluated the cognitive functioning of a sample of adolescents with diabetes (Ryan, Vega & Drash, 1985). Whilst participants still scored within normal limits, they were significantly worse than matched controls on tests of verbal intelligence. Patients who had been diagnosed with diabetes at five years or younger had lowered scores on neuropsychological tests than those who were diagnosed after this age. However, it is noteworthy that these differences, although statistically significant, were small in magnitude (Shillitoe, 1988).

1.5.2 Psychological sequelae of diabetes

Individuals with diabetes have long been regarded as being at high risk for developing psychological problems (Kovacs, Goldston, Obrosky & Bonar, 1997). Factors that may contribute to such vulnerability include the stresses of the chronic medical condition, the particularly demanding nature of diabetes self-care and the threat of future medical complications (Kovacs *et al*, 1997).

Consistent with the general literature on chronic illness, there have been conflicting and equivocal results when assessing the psychological effects of diabetes on young people. A significant proportion of young people are known to become psychologically distressed with the onset of the disorder (Cox & Gonder-Frederick, 1992). The first year following diagnosis has been found to be a high-risk period for secondary psychiatric disorder in general as well as depressive and childhood anxiety disorders in particular (Kovacs *et al*, 1997).

Perrin and colleagues found that conditions which have no overt physical manifestations, such as diabetes, are associated with less favourable adjustment than those which are more visible, for example an orthopaedic condition (Perrin, Ayoub & Willett, 1993). However, other studies suggest that there is little or no difference in the psychological effects of diabetes compared to other chronic illness (Brown, Kaslow, Sansbury, Meacham & Culler, 1991; Rover, Ehrlich & Hoppe, 1987). Nonetheless, psychological distress levels are often observed to be above those in the general population (Carney, 1998; Jacobson, Hauser, Wertlieb, Wolsdorf, Orleans & Vieyra, 1986).

It is difficult to draw an unequivocal conclusion regarding the psychological effects of having diabetes. The differences cited partly reflect different patient populations and methodologies (Evans & Hughes, 1987). Studies have also been criticised (Bradford, 1997) for grouping all the participants together when differences within groups have been found to be of significance, for example, age and time since diagnosis (Daviss *et al*, 1995). For example, children with poorly controlled diabetes have been found to

differ from those with better control on measures of psychological health (Anderson, Miller, Auslander & Santiago, 1981). It is therefore important to consider controlling for demographic characteristics and undertaking comparative analysis based on demographic variables and differing levels of HbA1c values.

There has been a recent interest in links between young people with diabetes and eating disorders, which pose a particularly serious risk to their health. It has been suggested that the emphasis on dietary issues and weight control in people with diabetes may render them particularly vulnerable to eating difficulties (Marcus & Wing, 1990). The extent of this problem has been difficult to establish. Different assessment approaches, sampling strategies and definitions have led to variable findings (Pollock, Kovacs & Charron-Prochownik, 1995). Other research has examined the characteristics of individuals who appear to have eating difficulties (for example, Polonsky, Anderson, Lohrer, Aponte, Jacobson & Cole, 1994). One study found significant differences in females who withhold insulin compared to those who do not. These differences include exhibiting more symptoms associated with the spectrum of eating disorders, higher levels of severe hyperglycaemia and diabetic ketoacidosis, as well as a more negative attitude towards their diabetes (Biggs, Basco, Patterson & Raskin, 1994). There also appears to be a link between eating problems and other psychological difficulties (Pollock *et al*, 1995). The conclusion can be drawn that there is a sub-group of young people with diabetes who have various difficulties in coping with the illness and require close monitoring (Pollock *et al*, 1995). Furthermore, healthcare professionals must remain vigilant to this potential difficulty.

In summary, the weight of evidence appears to point to an increased level of psychological distress in young people with diabetes (Blanz, Rensch-Riemann, Fritz-Sigmund & Schmidt, 1993).

Gender effects

Consistent with literature on gender differences in the rates of mental health difficulties in young people (Carr, 1993; Cohen, Cohen, Kasen, Velez, Hartmark, Johnson, Rojas, Brook & Streuning, 1993), discrepancies have been found between young males and females with diabetes. Adolescent females are more prone to depression as are young females with diabetes (Kovacs, Obrosky *et al*, 1997). Girls are more likely to report worries (Grey, Boland, Yu, Sullivan-Bolyai & Tamborlane, 1998; Ingersoll & Marrero, 1991). It has been observed that this might be in keeping with observations that teenage girls are more likely to admit negative emotions than boys (Ingersoll & Orr, 1989).

Time and age effects

It has been proposed that young people who have grown up with their disease might show different patterns of adjustment in comparison to those who have been healthy and then acquire a condition later in life (Bradford, 1997). However, in diabetes, adolescence appears to be a risk period for many young people's psychological health, irrespective of their duration of the disorder.

Ingersoll and Marrero (1991) found that newer onset adolescent clients were more likely to see their diabetes as having a negative impact and speculated that those who have had diabetes longer have learned more effective coping strategies. Kovacs and colleagues prospectively followed eighty-five adolescents for a five-year period from the time of initial diagnosis. The first year following diagnosis was associated with the highest rates of depressive disorders (Kovacs, Goldston *et al*, 1997).

Challen and colleagues investigated the effect of age on psychological adaptation to diabetes in a sample aged 10-17 years. They found that the older adolescents had a more negative attitude to their diabetes.

1.5.3 Psychological factors in diabetes

> Psychology is particularly important in diabetes management because the knowledge, beliefs and behaviour, both of the people with diabetes and of the health care professionals involved, affect diabetes control.
>
> (Bradley, 1994a, p.11)

Psychological factors may have an impact on long-term control, either directly through neurohormonal mechanisms, or indirectly through effects on patients' motivation and ability to maintain high levels of self-care (Helz & Templeton, 1990).

Early work on the links between psychology and diabetes focused on the role that stress might play in the aetiology of the disorder (Shillitoe, 1988). There has since been an increasing awareness of the importance of psychological factors in diabetes management and measurement of outcomes (Golden 1998). One study found that psychosocial factors predicted mortality from diabetes more accurately than many clinical and medical variables (Davis, Hess & Hiss, 1988).

The St Vincent Declaration (World Health Organization, 1990, 1995) is a statement of goals and recommendations for the care of people with diabetes. The report, advocated by representatives of government health departments and patient organisations from all European countries, recommends improving the quality of medical and psychosocial care of people with diabetes. Monitoring procedures of psychological well being and treatment satisfaction are indicated in the Declaration as important areas in an overall package of care. Recent advances in the auditing of diabetes care and outcomes (Wilson & Home, 1993) and the drafting of Scottish guidelines for the care of young people with diabetes (Scottish Intercollegiate Guidelines Network, 1996) have recognised the importance of measuring psychological as well as medical outcomes.

Many investigators have initiated psychosocial interventions following the identification of problems (Rubin & Peyrot, 1992). Others believe that it is more appropriate to incorporate psychosocial interventions, termed by some as 'psychological care'

(Nichols, 1996) as a routine and significant component of diabetes care (Anderson *et al*, 1995; Nichols, 1996).

1.5.4 Diabetes – a summary

There has been a call for a widening of treatment outcomes in diabetes: 'There is an overwhelming preoccupation with 'adherence' and 'compliance' ... as measurable outcomes in research' (Olsen & Sutton, 1998, p. 32). This extension of treatment results would include measures of psychological health and satisfaction with care received. Furthermore, the priorities of outcomes in young people with diabetes must be assessed. As Evans and Hughes stated: 'We would suggest that a balance be sought between closeness of diabetic control and psychological development' (1987, p. 372).

1.6 Adolescence

1.6.1 Models of adolescence

Coleman described adolescence as 'a complex stage of human development, having some common features but also involving enormously wide individual variations' (1995, p. 12). This period is characterised by an intricate set of developmental tasks or demands (Patterson & McCubbin, 1987).

There have been many conceptualisations of the experience of adolescence. It has been viewed as a time of inevitable struggle, or alternatively, the majority of adolescents cope well with the demands of this developmental stage. The numerous stereotypical and widely held images of adolescent rebellion that pervade in the Western world have tended to focus on a somewhat dismissive and unhelpful view of young people, which may encourage an observer to interpret their behaviour negatively (Bradbury & Jenkinson, 1996). It is important to realise that, for the majority, the adolescent period is relatively smooth. Current views of adolescent development emphasise its continuity with childhood and adulthood and the gradual nature of the changes that occur (Dusek & Flaherty, 1981; Powers, Hauser & Kilner, 1989).

The developmental stage of adolescence is characterised by a series of lifestyle changes and tasks to complete. One of the most obvious changes is in physical appearance (Dickinson, 1999). Lifestyle changes include a decrease in structure of life and a tendency to spend more time with peers (Golden, 1998). Consequently, there is increased scope for unpredictability. Issues faced by young people include the consumption of alcohol and drugs and a heightened awareness of sexual needs and identity.

1.6.2 Adolescents with diabetes

Adolescents with diabetes are first and foremost adolescents. They are faced with the same family, school and peer issues as adolescents without diabetes (Dickinson, 1999).

When compared with the apparent freedom of their peers, the lifestyle restrictions imposed by diabetes can result in young people perceiving their diagnosis as 'impossibly unjust' (Bradbury & Jenkins, 1996, p. 849). Adolescence is a period where young people are concerned with conforming to peer defined norms of behaviour and appearance. The demands of a chronic illness often make them stand out as markedly different (Reid, Dubow & Carey, 1995). In diabetes, regular insulin injections do not easily fit into the 'normal' adolescent experience. In summary, diabetes may be of secondary importance to a drive for independence and conforming to peer pressures.

Insulin resistance develops at the time of puberty (Caprio, Plewe, Diamond, Simonson, Boulware, Sherwin & Tamborlane, 1989). Reduced insulin sensitivity is linked to growth hormone peaks, especially during the night. This may partially explain the deterioration in glucose control during the teenage years (Brink, 1997; Jacobson *et al*, 1987; Mortensen, Hartling & Petersen, 1988). However, increasing age is also associated with decreases in adherence to exercise, injection regularity, eating and glucose testing frequency (Bond *et al*, 1992), with subsequent effects on glycaemic control. Adolescents are less likely to adhere to their regimes than either younger or older cohorts (Jacobson *et al*, 1987). This period is also associated with increased diabetic ketoacidosis, with some individuals prone to frequent admissions (Thompson *et al*, 1995). Furthermore, there is often a reduction in the frequency of clinic visits (Thompson *et al*, 1995).

While adolescents with diabetes may have no signs or symptoms of the progressive and chronic complications associated with the disease, there is unequivocal evidence that the genesis of some of these complications may occur early in the disease process (DCCT, 1993, 1994).

In the Diabetes Control and Complications Trial, adolescents in the intensive treatment group were unable to lower HbA1c levels as successfully as the older cohort, despite identical treatment (DCCT, 1993). Also, there were statistically significant differences in the number of severe hypoglycaemic episodes, diabetic ketoacidosis and increased

weight gain. (Brink, 1997). Among adolescents, 48% of those in the intensive treatment condition became overweight compared to 28% of those offered conventional care (DCCT, 1994).

Several authors have documented a worrying tendency among patients with poor glycaemic control to lie about their levels of self-care (Kyngas & Barlow, 1995; Wikbald, 1991). For example, one study found that 25% of adolescents admitted to missing insulin injections over a 10 day period, although they had originally informed healthcare professionals that they had been taking insulin as recommended (Weissberg-Benchell *et al*, 1995). Older adolescents engaged in more mismanagement of their diabetes than their younger counterparts. Lying about levels of self-management has been proposed as an important coping mechanism and preferable to perceived negative responses from honest disclosure (Wikbald, 1991).

Age effects on glycaemic control and psychological factors may be related to specific challenges at different stages of adolescence. Olsen and Sutton (1998) looked at two age bands, 14-16 years and 17-19 years. They found that the lives of older participants were increasingly complex, with greater diversity in the repertoire of situations that they faced. These included commencement of employment and the quandary of whether to tell colleagues/partners about their diabetes.

Career directed decision-making might be affected for young people with diabetes. For example, they cannot join the armed forces, police or fire service. There are also restriction on jobs requiring working at heights and depths. Furthermore, there is anecdotal evidence that individuals who disclose having diabetes on job applications are offered fewer interviews that their non-diabetic peers (Carson & Kelnar, 2000).

Ego development

Hauser and colleagues have extensively studied ego development in young people with chronic illness and found that adolescents with diabetes demonstrate lower levels of ego development than a control sample (Hauser, Jacobson, Noam, & Powers, 1983; Hauser,

Jacobson, Wertlieb, Wolsdorf, Herskowitz, Vieyra & Orleans, 1989). Ego development describes a complex set of developmental processes central to how an individual perceives his or her role and position in the larger world (Hauser, 1993). It has been proposed that ego development influences important health behaviours, such as levels of self-care, adjustment to short and long-term diabetes demands and judgements of risk. Golden raises the importance of this concept:

> An adolescent with diabetes ultimately needs to understand and accept a new identity, an uncertain one that includes the risk of sudden catastrophe and the possibility that long-term medical sequelae will have a definite effect on quality and perhaps length of life.
>
> (Golden, 1998, p. 886)

1.6.3 Treatment priorities

The treatment of adolescents with diabetes often results in conflicts between theory and practicality (Gordon & Mansfield, 1996). The goal of normalisation of blood glucose levels is unrealistic for many adolescents. Overall, a better approach is to perceive any improvement in blood glucose levels as worthwhile, regardless of magnitude (DCCT, 1993, 1994; Gordon & Mansfield, 1996).

As many healthcare professionals adhere to a medical model of care, judgements are made about adolescents with diabetes based solely on 'hard' parameters such as blood glucose levels (Dickinson, 1999). As explored above, the medical model often neglects the patients' social context and does not focus on the whole person. In addition, there is often little attention paid to discovering the meaning diabetes holds for each patient (Dickinson, 1999).

Thompson and colleagues stated that medical staff, when faced with an adolescent with poor glycaemic control, may see 'evidence of a feckless, indisciplined attitude' and the patient may, in turn, see the staff member as another 'judgemental, authority figure' (Thompson *et al*, 1995, p.2). Healthcare professionals must respond positively to

patients' needs in order to promote greater confidence in their ability to cope and thereby improve glycaemic control (Bradbury & Jenkinson, 1996).

In summary, adolescence can be a difficult time for people with diabetes. However, for a number of young people, the development of diabetes leads to positive changes, for example a better diet and exercise regime (Spack, 1991).

1.7 Satisfaction

1.7.1 Definitions

There appears widespread agreement upon the importance of patient satisfaction as a concept. Unfortunately, however, there is much less consensus as to its meaning. The most common definition describes satisfaction as patients' 'reactions to salient aspects of the context, process and results of their experience' (Pascoe, 1983, p. 76). In addition, satisfaction involves a '*cognitive evaluation* of and an *emotional reaction* to health care' (Fitzpatrick & Hopkins, 1993, p.1, author's italics). The importance of expectations is highlighted, whereby satisfaction is in part a product of what the patient brings to the healthcare contact and not just only what occurs during the consultation (Rutter, Quine & Chesam, 1993). Bradford (1997) sees satisfaction as having four key elements:

- the extent to which patients receive, understand and recall information
- whether expectations and concerns are elicited
- whether an opportunity is given to discuss emotional aspects of the illness
- whether the service correctly identifies and manages the medical aspects of the condition

In summary, satisfaction is thus a multidimensional variable (Fitzpatrick, 1991b).

Marshall and colleagues have identified some of the pertinent factors responsible for the increased interest in assessing patient satisfaction (Marshall, Hays & Mazel, 1996). These include the rise of 'consumerism' (Robertson, 1994) and awareness of the role of psychological factors in the process and outcomes of medical care (Bradley, 1994a, 1994b). In addition, Hardy and colleagues highlighted the growing trend in the United Kingdom for 'bench marking' standards of care (Hardy, West & Hill, 1996). Patients' views are now seen as legitimate, important measures of quality of care and customer satisfaction is proposed as an indirect measure of health outcome (Greenfield, Kaplan & Ware, 1985).

1.7.2 Difficulties measuring satisfaction

A commonly expressed reservation is that answers given to surveys of satisfaction will reflect essentially ill-considered whimsical or unstable thoughts and feelings (Fitzpatrick, 1991a). This could be especially relevant when it is young people who are asked and the illness is characterised, for many, by a great deal of frustration and limitations. An additional concern is that health care recipients are not competent to make sensible judgements regarding the technical complexities of their treatment (Fitzpatrick, 1991a). This has led some researchers to argue that patient satisfaction with treatment is irrelevant as only treatment effectiveness matters (Lebow, 1982).

Consumer surveys generally find high rates of reported satisfaction (Fitzpatrick & Hopkins, 1993). This may be due to the reluctance of many patients in the National Health Service to express critical comments about their health care, for fear of offending staff or affecting future treatment (Rothwell, 1990).

An additional difficulty is obtaining a high level of participation to ensure a representative sample of views. For results to be valid and meaningful, high compliance rates are required (Turpin, 1994).

Finally, it is relevant to consider how results from satisfaction studies are disseminated and acted upon. Feedback from patients regarding their care should lead to improvements in health care regimes (Stallard & Chadwick, 1991). One enquiry found that National Health Service managers rarely took any action following surveys of patient opinion (Hyde-Price, 1986).

1.7.3 Satisfaction versus outcome

Stallard and Chadwick (1991) highlighted that these two variables are often confused and used interchangeably, as if they are measuring the same dimension. However, satisfaction focuses upon aspects of the service the consumer receives, for example, length of time before first appointment, ease of talking to the health care professional and privacy of surrounding. Therapeutic outcome is a measure of how the situation has

changed as a result of the intervention (Stallard & Chadwick, 1991). Shaw (1984) draws the distinction between 'helpful people and useful outcomes' (p. 279).

Associations have been found between satisfaction and outcome in terms of health status, whereby poorer health status is associated with higher dissatisfaction (Bradley & Lewis, 1990; Fitzpatrick, 1993). Empirical findings typically suggest a positive association between health outcomes and satisfaction with care (for example, Hall, Feldstein, Fretwell, Rowe & Epstein, 1990; Linn & Greenfield, 1982; Patrick, Scriven & Charlton, 1983). This may be related to the association between patients reporting high satisfaction being more likely to co-operate with treatment (Ley, 1988).

1.7.4 Associations between satisfaction and other variables

Patient satisfaction with health services has been associated with various health-related behaviours, including adherence to medical regimens (Sherbourne, Hays, Ordway, DiMatteo & Kravitz, 1992) and whether patients reattend for treatment (Roghman, Hengst & Zastowny, 1979; Simonian, Tarnowski, Park & Bekeny, 1993).

There is evidence from studies that parental level of dissatisfaction is a factor in predicting family adjustment to chronic conditions (Bradford, 1990; Murray & Callan, 1988). Studies such as that of Bradford (1990) are conceptualised to yield clinically significant recommendations from the results.

Dissatisfaction with health care may be a manifestation of dissatisfaction with other aspects of life (Roberts, Pascoe & Attkisson, 1983). Physical and mental health covary to a significant degree (Hays, Marshall, Wang & Sherbourne, 1994; Hays & Stewart, 1990). In other words, individuals who experience good physical health also tend to report good mental health. An examination of data from the large scale Medical Outcomes Study, found that satisfaction with care is closely allied with an individual's mental health (Marshall, Hays & Mazel, 1996).

1.7.5 Satisfaction and diabetes

The St Vincent Declaration (WHO, 1990, 1995) suggested using the Diabetes Treatment Satisfaction Questionnaire (Bradley, 1993) as an outcome measure for quality of care.

There is a paucity of research on the satisfaction with medical services of young people with diabetes. It is a current priority in the National Health Service (Department of Health, 1989, 1997) that patients evaluate services.

Relationships between treatment satisfaction and glycaemic control have been reported (Lewis, Bradley, Knight, Boulton & Ward, 1988). Bradley and Lewis (1990) measured psychological well being and treatment satisfaction in people with Non Insulin Dependent Diabetes Mellitus and found that greater satisfaction with treatment, as measured by a diabetes-specific scale, was associated with better glycaemic control, that is, lower HbA1c levels.

The importance of increased positive relationships between patients and healthcare professionals has been emphasised (Bradbury & Jenkinson, 1996). This is in relation to concerns raised about the apparent mismatch between expected levels of self-care and adolescents' perceptions of their experiences. The authors also stress that the achievement and maintenance of well-controlled diabetes is dependent on the commitment of staff (Bradbury & Jenkinson, 1996).

Bradford has also highlighted the importance of satisfaction with the treatment environment:

> It is apparent that, in coming to terms with a chronic condition, the child and his or her family do not attempt to do so in isolation. The very fact that the child has an illness means that they are very likely to become involved with the medical care system.
>
> (Bradford, 1997, p.159)

1.8 Psychological measures

There has been a growing awareness of the need to measure the psychological impact of treatment of diabetes alongside medical outcomes (Bradley, 1994a, 1994b; Golden, 1998).

1.8.1 Adaptation

'Adaptation is the degree of psychological and psychosocial adjustment to the disease' (Lernmark, Persson, Fisher & Rydelius, 1999, p. 15). Researchers have highlighted the many problems involved in any attempt to measure a concept as vaguely defined as 'adaptation to diabetes' (Dunn, Smartt, Beeney & Turtle, 1986). Tansella (1995) described psychosocial adaptation as a 'composite construct', including:

- emotional and behavioural problems
- social competence
- self-concept
- physical / emotional health status
- satisfaction with life

Wallander and Thompson stated that adaptation should be defined in developmental-normative terms:

> Good adjustment, then, is reflected as behaviour that is age-appropriate, normative, and healthy, and that follows a trajectory toward positive adult functioning. Maladjustment is mainly evidenced in behaviour that is inappropriate for the particular age, especially when this behaviour is qualitatively pathological or clinical in nature.
>
> (Wallander & Thompson, 1995, p. 125-126)

Adjustment has also been described as a multidimensional concept involving three constructs (Challen *et al*, 1988):

- lack of emotional difficulty

- cooperative attitude
- confidence with diabetes management

Psychological adjustment in diabetes research is often considered primarily in terms of its impact on glycaemic control and treatment adherence (La Greca & Skyler, 1991). However, some authors (for example, Reid *et al*, 1995) have called for psychological adjustment itself to be considered as an important outcome variable, alongside glycaemic control.

1.8.2 Quality of life

The advance in contemporary thinking regarding the importance of measuring quality of life in diabetes research is reflected by the use of a quality of life instrument as a central outcome measure in the Diabetes Control and Complications Trial (DCCT, 1993, 1994; Ingersoll & Marrero, 1991). Additionally, other researchers support the idea that patient self-perceived quality of life is a valuable measure in its own right (for example, Guttmann-Bauman *et al*, 1998).

Diabetes practitioners have a tendency to equate good glycaemic control with quality of life (Ingersoll & Marrero, 1991). While the value of good glycaemic control is unequivocal, self-perceived quality of life may hold a different meaning to people with diabetes, particularly adolescents. Furthermore, research has shown that quality of life does not necessarily correlate with glycaemic control, suggesting that quality of life should be considered separately from the physical treatment goals of diabetes care (Ingersoll & Marrero, 1991; Grey, Boland, Yu *et al*, 1998).

