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The Experience Of Diabetes In Young People: A Test Of The Extended Health Belief Model (Aalto & Uutela, 1997)

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ABSTRACT

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THE EXPERIENCE OF DIABETES IN YOUNG PEOPLE: A TEST OF THE EXTENDED HEALTH BELIEF MODEL (AALTO & UUTELA, 1997)

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108 young people aged 16-25 years with Type 1 diabetes completed postal questionnaires. High levels of family support and low locus of control beliefs in powerful others to control their diabetes reduce the young person's perception of severity and vulnerability to diabetes-related complications. High levels of family support and high quality of life scores predicted low life threat due to diabetes. High internal locus of control beliefs and high levels of diabetes-related empowerment predicted that the young person would see the benefits of adhering to the self-care regime as outweighing the costs of doing so and adherence to self-care regime was predicted largely by high levels of family support. The final model proposed explained 11.5% of the variance in the young person's adherence to the diabetes self-care regime which was supported by the findings of Aalto & Uutela (1997). Interviews with the young people demonstrated that good metabolic control was characterised by acceptance of diabetes, practical social support and the young person's ability to cope with the day-to-day demands of diabetes as well as responding to changing needs on unique occasions. Young people in poor metabolic control appear to have difficulty accepting the diagnosis and are unwilling to admit to others that they have diabetes. The role of the spouse/partner in the young peoples' lives was cited as important providers of social support. 50 spouse/partner reports were obtained in the last study and the results indicate that the participants with diabetes reported a better quality relationship, more diabetes-specific social support, more life threat due to the diabetes and worse adherence to the diabetes self-care regime than did their partner/spouse. A better quality relationship correlated with high reported levels of diabetes-specific social support which in turn was correlated highly with reported adherence to the diabetes self-care regime for both the participant with diabetes and for the partner/spouse. For male participants with diabetes, relationship quality acts as a mediator between reported diabetes-specific social support and adherence to the diabetes self-care regime.

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Thanks too go to my family and last, and most certainly not least, I dedicate this thesis to Gavin Doyle whose unconditional love has given me the future.

Table of Contents

Tables

Figures

Diabetes

1.1 Definitions of diabetes

On-Line Medical Dictionary (http:// www.graylab.ac.uk/omd/index.html):

Relative or absolute lack of insulin leading to uncontrolled carbohydrate metabolism. In juvenile onset diabetes there may be an auto-immune response to pancreatic cells and the insulin deficiency tends to be almost total, whereas in adult onset diabetes there seems to be no immunological component but an association with obesity.

British Diabetic Association Web-Site (http:// www.diabetes.org.uk/home.html):

A disorder caused by decreased production of insulin, or by decreased ability to use insulin. Insulin is a hormone produced by the pancreas that is necessary for cells to be able to use blood sugar.

1.1.1 Diabetes Mellitus: Type 1

Type 1 diabetes is a form of diabetes which may occur at any age, but is most common in childhood or adolescence. Type 1 diabetes may also be referred to as juvenile onset diabetes or insulin-dependent diabetes. The exact cause of Type 1 diabetes is unknown at present but there is evidence to suggest that there is a genetic marker for diabetes on chromosome 11. The development of Type 1 diabetes is often triggered by viral illness which stimulates the autoimmune system to attack the insulin-producing Islets of Langerhans cells in the pancreas. Type 1 Diabetes Mellitus is characterised by insulin deficiency, sudden onset, severe hyperglycaemia, rapid progression to ketoacidosis and death unless treated with insulin.

1.1.2 Diabetes Mellitus, Type 2:

Type 2 Diabetes Mellitus is characterised by an impaired insulin secretory response to glucose and decreased insulin effectiveness in stimulating glucose uptake by the body. Type 2 diabetes is hereditary and particularly common in certain ethnic groups (Asian, Afro-Caribbean and Pica Indian populations). Insulin resistance is common in all populations and considered a by product of the ageing process. Most people with insulin resistance will not develop diabetes, however, as the body compensates by increasing insulin production. Type 2 diabetes can sometimes be treated with diet and exercise alone, but there are patients who require doses of insulin to maintain good metabolic control. The disease mostly occurs in middle to late adulthood, but there is data to suggest that Type 2 diabetes is starting to appear in adolescence (American Diabetes Association, 2000).