Grey and colleagues examined quality of life and found that teenagers who report diabetes having the greater impact have the following characteristics:

- less satisfied
- felt that management was more difficult
- used fewer rebellion strategies for coping

- had more symptoms of depression

In general, adolescents perceived their quality of life as good, but there was substantial variation within the sample (Grey Boland, Yu, *et al*, 1998).

There has been a growing demand for generic measures of quality of life, which look at similarities in care across different conditions. These offer convenient comparison across studies and disease groups, for example the Sickness Impact Profile (Bergner, Bobbitt, Carter & Gibson, 1981). An additional development has been the need to assess the unique demands of disorders. Generic measures may not be sensitive to the effects of particular treatments or illness specific factors. It has been shown that diabetes specific measures increase sensitivity (Bradley, 1994b). The most widely used diabetes specific measure is the Diabetes Quality of Life Scale (DCCT, 1988), developed exclusively for use in the Diabetes Control and Complications Trial.

In summary, it has become accepted that quality of life is a concept separate from glycaemic control and worthy of individual consideration.

1.9 Psychological well being

As discussed above, the unequivocal results of the Diabetes Control and Complications Trial (1993, 1994) have increased the pressure to attain normoglycaemia and there is a danger that this will be highlighted at the expense of psychological well being (Bradley, 1994b).

The dangers inherent in using scales developed for use with psychiatric populations, for example, the Beck Depression Inventory (Beck, Ward, Mendelson, Mock & Erbaugh, 1961) in assessing psychological well being in adults with diabetes have been highlighted (Bradley, 1994a, 1994b). Some questions relating to, for example, somatic symptoms can be indicative in the general population of depression but may be the result of poor glycaemic control in a diabetes population. With young people, many

studies have used the Child Behavior Checklist (Achenbach, 1991), which has also been criticised for several reasons (Bradford, 1997; Perrin, Stein & Drotar, 1991). Similar to the Beck Depression Inventory, the Child Behavior Checklist includes somatic symptoms, which could lead to artificially inflated scores, thus giving the possibly spurious impression that that young people with chronic illness have more psychological problems.

An alternative approach would be to use the diabetes specific well-being questionnaire developed by Bradley (1993). However, this was not used in this study, as it does not allow for one of the research hypotheses, that is, comparison with a community control.

Summary of psychological measures

There has been an increased awareness in recent years of the importance of including psychological measures as valid outcomes, alongside glycaemic control. Furthermore, diabetes-specific measures have been developed which increase sensitivity.

1.9 The basis of the present research

1.9.1 General points

This introduction has detailed the importance of a number of variables regarding adaptation to diabetes in adolescents. These can be regarded as 'risk' and 'resistance' factors. The present study aims to consider whether satisfaction with diabetes care can be considered a 'resistance' factor. It is proposed that satisfaction will be associated with better psychological health. Additionally, it is hoped to replicate the findings of a study which showed a relationship between treatment satisfaction and glycaemic control in adults with Non Insulin Dependent Diabetes Mellitus.

The aim of the Risk and Resistance model is to better understand the factors associated with successful adaptation, so interventions can be more effectively targeted to maximise physical and psychological well being in adolescents with diabetes.

In addition, there are several important factors, drawn from the theory and research described above, which have influenced the design of this research. These are briefly discussed below.

1.9.2 The range of factors to be studied

- Satisfaction

Wallander and Varni (1998), in their review of the literature, stated that further factors should be explored, including the treatment environment. An attempt has therefore been made to assess satisfaction with a wide range of factors in diabetes care. Questionnaires to be used incorporate aspects of both treatment outcome and service. Hardy and colleagues emphasise the importance of identifying which aspects of care contribute most to the patients' satisfaction with the service they receive (Hardy *et al*, 1996).

- Psychological factors

The study will incorporate measures of psychological well being, adaptation to diabetes and quality of life. In order to assess the general psychological health of the sample, the present research will use a generic scale of psychological well being. Therefore, a comparison can be made between levels of well being in a current sample of adolescents with diabetes with norms from a healthy adolescent population. For adaptation and quality of life, diabetes-specific measures, developed exclusively for use with young people, will be completed.

- Glycaemic control

In response to criticisms levelled at previous research which considered only the whole sample together, this research will divide the sample and examine young people with relatively good control versus those with poorer control, as measured by HbA1c levels.

1.9.3 Clinical relevance

The present research will assess satisfaction in order to make specific recommendations to the clinics from which participants were recruited. In addition, questions relevant to future planning of service delivery have been included. These include the most appropriate way to approach patients not attending appointments and whether to routinely provide written information after consultations.

It is recognised that evaluating services can be difficult, as patients may perceive a risk to their future treatment if they were to rate the service negatively. Thus an objective researcher, who is not a member of the health care team, is conducting the study to maximise the reliability of patients' answers to self-report measures.

As the clinics from which participants are recruited are representative of many in Scotland in terms of service delivery, it is hoped that the results could have wider applicability in the country.

1.9.4 Data collection methods

'Measurement of the variables of interest should employ the whole range of methods available' (Wallander & Varni, 1998, p. 42). In order to gain as wide a view on the variables of interest as possible, semi structured interviews will be conducted with a small sub-sample of the participants. Semi-structured interviews provide qualitative information, which may facilitate a deeper understanding of the individual's representations and experience of illness (Weinman, Petrie, Moss-Morris & Horne, 1996). Qualitative research is based on the concept that knowledge is best gathered from people as they experience situations. These experiences are then described and defined by the individuals themselves (Miller, 1995).

1.9.5 Sample

The aim is to include as wide a sample of participants as possible. Therefore, several decisions were taken, in conjunction with the clinical teams:

- No exclusions on the basis of number of complications
- No exclusions on time since diagnosis, which will therefore mean using some participants who have been diagnosed very recently and are still in the 'honeymoon' period (Kelnar, 1994)

1.9.6 Within-group design

The debate regarding the need for control groups in research into chronic illness has existed for some time. This could be either young people with another chronic illness, or a comparison with healthy peers. However, a counter argument is the appropriate use of diabetes specific measures, which this study is utilising (Bradley, 1994b). Also, this study is investigating the specific medical outcome of glycaemic control, which has no comparable measure in either another chronic illness nor a community sample (Bradley, 1994b). Therefore, the decision was taken not to employ a control group.

1.10 Aims and Hypotheses

- **Research aim**

Several demographic variables will be collected for use in analysis. These are age, gender, age at diagnosis, time since diagnosis and deprivation category.

- **Hypothesis 1: Satisfaction and quality of life**

Higher satisfaction levels will be associated with increased quality of life.

- **Hypothesis 2: Satisfaction and psychosocial adaptation to diabetes**

Higher satisfaction levels will be associated with increased levels of psychosocial adaptation to diabetes.

- **Hypothesis 3: Satisfaction and psychological well being**

Higher satisfaction levels will be associated with increased levels of psychological well being.

- **Hypothesis 4: Satisfaction and glycaemic control**

Higher levels of satisfaction will be associated with better glycaemic control, as measured by HbA1c. It is expected that HbA1c levels will be lower as satisfaction levels increase.

- **Hypothesis 5: Level of psychological well being**

Participants in the present study will have higher levels of psychological maladaptation compared to an adolescent community population.

METHOD

2.1 Design

This research employs a cross-sectional, correlational design, using self-report measures of satisfaction, adaptation, psychological well being and quality of life, as well as blood glucose levels, measured by the glycosylated haemoglobin test (HbA1c). Additional variables collected include age, gender, age at diagnosis, time since diagnosis and deprivation category, as measured by postcode.

A power analysis was conducted. Based on 80% power, a minimum number of 70 participants were required (one-tailed analysis) (Clark-Carter, 1997).

2.2 Ethical approval

The study was granted ethical approval by the Lothian Research Ethics Committee, Medical Research subcommittee, subject to the following changes:

- Minor rewording of the Research Information Sheet
- Inclusion of parental / guardian consent for the participants aged under 16 years

2.3 Participants

Selection criteria

Suitable participants for the research project were initially selected from the Diabetes Clinics by age. A sample aged between 14 and 18 years of age was deemed appropriate for the measures to be used. In addition, all young people eligible for the study had to have a diagnosis of Type I Insulin Dependent Diabetes Mellitus (IDDM). Participants were selected from the following clinics:

- Royal Infirmary of Edinburgh
- Western General Hospital, Edinburgh
- St John's Hospital, Livingston
- Roodlands Hospital, East Lothian

Efforts were made to recruit individuals who were newly diagnosed during the study period, in order to include as wide a range of young people as possible. Clinic staff were consulted as the appropriateness of approaching all eligible participants identified, in particular, those who had been very recently diagnosed.

Exclusion criteria

Any patients who had a history of learning difficulties were excluded from the study. This decision was taken because the young people's ability to understand the instructions for the self-report measures was essential.

Furthermore, young people who were currently taking part in any other study were excluded. This meets the condition stipulated by the Lothian Research Ethics Committee regarding ensuring that participants are not overburdened by research commitments. However, there was one exception to the above rule, for participants attending the Royal Infirmary of Edinburgh clinic. Patients could receive a sum of £10 from the Inverness Research Project for a fingerprick sample of blood, for trials to develop a new home blood-testing meter. The Lothian Research Ethics Committee agreed that these participants could still be included in the present study, as it was felt that an optional, brief participation in the Inverness project would not result in individuals feeling over burdened by research commitments.

2.4 Measures

The measures used are summarised in Table 2.1 and described in further detail below.

Table 2.1. Measures used in the study

Variable	Measures	Reference
Satisfaction with treatment	Diabetes Treatment Satisfaction Questionnaire	Bradley, 1993
	Diabetes Clinic Satisfaction Questionnaire	Bradley, 1993
	Diabetes Satisfaction from the Diabetes Quality of Life for Youths	Ingersoll & Marrero, 1991
	Satisfaction with Diabetes Care	Designed by author and clinic staff
Quality of life	Diabetes Quality of Life for Youths	Ingersoll & Marrero, 1991
Adaptation	Adaptation to Diabetes Scale	Challen, Davies, Williams, Haslum & Baum, 1988
Psychological well being	Strengths and Difficulties Questionnaire	Goodman, Meltzer, & Bailey, 1998
Glycaemic control	Single HbA1c Average HbA1c	

2.4.1 Satisfaction measures

i) Diabetes Treatment Satisfaction Questionnaire (DTSQ)

The DTSQ is designed to measure satisfaction with diabetes treatment regimens. The St Vincent Declaration (World Health Organization, 1990, 1995) suggested that the DTSQ should be used routinely to help increase the awareness of psychosocial outcomes in young people with diabetes. Additionally, the DTSQ focuses on the specific outcomes of diabetes care, which many researchers have felt is neglected in favour of focusing on the so-called 'hotel' aspects of care, for example, the waiting room (Fitzpatrick, 1991; Hall & Dorman, 1988).

The DTSQ was originally designed to assess satisfaction in a feasibility study of continuous subcutaneous insulin infusion in adults with insulin-dependent diabetes (Lewis *et al*, 1988). It is also appropriate for use with non-insulin dependent diabetes

(Bradley & Lewis, 1990). The author believed it would be useful for evaluating new treatments, education programmes and the routine auditing of established services (Bradley & Lewis, 1990).

The questionnaire consists of eight items, with six concerning various aspects of treatment satisfaction, for example:

- How **convenient** have you been finding your treatment to be recently?
- How satisfied would you be to **continu**e with your present form of treatment?

Two additional items ask about the perceived frequency of hyperglycaemia and hypoglycaemia during the previous few weeks. The authors recommend that these two questions not be included as part of the total score which is used in analysis. Each item is scored on a six-point Likert scale, which therefore gives a range of scores from six to 36, with higher scores reflecting increased levels of satisfaction.

Evidence for the construct validity of the scale has been provided by Bradley (1994) and Lewis and colleagues (1988). Alpha coefficient for the scale was 0.82. The DTSQ has been shown to be useful in clinical trials evaluating new technologies for insulin delivery (Lewis *et al*, 1988).

The DTSQ is presented in Appendix I.

ii) Diabetes Clinic Satisfaction Questionnaire (DCSQ)

As highlighted above, the DTSQ focuses on satisfaction with the **outcome** of diabetes treatment. The DCSQ attempts to complement the DTSQ by covering aspects of diabetes care delivery (Wilson & Home, 1993). Items include waiting times, privacy, continuity of care and communication, as well as aspects of relationships with doctors, nurses and other clinic staff.

There are 18 items, scored from one (dissatisfied) to three (satisfied). The total score can range from 18 to 54 and a higher score indicates more satisfaction.

The DCSQ is presented in Appendix II.

iii) Diabetes Quality of Life for Youths – satisfaction subscale

The Diabetes Quality of Life for Youths scale comprises four subscales, measuring satisfaction, impact, worries and self-reported health (Ingersoll & Marrero, 1991). The satisfaction scale assesses both diabetes-specific and more general satisfaction. Therefore, in a modification to the original scoring, this scale was split and seven questions reflecting satisfaction with diabetes care were included as a separate subscale and thus part of the independent variable of satisfaction with diabetes care.

This subscale is presented in Appendix III.

The other scales of the DQOL-Y are described in Section 2.4.2 below.

iv) Satisfaction with Diabetes Care

This short questionnaire was developed by the principal researcher to answer questions of clinical interest to the diabetes teams. These key areas were not specifically addressed by the three preceding questionnaires. The information to be obtained was not intended for computing statistical associations but was perceived as important for informing clinical practice at a local level. Examples are given of the questions posed:

- Do you feel that you get **different** (that is, conflicting) messages / advice from the doctors?
- When you leave the clinic, do you **understand** everything you have been told?
- Please tell me about the **best parts** of your diabetes care

This questionnaire was piloted on five young people attending the Royal Infirmary clinic, prior to the data collection period. Minor wording changes were suggested.

This scale is presented in Appendix IV.

2.4.2 Psychological measures

i) Diabetes Quality of Life for Youths (DQOL-Y)

This questionnaire is a modified version of the Diabetes Quality of Life measure developed to assess the psychosocial impact of intensified regimens in the Diabetes Control and Complications Trial (DCCT, 1988, 1993). In particular, the instrument was developed to assess participants' concerns over social and vocational issues related to their diabetes. In addition, their perceptions regarding the impact of their diabetes on general life satisfaction were sought. The research team of the DCCT believed it was appropriate to design a diabetes-specific quality of life measure, as it could lead to increased sensitivity to treatment effects than available generic measures (DCCT, 1996). Although the original instrument was intended for assessment within the context of the DCCT, it was presumed to be applicable to a wider range of research involving people with diabetes.

Several of the original items were thought to be of limited relevance to the lives of children and adolescents. These were removed and several questions relating specifically to school life were added. Consequently, the scale was revised to be more applicable to and appropriate for, young people (Ingersoll & Marrero, 1991). The youth scale retained the same structure of four subscales.

Each item is answered on a five point Likert scale. On the Impact and Worries scales, higher scores indicate poorer quality of life. As mentioned above, the Satisfaction scale was divided, resulting in a new scale, which the author has termed Life satisfaction. This scale is scored such that higher scores reflect levels of increased satisfaction. Finally, a single item of overall health is included. This is a global health perception that is derived from asking patients to compare their health with that of other individuals their age and choose from: excellent, good, fair, or poor.

Seventy-four participants were used to validate the revised youth scale. Cronbach's alpha values for the Impact and Worries scales are presented in Table 2.2.

Table 2.2. Impact and Worries Scales

Scale	Cronbach's Alpha
Disease Impact Scale	0.83
Diabetes Related Worries Scale	0.82

The DQOL-Y is presented in Appendix V.

ii) Adaptation to Diabetes Scale (ADS)

The authors of this scale commented on a clinical impression regarding the variability in how young people adapt to their diabetes. This scale was therefore devised as a method of quantifying adaptation to diabetes. Two factors from the psychometric data emerged, namely, **attitude** towards diabetes and diabetes-related **emotional** difficulties (Challen *et al*, 1988).

There are twenty items in the scale, but four are not included in the scoring criteria. The authors felt that the items included for the final version of the scale were predominantly negative, resulting in an overall negative tone and the possibility of responder bias. They have therefore included four items describing positive adaptation to diabetes, which are then not scored. It was hoped that the inclusion of these items gives a greater balance to the scale. Total scores of the 16 items can therefore range from 16-80, with a higher score implying less healthy adaptation towards diabetes. Items from the two subscales include:

- **Emotional difficulty with diabetes**

  I get cross about having diabetes

  It's depressing to think that I'll always have diabetes

- **Attitude to diabetes**

  I don't really bother with the diet, I just eat what I like

  There are good things about my diabetes

Despite the small size of the sample with which it was piloted, high levels of internal consistency and test-retest correlations support the scale's reliability, as shown in Table 2.3. The scale's validity is verified by correlations with the children's reports of self-esteem, anxiety and depression as well as parents' assessments of their children's adaptation to diabetes and adherence behaviours (Challen *et al*, 1988).

Table 2.3. Adaptation to Diabetes Scale

Scale	**Cronbach's Alpha**	**Test-retest**
Emotion	0.85	6-12 months: 0.85
Attitude	0.78	6-12 months 0.66
Total Adaptation	0.80	1-2 weeks: 0.88 6-12 months: 0.74

The ADS is presented in Appendix VI.

iii) Strengths and Difficulties Questionnaire (SDQ)

Although other measures of well being do exist, including a diabetes-specific well being questionnaire (Bradley & Lewis, 1990), the SDQ was chosen for its ability to test one of the research hypotheses. The scale has been published with normative data, which enable a comparison between the current sample and a community sample of adolescents. Furthermore, the scale's emphasis on strengths as well as weaknesses makes it particularly acceptable to community samples (Goodman & Scott, 1999).

The SDQ is a brief behavioural screening questionnaire, developed for a variety of purposes, such as clinical assessment, evaluating outcome, epidemiology and screening. It has several different formats, including one to be rated by parents/teachers (Goodman, 1997) and a self-report format (Goodman *et al*, 1998), the latter of which was used in the present study.

The scale has 25 items, comprising five scales of five items each, examples of which are detailed below.

- **Emotional symptoms scale**

  I worry a lot

  I am often unhappy, downhearted or tearful
- **Conduct problems scale**

  I get very angry and often lose my temper

  I fight a lot
- **Hyperactivity scale**

  I am restless. I cannot stay still for long

  I am constantly fidgeting or squirming
- **Peer problems scale**

  I have one good friend or more

  Other people my age generally like me
- **Prosocial scale**

  I try to be nice to other people

  I often volunteer to help others

Answers range on a three-point scale, of 'not true', 'somewhat true' and 'certainly true'. 'Somewhat true' is always scored as one, but the scoring of the other two as zero or two varies across the items. Higher scores indicate a greater incidence of psychological difficulties. Summation of all the scales except the Prosocial scale generates the Total Difficulties score. This resultant score can range from 0 to 40. The Prosocial score is not incorporated in the reverse direction into the Total Difficulties score since the absence of prosocial behaviours is conceptually different from the presence of psychological difficulties (Goodman *et al*, 1997). It is therefore proposed not to use the Prosocial scale in hypothesis testing.

Table 2.4 shows the Cronbach's alpha values for the SDQ.

Table 2.4. Strengths and Difficulties Questionnaire

Scale	Cronbach's Alpha
Emotional problems	0.75
Conduct problems	0.72
Hyperactivity problems	0.69
Total difficulties	0.82
Prosocial	0.65

The authors have set three cut-off scores, to guide classification of individuals. The levels are such that approximately 80% of a community sample should fall into a 'normal' range and 10% into a 'borderline' and 'abnormal' range, respectively. The SDQ was administered to two groups, 83 from a community sample and 116 young people attending a mental health clinic. It was found to discriminate satisfactorily between the two samples, with a clinic sample mean for Total Difficulties 1.4 standard deviations above the community sample mean. Additionally, mental health clinic participants were six times more likely to have a Total Difficulties score in the 'abnormal' range.

The SDQ is presented in Appendix VII.

2.5. Glycosylated haemoglobin test

Glycosylated haemoglobin values are recognised as the most accurate measure of general glycaemic control, with higher glycosylated haemoglobin reflecting poorer diabetic control over the previous two to three months (Dunn *et al*, 1979; Gonen *et al*, 1979). The non-diabetic range for HbA1c levels is 4.1 to 5.3, with values from 9.1 to 14.0 reflecting increasingly poor control. A local target of HbA1c less than 8.5% has been set as a realistic level for this group of patients (Carson *et al*, 2000).

The blood required was obtained by a fingerstick, on the same day the self-report data was collected. It was analysed by biochemists in each clinic site and the results recorded by the researcher.

Average HbA1c

Several researchers have highlighted that an average value of HbA1c is a more reliable measure than one single HbA1c (Guttman-Bauman *et al*, 1998). Therefore, where the information was available, HbA1c results taken in the 12 months preceding the clinic appointment date were combined, to give an average level. For participants diagnosed very recently previous HbA1c levels were not available.

2.6 Procedure

i) Participant selection

All participants were recruited via liaison with the Diabetes Nurse Specialist for Adolescents, who has responsibility to the four clinic sites. Therefore, the researcher had access to the clinic lists and medical records for the four hospitals and could gain information on relevant inclusion and exclusion criteria for each potential participant.

ii) Questionnaire Completion

Each potential participant was sent a letter of introduction (Appendix VIII) and the research information sheet (Appendix IX) approximately one week prior to their clinic appointment. This information was included with routine reminder letters for clinic appointments. Participants were drawn from five successive monthly clinics at the Royal Infirmary of Edinburgh and single quarterly clinics at the other three sites.

The research information sheet described the rationale for the study, the nature of their participation and proposed use of the study for improved knowledge for clinical interventions.

At the clinic, the researcher saw participants individually. After an introduction to the study, they were encouraged to ask questions or express concerns. If patients wished to participate, they were then asked to complete a consent form (Appendix X). Where a participant was under the age of 16 years, a parent or guardian signed a second consent form (Appendix XI). Participants were then given the package of questionnaire to complete in the waiting room. The author was on hand throughout the duration of the clinic to answer any questions and to collect completed questionnaire packs. The measures were presented with the most demanding first to ensure concentration was maximised. Therefore, the booklet contained the questionnaires in the following order:

- Diabetes Quality of Life for Youths
- Diabetes Treatment Satisfaction Questionnaire
- Diabetes Clinic Satisfaction Scale

- Strengths and Difficulties Questionnaire
- Adaptation to Diabetes Scale
- Satisfaction with diabetes care

Demographic factors, such as age, gender and date of diagnosis were collected to be included in the final analysis. This information was obtained from the participants' medical records, with permission from the participant and the hospital staff. Each participant's HbA1c was also recorded.

Finally, participants' postcodes were also noted. This was for the purpose of computing a deprivation category, based on the work of Carstairs and Morris (1991). The analysis is based on postcodes, to the level of approximately 5,000 population per category. Although no clear-cut and universally accepted definition of deprivation exists, the authors included the following factors in their calculations:

- Extent of overcrowded households
- Male unemployment levels
- Car ownership
- Socio-economic group

Categories range from one (affluent) to seven (deprived), reflecting increasing levels of deprivation (Carstairs & Morris, 1991).

Following the completion of questionnaires, letters of their participation informed each young person's General Practitioner (Appendix XII).

iii) Semi-structured interviews

Ten participants also completed a semi-structured interview. Young people attending the clinic at the Royal Infirmary were invited to participate in this second stage of the study. Where a participant was interested, their telephone number was noted and they were then contacted approximately 2-3 days later to arrange a convenient time. This phone call also gave them the opportunity to withdraw their consent for the interview, having had a period of time for consideration. Where arrangements were made, a confirmation letter was sent with the details of the date and time (Appendix XIII).

Participants were interviewed in their homes. A semi-structured interview schedule was administered, consisting of a series of open-ended questions devised by the researcher in collaboration with the four clinic teams. The set questions were supplemented by reflections on the emotion or content of the responses, requests for clarification and probes, for example, 'can you tell me more about that?' The main content areas of the schedule were as follows:

- Diagnosis (when, what age, context, feelings)
- Words used to describe having diabetes
- The course of their diabetes
- Coping strategies
- Clinic (worst and best parts, improvements)
- Future (any impact from diabetes?)

However, there was also considerable scope for the participant to influence the direction of the interview. Interviews lasted between 15 and 45 minutes and were tape recorded and subsequently transcribed. An example of a completed interview is available in Appendix XIV.

2.7 Analysis

i) Participant confidentiality

In order to preserve confidentiality, each participant was assigned an identification number, which was used when the data was entered into the computer. Following this, all other identifying factors, such as clinic attended, name or date of birth, were removed from the questionnaire responses.

ii) Data analysis

Data were analysed using the Statistical Package for the Social Sciences (SPSS) for Windows, Version 9.0. Frequency distribution charts were used to check the accuracy of data input and all incorrectly entered values corrected. Means, range and standard deviations were calculated for demographic variables, self-report measures and HbA1c levels. Modal scores were used for categorical variables.

Descriptive statistics were calculated for the four clinic sites. Following this, analyses were performed on the whole sample, using Pearson's correlation coefficients and t tests, as well as stepwise multiple regression analysis (with probability levels set at 0.05 for entering a variable and 0.10 for removing it form the equation). A second level of analysis was to compare sections of the sample against each other, using gender, age and HbA1c levels.

For the purposes of this study and based on the power calculation and sample number, a minimum significance value was set at $p>.05$.

The information derived from the newly developed Satisfaction with Diabetes Care was examined. Finally, a thematic analysis was conducted on the information provided at semi-structured interviews.

RESULTS

3.1 Participants

3.1.1 Number of participants approached

Table 3.1 describes the number of young people who were approached to take part in the research. As described above, four clinic sites were used in the recruitment process.

Table 3.1. Descriptions of numbers approached and consented, by clinic

Clinic	Number approached	Number consented	Number completed study	% of original sample approached
Royal Infirmary	52	50	48	92.3 %
Western General Hospital	20	19	19	95 %
Roodlands Hospital	10	10	10	100 %
St John's Hospital	8	7	6	75 %
TOTAL	**90**	**86**	**83**	**92 %**

As can be seen from Table 3.1, 92% of the total number of young people approached completed the study. Two participants from the Royal Infirmary and one from St John's Hospital agreed to take part in the research but did not complete questionnaires. These three participants were given packs of questionnaires, but at the end of the clinics, their questionnaires had not been returned and the patients had left. Therefore, 96.5% of those who consented to participate in the study returned completed questionnaires.

In addition, one potential participant at the Royal Infirmary was not approached for the study. This person had failed to attend appointments for approximately six months and had a history of sporadic attendance at the clinic. The Consultant Physician felt it would be inappropriate to ask her to participate on that day, as several members of the diabetes

team wished to speak with her at the clinic. Thus, there was a possibility that she might feel overly burdened.

In summary, a total of 83 adolescents from the four clinic sites agreed to take part in the study. The number from each clinic is shown in Table 3.2. Of the participant group, 45 were female (54%) and 38 were male (46%).

3.1.2 Numbers from each clinic

Table 3.2. Number of participants from each clinic

Clinic site	**Number of participants**	**Percentage of total sample**
Royal Infirmary	48	58%
Western General Hospital	19	23%
St John's Hospital	6	7%
Roodlands Hospital	10	12%

3.2 Demographic variables

The demographic details of the four clinic sites are presented in Table 3.3.

Table 3.3. Demographic information (M= means, s.d. = standard deviation)

	Royal Inf. n=48	**Western n=19**	**Roodlands n=10**	**St John's n=6**	**Statistic**	**Sig. level (p =)**
ANOVA						
Age						
***M* (s.d.)**	**16.37** (1.29)	**16.01** (1.27)	**15.62** (1.36)	**15.46** (1.01)	$F = 1.74$	p=.167 NS
Age at diag.						
***M* (s.d.)**	**10.6** (3.55)	**10.43** (4.29)	**5.57** (3.92)	**9.03** (3.09)	$F = 5.24$	p=.002
Time since diag.						
***M* (s.d.)**	**5.78** (3.89)	**5.59** (4.04)	**10.06** (4.16)	**6.44** (3.16)	$F = 3.58$	p=.018
CHI SQUARE						
Sex (M/F)						
NO.	20/28	9/10	4/6	5/1	X^2 =	p = .274
%	42/58	47/53	40/60	83/17	3.89	NS
Dep.Cat.						
1	16	1	0	1	X^2 =	p = .094
2	9	6	2	2	26.25	NS
3	7	2	4	1		
4	7	7	4	1		
5	2	0	0	1		
6	1	2	0	0		
7	0	1	0	0		

The data were analysed using an Analysis of Variance for independent groups (two-tailed). The four clinic sites did not differ significantly in terms of age ($F = 1.74$, df = 3, $p = .167$). However, they were significant differences between the four groups in terms of age at diagnosis ($F = 5.24$, df = 3, $p = .002$) and time since diagnosis ($F = 3.58$, df = 3, $p = .018$). The Roodlands Hospital sample was younger in age at diagnosis and consequently this sample has had a longer duration of diabetes.

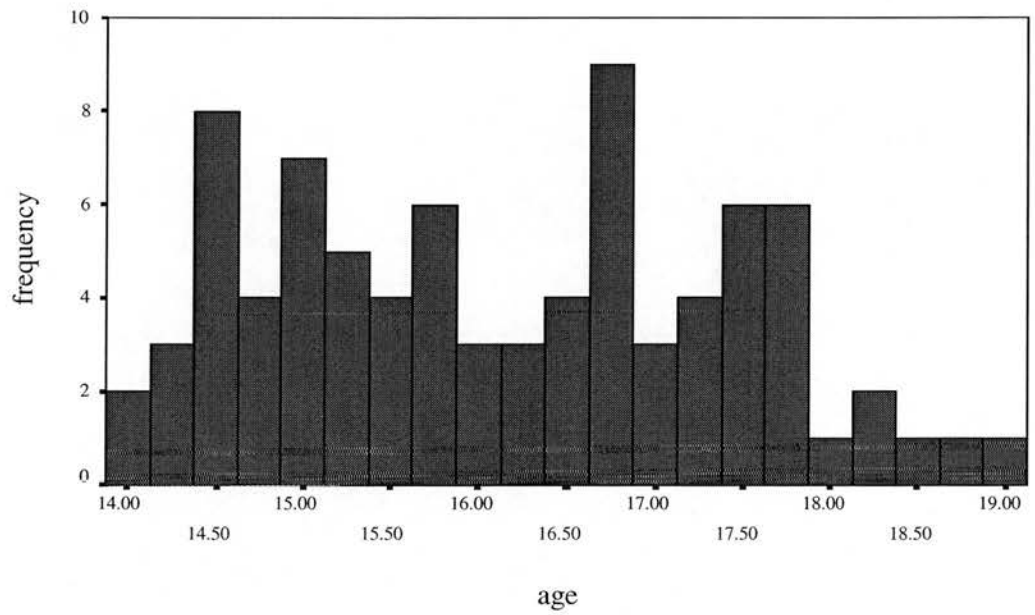
Further analyses of the categorical data were carried out using Chi-square tests. The four groups were comparable for gender ($X^2 = 3.89$, df = 3, $p = .274$) and deprivation category ($X^2 = 26.25$, df = 18, $p = .094$).

The results therefore indicate that the four clinic samples are well matched in terms of age, gender and deprivation category, but less so in terms of age at diagnosis and time since diagnosis, as a result of the inclusion of participants from the Roodlands Hospital clinic.

Age

To account for the six-month data collection period, the exact age of each participant at the time of clinic appointment was calculated. The ages ranged form 14.05 to 18.99 years, with a mean of 16.13 years, standard deviation 1.29 years. Their distribution is shown in Figure 3.1.

Figure 3.1. Age when completed questionnaires, whole sample

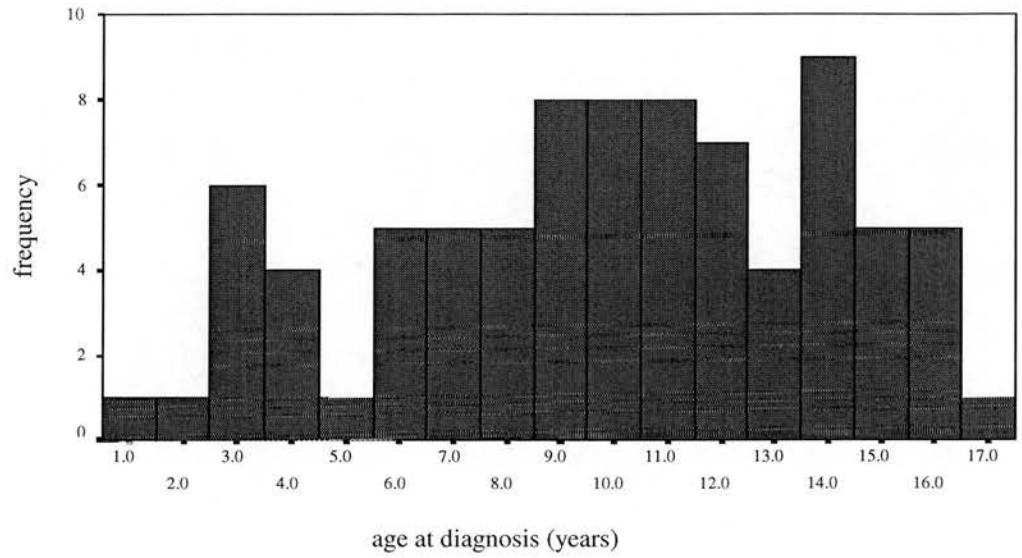


Age at diagnosis

The age of participants when diagnosed with diabetes was computed, by subtracting their date of birth from their date of diagnosis. This ranged from 0.98 years (11.76

months) to 16.94 years, with a mean of 9.84 years (standard deviation 4.03 years). The distribution of age at diagnosis is shown in Figure 3.2.

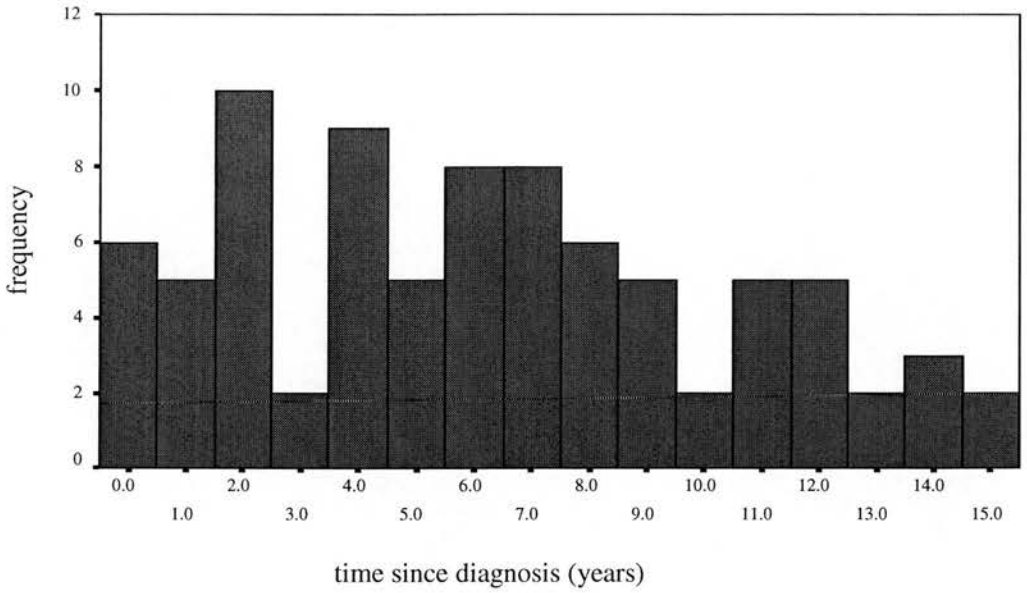
Figure 3.2. Age at diagnosis, whole sample



Time since diagnosis

The number of years since diagnosis of diabetes was also calculated, by subtracting the participants' date of diagnosis from their clinic date. With a mean of 6.29 years (standard deviation 4.09 years), this ranged from 0.1 years (1.2 months) to 15.86 years. The distribution of this is shown in Figure 3.3.

Figure 3.3. Time since diagnosis, whole sample



Relationship between age, age at diagnosis and time since diagnosis

Time since diagnosis, age at diagnosis and participants' ages are often associated in studies (for example, Kovacs *et al*, 1992). Therefore, a correlation was conducted to compare the associations between age, age at diagnosis and time since diagnosis. The results are presented in Table 3.4.

Table 3.4. Correlation of age, age at diagnosis and time since diagnosis

	1	**2**	**3**
1. Age	—	—	—
2. Age at diagnosis	.118	—	—
3. Time since diagnosis	.202*	-.949*	—

* $p < .05$

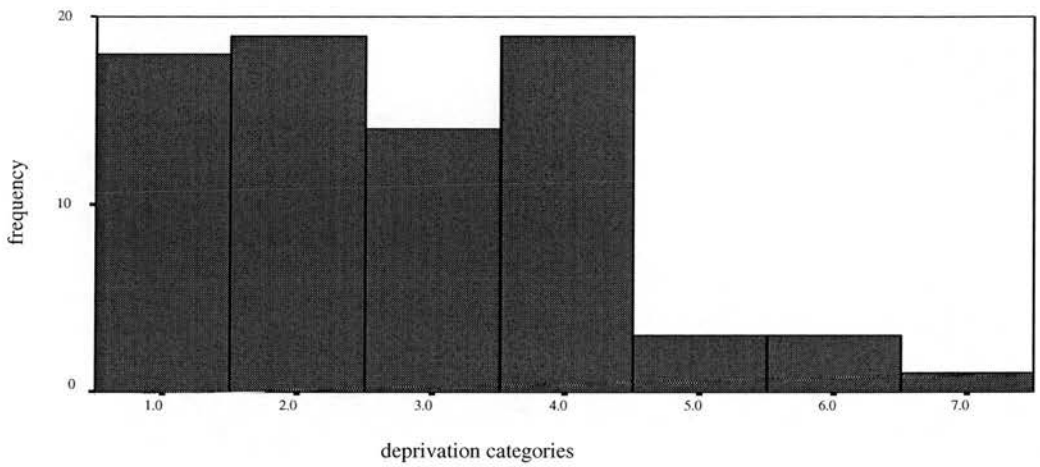
In the present study, there is no relationship between age and age at diagnosis ($r = .118$, $p = .143$). There is a statistically significant association between age and time since diagnosis ($r = .202$, $p = .034$) and, as expected, between age at diagnosis and time since diagnosis ($r = -.949$, $p < .001$). For fullness of reporting, all three variables will be used

when exploring the effects of demographic characteristics on the sample's HbA1c levels and psychological health.

Deprivation categories

Where available, the participant's postcode was noted. This was possible for 93% of the sample studied. Deprivation categories were subsequently computed, based on the postcode recorded. The categories range between one (affluent) and seven (deprived), with higher numbered categories therefore reflecting increasing deprivation. Categories calculated in this study ranged from one to seven, with a modal score of two and a median score of three. The distribution of deprivation categories is presented in Figure 3.4.

Figure 3.4. Frequency of deprivation categories, whole sample



As can be seen from Figure 3.4, the deprivation data is positively skewed, reflecting a higher number of participants in the top four categories. This reflects the relative affluence of the area from which the sample was drawn (Carstairs & Morris, 1991). The results from the current sample can be compared against the distribution of the population of Scotland as a whole, as seen in Table 3.5.

Table 3.5. Comparison of deprivation categories, Scotland-wide versus current study

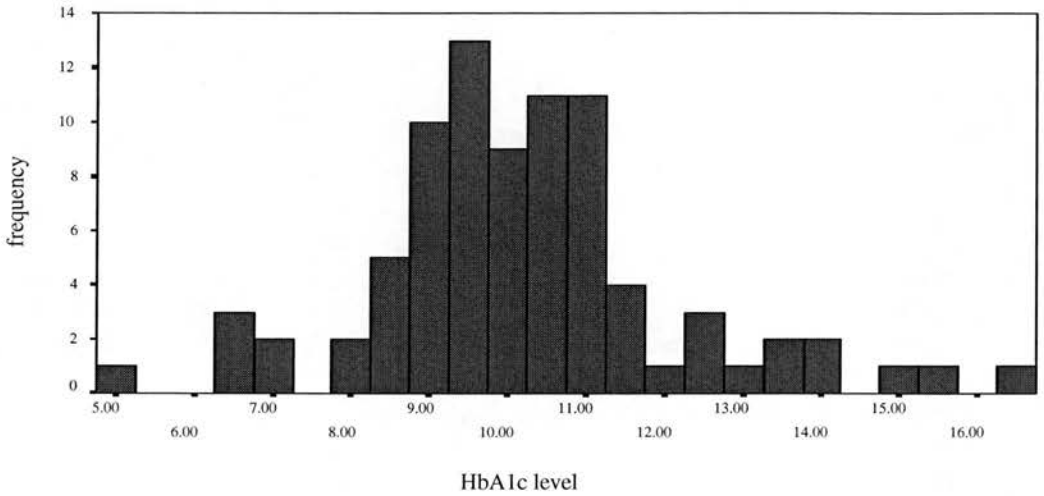
Deprivation category	% of population in Scotland (Carstairs and Morris, 1991)	% of sample in current study
1	6.1%	23.4%
2	13.7%	24.7%
3	21.8%	18.2%
4	25.5%	24.7%
5	14.8%	3.9%
6	11.4%	3.9%
7	6.8%	1.3%

As evident from the data in Table 3.5, there is a different pattern of results in the current study, compared to that of Carstairs and Morris (1991). In the present sample, there is a larger number of participants in the most affluent categories. Also, there are fewer people in the most deprived categories, as compared to the figures for the general population for Scotland. In summary the present sample has, on average, a relatively affluent background.

3.3 HbA1c levels

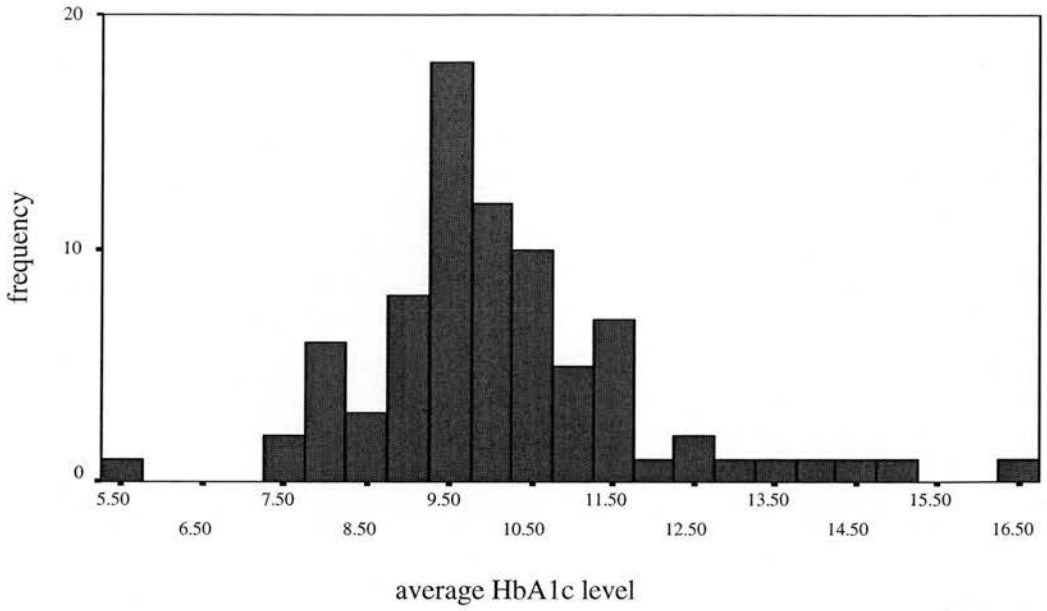
HbA1c levels ranged from 5.2% to 16.7%, with a mean of 10.22%, standard deviation 1.97%. The distribution of these levels is presented in Figure 3.5.

Figure 3.5. Frequency of HbA1c levels, whole sample



Where possible (97% of sample), the average HbA1c levels were also recorded, by calculating the mean of HbA1c results for the 12 months preceding the data collection date. These values ranged from 5.7% to 16.7%, with a mean of 10.11 (standard deviation 1.7), as shown in Figure 3.6. Where HbA1c levels were not available for the full twelve months, the recorded levels available were used. Thus, some averages used in the analysis are for less than twelve months.

Figure 3.6. Frequency of Average HbA1c levels, whole sample



As would be expected, there is a significant correlation between the single HbA1c level and the 12month Average HbA1c (r = .688, p= <.001).

Descriptive statistics of the HbA1c and Average HbA1c values for the four clinic sites are presented in Table 3.6. The data were analysed using an Analysis of Variance for independent groups (two-tailed).

Table 3.6. Descriptions of HbA1c and Average HbA1c, by clinic

	Royal Infirmary n = 48	**Western General n = 19**	**Roodlands Hospital n = 10**	**St John's Hospital n = 6**	***F***	**Sig.**
HbA1c Mean (s.d.)	10.44% (2.07)	9.48% (1.67)	10.05% (1.67)	11.15% (2.16)	1.60	.196 NS
Ave. HbA1c Mean (s.d.)	10.13% (1.82)	9.97% (1.98)	10.24% (1.16)	10.19% (1.3)	.064	.979 NS

NS = not significant

The four clinic sites did not differ significantly in terms of HbA1c (F = 1.60, df = 3, p = .196) or Average HbA1c (F = .064, df = 3, p = .979).

Banding HbA1c results

The Clinic staff proposed banding HbA1c results, to give additional information on the frequency of HbA1c levels in their clinic populations. Subjective levels were agreed, as detailed below and the distribution of the sample amongst these four categories outlined in Table 3.7.