1.2 Prevalence and indicators of diabetes

Diabetes Mellitus affects approximately 2 percent of the population of Britain and is the third most commonly occurring illness in young people after asthma and cerebral palsy (Olsen & Sutton, 1998). The term Diabetes Mellitus refers to a group of metabolic diseases characterised by hyperglycaemia (high levels of glucose in the blood) as a result of defects in insulin secretion, insulin action or both. Long-term hyperglycaemia is a serious problem and can trigger dysfunction and failure of the eyes, kidneys, nerves, heart and blood vessels. Diabetes occurs because there is an autoimmune reaction within the body that causes the destruction of beta cells in the pancreas. This prevents or impairs the production of insulin and consequently the body becomes resistant to the action of insulin, or produces no insulin whatsoever resulting in abnormal carbohydrate, fat and protein metabolism. Often impairment of insulin secretion and defects in insulin secretion and action coexist so it is often unclear which abnormality, if either, is the primary cause of hyperglycaemia (The Expert Committee on the Diagnosis and Classification of Diabetes Mellitus. 2000). There are certain viruses associated with beta cell destruction: congenital rubella, coxsackievirus B, cytomegalovirus, adenovirus and mumps; and there are a few genetic syndromes associated with increased incidence of diabetes: Down's syndrome, Klinefelter's syndrome and Turner's syndrome. However, the vast majority of cases of diabetes occur in otherwise 'healthy' people.

The symptoms of hyperglycaemia include excess urination, cold sweats, weight loss - sometimes with excessive eating and blurred vision. In the medium-term there can also be an impairment of growth, susceptibility to infections and impairment of cognitive functions. The long-term complications of diabetes include retinopathy with potential loss of vision; nephropathy leading to renal failure; peripheral neuropathy causing gastrointestinal, genitourinary and cardiovascular symptoms and sexual dysfunction.

The treatment of Type 1 diabetes aims to improve metabolic control and involves continuous monitoring of blood glucose levels, daily injections of insulin and co-operation with a healthy low-fat/high fibre diet and a moderate exercise regime.

1.3 Genetic factors in diabetes

The major genetic determinant for diabetes appears to be the major histocompatibility complex of chromosome 6 and the minor genetic risk marker is the variable number of tandem repeats in the insulin gene region of chromosome 11 p15.5 (Halminen, Veijola, Reijonen, Ilonen et al., 1996). Although not predicting diabetes completely, genetic factors are involved in Type 1 diabetes susceptibility (Undlien, Bennett, Todd, Akselsen et al., 1995; Bui, Luo, She, McLaren et al., 1996). Diabetes is a complex disease and it is likely that, for this very reason, having the insulin gene only confers the possibility of developing diabetes (Rich, 1995). There is a 4.1kb genomic region spanning the insulin gene (Lucassen, Screaton, Julier, Elliott et al., 1995), a greater influence of alleles 3 and 6 in patients with Type 1 diabetes (Awata, Marsumoto, Urakami, Hagura et al., 1994) and also a greater incidence of dq alpha and beta-heterodimes (Faas & Trucco, 1994). Confirming the notion of genetic propensity for developing diabetes, an increase in incidence of Type 1 diabetes has been observed in populations with a high frequency of susceptible genes (Green, 1996). There is also found, moreover, a higher level of antibodies (>97.5 percentile) for islet cells and auto-antibodies to insulin and other proteins involved in the maintenance of the 'non-diabetic state' in people with Type 1 diabetes indicating that the body's autoimmune system is primed to act against all agents working towards maintaining the 'non-diabetic state' (Bingley, Bonifacio, Williams, Genovese et al., 1997).