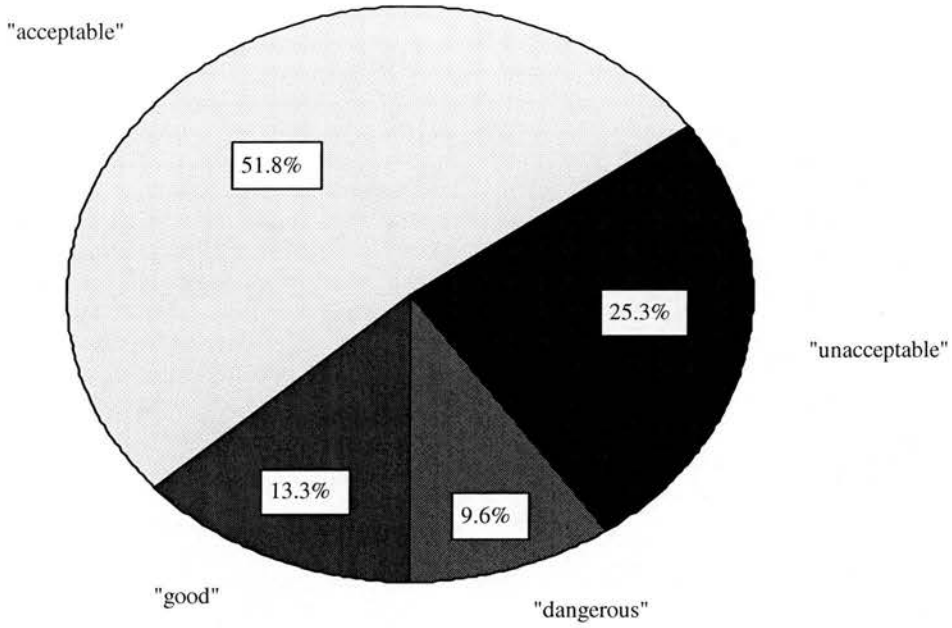
- 8.5 % and below = "Good"
- 8.6 - 10.5 % = "Acceptable"
- 10.6 - 13 % = "Unacceptable"
- 13.1 % and above = "Dangerous"

Table 3.7. Frequencies and percentages of the four subjective levels of HbA1c, as a whole sample and by clinic

	Clinic				
Subjective HbA1c banding	**Whole sample n = 83**	**Royal Infirmary n = 48**	**Western General n = 19**	**Roodlands Hosp. n =10**	**St John's Hosp. n = 6**
"Good"	**(11) 13.3%**	(5) 10.4%	(5) 26.3%	(1) 10%	0 0%
"Acceptable"	**(43) 51.8%**	(24) 50%	(10) 52.6%	(6) 60%	(3) 50%
"Unacceptable"	**(21) 25.3%**	(14) 29.2%	(4) 21.1%	(2) 20%	(1) 16.7%
"Dangerous"	**(8) 9.6%**	(5) 10.4%	0 0%	(1) 10%	(2) 33.3%

Figure 3.7 presents a visual representation of the percentages of the whole sample in each of the four subjective bandings.

Figure 3.7. Levels of HbA1c, as a whole sample



HbA1c levels were also examined for gender differences, by calculating a two-tailed independent samples *t*-test (Table 3.8).

Table 3.8. Comparison of males and females for HbA1c levels

	Male n = 38	**Female n = 45**	***t***	**df**	**Sig.**	**Mean difference**
HbA1c Mean (s.d.)	10.2 (1.97)	10.24 (1.99)	-.086	81	.932	1.49
Average HbA1c Mean (s.d.)	10.12 (1.70)	10.11 (1.79)	.036	79	.971	-3.73

As shown in Table 3.8, there are no significant differences between males and females with regards to HbA1c (t = -.086, df = 81, p = .932) or Average HbA1c (t = .036, df = 79, p = .971).

3.4 Characteristics of participants who completed semi-structured interviews

Ten semi-structured interviews were completed. One additional participant was not available for two home visits and thus did not complete an interview. Table 3.9 shows the demographic characteristics for this sample.

Table 3.9. Characteristics of ten participants who completed semi-structured interviews

Study no	Gender	Age	HbA1c	Dep'n category	Age at diagnosis	Time since diagnosis
1	female	17.70	9.0	4	15.93	1.78
6	female	16.45	10.3	4	12.36	4.10
7	male	17.64	16.7	2	2.89	14.76
20	female	14.56	11.4	4	10.02	4.54
31	female	16.49	9.6	missing	16.16	0.34
36	male	15.07	10.4	2	10.33	4.75
37	female	17.61	9.10	2	10.2	7.42
43	male	16.15	10.4	2	3.23	12.93
46	male	15.46	11.10	1	8.8	6.67
49	female	15.78	9.6	1	11.44	4.35

The averages of the interview sub-sample were also compared against the average values for the whole sample, as presented in Table 3.10.

Table 3.10. Comparison of characteristics, whole sample versus interview sample

	Gender	**Age** (Mean, years)	**HbA1c** (Mean)	**Dep'n cat.** (Mode, Median)	**Age at diagnosis** (Mean, years)	**Time since diagnosis** (Mean, years)
Whole sample n= 83	male: 46% female: 54%	16.13	10.22%	mode: 2 median:3	9.8	6.45
Interview sample n = 10	male: 40% female: 60%	16.29	10.89%	mode:2 median:2	10.14	6.16

As shown in Table 3.10, the interview sample is representative of the whole sample, in terms of the above characteristics.

The interview sample was also compared against the whole sample with regards to mean scores and standard deviations on the self-report measures. This information will be presented in Table 3.12 below, following descriptive statistics of these measures for the full sample.

3.5 Descriptive statistics of self-report measures

To determine the distribution of the data, the self-report questionnaire data were examined for skewness and kurtosis. The data are presented in Table 3.11.

Table 3.11. Descriptive statistics of self-report measures, including tests for normal distribution

Scale	Mean	S.d.	Min	Max	Kurtosis	Skewness
Impact (DQOL-Y)	49.07	10.59	29	78	-.05	.55
Worries (DQOL-Y)	18.69	5.65	11	42	2.62	1.35
Life Satisfaction (DQOL-Y)	38.90	7.02	23	49	-.51	.26
Health (DQOL-Y)	2.83	0.75	1	4	.17	-.43
DTSQ	27.00	5.16	16	36	-.96	-.21
DCSQ	43.28	6.16	29	54	-.24	-.49
Diabetes Satisfaction (DQOL-Y)	25.82	5.78	9	35	.72	-.86
Emotion (ADS)	19.75	7.52	8	40	.55	-.23
Attitude (ADS)	21.23	5.37	9	34	.13	-.10
Adaptation to Diabetes	41.02	10.53	21	67	-.47	.38
SDQ: Difficulties Total	11.06	5.09	0	26	.33	.45

As can be seen from Table 3.11, the self-report measures meet the necessary criteria for the use of parametric statistics.

Table 3.12 shows the self-report measures for the whole sample compared to the interview sub-sample.

Table 3.12. Comparison of self-report measures, whole sample versus interview sample

	Whole sample n = 83			**Interview sample n = 10**	
Scale	**Mean**	**S.d.**		**Mean**	**S.d.**
Impact (DQOL-Y)	49.07	10.59		49.70	8.93
Worries (DQOL-Y)	18.69	5.65		19.90	5.23
Life Satisfaction (DQOL-Y)	38.90	7.02		38.80	7.16
Health (DQOL-Y)	2.83	0.75		2.60	0.84
DTSQ	27.00	5.16		26.00	6.70
DCSQ	43.28	6.16		42.00	4.69
Diabetes Satisfaction (DQOL-Y)	25.82	5.78		25.10	5.70
Emotion (ADS)	19.75	7.52		20.20	6.79
Attitude (ADS)	21.23	5.37		23.40	5.27
Adaptation to Diabetes	41.02	10.53		43.70	9.90
SDQ: Difficulties Total	11.06	5.09		11.10	4.79

Summary of interview sample

For each of the measures presented in Table 3.12, the mean of the interview sub-sample is within one standard deviation of the whole sample mean. Consequently, as evident from the data in Tables 3.10 and 3.12, the interview sample is representative of the whole sample.

3.6 Hypothesis testing

The four hypotheses regarding the associations between the independent variable, satisfaction with treatment, and psychological and medical outcomes, were initially explored using correlational methods. The influences of demographic factors were then investigated, followed by further analysis using HbA1c levels. Finally, multiple regression calculations were completed.

Independent variable: satisfaction

The three satisfaction measures used, the Diabetes Treatment Satisfaction Questionnaire (DTSQ), the Diabetes Clinic Satisfaction Questionnaire (DCSQ) and the Diabetes Satisfaction subscale from the Diabetes Quality of Life for Youths, are all designed such that higher scores reflect increasing levels of satisfaction.

3.6.1. Hypothesis One: Satisfaction and quality of life

Higher satisfaction levels will be associated with increased quality of life.

The Diabetes Quality of Life for Youths (DQOL-Y) total score has not been used in hypothesis testing. The Satisfaction subscale has been divided into Diabetes Satisfaction, part of the independent variable under investigation, and Life Satisfaction, which is one of the psychological outcome variables. Therefore, as the scale has been modified for use in the present study, the total score was thought to be inappropriate.

The four subscales of the DQOL-Y used are scored in different directions. High scores both on the Impact and Worries scales indicate a higher level of worries about diabetes and perceived impact of the condition. Hypothesis One therefore predicts an inverse relationship between the independent variable and scores on the Impact and Worries subscale. The Life Satisfaction and self-reported Health subscales are scored in the opposite direction, thus higher scores reflect increasingly positive life satisfaction and perceived physical health. Therefore, a positive relationship is expected between the satisfaction measures and these subscales.

The associations between these variables are reported in Table 3.13.

Table 3.13. Correlation of Satisfaction measures with Impact, Worries, Life Satisfaction and Health subscales

	Impact	**Worries**	**Life Sat'n**	**Health**
DTSQ	-.319*	-.166	.353*	.338*
DCSQ	-.275*	-.216*	.262*	.113
Diabetes Satisfaction from DQOL-Y	-.401*	-.262*	.405*	.242*

* $p < .005$

Table 3.13 shows statistically significant correlations, between quality of life measures and satisfaction with treatment measures. There are negative associations between the Impact subscale and the DTSQ (r = -.319, p = .003), the DCSQ (r = -.275, p = .006), and the Diabetes Satisfaction from the DQOL-Y (r = -.401, $p <$ .001).

Additionally, there are negative relationships between the Worries subscale and both the DCSQ (r = -.216, p = .025) and the Diabetes Satisfaction subscale from the DQOL-Y (r = -.262, p = .008). However, there is no relationship between Worries and the DTSQ (r = -.166, p = .134).

Furthermore, there are positive relationships between Life satisfaction and the three treatment satisfaction measures, the DTSQ (r = .353, p = .001), the DCSQ (r = .262, p = .008) and the Diabetes Satisfaction from DQOL-Y (r = .405, $p <$ .001).

Finally, there are positive associations between self-reported Health assessment and the DTSQ (r = .338, p = .002) and the Diabetes Satisfaction subscale from the DQOL-Y (r = .242, p = .014). There is no association between Health and the DCSQ (r = .113, p = .156).

The above correlational data suggest that as satisfaction with diabetes care increases, diabetes has a lesser impact, there are fewer diabetes related worries, individuals are more satisfied with their everyday life and they have a more positive self-perceived physical health status. Hypothesis One is therefore supported by the above results.

3.6.2 Hypothesis Two: Satisfaction and adaptation to diabetes

Higher satisfaction levels will be associated with increased levels of psychological adaptation to diabetes.

High scores on the Adaptation to Diabetes scale imply less healthy adaptation towards diabetes. This is the case for the two subscales, Emotion and Attitude to Diabetes, as well as the overall score. Therefore Hypothesis Two anticipates an inverse relationship between the independent variable and scores on the Adaptation to Diabetes Scale. The results of the correlations are presented in Table 3.14.

Table 3.14. Correlations of satisfaction scales with Emotion subscale, Attitude subscale and Total Adaptation to diabetes

	Emotion subscale	**Attitude subscale**	**Adaptation to diabetes**
DTSQ	-.405*	-.329*	-.453*
DCSQ	-.330*	-.579*	-.527*
Diabetes Satisfaction from DQOL-Y	-.407*	-.398*	-.483*

*$p < .001$

Table 3.14 shows statistically significant correlations, between the Emotion subscale, Adaptation subscale and total Adaptation to diabetes and the three measures of satisfaction with treatment. The DTSQ correlates negatively with the total Adaptation score (r = -.453, $p < .001$); as does the DCSQ (r = -.527, $p < .001$); and Diabetes Satisfaction from DQOL-Y (r = -.483, $p < .001$).

Based on the above correlational data, as satisfaction with treatment increases, individuals have less emotional difficulty with their diabetes and better adaptation to the condition. Hypothesis Two is therefore supported by the correlational data.

3.6.3. Hypothesis Three: Satisfaction and psychological well being

Higher satisfaction levels will be associated with increased levels of psychological well being.

A high score on the SDQ indicates an increased level of psychological distress. A negative relationship was therefore predicted between scores on the SDQ Scale and the three satisfaction measures. The correlation results are presented in Table 3.15.

Table 3.15. Correlations of satisfaction scales with Total Difficulties

	Total Difficulties
DTSQ	-.421*
DCSQ	-.286*
Diabetes Satisfaction from DQOL-Y	-.397*

* $p < .001$

Table 3.15 shows statistically significant correlations between psychological well being and satisfaction, as measured by the DTSQ (r =-.421, p<.001); the DCSQ (r = -.286, p< .001) and Diabetes Satisfaction from the DQOL-Y (r = -.397, p<.001). As predicted, the correlations are negative in direction, and thus support Hypothesis 3.

3.6.4 Hypothesis Four: Satisfaction and glycaemic control

Higher levels of satisfaction will be associated with better glycaemic control, as measured by HbA1c.

As scores on satisfaction questionnaires increase, HbA1c levels should decrease, reflecting better overall glycaemic control. Correlations between the independent variable of satisfaction and the dependent variables of HbA1c and Average HbA1c are shown in Table 3.16.

Table 3.16. Correlations of satisfaction measures and HbA1c and Average HbA1c levels

	HbA1c	**Average HbA1c**
DTSQ	-.240*	-.252*
DCSQ	-.074	-.075
Diabetes Satisfaction from DQOL-Y	-.331*	-.281*

* $p < .05$

The data in Table 3.16 illustrate significant correlations between satisfaction and HbA1c, as measured by both the DTSQ (r= -.240, p = .029) and the Diabetes Satisfaction subscale from the DQOL-Y (r = -.331, p<.001). There was no relationship between HbA1c and DCSQ (r = -.074, p = .254).

Significant relationships were also found between Average HbA1c and the DTSQ (r = -.252, p = .023) and the Diabetes Satisfaction subscale from the DQOL-Y and Average HbA1c (r = -.281, p<.001). There was again no relationship between the DCSQ and Average HbA1c (r = -.075, p =.253).

Data suggests that as satisfaction with diabetes care increases, as measured by the both the DTSQ and the Diabetes Satisfaction subscale of the DQOL-Y, HbA1c levels are lower, reflecting better overall glycaemic control. Therefore, this hypothesis is supported by the correlational data.

3.6.5 Hypothesis Five: Levels of psychological well being

Participants in the present study will have higher levels of psychological maladaptation compared to an adolescent community population.

The Strengths and Difficulties Questionnaire (SDQ) was designed to measure psychological well being and maladaptation. Normative data has been published, to enable comparisons against a community sample (Goodman *et al*, 1998). This data includes bandings, set to reflect approximately 80% of children in the community as 'normal', 10% 'borderline' and 10% 'abnormal' (Goodman *et al*, 1998). Table 3.17 shows the numbers and percentages from the present study in each of the three bandings for the subscales and Total Difficulties score of the SDQ.

Table 3.17. Frequency and percentage of current participants in each category of the SDQ

	'Normal' (N, %)	**'Borderline' (N, %)**	**'Abnormal' (N, %)**
Total difficulties	67 **80.7%**	11 **13.3%**	5 **6.0%**
Emotional symptoms	70 84.4%	6 7.2%	7 8.4%
Conduct problems	59 71.1%	9 10.8%	15 18.0%
Hyperactivity	58 69.9%	12 14.4%	13 15.7%
Prosocial behaviour	68 82.0%	8 9.6%	7 8.4%

As described in the Method section, the Total Difficulties scale is an amalgamation of the emotional, conduct, hyperactivity and peer problems subscales. The distribution of the Total Difficulties scale is presented in Figure 3.8.

Figure 3.8 Percentages of normal, borderline and abnormal categories of the Total Difficulties scale, whole sample

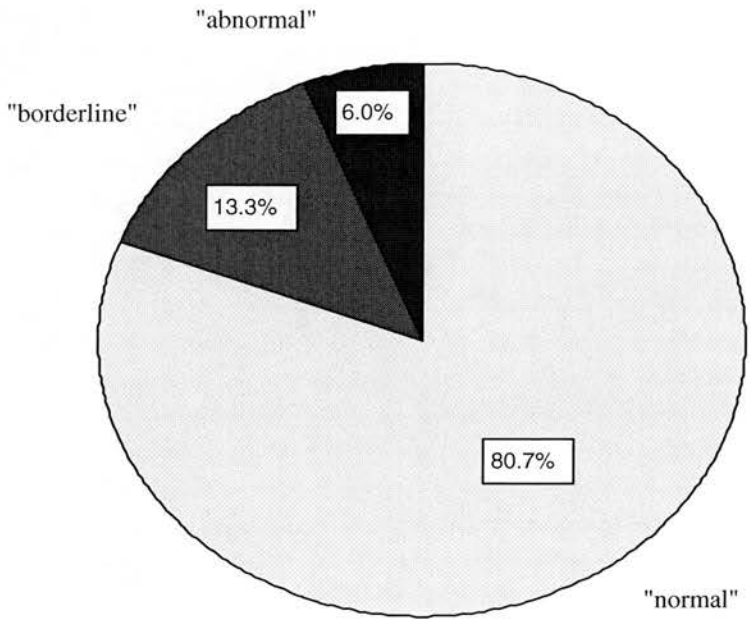


Table 3.17 and Figure 3.8 indicate that the data from this study is comparable to the distribution of data within the community sample used in the normative data. Therefore, the hypothesis that there will be heightened levels of psychological distress in the current sample of young people with diabetes is not supported, as there is not the expected increase in distribution of adolescents with diabetes in the 'borderline' and 'abnormal' categories.

3.7 Effects of demographic variables

3.7.1 Gender

Two-tailed independent samples *t*-tests were conducted to compare males and females on satisfaction measures, psychological variables and HbA1c levels. These results are presented in Table 3.18.

Table 3.18. t test comparison of males versus females, whole sample

Measure	***t***	**df**	**sig. (2 tailed)**	**mean difference**
DTSQ	-1.148	81	.254	-1.334
DCSQ	-.517	81	.606	-.705
Diabetes Satisfaction from DQOL-Y	-1.385	81	.170	-1.754
Impact of diabetes	-2.028	81	.046*	-4.647
Worries about diabetes	-4.046	79	.000*	-4.422
Self reported health	2.592	80	.011*	.416
Life satisfaction	2.443	79	.017*	3.575
Emotion	-2.012	81	.048*	-3.270
Attitude to diabetes	-.724	81	.471	-.859
Adaptation total	-1.734	81	.087	-3.976
SDQ: Total Difficulties	-1.467	79	.146	-1.656
HbA1c	-.086	81	.932	-3.737
Average HbA1c	-.086	79	.971	1.409

* $p < 0.05$

No gender differences were noted on the three measures of satisfaction, the DTSQ (t = -1.148, df = 81, p = .254); the DCSQ (t = -.517, df = 81, p = .808) and the Diabetes Satisfaction from the DQOL-Y (t = -1.385, df = 81, p = .170).

There are significant differences between males and females on the impact of diabetes (t = -2.028, df = 81, p = .046) and worries about diabetes (t = -4.046, df = 81, p <.001), self-reported health (t = 2.592, df = 80, p = .011), life satisfaction (t = 2.443, df = 79.03,

p = .017) and emotions regarding diabetes (t = -2.012, df = 81, p = .048). There is a trend towards significance for adaptation to diabetes (t = -1.743, df = 81, p = .087).

Furthermore, there were no gender differences with regards to glycaemic control, as measured by HbA1c (t = -.086, df = 81, p = .932) or Average HbA1c (t = -.086, df = 79, p = .971).

In summary, gender differences are apparent in several of the psychological variables. Females reported a higher impact of diabetes, more worries about diabetes and poorer self-reported physical health. Females are also describing lower satisfaction with aspects of daily living. Males and females are comparable in terms of satisfaction with diabetes care and HbA1c levels.

3.7.2 Age

A correlation between age and the satisfaction measures was calculated, as shown in Table 3.19.

Table 3.19. Correlations of age and satisfaction measures

	DTSQ	**DCSQ**	**Diabetes Satisfaction from DQOL-Y**
Age	-.040	-.197*	-.102

* $p < .05$

There is a negative correlation between scores on the DCSQ and age (r = -.197, p = .037). There is no significant correlation between age and the DTSQ (r = -.040, p = .359) or the Diabetes Satisfaction sub-scale from the DQOL-Y (r = -.102, p = .178). Increasing age is therefore associated with more dissatisfaction as measured by the DCSQ.

Analysis of the relationship between age and the psychological measures under investigation was also conducted and is reported in Table 3.20.

Table 3.20. Correlations of age and satisfaction measures

	Impact subscale	Worries subscale	Life satisfaction	Health subscale		Emotion subscale	Attitude subscale	Adaptation total		SDQ: Total Difficulties
Age	.068	.184*	-.276*	-.160		.158	.243*	.231*		.213*

* $p < .05$

Table 3.20 indicates statistically significant associations between age and worries about diabetes (r = .184, p = .048), life satisfaction (r = -.276, p = .006), attitude towards diabetes (r = .243, p = .027), adaptation to diabetes (r = .231, p = .036) and psychological well being (r = .213, p = .028). The scoring criteria of each measure and the direction of the correlation coefficient suggests that increasing age is associated with higher levels of worries about diabetes, less life satisfaction, a poorer attitude towards diabetes and poorer general adaptation to diabetes. Furthermore, higher age levels are also associated with more psychological difficulties.

Finally, the relationship of age and glycaemic control, as measured by single HbA1c and Average HbA1c levels was examined. The results are presented in Table 3.21.

Table 3.21. Correlations of age, HbA1c and Average HbA1c levels

	HbA1c	Average HbA1c
Age	.146	.129

No significant association was found between age and diabetes control, in terms of HbA1c (r = .146, p = .094) and Average HbA1c (r = .129, p = .126). However, the relationship between age and HbA1c is approaching significance.

Age banding

Comparative analysis was conducted by dividing the sample into two age groups. The subjective level of 16 years was chosen, as this reflects a society-defined increase in independence, including the right to leave school and the age of sexual consent. Forty-one participants were up to 16 years and the other 42 were between 16 and 18 years. The results of an independent samples *t* – test are presented in Table 3.22.

Table 3.22. t test comparison of age groups

Measure	***t***	**df**	**Sig. (2 tailed)**	**Mean difference**
DTSQ	.874	81	.850	1.016
DCSQ	1.166	81	.247	1.573
Diabetes Satisfaction from DQOL-Y	1.352	81	.180	1.707
Impact of diabetes	-.868	81	.388	-2.023
Worries about diabetes	-1.981	81	.051	-2.417
Self reported health	1.431	80	.156	.236
Life satisfaction	2.309	81	.023*	3.468
Emotion	-2.264	81	.026*	-3.645
Attitude to diabetes	-1.754	81	.083	-2.043
Adaptation total	-2.486	81	.015*	-5.566
SDQ: Total Difficulties	-1.697	79	.037*	.897
HbA1c	-.616	81	.540	-.267
Average HbA1c	-1.033	79	.305	-.399

* $p < 0.05$

Significant differences were found between the two groups in terms of Life satisfaction (t = 2.309, df = 81, p = .023); diabetes-related Emotions (t = -2.264, df = 81, p = .026); Adaptation to diabetes (t = -2.485, df = 81, p = .015) and Total Difficulties from the SDQ (t = -1.697, df = 79, p = .037). There were also trends towards significance for worries about diabetes (t = -1.981, df = 81, p = .051) and attitude towards diabetes (t = -1.754, df = 81, p =.083).

The older age group had lower levels of life satisfaction, more difficulties as measured by the diabetes-related emotions and worries, poorer adaptation to the disease and poorer psychological well being as measured by the SDQ.

3.7.3 Age at diagnosis

Correlations were computed between age at diagnosis and satisfaction, as presented in Table 3.23.

Table 3.23. Correlations of age at diagnosis and satisfaction measures

	DTSQ	**DCSQ**	**Diabetes Satisfaction from DQOL-Y**
Age at diagnosis	.037	.163	.075

As shown in Table 2.23, there are no relationships between age at diagnosis and satisfaction with diabetes care.

Relationships between age at diagnosis and psychological measures were also considered, as presented in Table 3.24.

Table 3.24. Correlations of time since diagnosis and psychological measures

	Impact subscale	**Worries subscale**	**Life satisfaction**	**Health subscale**	**Emotion subscale**	**Attitude subscale**	**Adaptation total**	**SDQ: Total Difficulties**
Age at diagnosis	.069	.185	-.253*	-.122	.136	-.063	.059	.018

Table 3.24 indicates only one significant relationship. Age at diagnosis and Life satisfaction were negatively correlated (r = -.253, p = .021), indicating that an older age at diagnosis is associated with less everyday life satisfaction. There was a trend towards

a positive relationship for the Worries subscale (r =.185, p =.093), reflecting a relationship between older age at diagnosis and increasing levels of diabetes-related worries.

Finally, age at diagnosis was compared with glycaemic control, as measured by single HbA1c and Average HbA1c levels. The results are presented in Table 3.25.

Table 3.25. Correlations between age at diagnosis, HbA1c and Average HbA1c levels

	HbA1c	**Average HbA1c**
Age at diagnosis	-.218*	-.109

* $p < .05$

There is a significant negative association between age at diagnosis and single HbA1c (r = -.218, p = .047), but this is not replicated with Average HbA1c (r = -.109, p = .334). Given that higher HbA1c levels reflect poorer glycaemic control, this relationship highlights that a younger age at diagnosis is associated with higher HbA1c levels.

3.7.4 Time since diagnosis

Correlations were computed between time since diagnosis and satisfaction, as presented in Table 3. 26.

Table 3.26. Correlations of time since and diagnosis and satisfaction measures

	DTSQ	**DCSQ**	**Diabetes Satisfaction from DQOL-Y**
Time since diagnosis	-.049	-.223*	-.107

*$p < .05$

Table 3.26 demonstrates that time since diagnosis is significantly associated with the DCSQ (r = -.223, p =.022). There is no significant association between time since diagnosis and the DTSQ (r = -.049, p = .333), nor the Diabetes Satisfaction subscale

from the DQOL-Y (r = -.107, p = .155). The negative direction of the correlation suggests that an increasing time since the diagnosis of diabetes is linked to lower scores on a diabetes care satisfaction measure.

Time since diagnosis was also correlated with psychological measures (Table 3.27).

Table 3.27. Correlations of time since diagnosis and psychological measures

	Impact subscale	Worries subscale	Life satisfaction	Health subscale	Emotion subscale	Attitude subscale	Adaptation total	Difficulties total
Time since diagnosis	-.047	-.124	.161	.069	-.085	.139	.014	.050

Table 3.27 indicates no statistically significant relationships between time since diagnosis and the psychological measures under investigation.

Finally, time since diagnosis was compared with glycaemic control, as measured by single HbA1c and Average HbA1c levels. The results are presented in Table 3.28.

Table 3.28. Correlations of time since diagnosis, HbA1c and Average HbA1c levels

	HbA1c	Average HbA1c
Time since diagnosis	.262*	.212*

* $p < .05$

There are statistically significant associations between time since diagnosis and single HbA1c (r = .262, p = .008), and average HbA1c (r =.212, p = .029). Given that higher HbA1c values are indicative of poorer glycaemic control, these correlations suggest that glycaemic control worsens with a longer duration of diabetes.

3.8 Further analysis using HbA1c levels

The sample was divided into two groups on the basis of HbA1c levels. The subjective cut-off point of 10.5% was chosen as this comprises the two bandings of 'good' and 'acceptable' in one group and 'unacceptable' and 'dangerous' in the other. Means and standard deviations for the two groups are presented in Table 3.29.

Table 3.29. Comparison of the two groups of HbA1c levels

	HbA1c lower than 10.5% n = 51		**HbA1c 10.5% and above n = 32**
Measure	**Mean**(s.d.)		**Mean**(s.d.)
DTSQ	**33.71** (5.27)		**32.25** (5.27)
DCSQ	**43.55** (5.54)		**42.84** (7.10)
Diabetes Satisfaction from DQOL-Y	**26.96** (5.40)		**24.00** (5.97)
Impact of diabetes	**47.74** (10.58)		**51.19** (10.44)
Worries about diabetes	**19.14** (6.07)		**17.97** (4.93)
Self reported health	**2.98** (0.68)		**2.59** (0.80)
Life satisfaction	**40.08** (6.87)		**37.03** (6.94)
Emotion	**19.33** (7.51)		**20.41** (7.59)
Attitude to diabetes	**20.82** (4.65)		**21.87** (6.38)
Adaptation total	**40.27** (9.85)		**42.25** (11.56)
SDQ: Total Difficulties	**10.3** (5.33)		**12.29** (4.50)

An independent samples t-test was calculated to assess the significance in the differences between the two groups (Table 3.30).

Table 3.30. t test results of two HbA1c groups

Measure	*t*	df	Sig. (2 tailed)	Mean difference
DTSQ	1.225	81	.224	1.456
DCSQ	.478	79	.635	.705
Diabetes Satisfaction from DQOL-Y	2.333	81	.022*	2.961
Impact of diabetes	-1.450	81	.151	-3.442
Worries about diabetes	.915	81	.363	1.168
Self reported health	2.258	79	.028*	.386
Life satisfaction	1.958	81	.054	3.047
Emotion	-.631	81	.530	-1.073
Attitude to diabetes	-.867	81	.389	-1.051
Adaptation total	-.831	81	.408	-1.975
SDQ: Total Difficulties	-1.729	79	.088	-1.990

* $p < 0.05$

There are significant differences between the two groups in terms of the Diabetes Satisfaction subscale from the DQOL-Y ($t = 2.333$, df = 81, $p = .022$) and self-reported Health ($t = 2.258$, df = 79, $p = .028$). In addition, Life satisfaction ($t = 1.958$, df = 81, $p = .054$) and Total Difficulties from the SDQ are approaching significance ($t = -1.729$, df = 79, $p = .088$).

Examining the differences in means highlights that the group with HbA1c lower than 10.5% have the following characteristics:

- higher levels of satisfaction with their care
- better self perceived physical health status
- increased levels of life satisfaction
- less psychological difficulties

3.9 Multiple Regression

The relationship between the dependent variable and potential independent predictor variables was examined using multiple regression methods. Forward stepwise selection of variables was used.

The dependent criterion variables to be explored are quality of life, adaptation to diabetes and psychological well being, as well as HbA1c and Average HbA1c. Investigation of potential effects will be conducted by controlling for demographic factors as recommended by Bradford (1997). For fullness of reporting, age at diagnosis and time since diagnosis will both be used, although the two variables correlate significantly (r = -.949, p< .001). Therefore, the predictor variables to be investigated are:

- **Demographics**
  Age
  Gender
  Age at diagnosis
  Time since diagnosis
- **Satisfaction measures**
  Diabetes Treatment Satisfaction Scale
  Diabetes Clinic Satisfaction Scale
  Diabetes Satisfaction from DQOL-Y

As a measure of predictive value, the adjusted R^2 value will be used. This value multiplied by 100 gives an estimate of the percentage of the variability in the dependent variable that is explained by the multiple regression models.

Reference will be made, where applicable, to evidence supporting the hypotheses.

Dependent variable: Quality of life

i) Impact of diabetes

Multiple stepwise regressions were calculated for the Impact subscale and the seven predictor variables (Table 3.31).

Table 3.31. Multiple stepwise regression of predictor variables for criterion (dependent) variable Impact of diabetes

Predictor variables entered in model	**Beta**	**t**	**Sig.**
Diabetes Satisfaction from DQOL-Y	-.444	-4.510	.000
Gender	.287	2.917	.005

R^2 = .241
Adjusted R^2 = .222

Predictor variables removed from model			
Age	.025	.258	.797
DTSQ	-.091	-.737	.463
Time since diagnosis	-.029	-.291	.772
Age at diagnosis	.036	.357	
DCSQ	-.093	-.829	.409

The Diabetes Satisfaction from DQOL-Y and gender account for 22% of the variance in Impact of diabetes (R^2 = .222, p = .005). The five other variables were excluded from the equation and therefore do not contribute a significant proportion of the variance.

ii) Worries about diabetes

Multiple stepwise regressions were calculated for the Worries subscale and the seven predictor variables. The results are shown in Table 3.32.

Table 3.32. Multiple stepwise regression of predictor variables for criterion (dependent) variable Worries about diabetes

Predictor variables entered in model	**Beta**	**t**	**Sig.**
Gender	.442	4.538	.000
Diabetes Satisfaction from DQOL-Y	-.329	-3.379	.001
R^2 = .259			
Adjusted R^2 = .241			
Predictor variables removed from model			
Age	.150	1.567	.121
DTSQ	.032	.260	.795
Time since diagnosis	-.061	-.609	.544
Age at diagnosis	.111	1.116	.268
DCSQ	-.103	-.924	.358

Gender and Diabetes Satisfaction from DQOL-Y explain 24% of the variance in Worries about diabetes (R^2 = .241, p<.001). The five other variables were excluded from the equation and therefore do not contribute a significant proportion of the variance.

iii) Life satisfaction

Multiple stepwise regressions were calculated for the Life satisfaction subscale and the seven predictor variables. The results are shown in Table 3.33.

Table 3.33. Multiple stepwise regression of predictor variables for criterion (dependent) variable Life Satisfaction

Predictor variables entered in model	**Beta**	**t**	**Sig.**
Diabetes Satisfaction from DQOL-Y	.440	4.751	.000
Gender	-.271	-2.861	.005
Age	-.271	-2.903	.005
Time since diagnosis	.200	2.092	.040

R^2 = .356
Adjusted R^2 = .323

Predictor variables removed from model			
DTSQ	.143	1.240	.219
Age at diagnosis	13.717	1.392	.168
DCSQ	.070	.646	.520

Analysis of the variance in Life Satisfaction made by the predictor variables show that Diabetes Satisfaction from DQOL-Y, gender, age and time since diagnosis explain 32% of the variance in Life satisfaction (R^2 = .323, p <.001). The three other variables were excluded from the equation and therefore do not contribute a significant proportion of the variance.

iv) Health

Multiple stepwise regressions were calculated for the Health subscale and the seven predictor variables. The results are shown in Table 3.34.

Table 3.34. Multiple stepwise regression of predictor variables for criterion (dependent) variable self-reported Health

Predictor variables entered in model	**Beta**	**t**	**Sig.**
DTSQ	.351	3.487	.001
Gender	-.294	-2.919	.005

R^2 = .201
Adjusted R^2 = .180

Predictor variables removed from model			
Age	-.126	-1.254	.214
Time since diagnosis	.031	.300	.765
Diabetes Satisfaction from DQOL-Y	.118	.915	.363
Age at diagnosis	-.077	-.743	.460
DCSQ	.009	.084	.933

Gender and the DTSQ explain 18% of the variance in self-reported Health (R^2 = .180, p = .005). The five other variables were excluded from the equation and therefore do not contribute a significant proportion of the variance.

Evidence for Hypothesis One

The Diabetes Satisfaction from DQOL-Y was the most frequently entered treatment satisfaction variable, followed by the DTSQ. Hypothesis One is therefore further supported by the regression analysis.

Dependent variable: Adaptation

The seven predictor variables were entered into a stepwise regression with the dependent variable adaptation to diabetes (Table 3.35).

Table 3.35 Multiple stepwise regression of predictor variables for criterion (dependent) variable Adaptation to diabetes

Predictor variables entered in model	**Beta**	**t**	**Sig.**
DCSQ	-.431	-4.650	.000
DTSQ	-.308	-3.331	.001
Gender	.225	2.592	.011

R^2 = .409
Adjusted R^2 = .386

Predictor variables removed from model			
Age	.126	1.437	.155
Time since diagnosis	-.055	-.604	.547
Diabetes Satisfaction from DQOL-Y	-.217	-1.834	.070
Age at diagnosis	.096	1.070	.3288

Analysis of the variance in adaptation made by the predictor variables shows that DCSQ, DTSQ and gender explain a significant proportion of the variance in adaptation to diabetes. The three variables account for 38.6% of the variance (R^2 = .386, p <.001). The other four variables were excluded from the model and therefore do not contribute a significant proportion of the variance.

Therefore, Hypothesis Two is further supported by the inclusion of two measures of treatment satisfaction in the regression analysis, illustrating the importance of their contribution to the variance in adaptation.

Dependent variable: Psychological well being

A stepwise multiple regression was computed, using the seven predictor variables for the dependent variable psychological well being (Table 3.36).

Table 3.36. Multiple stepwise regression of predictor variables for criterion (dependent) variable Psychological Well being

Predictor variables entered in model	**Beta**	**t**	**Sig.**
DTSQ	-.412	-4.019	.000
R^2 = .170 **Adjusted R^2 = .159**			
Predictor variables removed from model			
Gender	.189	1.868	.066
Age	.194	1.921	.058
Time since diagnosis	.020	.193	.848
Diabetes Satisfaction from DQOL-Y	-.227	-1.727	.088
Age at diagnosis	.043	.417	.678
DCSQ	-.157	-1.432	.156

From Table 3.36 it can be seen that the DTSQ accounts for 15.9% of the variance in psychological well being (R^2 = .159, $p < .001$. The five other predictor variables were excluded from the analysis and therefore do not contribute a significant proportion of the variance.

The findings support Hypothesis Three, that is, a measure of treatment satisfaction explains a significant proportion of the variance in psychological well being.

Summary of psychological dependent variables

Gender is the only demographic variable to be entered into the regression models for all the psychological dependent variables. It therefore appears to be the best predictor of variance from the four demographic characteristics offered in the regression equations.

Diabetes Satisfaction from the DQOL-Y appears to be the best satisfaction predictor of variance in the psychological measures.

Dependent variables: HbA1c and Average HbA1c

A stepwise multiple regression was calculated, by offering the seven predictor variables (Table 3.37).

Table 3.37. Multiple stepwise regression analyses of predictor variables for criterion (dependent) variable HbA1c

Predictor variables entered in model	**Beta**	**t**	**Sig.**
Diabetes Satisfaction from DQOL-Y	-.256	-2.442	.017
Time since diagnosis	.234	2.239	.028
R^2 = .133			
Adjusted R^2 = .111			
Predictor variables removed from model			
Gender	.110	1.023	.310
Age	.078	.726	.470
DTSQ	-.110	-.829	.409
Age at diagnosis	.233	.704	.483
DCSQ	.146	1.197	.235

Diabetes Satisfaction from the DQOL-Y and time since diagnosis explain 11% of the variance in dependent variable HbA1c (R^2 = .111, p = .028). The five other variables were all excluded form the analysis and therefore do not explain a proportion of the HbA1c variance.

A second regression analysis was undertaken, using Average HbA1c as a dependent variable. The results are presented in Table 3.38.

Table 3.38. Multiple stepwise regression analyses of predictor variables for criterion (dependent) variable Average HbA1c

Predictor variables entered in model	Beta	t	Sig.
Diabetes Satisfaction from DQOL-Y	-.331	-3.120	.003

R^2 = .110
Adjusted R^2 = .098

Predictor variables removed from model			
Gender	.051	.473	.637
Age	.092	.862	.392
DTSQ	-.076	-.561	.577
Time since diagnosis	.110	1.033	.305
Age at diagnosis	-.080	-.752	.454
DCSQ	.148	1.171	.245

Diabetes Satisfaction from the DQOL-Y accounts for 9.8% of the variance in dependent variable Average HbA1c (R^2 = .098, p = .003). The six other variables were all excluded form the analysis and therefore do not explain a proportion of the HbA1c variance.

Summary of glycaemic control dependent variables

Diabetes Satisfaction from DQOL-Y appears to be the best predictor of variance in HbA1c levels. Time since diagnosis is also important for a single HbA1c measure, but not Average HbA1c. Hypothesis Four is therefore supported by the inclusion of treatment satisfaction measures in the regression analyses.

3.10 Qualitative data

3.10.1 Results from Satisfaction with Diabetes Care Questionnaire

The final questionnaire was designed to obtain more detailed information regarding the following:

- Routine practices of the clinic
- Best and worst parts of diabetes care
- Suggestions for change

Tables 3.39 to 3.47 give descriptions of the responses to the nine questions.

Table 3.39. Responses to Q.1. 'If you miss an appointment, what would you like to happen?'

Response	**Frequency**	**%**	**Valid %**
Staff send me another appt. by post	45	54.2 %	55.6 %
Staff contact me by telephone	19	22.9 %	23.5 %
Leave it to me to contact	17	20.5 %	21 %
Something else	0	0 %	0 %
(Missing	2	2.4 %	N/A)

The majority of responders favour staff routinely sending a new appointment by post if they have failed to attend the clinic. However, 1 in 5 young people would prefer to initiate contact themselves.

Table 3.40 Responses to Q.2 'Do you feel that you get different (that is, conflicting) messages /advice from the doctors?'

Response	**Frequency**	**%**	**Valid %**
Yes	12	14.5%	15%
No	68	81.9%	85%
(Missing	3	3.6%	N/A)

An overwhelming majority of responders reported feeling that they do not receive conflicting messages from the medical staff. Fifteen percent of young people reported that they do receive different messages. Eleven participants wrote a reply to this question. Ten of these were negative in nature, for example, conflicting advice regarding insulin doses. One participant stated that staff 'Tell me a load of crap all the time'. Another participant wrote of the benefits of learning different things from different doctors. A full list of the responses can be found in Appendix III. XIII .

Table 3.41. Response to Q3. 'When you leave the clinic, do you understand everything you have been told?'

Response	**Frequency**	**%**	**Valid %**
Yes	70	84.3%	86.4%
No	10	12%	12.3%
Another response	1	1.2%	1.2%
(Missing	2	2.4%	N/A)

The vast majority of the sample feels that they have understood everything when they leave their clinic appointment. One participant declined to tick either box and instead wrote 'sometimes' on the questionnaire.

Table 3.42. Response to Q.4 'Would you like information from the day written down?'

Response	**Frequency**	**%**	**Valid %**
Yes	37	44.6	45.7
No	43	51.8	53.1
Another response	1	1.2	1.2
(Missing	2	2.4	N/A)

The sample was divided over this issue. Slightly more people did not feel that receiving written information was appropriate. One participant declined to tick either box and instead wrote 'don't care' on the questionnaire.

Table 3.43. Response to Question 5 'Would you like to get a copy of the letter that is sent to your GP after each clinic visit?'

Response	Frequency	%	Valid %
Yes	51	61.4%	63%
No	30	36.1%	37%
(Missing	2	2.4%	N/A)

Sixty-three percent of young people would not like a copy of the GP letter that is written after each clinic visit. However, the other 37% felt that this would be beneficial.

Table 3.44. Responses to Q.6 'What would be the right amount of time between clinic visits?'

Response	Frequency	%	Valid %
1 month	10	12%	12.5%
2 months	12	14.5%	15%
3 months	39	47%	48.8%
6 months	16	19.3%	20%
1 year	1	1.2%	1.3%
Longer	2	2.4%	2.5%
(Missing	3	3.6%	N/A)

Almost half of responders believe that clinic appointments every three months is most appropriate. Twenty-seven percent felt that one or two months were the best time between clinic visits.

Best and worst parts of diabetes are

Responses to these two open-ended questions regarding aspects of diabetes care were analysed by highlighting themes. Some participants gave more than one answer to each question. Themes and frequencies are shown in Tables 3.45 and 3.46. See Appendix IV for a full list of responses.

*Table 3.45. Responses to Q.7. 'Please tell me about the **best parts** of your diabetes care'*

Category	N	Examples of responses
£10 for fingerprick of blood	3	getting £10 for a wee prick of blood
No parts are best	5	it's all rubbish being diabetic there is no best part
Staff characteristics	15	the nurses are nice the staff are always helpful and friendly people listen to me a lot
Advice / information	10	advice on how to make the injections fit in with my life encouragement of a healthy diet
Improved lifestyle	10	I get somewhat of a proper diet I stay fit keeps me healthy don't eat as much junk food as others
Aspects of self-care	12	I can inject automatically, without thinking my overall count is getting better
Meeting people	2	meeting lots of different people
Diabetes has no effects	1	having diabetes doesn't really affect any part of my life
Unsure	1	
No response	24	

Twenty-four participants (29% of the sample) gave no response to this question.

*Table 3.46. Responses to Q.8. 'Please tell me about the **worst parts** of your diabetes care'*

Category	**N**	**Examples of responses**
Having diabetes	2	the fact I have diabetes most of it
Injections	25	injection sites getting sore having to inject in front of people who don't know what it's all about
Home blood tests	18	checking my blood sugar levels
Diet restrictions	7	not eating certain things not being able to eat many sweets
Variations in blood sugar levels	4	high and low blood counts and trying to keep them under control
Waiting at clinic appts	11	waiting around
Staff attitude	5	I always feel like I'm being told off feel as if treated like a child lectures from doctors
Clinic appts	3	having to come to clinics!
Blood tests at clinic	4	
Unsure	1	
No response	14	

Fourteen participants gave no response to Question eight, which is 13% of whole sample. Many respondents mentioned both insulin injections and home blood monitoring as the worst parts of their diabetes care.

Fourteen participants, (17% of the sample) gave no answer to this question.

Suggested improvements to diabetes care

The responses are presented in Table 3.47. A full list of the responses is available in Appendix IV.