Parental transmission is an important factor in childhood development of diabetes. In children with Type 1 diabetes there is a greater transmission of dr4 and dqbl*0302 (alleles found on chromosome 11) from both parents and in particular a greater transmission of dqbl*0302 from the mother (Kockum, Wassmuth, Holmberg, Michelsen & Lernmark, 1994). Tolerance during foetal life to maternal non-inherited human leucocyte antibody molecules may be important to diabetes development (Kockum et al., 1994). Human leucocyte antibodies (hla) are present in the blood flow and are coated in genetic material specific to the antigen. When the hla encounters its specific antigen the two lock together (as would the correct piece of jigsaw to a jigsaw puzzle) and the antibody attacks the antigen, thus preventing the spread of antigens throughout the body. If the antigen is a health-threatening virus, this process is beneficial to the body in preventing spread of disease and the antibody acts as part of the immune system dealing with the presence of threatening foreign bodies in the blood stream. However, in the case of diabetes, hlas exist where their specific antigen could be insulin, the islets of Langherans or even pancreatic tissue and once activated, the antibodies attach to the diabetes-related antigens and proceed to destroy them.

In the US, the insulin gene appears to be transmitted by the father, whilst in the UK it appears to be transmitted by the mother (Bennett, Wilson, Cucca, Nerup et al., 1996). This is an unusual finding and could be explained with regard to genomic imprinting. When DNA is copied from the alleles of the parent (in the case of humans, the alleles X and Y indicate male gender and alleles X and X indicate female gender) to produce gametes (X and Y located within sperm and X and X located within the ova), the copying may not occur precisely and the imperfect genetic code in the gametes produced may result in sections of the DNA being inactive. When the gametes come together, the resultant offspring may receive one set of DNA that is active and one set of DNA that is inactive. When the two sets of DNA combine, for protein production to be enabled, there needs to be both active genes present and if one is inactive, protein production may either not occur or may occur deficiently (Peterson & Saprienza, 1993). For there to be differences in insulin gene transmission as reported by Bennett et al., (1996), there must be something occurring differently in the UK and in the US. Diabetes is affected both by genetics and by environment and it could be that the environmental factors present in the US are affecting the gene copying process in the males more than in the females, whereas in the UK, the environmental factors affecting the gene copying process are having more of an impact on the females than the males.

Mono-zygotic twin siblings are more likely to experience diabetes compared with di-zygotic twin and non-twin siblings. In a study of 404 twin participants concordant for Type 1 diabetes, the age of diagnosis was highly correlated (Fava, Pyke, Gardner & Leslie, 1998). In comparison, in Northern European families where twins are not present, patients with Type 1 and Type 2 diabetes do not appear to share common genetic factors where two or more siblings have Type 2 diabetes (Elbein, Hoffman, Mayorga, Barrett et al., 1997). However, the presence of islet cell antibodies is less predictive of Type 1 diabetes in children in the general population than found in siblings of children with Type 1 diabetes (Knip, Karjalainen & Akerblom, 1998).

1.4 Treatment of diabetes

The immediate goals of treatment are to stabilise the metabolism, restore normal body weight, and eliminate the symptoms of high blood-glucose. The long-term goals of treatment are to prolong life, improve the quality of life, relieve symptoms, and prevent long-term complications through education, careful dietary management and weight control, medication, physical activity, self testing of blood glucose levels, and foot care.

Education

Diabetes education consists of basic principles, called survival skills, and includes: how to recognise and treat low and high blood sugar; how to select the kinds of food to eat and when to eat them; how to administer insulin or how to take oral hypoglycaemic agents; how to test and record blood-glucose and urine ketones; how to adjust insulin, food intake, or both for changes in the usual exercise and eating habits; how to handle sick days; where to buy diabetes supplies and how to store them. Continually updating personal knowledge of diabetes is advised because new and improved ways to treat the disease are constantly being developed. Coates and Boore (1998) investigated the role of education in adhering to the diabetes self-care regime in a population of young people with Type 1 diabetes mellitus. The participants were knowledgeable about diabetes (mean score = 16.6 out of a possible 19 on the Diabetes Knowledge Scale (Dunn, Bryson, Hoskin, Alford et al., 1984)) but good knowledge, although related to adherence, was not directly related to better metabolic control. Although the link between adherence and metabolic control is weak (and discussed later in the thesis), the authors concluded that the effect education has on metabolic control is not direct but influences the development of health beliefs about the vulnerability and severity of diabetes which in turn affect adherence (Coates & Boore, 1998).