*Table 3.47. Responses to Q.9 'Please tell me about the parts of your diabetes care that could be **done differently**'*

Category	**N**	**Examples of responses**
Waiting times	4	it takes ages for me to be seen by anyone
Staff attitude	2	be less patronising could be spoken to in a less condescending manner
Nothing	10	happy with the care I receive
Clinic practice	3	make urine sampling more discreet use email to pass results back and forward to clinic access to notes for patients
Aspects of self-care	11	could improve my diet more blood testing to get better control
New methods	6	blood meter could be faster I would like a different way of taking insulin
Unsure	3	don't know not sure
No response	39	

Thirty -nine participants (47% of the sample) gave no response to this question.

3.10.2 Thematic analysis of interview data

The tapes made of the participants' responses to questions at interview were transcribed and reviewed for themes. The identification of themes was guided by the researcher's interpretation and understanding of the participants' individual responses and by the literature. This analysis will be presented in sections covering selected areas of questions in the interview. Quotes are given to illustrate the themes and an example of a full interview is shown in Appendix XIV.

The figures in the brackets represent the participant's study number and also their gender.

Words used to describe diabetes

In response to questions about the first words they would use to describe having diabetes, participants spoke of the condition as difficult but also a way of life:

(F1) *struggle at first. way of life now, I suppose*

(M36) *irritant, just that, it's an irritable thing*

(M43) *I feel kind of normal now...for me, it's not serious, it's not like a really really serious problem. I just kind of get on with it – it's not too bad*

(F49) *restricting, but not too different from the life I had before*

(M7) *part of life. I'd say it can be a nuisance*

(F20) *it's okay. its not as bad as it seems*

Other participants felt much more strongly:

(F31) *I don't know if I can say this...(prompt)...it's s***. I've found that people don't really understand it*

(F6) *(pause) I just hate it. (prompt) frustrating. annoying*

Describing a good quality of life

Most participants mentioned similar themes, including having fun and having important people in their life:

(M36) *having as much as fun as possible*

(F49) *having people around me – friends and family*

(F6) *clothes, pals, family*

(M7) *having a good time. friends*

Another spoke of:

(F37) *having a life where nothing majorly bad happens*

Two participants mentioned school achievements and health, respectively:

(F20) *doing well at school*

(F1) *health. family and friends. happiness*

Time spent thinking about diabetes

This ranged from very little:

(F20) *it's kind of just habit now. I'm not conscious of it*

(M7) *hardly any*

(F37) *it varies... I could go weeks*

to being unable to stop thinking about diabetes:

(F31) *all the time*

(F1) *lot*

another participant tried to not think about her condition:

(F6) *I don't. I try to forget about it*

Communication styles in the clinic

Some of these responses were negative:

(F6) *they look down on you. tell you what to do*

(F1) *felt judged. hospital can't tell you how to feel. doctors focus on the negatives*

(F37) *doctor made assumptions. also, started talking about contraception and complications in pregnancy – I hadn't asked for that*

On a more positive note

(M7) *have always been respected. staff have got a good approach. Dr __ treats me like an adult*

(F20) *the staff work closely with me*

(F31) *Dr __ was interested in me, my whole life*

Feelings about the future

Several participants mentioned the impact they believe that diabetes will have on their future:

(M43) *I feel I'll be able to get by. it will everything slightly more difficult*

(F6) *it's horrible to know I'll always have it. And then they say frightening things like I might have to get my leg amputated or go blind*

(M36) *they said when I was diagnosed that there would be a cure for diabetes in 5 years – well, double that time has passed. I would like to find out how it's caused*

One participant, who has already undergone laser treatment on her eye as a result of having diabetes:

(F37) *I sort of wonder, well I've had that done, probably my kidneys are next or my feet*

Others did not mention diabetes in relation to this question:

(M7) *going abroad. having a good time*

Some participants deliberately avoid thinking about the future:

(F1) *try not to think about it*

(F14) *I don't think that far ahead. I just take every day as it comes*

Other areas

As with the above responses, there was a variety in the feelings expressed regarding having diabetes. These ranged from:

(F1) *I feel like I'll never be normal*

(F6) *I can't see I'll ever be more accepting*

(F31) *[when diagnosed] meant it was going to be forever*

to:

(F14) *[diabetes] might help me it makes me think more about other people*

(M43) *I'm just completely used to it – I don't really think about not having it*

(M36) *I control my diabetes – it doesn't control me*

Several participants had reported significant difficulty in coming to terms with their diagnosis. In particular, two females who had been diagnosed around the age of sixteen:

(F1) *I think the person has to come to terms with it themselves. the more I found out, the more I felt doomed*

(F31) *I'm quite a spontaneous person and I can't be like that anymore*

(F1) *I used to be really independent*

Several participants also mentioned periods when they had lied about their level of self-management:

(F1) *I told a lot of lies. I'm not usually a liar. I was lying about insulin.*

(F37) *My Mum was giving me my insulin and I would load it up and squirt it onto the couch, on the carpet, anywhere*

Three young people felt that the paediatric clinic staff of the Royal Hospital for Sick Children were more patronising and royal infirmary clinic is much better in this regard:

(F49) *at the Sick Kids...I felt like one of the doctors was really getting at me*

(M36) *the doctors at the Sick Kids...found them patronising*

Finally, one female participant gave a concerning answer when asked about the aspect of care she most liked:

(F37) *being able to control my weight through insulin*

Summary

A wide variety of responses was obtained from the ten participants. These ranged from individuals who perceive their diabetes as integrated into their daily life to others (predominantly female) who feel that having this chronic illness is much more problematic. Several female participants continued that they could not perceive feeling any differently in the future. This is consistent with the finding from quantitative data that females feel more of an impact from their diabetes.

DISCUSSION

4.1 The aims of the present research

The present research was primarily concerned with demonstrating an association between young people's satisfaction with their diabetes care and psychological variables as well as their glycaemic control.

4.2 Summary of main findings

Psychological effects of diabetes

The results suggest that most adolescents in this study have healthy psychological well being, as measured by the Strengths and Difficulties Questionnaire (SDQ). Therefore, the research hypothesis that adolescents with diabetes are more vulnerable to psychological difficulties compared to a community sample is not supported. The current sample may not be as vulnerable to psychological difficulties as previous research has demonstrated (Blanz *et al*, 1993; Carney, 1988: Jacobson *et al*, 1986). This would support the findings of, for example, Lavigne and Faier-Routman (1992, 1993).

Alternatively, it may be that the current sample has a level of psychological well being such that the SDQ lacks any discriminative or predictive power (Brown *et al*, 1991; Wertlieb *et al*, 1986). Furthermore, the authors of the pilot study of the SDQ stated that the scale 'discriminates satisfactorily between high and low risk samples' (Goodman *et al*, 1998, p. 129). It is possible that the scale is not sensitive enough to identify mild adjustment difficulties, a criticism which has also been levelled at Achenbach's (1991) Child Behaviour Checklist (Bradford, 1997; Perrin *et al*, 1991).

The variability in findings amongst studies on the psychological effects of having diabetes may be accounted for in several ways. Firstly, sample sizes, ages and compositions vary widely. For example, Blanz and colleagues, who found that adolescents with diabetes are at high risk for psychological difficulties, used only 17-19 year olds (Blanz *et al*, 1993). It is possible that the current findings are partially explained by the inclusion of younger adolescents in the sample, who appear to

demonstrate less psychological maladaptation. Secondly, a wide range of measures and methods for identifying difficulties, for example, structured diagnostic interview schedules, are utilised and these may produce results that are not comparable. As highlighted, different instruments may have varying levels of discriminative power. The SDQ is a relatively new instrument and has not been used in any studies similar to the present research. It may be that the SDQ is not the most appropriate measure to use with a paediatric population until further examination of its discriminative properties with this specific group.

In summary, it is difficult to speculate as to the most likely reason for this finding. The present sample may well be functioning on a psychological level comparable with their non-diabetes peers. Equally, the SDQ may not be of sufficient sensitivity to distinguish any adjustment difficulties. A final consideration is socio-economic conditions. The present sample was found to come from a higher than average affluent background. It is possible that this has had an effect on the levels of psychological well being.

Association between satisfaction and psychological variables

Perceived level of satisfaction with diabetes care was significantly correlated with the three measures of psychological health. Higher levels of perceived satisfaction were associated with better-reported quality of life, less psychological distress and improved adaptation to diabetes. When multiple regressions were calculated, satisfaction explained a significant amount of the variance of quality of life, adaptation and psychological well being.

It can therefore be proposed that satisfaction is an important variable to measure and can act as a 'resistance' factor in the psychological adaptation of young people to their diabetes. The three research hypotheses related to the association between satisfaction and psychological variables have been supported in this population.

Glycaemic control

A local target of HbA1c less than 8.5% has been set as a realistic level for the group of patients studied (Carson *et al*, 2000). The average HbA1c for the whole sample was 10.22% and ranged from 5.2% to 16.7%. This average is therefore significantly higher than the recommended level and it is interesting to note that only 11 out of 83 participants (13% of the total sample), had an HbA1c level of less than 8.5 %.

Adolescents have consistently been found to have poorer glycaemic control than younger children or adults (Carson *et al*, 2000). Several reasons for this have been advocated, including in part the physiological changes that occur during puberty (Caprio *et al*, 1989). There are also documented decreases in diabetes self-care tasks in the adolescent period (Kovacs *et al*, 1992). Additionally, increased abstract reasoning skills develop during adolescence. This may lead to an awareness that the immediate physical effects of poor glycaemic control are few and, despite good levels of self-management, the long-term complications appear to be almost inevitable (Reid *et al*, 1995).

Furthermore, adolescents may perceive their diabetes as secondary to issues such as the desire to conform to peer defined norms (Gordon & Mansfield, 1996). The increased unpredictability of routine in adolescence is an additional challenge for individuals managing their self-care tasks. Young people may feel reluctant testing blood for sugar levels and doing insulin injections outside their home (Carson & Kelnar, 2000).

Association between satisfaction and glycaemic control

In this study, significant associations were measured between level of satisfaction with diabetes care and both a single HbA1c measure and a 12 month Average HbA1c. These relationships were negative in direction. That is, as scores on satisfaction questionnaires increased, HbA1c values fell, reflecting better overall diabetes control. When multiple regressions were calculated, satisfaction explained a significant amount of the variance within single and Average HbA1c values.

Empirical findings typically suggest a positive association between health outcomes and satisfaction with care (for example, Hall *et al*, 1990; Linn & Greenfield, 1982; Patrick *et al*, 1983). However, several important issues concerning the link between satisfaction and health outcome require greater consideration (Marshall et al, 1996). Satisfaction and health status may be reciprocally related. Thus, satisfaction with health care may be both a consequence and a determinant of health status.

In summary, satisfaction and outcome are both important in this area but the results are suggestive of a complex inter-relationship. Ways of clarifying this picture with additional research will be discussed below.

Satisfaction measures

Treatment satisfaction was found to be significantly associated with all psychological and medical outcomes employed. The correlations between specific satisfaction measures and dependent variables differed in strength. Additionally, only two of the three satisfaction scales demonstrated a significant relationship with glycaemic control. These results reflect the multidimensional nature of satisfaction, whereby specific aspects of the concept are more likely to relate to certain outcome variables.

Generally, the Diabetes Satisfaction subscale of the DQOL-Y performed well, often producing stronger correlations than the other two satisfaction measures and explaining variance in five of the eight outcome variables. Additionally, this measure demonstrated a significant relationship with both single HbA1c and Average HbA1c and was the only satisfaction measure to be entered into the regression model for both single Hba1c and Average HbA1c.

Analysis of the variance in self-reported health, adaptation and psychological well being shows that the DTSQ explains a significant proportion of the variance. However, despite a significant correlation between the two variables, the DTSQ failed to account for a significant amount of the variance in glycaemic control.

The DCSQ appeared to be the weakest of the three independent variable measures. Where all three satisfaction scales were significantly associated with outcome measures, the DCSQ often had the weakest correlation coefficient. Additionally, the DCSQ did not show a significant relationship with HBA1c levels. It may be that there is a less strong relationship between the outcome measures and satisfaction with so-called 'hotel' aspects of care, which the DCSQ is designed to measure

Gender effects

Consistent with the research literature (Carr, 1993; Cohen *et al*, 1993), statistically significant gender differences were found for many psychological variables. Females expressed more difficulties than males on several measures. These included an increased impact of diabetes and worries about diabetes, as well as poorer adaptation to diabetes and lower levels of everyday life satisfaction.

No gender differences in levels of treatment or HbA1c levels were found.

Developmental effects

Current age, age at diagnosis and time since diagnosis were used to highlight the importance of demographic variables in this type of research as proposed by, for example, Daviss and colleagues (1995).

i) Age

Increasing age was associated with higher levels of maladaptation, poorer psychological well being and lower levels of everyday satisfaction. These relationships are consistent with the findings of Challen and colleagues (1988) who found that older adolescents in their sample had a more negative attitude to their diabetes.

There was no effect of age on HbA1c levels. Conflicting results were found with satisfaction levels. Specifically, there was a relationship between increased age and lower reported satisfaction, as measured by the DCSQ, but this was not replicated with

the DTSQ or the Diabetes Satisfaction subscale from the Diabetes Quality of Life for Youths.

ii) Age at diagnosis

Age at diagnosis had no effect on level of treatment satisfaction. There was, however, a relationship between an older age at diagnosis and lower everyday life satisfaction.

There was also a conflicting picture with the effect of age at diagnosis on glycaemic control. There was a significant relationship with single HBA1c, illustrating that a younger age at diagnosis is associated with higher HBA1c levels, that is, poorer glycaemic control. However, there was no association between age at diagnosis and Average HbA1c. It is possible that these inconsistent findings reflect the inclusion of individuals recently diagnosed with diabetes who did not have previous HbA1c levels to record, thus skewing the data.

iii) Time since diagnosis

Time since diagnosis was significantly associated with glycaemic control, indicating that control worsens as duration of diabetes lengthens. This is consistent with the finding that an increasing time since diagnosis is related to decreasing levels of diabetes self-care (Kovacs *et al*, 1992), which would adversely affect glycaemic control.

Individuals with a longer time since diagnosis had lower levels of satisfaction, as measured by the Diabetes Clinic Satisfaction Questionnaire, but not the other two satisfaction measures. It is plausible that young people who have been attending clinic appointments for a longer time would be more dissatisfied with aspects such as waiting times, continuity of care and lack of privacy in the clinic.

Summary of quantitative data

All hypotheses were supported, with the exception of the high level of psychological well being within the sample. However, the cross-sectional, correlation design of this research does not allow a firm causative conclusion to be drawn from the results reported above.

The main hypotheses, linking levels of satisfaction with psychological variables and medical outcome, were confirmed with statistically significant correlations. Many of the correlations were small (r =0.30 or lower) or modest (r = 0.40 to r = 0.69) but in the expected direction (Cohen & Halliday, 1982). As in most bio-behavioural relationships, although the associations between the variables were significant, much of the variance in glycaemic control is unexplained (Hanson *et al*, 1995). However, the Risk and Resistance model has highlighted several domains responsible for contributing to the degree of physical and psychological adaptation in chronic illness and if these were combined with the variables in the present study, then the amount of variance explained should increase. This research examined a new, previously untested variable for the model and therefore there was not an expectation that total variance in outcome measures would be explained by treatment satisfaction.

Despite the confirmation of the research hypotheses, there are three possibilities to consider, which could account for the results. Firstly, as hypothesised, psychological health and good glycaemic control may be as a result of high satisfaction with diabetes care. Secondly, individuals with positive psychological and glycaemic control may be highly satisfied with their care. Finally, psychological health/glycaemic control and satisfaction with services may be associated with a third unknown variable.

Finally, the results from this clinic population must be treated with caution, as they are a relatively affluent sample, as highlighted by the inclusion of deprivation category (Carstairs & Morris, 1991). Therefore, the aim to use the results of this study to help inform clinics in other areas country has been compromised.

Information from Satisfaction with Diabetes Care Questionnaire

This scale was designed to answer service delivery issues raised by the clinic staff. Almost 80% of responders believed that the responsibility should lie with the clinic to contact patients if they have failed to attend an appointment. The other 20% of patients felt that they should be the ones to initiate contact.

Fifteen percent of responders felt that they receive conflicting messages from medical staff. Although this is a small percentage of the responders, it is worth noting that these people may be confused by the messages they have received and their identification may be important. A majority of the sample reported that they understood everything they had been told at the clinic although the participants were evenly split regarding portable written material. Two-thirds of the sample was positive about receiving a copy of the report that is sent to their GP, which is a service development currently under consideration. There were a variety of responses to the right amount of time between appointments, with almost half of participants thinking that every three months was most appropriate.

Participants were also asked to write responses to three questions regarding the best and worst aspects of their diabetes care and any suggestions for improvement. There was a high rate of missing answers for these questions, as highlighted in Section 3.10.1.

As discovered when analysing the responses to the above questions, the use of the term 'diabetes care' is potentially ambiguous. Although the intention was for participants to think about the service they receive, many talked of aspects of their self-care. This was less of a problem in answering questions about the best aspects for care, as the majority of respondents mentioned issues related to the clinic, for example, staff characteristics. Some participants also commented on improvements to their diet and exercise as a benefit of having developed diabetes. This reflects the findings of Spack (1991).

When asked about the worst aspects of their diabetes care, many young people mentioned blood tests (both at home and having blood taken at the clinic) and insulin

injections. Additionally, waiting around at clinics and negative staff attitudes were mentioned.

Finally, the sample was asked for suggestions to improve their care. Ten respondents said 'nothing' and a similar number mentioned aspects of their self-care. Issues of clinical practice included making urine sampling more discreet and having access to patients' notes. Two respondents mentioned staff attitude, in that communication styles could be less patronising.

Information from semi-structured interviews

Much of the material from the interviews was complementary to the quantitative findings. Firstly, females described a higher rate of emotional difficulties, connected to their diabetes. Secondly, the range of reactions to diabetes was apparent, for example, in the words used to describe having diabetes. Thirdly, some respondents felt that doctors at the clinic were judgemental and negative.

The interviews were an invaluable way of obtaining information, which is not easily highlighted by questionnaires. For example, an interesting observation was made by several of the interviewed participants, highlighting the effect of clinic attendance on levels of self-care. It was felt that the first weeks following a clinic visit saw an increase in several areas of diabetes self-care, most notably in the frequency of blood monitoring. This then appeared to decrease in the midpoint between appointments, followed by an increase in the weeks preceding the next clinic visit. Furthermore, time spent thinking about having diabetes and views and concerns regarding the future were elicited.

In summary, the addition of the semi-structured interviews emphasises the concept of triangulation, whereby information is sought from multiple sources, theories and interpretations. Convergence of results across several perspectives enhances validity of the findings (Stiles, 1993). In this study, convergence was achieved, for example, regarding gender differences. Furthermore, the context-specific and highly individual ways in which the participants perceived their experiences should alert researchers and

clinicians to the dangers of using too simplistic a model of adolescence in professional support of young people (Olsen & Sutton, 1998).

4.3 Implications for clinical practice

The findings from the present research have noteworthy implications for diabetes services. Generally, there should be an increased awareness regarding the importance of ensuring optimal satisfaction levels for young people with diabetes. Also, changes in clinical practice are being considered, for example, the introduction of routinely giving written information, with the opportunity for patients to receive a copy of the letter that is sent to their GP. These are likely to be actioned on the basis of the findings of this research.

Furthermore, an essential part of the concept of satisfaction is the ability to meet an individual's expectations of health care. This requires eliciting expectations from services and then attempting to meet them (Bradford, 1997). In clinical practice, this could be achieved by routinely assessing patients' satisfaction with all aspects of their health care and identifying areas of need. The author of the DTSQ recommended that clinicians might find it useful to look at scores for individual items in addition to the total score with a view to identifying particular reasons for any dissatisfaction with treatment (Bradley, 1994). The author also suggested using the DTSQ along with the Diabetes Clinic Satisfaction Scale in order to determine more precisely the nature of any dissatisfaction.

The changing nature of diabetes treatment presents an opportunity to measure satisfaction with alterations in care, as carried out by, Bradley and colleagues (1987), for example.

The general context within which diabetes services are delivered must also be taken into consideration. Additionally, the context of each individual young person must be taken into account:

> Health professionals' expectations of adolescents with diabetes must be realistic and take into consideration the social, psychological and environmental influences on the individual
>
> (Carson & Kelnar, 2000, p. 25)

The results of this research, highlighting the importance of service evaluation and its effects on physical and psychological health, has occurred in a context of changing priorities in services. There is a shifting emphasis in the National Health Service, which has been described as a move towards 'commercialism' (Robertson, 1994). Furthermore, there is a growing perception among professionals that young people have the ability to give informed opinion regarding the services they receive (Hennessy, 1999). Article 12 of the United Nations Convention on the Rights of the Child highlights this notion:

> State parties shall assure to the child who is capable of forming his or her views the right to express those views freely on all matters affecting the child, the view of the child being given due weight in accordance with age and maturity of the child
>
> (United Nations, 1990)

In summary, the main implication for clinical practice is highlighting the importance of delivering the best service possible to this group of patients. This may require a tailored approach for each individual young person.

4.4 Methodological issues

4.4.1. Strengths of the present research

There are a number of strengths in this research design.

i) Sample

Firstly, this study had a large sample size. The power analysis proposed a sample of 70 participants (Clark-Carter, 1997), whereas the final population consisted of 83 young people. Adequate sample size in research is crucial and sample sizes of less than 50 in this type of study have been criticised (Glasgow & Anderson, 1995).

Secondly, the type and characteristics of the sample are also important. Some studies have employed 'convenience samples', for example, young people attending a diabetes summer camp (Spirito, Stark, & Williams, 1988). The present study used four clinics within one large health board area. As the non-participation rate was also very low (8% declined), it is felt that a representative sample was obtained. Furthermore, there were a number of participants who are clearly having a difficult time coping with their diabetes, as well as those who appear to accept it as part of their daily life.

Sample size and representation is not only important for adequate statistical power. With regards to service evaluation, it is often unusual for more than a small proportion of a population to complete an evaluation of the service they receive. Researchers in service evaluation have proposed that compliance rates must be high for results to be valid and meaningful, (Turpin, 1994). This has been achieved in this study.

Finally, the large sample size allowed for the use of sub-grouping and comparison analyses. In particular, contrasts of gender as well as grouping of age and HBA1c levels were undertaken.

ii) Measures

Previous research has been criticised for constructing new unvalidated self-report measures (Glasgow & Anderson, 1995). Researchers in this area have been

recommended to use diabetes-specific psychological scales, which have had adequate validation. Specifically, a book purposely written to aid researchers in this area has been highlighted an invaluable resource (Bradley, 1994). In this study, the Diabetes Treatment Satisfaction Questionnaire and the Diabetes Clinic Satisfaction Questionnaire are measures taken from the Bradley (1994) book. Greater use of standardised measures should also facilitate comparisons across diabetes studies (Garrison & McQuiston, 1989).

iii) Model

The use of the Risk and Resistance model (Varni & Wallander, 1998) and, in particular, evaluating satisfaction as a resistance variable, is an extension of previous research based on sound theoretical structure. This is in response to criticism that studies often do not have a rigorous theoretical basis nor do they extend upon previous work (Glasgow & Anderson, 1995). The present study has contributed to the field by examining the variable of perceived satisfaction with diabetes care, which has previously received scant attention.

In addition, the Risk and Resistance model does not assume that all young people with diabetes will have difficulty coping and adapting to their illness. As can be seen from quantitative and qualitative results, a substantial number of the research participants were coping admirably with their chronic disorder. Using a context such as the Risk and Resistance model is thus an optimistic and more realistic way of viewing young people with diabetes.

iii) Young people's self report

There is increasing recognition that young people can reliably give accurate indications of their adaptation to a disorder and their satisfaction with treatment (Hennessy, 1999). As advocated by the empowerment paradigm (Anderson, 1995; Feste, 1992), it is important for health care professionals to intervene effectively to enable young people feel a sense of control and empowerment over their diabetes. Several authors have

advocated that asking young people's opinions is one way of achieving this (Davie & Galloway, 1996; Hennessy, 1999).

iv) Variables

Demographic variables included in this study were age, gender, age at diagnosis, time since diagnosis and deprivation category (based on postcode). Research has shown that the relationships between psychosocial variables and diabetes-specific outcomes can be significantly attenuated when important demographic variables are controlled for (Hanson *et al*, 1995). In this study, the relationships between satisfaction and psychological factors, as well as between satisfaction and HbA1c, were examined whilst attempting to take into account the effects of demographic variables.

This study also used a 12 month average HbA1c value, in addition to the value recorded on the date of data collection. Some authors have found the average value to have stronger correlations with the predictor variables than a single HbA1c (Guttmann-Bauman *et al*, 1998). In this study, several things were found, including similar strength of relationships with satisfaction and time since diagnosis, as single Hba1c. Also, there was no relationship between age at diagnosis and Average HbA1c although this existed for single HbA1c. The reason for this discrepancy from the findings of Guttman-Bauman and colleagues (1998) was explored above, whereby the inclusion of newly-diagnosed people may have influenced the data.

Although HbA1c levels were assessed in this study, it was only one of several outcome measures for diabetes care. Behavioural functioning and quality of life have been termed the 'ultimate outcomes of health care' (Kaplan, 1990, p.1212). Several researchers, for example Bradley (1994a, 1994b), have called for psychologists to lead the multidisciplinary field of diabetes research. It is hoped that this would lead to a greater focus on psychological outcomes rather than 'contribute to the reification of glycosylated hemoglobin as the only outcome worthy of investigation' (Glasgow & Anderson, 1995, p. 397). Many studies use either medical or psychological outcome measures (for example, Frank *et al*, 1997), whereas the current study employed both.

Olsen and Sutton (1998) have described two differing paradigms, one which emphasises compliance and glycaemic control and the other which is increasingly aware of the quality of life of adolescents with diabetes and has patient empowerment at its core (Olsen & Sutton, 1998). Their study was firmly in the latter category and the authors therefore deliberately avoided employing glycaemic control as a variable to be investigated. However, the present author believes that a compromise, employing medical and psychological outcome measures, is feasible whilst also highlighting the importance of individual differences and the empowerment paradigm.

v) Semi-structured interviews

Satisfaction questionnaires have been criticised for several reasons (Stallard & Chadwick, 1991). For example, the service provider usually sets the agenda for the measures and there can be little scope for additional comments (McIver, 1991). Interviews with service users are therefore a means of widening the focus of the agenda of service evaluation. They have also been advocated as a way of avoiding the problems inherent in a single method data collection (Eiser, 1990a; Lavigne & Faier-Routman, 1992). In one study employing both standardised measures and a semi-structured interview, it was found that the interview was a valid tool in obtaining information not available from the standardised questionnaires (Cappelli, McGrath, Heick, MacDonald, Feldman, & Rowe, 1989). In this study, additional information was gathered on, for example, how patients perceived the clinic staff's attitudes, as well as how they feel about their future.

The characteristics of those who agreed to partake in semi-structured interviews were analysed. This selected sample comprised only of patients attending the clinic at the Royal Infirmary, therefore introducing a possible bias. In addition, the researcher only telephoned those participants who seemed enthusiastic regarding participation, as it was felt that completing a home-based interview was potentially intrusive. Although sample representation is not necessary for qualitative research (Olsen & Sutton, 1996), the evidence from the interviews will potentially contribute to the future practice of the diabetes clinics. It is therefore positive that the sub-sample was comparable to the

whole sample in terms of demographic variables and scores on the self-report measures. Furthermore, a range of people agreed to be interviewed. Individuals had varying HbA1c levels, including one individual with a very high HbA1c level, of 16.7%. In addition, there were greatly varying degrees of adaptation and psychological health, as evidenced by the responses to certain questions, for example, the words used to describe having diabetes.

4.4.2 Methodological criticisms

Whilst the study has a number of strengths in terms of its sample size and inclusion of variables, there are a number of criticisms that could be made. Additionally, suggestions for future research in this area are proposed.

Some limitations have already been illustrated, for example the potentially inappropriate use of using the Strengths and Difficulties Questionnaire as a measure of psychological well being.

It is relevant to note that this research was undertaken within a strict time boundary. Therefore, some of the difficulties noted below may be as a consequence of this limitation. In particular, a longitudinal design, which has been advocated as an ideal in this type of research, was outwith the time constraints imposed by the nature of this doctoral thesis.

i) Design

Correlations can highlight associations between factors, but cannot identify the direction of the relationship (Olson, Johansen, Powers, Pope, & Klein, 1993). This limits the conclusions that can be drawn and the nature of theoretical questions. Therefore, it can be assumed that although a relationship has been demonstrated between higher levels of satisfaction with diabetes care and both psychological and medical outcomes, it does not predict the direction of that relationship. Research in this field could therefore focus on determining causal relationships.

Cross-sectional design has also been criticised (Glasgow & Anderson, 1995). This is perhaps especially pertinent with a sample of young people, as the lives of adolescents can change greatly in a short period of time. Prospective, longitudinal studies have been proposed as a means of overcoming the difficulties inherent within cross-sectional designs. In particular, developmental studies that follow cohorts using repeated measurements over time are recommended (Glasgow & Anderson, 1995). This would be particularly beneficial with the present research age group, in which increasing age

was associated with worsening psychological health and less satisfaction with health care, as measured by the Diabetes Clinic Satisfaction Questionnaire.

ii) Control group

The current research did not include a control group. Other research has included a matched control group with a comparative chronic illness. For example, Cappelli and colleagues examined diabetes and cystic fibrosis (Cappelli *et al*, 1989). A second method has been to make comparisons with a healthy sample, particularly when assessing the extent of psychological distress within young people experiencing a chronic illness (Blanz *et al*, 1993).

However, there are many studies, similar to the current research, which are interested in the relationships between variables, for example psychological or family variables and glycaemic control and are less interested in comparisons with non-diabetes populations (for example, Grey *et al*, 1998; Guttmann-Bauman *et al*, 1998). Furthermore, for the purposes of this study, several diabetes-specific measures were deemed the most appropriate measures to use. This, along with the medical outcome measure of HbA1c, renders comparison impractical.

iii) Status of participants

The present study did not record whether participants were at school, college/university or working. Additionally, living circumstances were not taken into consideration, for example, whether participants were living with parents, alone, in shared accommodation or with a partner. Had these factors been recorded, additional analyses could have been performed. It may be that, as young people leave school or begin an intimate relationship, they face new challenges associated with their diabetes. One study found that older adolescents (aged 16 years and above) had a far more complex and intricate set of pressures, constraints and issues to deal with in managing their diabetes (Olsen & Sutton, 1998).

A second difficulty with this issue is that a small number of the questionnaire items related specifically to school life, for example, 'I talk about my diabetes at school'. Several participants left these blank, or wrote 'non-applicable', both of which increased the amount of missing values.

iv) Developmental stage

Chronological age was utilised as one variable under investigation. However, it has been proposed that in research of this nature, developmental stage cannot be equated with chronological age. It would have been desirable to assess young people's cognitive level formally, as carried out by, for example, Kovacs and colleagues, when they used two subtests of the Wechsler Intelligence Scale for Children, Revised (Wechsler, 1991) (Kovacs *et al*, 1985). This may have been preferable rather that to imply a certain developmental stage by chronological age only. Furthermore, the age banding and comparative analyses could have been supplemented by comparison of cognitive level.

v) Family information

The variables collected did not include any measure of family functioning or composition. Several studies have highlighted the importance of a range of family variables. For example, one research paper has shown that a family-centred approach to diabetes care facilitates positive family functioning and results in improved health outcomes (Hanson *et al*, 1995). In addition, family relations were most predictive of high levels of diabetes self-management during the first few years of the disorder.

Family can exert a powerful influence on health and illness. Through support, modelling and communication, the family can contribute to, or hinder, the successful coping with, a chronic illness (Papadopoulos, 1995). A number of researchers have highlighted a link between a relaxed, uncompetitive, family atmosphere with better outcome and adjustment (Anderson *et al*, 1981).

However, this research aimed to explore specifically a new resistance factor in the model of adaptation to chronic illness. The results from the present study could be perceived as complementary to the research on family variables.

vi) Self report

With the exception of HbA1c levels, the current research relies solely on self-report measures. In satisfaction research, previous studies have found disagreement between the views of young people and their parents (Eiser, Levitt, Leiper, Havermans & Donovan, 1996; Simonian *et al*, 1991). An interesting addition to this study would have been discerning the views of parents regarding the treatment their children.

Furthermore, the authors of the Strengths and Difficulties Questionnaire suggested that, where possible, informant rated SDQs should be collected in parallel with the young people's self-report version (Goodman *et al*, 1997). As the two versions of the SDQ are virtually identical, this would have enabled a direct comparison between young people's report and that of their parent or doctor.

Nevertheless, the adolescent clinic model used aims to foster independence and responsibility in the young people receiving services. Consistent with the empowerment paradigm, an active decision was made to exclusively utilise self-report data. Concurrent to this, on a practical note, the majority of the participants in this study attend their appointments by themselves.

vii) Time since diagnosis

Discussion with the Clinic teams prior to the data collection phase resulted in the decision to use all patients attending appointments, regardless of time since diagnosis. Many research studies use a cut-off period of one year, which results in anyone diagnosed with diabetes for less than twelve months being excluded (for example, Guttmann-Bauman *et al*, 1998). In this study, there were nine participants, 10.8 % of the total sample, who had been diagnosed with diabetes for less that one year. Consequently, this group of participants may continue to be in their 'honeymoon

period', whereby the pancreas continues to produce small amounts of insulin (Kelnar, 1994). Diabetes control is normally easier to obtain during this period and the inclusion of these participants could have biased the results. However, with a sample average HbA1c of 10.22%, well above the target value for this age group, it is not thought that the inclusion of this group has had a significant impact on HbA1c levels. Conversely, the inclusion of this group does appear to have affected the variable of Average HbA1c, in that twelve month previous levels would not have been available for 10% of the participants.

An additional complication with the inclusion of this sample is potentially the high level of psychological difficulty, which has been documented in the first year following diagnosis (Kovacs, Feinberg, Paulauskas, Finkelstein, Pollock, Crouse-Novak, 1985). Inspection of the results of the psychological measures, reveals a sample which appears to be experiencing positive psychological health.

An interesting further study would be to follow the sample used in the current research, for example, to examine the effects of time on the newly diagnosed individuals.

viii) Quantitative and qualitative information

In this study, the semi-structured interviews were conducted after the quantitative data collection period. It may have been preferable to complete the interviews prior to devising the Satisfaction with Diabetes Care questionnaire. A period of open-ended, exploratory interviewing would have enabled a fuller range of patients' views to be assessed, before deciding on the areas to be examined in a closed questionnaire (Fitzpatrick, 1991b). However, the questionnaire items were chosen to answer issues highlighted by the clinical staff and, along with the time constraints, this was therefore not possible.

4.5 Implications for future research

This research has highlighted the importance of the role of satisfaction with diabetes care. However, it is also important to now identify which aspects of care are significant for individuals and best predict medical and psychological outcomes. This suggests widening the focus of factors considered in diabetes research in general and satisfaction with diabetes services in particular.

The relationship between parental satisfaction with hospital services and subsequent psychological adjustment of both the young individual with diabetes and the family is an area, which has received little attention. There are good reasons for assuming that this interface is important based on the work of Bradford (1990, 1997).

One area, which could be further explored, is that of the therapeutic relationship. The level of congruence in causal attributions and diabetes-specific perceived control between doctor and patients has been investigated (Gillespie & Bradley, 1988). Although blame has been placed both on the 'noncompliant patient' and the 'insensitive practitioner', the reality is that both patient and provider must work together as team members (Strauss, 1996). The widely accepted tradition in diabetes care is that the quality of glycaemic control requires an active, knowledgeable, committed patient who believes in the value of sustained effort in relation to the daily demands of self-management. These patient-oriented notions have tended to assume that health outcomes are largely independent of the attitudes and beliefs of the health professionals (Gillespie & Bradley, 1988). It is clear that healthcare professionals expect to improve patients' behaviour, though few researchers have considered this group suitable material for investigation. Tercyak and colleagues have also advocated that there should be a shift from focusing exclusively on patient characteristics to look at provider behaviour as an equal, if not more important, area for further study (Tercyak, Johnson, Kirkpatrick & Silverstein, 1998).

In addition to these new foci for research, study designs should be adjusted. Based on the 'three generations' model of research in diabetes (Hanson *et al*, 1995), there is now a

call for longitudinal studies. An example of this approach is in a series of studies conducted by Kovacs and colleagues, in which children were followed longitudinally to assess initial coping responses following a diagnosis of diabetes (Kovacs, Brent, Steinberg, Paulauskas & Reid, 1986; Kovacs, Feinberg, Paulauskas, Finkelstein, Pollock & Crouse-Novak, 1985). Parental variables were also included in their studies (Kovacs, Finkelstein, Feinberg, Crouse-Novak, Paulauskas & Pollock, 1985). However, the above studies only followed participants for one year, thus not allowing for the investigation of medium and long-term adaptation to the illness. This is particularly important as the honeymoon period of insulin secretion ends approximately one year following onset of diabetes.

Young people may experience a variable course of adaptation, contingent on factors other than illness variables (Frank, Hagglund, Schopp, Thayer, Vieth, Cassidy, Goldstein, Beck, Clay, Hewett, Johnson, Chaney & Kashani, 1998). Consistent with the call for longitudinal designs, the concept of 'adaptation trajectories' may provide an avenue for more accurately describing the multiple influences on adaptation to diabetes (Frank, Thayer, Hagglund, Vieth, Schopp & Beck, 1998).

4.6 Concluding comment

This study was primarily concerned with the contribution that perceived satisfaction with diabetes care, makes to medical and psychological outcomes in adolescents with diabetes. Significant findings were found, linking higher satisfaction levels to better medical and psychological adaptation. Therefore, the study highlights the importance of maximising young people's satisfaction with their diabetes care.

A key message from the findings of the Diabetes Control and Complications Trial (DCCT, 1993, 1994) was that any improvement in diabetes control produces a lowering in the risks of diabetes-related complications. Therefore, every intervention, which can result in even small improvements in glycaemic control in adolescents with diabetes, is worthwhile (Brink, 1997). The present research proposes that efforts be made to improve young people's satisfaction with their diabetes care, as a way of enhancing glycaemic control. This is especially pertinent in a sample that has HbA1c levels consistent with increased vulnerability to future complications. A second message from the DCCT is the recognition of the importance of psychological well being and quality of life, which can also be enhanced with improved satisfaction with care (Ingersoll & Marrero, 1991).

It is proposed that future research should take heed of the methodological issues discussed herein and move into the 'third generation' (Hanson *et al*, 1995) of research in the area of diabetes. Furthermore, studies could assess whether interventions aimed at increasing perceived satisfaction with care have an impact on medical and psychological outcomes.

Finally, the addition of an evaluation of the treatment environment to the Risk and Resistance model emphasises the importance of factors other than individual attributes in the adaptation to a chronic illness (Bradford, 1997).

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APPENDICES

APPENDICES

APPENDIX I

Diabetes Treatment Satisfaction Questionnaire

The following questions are about your treatment for your diabetes (including insulin and / or diet) and your experience over the past few weeks.
Please answer each question by **circling a number**.
Example:

How satisfied are you with your homework?

very satisfied 6 5 4 3 2 1 very dissatisfied

---

1. How **satisfied** are you with your current treatment?

very satisfied 6 5 4 3 2 1 very dissatisfied

2. How often have you felt that you blood sugars have been unacceptably **high** recently?

most of the time 6 5 4 3 2 1 none of the time

3. How often have you felt that your blood sugars have been unacceptably **low** recently?

most of the time 6 5 4 3 2 1 none of the time

4. How **convenient** have you been finding your treatment to be recently?

very convenient 6 5 4 3 2 1 very inconvenient

5. How **flexible** have you been finding your treatment to be recently?

very flexible 6 5 4 3 2 1 very inflexible

6. How satisfied are you with your **understanding** of your diabetes?

very satisfied 6 5 4 3 2 1 very dissatisfied

7. Would you **recommend** this treatment to someone else with your kind of diabetes?

yes, I would definitely recommend the treatment 6 5 4 3 2 1 No, I would definitely not recommend the treatment

8. How satisfied would you be to **continue** with your present form of treatment?

very satisfied 6 5 4 3 2 1 very dissatisfied

APPENDIX II

Diabetes Clinic Satisfaction Questionnaire

Please tick or cross the appropriate box on each of the scales below to show if you are either **satisfied**, **dissatisfied** or **neither** with the following aspects of your diabetes clinic / care.

	Satisfied	**Neither satisfied nor dissatisfied**	**Dis-satisfied**
1. The amount of time spent talking to the staff (including doctors, nurses and other staff)			
2. The value to me in talking to the staff			
3. Continuity of care, that is, whether or not patients see the same doctor on each visit			
4. The extent to which I feel understood by the staff			
5. Discussing with staff any problems I may have			
6. The amount of information given to me by staff regarding my results (e.g. overall diabetes control)			
7. How I am treated as a person by the staff			
8. The ease in making appointments			
9. The treatment recommended including diet, footcare, and any medication for diabetes			
10. The timing of appointments			
11. Time spent waiting in clinic/centre			
12. The amount of privacy			
13. The comfort of the waiting area			
14. Availability of refreshments			
15. Availability of diabetes education, including books, pamphlets, videos about diabetes			
16. Availability of dietary advice			
17. Availability of chiropody (foot care) service			
18. Ease of getting to the clinic, including public transport and/or parking facilities			

APPENDIX III

Diabetes Satisfaction

	Very unsatisfied	Somewhat unsatisfied	Neither	Somewhat satisfied	Very satisfied
1. How satisfied are you with the amount of time it takes to manage your diabetes?					
2. How satisfied are you with the amount of time you spend getting checkups?					
3. How satisfied are you with the time it takes to determine your sugar level?					
4. How satisfied are you with your current treatment?					
5. How satisfied are you with the flexibility you have in your diet?					
6. How satisfied are you with the burden your diabetes is placing on your family?					
7. How satisfied are you with your knowledge about your diabetes?					

APPENDIX IV

Satisfaction with Diabetes Care

1. If you **miss an appointment**, what would you like to happen:

- ❑ staff send me another appointment in the post
- ❑ staff contact me by telephone
- ❑ leave it to me to contact
- ❑ something else (please specify)

.....

2. Do you feel that you get **different** (that is, conflicting) messages / advice from the doctors?

❑ yes ❑ no

if yes, can you give an example:

.....

.....

3. When you leave the clinic, do you **understand** everything you have been told?

❑ yes ❑ no

4. Would you like information from the day **written** down?

❑ yes ❑ no

5. Would you like to get a copy of the **letter** that is sent to your GP after each clinic visit?

❑ yes ❑ no

6. What would be the right amount of **time** between clinic visits?

- ❑ 1 month
- ❑ 2 months
- ❑ 3 months
- ❑ 6 months
- ❑ 1 year
- ❑ longer

7. Please tell me about the **best parts** of your diabetes care.

.....

.....

8. Please tell me about the **worst parts** of your diabetes care.

.....

.....

9. Please tell me about the parts of your diabetes care that could be **done differently.**

.....

.....

APPENDIX V

Diabetes Quality of Life for Youths

For each item, please mark the column with a tick or a cross.

Impact of diabetes

	Never	Very seldom	Sometimes	Often	All the time
1. How often do you feel pain associated with the treatment?					
2. How often are you embarrassed by having to deal with your diabetes in public?					
3. How often do you feel physically ill?					
4. How often does your diabetes interfere with your family life?					
5. How often do you have a bad night's sleep?					
6. How often do you find your diabetes limiting your social relationships and friendships?					
7. How often do you find your diabetes limiting your social relationships and friendships?					
8. How often do you feel good about yourself?					
9. How often do you feel restricted by your diet?					
10. How often does your diabetes keep you from driving a car or using a machine (for example, a typewriter)?					
11. How often does your diabetes interfere with your exercising?					
12. How often do you miss work, school or household duties because of your diabetes?					
13. How often do you find yourself explaining what it means to have diabetes?					
14. How often do you find that your diabetes interrupts your leisure time activities?					
15. How often are you teased because of your diabetes?					
16. How often do you feel that because of your diabetes you have to go to the bathroom more than others?					
17. How often do you find you eat something that you shouldn't rather than tell someone that you have diabetes?					
18. How often do you hide from others the fact that you are having an insulin injection?					
19. How often do you find that your diabetes prevents you from participating in school activities (for example, being in a sports team, in a school play)?					
20. How often do you find that your diabetes prevents you from going out to eat with your friends?					
21. How often do you feel that your diabetes will limit what job you will have in the future?					
22. How often do you find that your parents are too protective of you?					
23. How often do you feel that your parents worry too much about your diabetes?					
24. How often do you find that your parents act like diabetes is their disease, not yours?					

APPENDIX V

Worries about diabetes

	Never	Very seldom	Sometimes	Often	All the time
1. How often do you worry about whether you will get married?					
2. How often do you worry about whether you will have children?					
3. How often do you worry about whether you will **not** get a job you want?					
4. How often do you worry about whether you will pass out?					
5. How often do you worry about whether you will be able to complete your education?					
6. How often do you worry that your body looks different because you have diabetes?					
7. How often do you worry that you will get complications from your diabetes?					
8. How often do you worry about whether someone will **not** go out with you because you have diabetes?					
9. How often do you worry that your teachers treat you differently because of your diabetes?					
10. How often do you worry your diabetes will disrupt something you are currently doing in school (for example, continue in the sports team, play in the school band)?					
11. How often do you worry that because of your diabetes you are behind in terms of dating, going to parties and keeping up with your friends?					

Satisfaction with life

speaking generally:

	Very unsatisfied	Somewhat unsatisfied	Neither	Somewhat satisfied	Very satisfied
1. How satisfied are you with your sleep?					
2. How satisfied are you with your social relationships and friendships?					
3. How satisfied are you with your work, school and household activities?					
4. How satisfied are you with the appearance of your body?					
5. How satisfied are you with the time you spend exercising?					
6. How satisfied are you with your leisure time?					
7. How satisfied are you with life in general?					
8. How satisfied are you with your performance in school?					
9. How satisfied are you with how tour classmates treat you?					
10. How satisfied are you with your attendance in school?					

APPENDIX V

Compared with others your age, would you say your health is:

- ☐ Excellent
- ☐ Good
- ☐ Fair
- ☐ Poor

APPENDIX VI

Adaptation to Diabetes Scale

Here are some things that other young people have said about having diabetes. Could you tell me if they:

- **Almost always** describe what you think or do
- **Often** describe what you think or do
- **Sometimes** describe what you think or do
- **Seldom** describe what you think or do
- **Almost never** describe what you think or do

You can mark your answer with a tick or a cross on the sheet. It's a bit like a multiple choice test at school, but it's difference as there are no right answers; you just have to mark the answer as near as you can to what you feel……

	almost always	often	sometimes	seldom	almost never
1. I can go on any holiday with my diabetes					
2. Diabetes is a nuisance when I'm out enjoying myself					
3. Diabetes takes up too much of my day					
4. I don't really bother with the diet, I just eat what I like					
5. I get fed up when everybody else buys a load of sweets					
6. I know what to do to correct my sugar levels if my tests are too high or too low					
7. My injections make me cross					
8. It is important to keep my blood sugar normal					
9. I can't be bothered with blood tests					
10. I would rather forget about diabetes than learn about it					
11. It's important to keep up to date about diabetes					
12. I get cross about having diabetes					
13. I just take having diabetes as part of my normal life					
14. It's depressing to think I'll always have diabetes					
15. There are good things about my diabetes					
16. Diabetes does tend to rule my life					
17. I find it upsetting to tell other people about my diabetes					
18. I must be on guard about my diabetes all the time					
19. I talk about my diabetes at school					
20. Coping with my diabetes is helping me to become more independent					

APPENDIX VII

Strengths and Difficulties Questionnaire

For each item, please mark the column (with a tick or a cross) for **Not true**, **Somewhat true** or **Certainly true**.

It would help us if you answered all items as best you can even if you are not absolutely certain or the item seems daft! Please give your answers on the basis of how things have been for you over the last **six months**.

	Not true	**Somewhat true**	**Certainly true**
1. I try to be nice to other people. I care about their feelings			
2. I am restless, I cannot stay still for long			
3. I get a lot of headaches, stomach-aches or sickness			
4. I usually share with others (food, games, pens, etc.)			
5. I get very angry and often lose my temper			
6. I am usually on my own generally play alone or keep to myself			
7. I usually do as I am told			
8. I worry a lot			
9. I am helpful if someone is hurt, upset or feeling ill			
10. I am constantly fidgeting or squirming			
11. I have one good friend or more			
12. I fight a lot. I can make other people do what I want			
13. I am often unhappy, downhearted or tearful			
14. Other people my age generally like me			
15. I am easily distracted, I find it difficult to concentrate			
16. I am nervous in new situations. I easily lose confidence			
17. I am kind to younger children			
18. I am often accused of lying or cheating			
19. Other children or young people pick on me or bully me			
20. I often volunteer to help others (parents, children, teachers)			
21. I think before I do things			
22. I take things that are not mine from home, school or elsewhere			
23. I get on better with adults than with people my own age			
24. I have many fears, I am easily scared			
25. I finish the work I'm doing. My attention is good			

APPENDIX VIII

COVERING LETTER

(headed paper)

Date

Dear _____

My name is Clare Roberts, and I am a Clinical Psychologist in Training. I am currently working at St John's Hospital, Livingston.

As part of my training, I am undertaking some research which involves asking young people to complete questionnaires about diabetes and their visits to the clinic. I am hoping to find out how we can change the running of the clinic to allow young people to gain the most from their visits.

I understand that you have an appointment to attend the Diabetes Clinic at _____ Hospital on _____. I have enclosed some information for you to read, which should explain the research in more detail. I will be available to answer any questions when you attend. If you, or your family, would like to discuss this more, please contact me at the telephone number below.

If you are happy to take part in the study, I will give you a series of questionnaires fill in while you are waiting to see one of the Doctors.

You don't have to do anything just now. I look forward to hopefully meeting you on _____.

Yours sincerely,

Clare Roberts
Principal Researcher

Dr Ion Wyness
Clinical Psychologist
Research Team

APPENDIX IX

ADOLESCENTS WITH DIABETES – SATISFACTION WITH SERVICES

RESEARCH INFORMATION SHEET

This study aims to improve knowledge of the views of young people with diabetes. It is hoped to look at the links between how satisfied you are with what happens at the Clinic, and how it affects your quality of life and blood glucose levels. This is an invitation to participate in the study.

If you are interested in taking part you will be asked to fill in six questionnaires. When you arrive at the clinic, you will be asked to sign a consent form and you can ask questions. The questionnaires will take about 20 minutes to complete and you can fill them in at the Clinic while waiting to see the Doctor.

Your participation is entirely voluntary and, should you decide not to take part, this will have no effect on the treatment you receive at the Clinic.

The questionnaires will ask you about your diabetes, how you feel about your treatment, and how you feel generally.

Additionally, a small number of you will be asked to participate in a 30 minute interview, conducted at your home, to get more information about the Clinic. These interviews will be recorded on a tape recorder, and the tapes will be destroyed shortly after the interview.

All information (questionnaires and tapes) will be confidential. Nobody but the research team will have access to what you write. Questionnaires will be kept only while the research is ongoing (approximately 8 months) and then destroyed.

If you, or your family, have any questions, you can contact a member of the research team or Mrs Curran, who is outwith the research team and the diabetic team.

research team:
Clare Roberts
Research Team Member
Dept. of Clinical Psychology
St. John's Hospital
Livingston
West Lothian
Tel: 01506 422769

outwith research:
Mrs Artemis Curran
Clinical Psychologist
Dept. of Clinical Psychology
St. John's Hospital
Livingston
West Lothian
Tel: 01506 422769

THANK YOU FOR YOUR HELP

APPENDIX X

The University of Edinburgh, Department of Clinical Psychology

Patient Identification Number:

CONSENT FORM

Title of project: Satisfaction with diabetes care in adolescents

Name of researcher: Clare Roberts

1. I confirm that I have read and understand the information sheet provided for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

3. I understand that sections of any of my medical notes may be looked at by the researcher where it is relevant to my taking part in this research. I give permission for the researcher to have access to my records.

4. I agree to take part in the above study.

_____	_____	_____
name of patient	date	signature
_____	_____	_____
name of researcher	date	signature

APPENDIX XI

The University of Edinburgh, Department of Clinical Psychology
Patient Identification Number:

CONSENT FORM – PARENT / GUARDIAN

Title of project: **Satisfaction with diabetes care in adolescents**

Name of researcher: Clare Roberts

Name of potential participant: _____

1. I confirm that I am the parent/guardian (please specify) of the abovenamed child, who is a potential participant in this study
2. I confirm that I have read and understand the research information sheet provided and had the opportunity to ask questions
3. I understand that participation of the abovenamed child is voluntary and that he / she is free to withdraw at any time, without giving any reason, without medical care or legal rights being affected
4. I understand that sections of the abovenamed child's medical notes may be looked at by the researcher where it is relevant. I give permission for the researcher to have access to the records.
5. I understand that if the abovenamed child is interviewed by the researcher, it will be audiotaped
6. I agree to the abovenamed child taking part in the above study

_____	_____	_____
name of parent/guardian	date	signature
_____	_____	_____
name of researcher	date	signature

APPENDIX XII

LETTER TO GP

(headed paper)

Dear (GP)

Re: (subject's name, date of birth and address)

The above named has agreed to take part in a research project being carried out as part of my Doctorate in Clinical Psychology. The research aims to assess satisfaction with the Adolescent Diabetic Clinic, Royal Infirmary of Edinburgh, which your patient attended recently.

This research involves completing a series of questionnaires whilst the young person is in attendance at the clinic. Participation is entirely voluntary and will have no bearing on treatment.

A summary of the results will be available in August 2000 and can be obtained from myself at St John's Hospital.

If you would like information from myself, or someone independent of the study, please feel free to contact either:

Clare L. Roberts
Clinical Psychology Department
St John's Hospital
Livingston

tel. 01506 422769

Mrs Artemis Curran
Clinical Psychology Department
St John's Hospital
Livingston

tel. 01506 422769

Yours sincerely

Clare L. Roberts
Clinical Psychologist in Training
Principal Researcher

Dr Ion Wyness
Clinical Psychologist
Research Team

APPENDIX XIII

LETTER RE. INTERVIEW

(headed paper)

Name
Address

date

Dear

Re: Interview for Diabetes Research

Thanks again for agreeing to take part in my research. I thought I would drop a note confirming the arrangements we made.

Day:
Date:
Time:

I would appreciate it if you could contact me on the number below if you are unable to make this time. Otherwise, I look forward to seeing you on the 14th.

Thanks again.

Yours sincerely

Clare Roberts
Principal Researcher

tel. (mobile):

APPENDIX XIV

Example of an interview transcript
(participant no.37: female, aged17)

I'd like to start by getting a sense of how things have been for you and how you've coped from the time of your diagnosis until the present day. When was the diagnosis for you?
I was in primary 5, so I think I was 9...I don't know the actual year... I was born in '82, so...

Do you remember what happened in the days immediately after your diagnosis?
I remember before being diagnosed and then em I think I was just in hospital, em... it was fine... watched TV ...I mean doctors and nurses came and talked to me... I don't know how long I was in there...might have been a week... I remember they checked to see what sort of symptoms I had... if I had a hypo and that's about it

You say you remember the time leading up to the diagnosis - what was that like?
I was drinking a lot... I mean, I needed to actually beg my mum to give me a glass or water or whatever em and I had em I think it must have been thrush on my tongue because I had had that when I was younger and I went to the chemist and they said I would have to go to the doctors so I went to the doctors and he checked my blood sugars he obviously realised - he smelt ketones and then he said oh well I think you might be diabetic and sent me up to the hospital

So you've lived with it for quite a long time – how do you feel things have been in that time?
well, I've always kind of ignored it which on the one hand might be quite a good thing but on the other hand it's kind of stupid but em I used to have really really bad control it was always really high - I stopped doing my injections, my parents split up – I don't know if it was connected, whatever, but, you know, I suppose if you're looking at it in detail and... then I had to get laser surgery done on my eyes because my control was really bad and from then and now I'm really low at the time – I ignore it, but I'm more sort of aware now

What do you mean by ignore it?
I don't pay attention to what I eat – I used to use this system called exchanges – counting how much you'd had for your breakfast – it's like you've got money and can spend it but I sort of don't follow it – I always followed it to an extent but then less and less and then I brought it up one time at the clinic and they said oh no we don't really follow that anymore – I don't know what system they do have but I just always avoid the dietician

APPENDIX XIV

You mentioned you don't know if there's a link between your parents splitting up and poor control – was it around the same time?
em, it was a wee bit afterwards, I just stopped doing my injections, I don't know why the doctors were always amazed and said well what did you do with it and I said I loaded it and squirted it out – they couldn't come to terms with that – they thought it was so ridiculous but it was quite easy, my mum was giving me my insulin and I would load it up – I was on syringes then and would squirt it on the couch, on the carpet, anywhere

How long do you think you did that for?
I don't know - I missed – I'd never go a day without it – it was always sort of one – either in the morning or at night – but then I'd forget… there was two weeks before I went into hospital when I was really bad – I don't know, I was probably worse than when I was diagnosed – I was just more aware of what it was that time but again I just ignored it

Do you remember how you felt about yourself and your diabetes at that time?
it's not that I resented having to do the injections – it didn't bother me…it wasn't…it didn't hurt I just couldn't be bothered doing it. I remember went on a school trip – down in London for a week or something and one of the teachers – her mum had been diabetic and I remember we went out for a meal and I said well was going to have to do it injection but she said it was okay of you don't wait for thirty minutes so from that time on…I mean I don't want to blame her but I thought it's okay to inject and eat straight afterwards and then there's just times when I can't really be bothered.

You mentioned laser surgery. do you think that changed things?
yeah - I can't remember why actually I hadn't had my eyes checked before and I don't know why they checked it but they did and I can't actually remember but they sent me to Dundee to get it checked I think they realised straight away and they had me like - I mean I don't know if they made an appointment straight away to have it done in Dundee or I went for a check up first but anyway I can't remember what it was, things at the back of my eye and then well I was really shocked I mean you're never even really told about those sorts of complications – it's so unlikely of you getting them that young so it came as this huge shock em my dad was totally floored whatever I mean he never thought and it just seemed so serious and it was… it's fine now – I just think about it sometimes and worry about things going wrong – I sort of wonder well I've had that done probably my kidneys are next or my feet or…

Do you think that had an effect on how you feel about your control and injections?
I was really good for a couple of weeks – better than I'd ever been before em then I sort of loosened up a bit but my control generally has been a lot better since– I had that done about two years ago. I always used to be – my hbm or whatever that always used to be about 16 and then in the last year maybe year and a half it's gone down been sort of

APPENDIX XIV

about 9 and I mean 9 is still quite I mean I don't know if it's high because it's better than it used to be but the doctor even sent a letter saying oh well done – all the nurses were coming up to me…I never used to pay attention -I never realised 16 – how bad that was – never thought about it – then probably after my eyes, I just thought about it a bit more – just realised. I knew it wasn't good but I thought if there was a serious problem with it always being so high the doctors would have something would have been done I mean I don't know what could have been done I think I was eating too much and I was on a lot of insulin which would explain part of why I was eating so much

What words would you use to describe your diabetes?
I don't know…it's hard to say – I suppose I'm used to it now

What about now – how much time do you spend on your diabetes – doing tasks?
about 1 minute per day – I do two injections. I rarely test my blood.

How much time do you spend thinking about your diabetes?
it varies – I could go weeks… I don't know I suppose if I know that I've eaten too much then I'll think oh I'll have to do some exercise – see in theory, I'll think oh I better do some exercise but I might not – I don't do a lot of exercise

Which aspects of your care do you most like?
being able to control my weight through insulin

Which aspects of your care do you least like?
injections

What could be changed about the clinic?
the times – spend too long waiting. I get out late – quite often I have a hypo- it's not fair on my mum for me to be having one of them every few months

Has anyone at the clinic ever spoken to you in a way that you didn't like?
I was there recently – the doctor assumed I hadn't been injecting as if he had read my file and made assumptions. another time, the doctor started talking about contraception and complications in pregnancy – I hadn't asked for that kind of information

What could the clinic do to improve things?
If I got a copy of letter to GP, I'd know exactly how the doctor meant things. maybe as well I could have just two doctors that I see
the best thing would be a mobile McDonalds – so I wouldn't get a hypo

Who is the most important person in the team?
Carol Carson – can take lots of different worries to her – things like social problems. also, she arranged for me not to see a certain doctor I hadn't liked

APPENDIX XIV

What do you see constitutes a good quality of life?
not sure how to answer that question. I suppose having a life whether nothing majorly bad happens

How do you see the future?
I worry what happens when I go to university and when do I leave the adolescent clinic – is there an adult clinic ??

Anything you'd like to add?
I don't think so, no

APPENDIX XV

Answers to Q.2 of 'Satisfaction with Diabetes Care'

Do you feel that you get **different** (that is, conflicting) messages / advice from the doctors?
If yes, can you give an example:

- But they sometimes hide or do not tell you what they are thinking about you. If you're a teenager this is annoying.
- I sometimes think they have different methods/ideas
- One doctor said don't need to inject in stomach just legs, another said to do both
- Some concentrate on weight and control, others deal with control, then weight
- Some say 'test' others say 'that's ok we accept you won't test. Some say 'you must do this' others say 'it is up to you'
- Tell me a load of crap all the time
- The amount of insulin to have
- The doctor at the clinic told me to get a flu injection, my GP said not to bother
- Told to up insulin told by another not to
- You learn different things from seeing various doctors, which I find helpful

APPENDIX XVI

Clin.	N	Best parts of diabetes care	Worst parts of diabetes care	Changes suggested
RIE	1	I can now control my injection times a lot easier. I don't have to wait as long	the fact I have diabetes	can't think of any
RIE	4	N/R	N/R	N/R
RIE	5	getting told information on my health	injection sites getting sore	just to feel everything is done properly to make sure I'm healthy
RIE	6	most of the staff are kind and helpful. I also like the £10 I get from Inverness research	having to take my jag twice a day. doing a blood test every day	it takes ages for me to be seen by everyone. I am always in the clinic for over an hour
RIE	7	diet	injections	blood monitoring
RIE	8	all parts are good	n/a	happy with care I receive
RIE	9	N/R	N/R	N/R
RIE	10	none. actually, getting £10 for research was good	tests. injections. not eating certain things. possibility of complications. lectures from doctors.	access to notes for patients. told info about different ways to do things
RIE	11	the staff are extremely helpful and kind	I don't particularly like having blood taken	nothing
RIE	12	support from family and clinic	injections and blood tests	improve my diet
RIE	13	I know their's always someone to phone if I have a problem	N/R	N/R
RIE	14	getting it out of the way and getting £10 for giving a wee bit of blood	waiting around	waiting around

RIE	15	people listen to me a lot especially my doctor	it's slightly painful and very time consuming	I would like a different way of taking insulin
RIE	16	the nurses are nice	taking injections	N/R
RIE	18	N/R	N/R	N/R
RIE	19	N/R	not eating sweets	N/R
RIE	20	the best part is the helpfulness of the staff. they are always friendly and helpful	the worst part is waiting around for ages.	it would be good if some members of staff could be a bit less patronising
RIE	21	nice doctors	waiting to get seen. giving urine samples	making urine sampling more discreet
RIE	22	N/R	having to do blood tests	N/R
RIE	23	one to one with doctor – getting	long waiting times	is there any way to shorten waiting times?
RIE	25	N/R	having daily injections (get lumps and bruises). getting blood from arm at the clinic	N/R
RIE	26	N/R	long wait in clinic. expensive needles – not free	free needles
RIE	27	N/R	N/R	N/R
RIE	28	advice on how to make the injections fit in with my life	I always feel like I'm being told off	N/R
RIE	30	N/R	N/R	N/R
RIE	31	N/R	the various problems like feeling unwell often	injections when I eat so it can be varied

RIE	32	having a nurse and doctor that know me well and not having to explain my situation each time I come to clinic, as they already know	having to inject in front of people, people who don't know what it's all about. high blood sugar. hypos. the list is endless	regular injections and blood tests. eating the correct foods.
RIE	33	constant medical care and encouragement of a healthy diet	daily injections	N/R
RIE	35	N/R	doing jags	N/R
RIE	36	N/R	blood tests	N/R
RIE	37	inject automatically, without thinking	don't pay too much attention to what I eat. just sort of balance it very very loosely.	maybe learn to adjust insulin better instead of on autopilot. clinic times are difficult because often don't get out till about 6.45 onwards, disrupts my routine and end up having the type of hypo when I despair and everything is uncontrollable and get very impatient, even when get food, no longer want it.
RIE	38	the help that the doctors and nurses give you	N/R	injections
RIE	39	better health	eating	blood tests
RIE	41	? it's all rubbish being diabetic	it's most boring having to wait and do blood tests	all
RIE	42	advancements in blood testing	doing blood tests	N/R
RIE	43	the people are quite friendly	waiting around	N/R
RIE	44	the knolage that support is available	paying for needle tips	could be spoken to in a less condasending manner
RIE	45	N/R	N/R	N/R

RIE	46	good advice from doctors	long time spent waiting on the doctor	nothing
RIE	47	overall count is getting better	it makes me depressed	N/R
RIE	48	N/R	N/R	N/R
RIE	49	I get a good amount of home visits and then there is the clinic so I get plenty attention	injections, b.m.s, not being able to eat many sweets	N/R
RIE	50	N/R	getting blood taken	N/R
RIE	51	the help you get from staff	N/R	N/R
RIE	52	there is no best part	most of it (injecting insulin and blood tests)	N/R
RIE	53	N/R	the fact of having to travel all the way to hospital for 30 minute visit	N/R
SJH	58	the staff are all friendly and all helpful. you can contact your nurse at any time.	N/R	N/R
SJH	59	N/R	N/R	N/R
SJH	63	taking injections	testing my blood sugar level	set meals e.g. snacks less
SJH	64	my diet and I stay fit	the injections and how I can't have some foods when I want them	none
SJH	66	meeting lots of different people	getting blood taken from arm	none
SJH	68	having to stay fit and healthy all the time	the injections, b.m. etc	none
SJH	69	taking the last injection at night	waking up in the morning	N/R
RIE	70	N/R	inconvenience	N/R
RIE	71	keeps me healthy	injecting	N/R
WGH	72	when my blood counts are normal	after the jags I get small lumps and bruises	N/R

WGH	73	don't eat as much junk food as others, therefore I'm healthier	injections	N/R
WGH	74	N/R	the worst parts are when I take my injection, sometimes it is sore	N/R
WGH	75	I get somewhat of a proper diet	having to have injections	none
WGH	76	your in controle	N/R	N/R
WGH	77	there is no best part	there is no worst part	none
WGH	78	I know how and when to adjust my insulin myself. it doesn't really interfere with my life. I don't not do anything because of my diabetes.	blood testing, I am always so busy, so tend to forget. running out of injection sites.	more blood testing to get better control
WGH	79	the injections	the clinic visits	N/R
WGH	80	N/R	having to come to clinics !	N/R
WGH	81	because I am quite recently diagnosed I feel that people sometimes worry about me	I don't like blood tests and sometimes I don't like injections	none
WGH	83	having a controlled diet	having to have every single meal and at certain times	N/R
WGH	84	it is more healthy than ordinary peoples diets because there isn't much sugar in my diet	high and low blood counts and trying to keep them under control	my blood counts because the meter could be faster
WGH	86	N/R	waiting and sometimes feel as if I'm treated like a child	less visits to the clinic
WGH	88	the fact that having diabetes doesn't really affect any part of my life	the inconvenience of the blood sugar test!	perhaps a blood testing device similar to that of the 'oxygen in the blood' machine
WGH	89	N/R	injections, blood tests, diet	fewer injections

WGH	90	attention you get from the doctors and nurses	waiting to be taken in	none
WGH	91	seeing the doctors at the clinic	don't really think about it that much – just accept it as part of my life	the long waits at the clinic!
WGH	95	I get to eat most foods due to me being into sports	B.M.s	B.M.s could be done more often
Rood	96	my diabetes helps me keep track of my general health. it also means that I have a better diet than most others too	the worst part would be when I am having a hypo but I can deal with them quite easily on my own now	N/R
Rood	97	taking my injections at the proper times!	checking my blood sugar levels!	I would like my blood sugar levels to be done differently. I have just been given a new meter so it should make it much easier!
Rood	98	medication is available on nhs. always a hospital contact if you get ill. nice relaxed waiting areas and staff	staff are not always crystal clear with you. (dubious about the info you give them)	since moving to roodlands 5 months ago I am satisfied with all aspects mentioned in this questionnaire
Rood	99	not sure	not sure	not sure
Rood	101	the clinic being local. being able to discuss my diabetes with the doctor and nurse	having to have injections	use email for results e.g. email them to clinic
Rood	102	none	injections, blood tests	don't know
Rood	103	N/R	N/R	N/R
Rood	105	N/R	blood tests	N/R
Rood	106	only have to take jags twice daily	coming to the clinic	less jags
Rood	107	meeting new people	having to do jags	no jags