Diet

Meal planning includes choosing healthy foods, eating the right amount of food, and eating meals at the right time. With Type 1 diabetes mellitus, consistency in the time meals are eaten and the amounts and types of food eaten is very important to allow food and insulin to work together to regulate blood-glucose levels. If meals and insulin are out of balance, extreme variations in blood glucose can occur. Current recommendations for diet for a person with diabetes are no different to the recomendations for people without diabetes. The days caloric intake must together be composed of 10-20% protein, less than 30% fat (of which less than 10% should be saturated fat) and the remainder from carbohydrates including 20-35 grams of soluble and insoluble fibre (American Diabetes Association. 2000a).

Insulin

People with type 1 diabetes cannot make their own insulin and must take insulin injections every day to survive. People with Type 2 diabetes make insulin, but are not able to use it effectively. People with Type 2 diabetes can survive without insulin injections, but many may take insulin shots to more effectively control blood-glucose levels. Insulin is not available in an oral form and therefore must be injected under the skin using a needle and syringe, or in some cases, an insulin pump. Insulin injections are usually needed from 1 to 4 times per day.

Physical activity

Regular exercise is especially important for the person with diabetes. It helps control the amount of sugar in the blood and helps burn excess calories and fat to achieve optimal weight. Exercise improves overall health by improving blood flow and blood pressure. Exercise also increases the energy level, lowers tension, and improves the ability to handle stress (Lasker, 1993). The long term effects of exercise are as important in the person with diabetes as in the person without diabetes by reducing blood lipid levels and improving cardiovascular performance whilst reducing risk of atherosclerosis and reducing blood pressure (American Diabetes Association. 2000b).

Self-testing

Blood-sugar testing or self monitoring of blood glucose is done by checking the glucose content of a small drop of blood. The testing is done on a regular basis and informs the person with diabetes how well diet, medication, and exercise are working together to control diabetes. The results can be used to adjust meals, activity, or medications to keep blood-sugar levels within an appropriate range. Testing helps to identify high and low blood-sugar levels before serious problems develop.

Glycosylated Haemoglobin (HbA_{1C}*) Readings*

Metabolic control is measured in terms of the person's glycosylated haemoglobin (HbA_{1C}) levels. Following digestion of a meal, excess glucose is released into the blood stream. The pancreas is stimulated to produce insulin to counteract this release of glucose and to restore blood glucose to the normal level of 6.01%. In a person with diabetes the production of insulin is impaired or non-existent and the levels of glucose in the blood rise unchecked. When the blood glucose levels reach a maximum level the kidneys take over and release the glucose into the urine. The person with diabetes injects insulin to reduce the amount of glucose in the blood to levels matching those of a person without diabetes (6.01%). To measure the blood glucose levels a blood sample is taken every two to three months and the level of glucose present in the red blood cells measured. Red blood cells have an average life span of three to four months and during that time the cells will absorb any excess glucose present in the blood stream. The amount of glucose absorbed by the blood cells over the few months is affected by insulin production in a person without diabetes and by insulin injection in a person with diabetes. The amount of glucose absorbed by the red blood cells is called the glycosylated haemoglobin level and although the reading for a person without diabetes is 6.01%, a reading between 5 and 8% in a person with diabetes is considered to indicate good metabolic control. A reading below 5% indicates the person is approaching a state of hypoglycaemia and a reading above 8% indicates the person is approaching a state of hyperglycaemia. The glycosylated haemoglobin reading differs to the daily blood glucose test reading in that it offers an 'average' metabolic control report for the past few months.

1.5 Implications of metabolic control

Attaining good metabolic control appears to have a health protective effect. The Diabetes Control and Complications Trial demonstrated the effect of an intensive treatment regime compared with a conventional treatment regime in a longitudinal study on a large population with diabetes. The aim of the intensive treatment regime was to attain and retain an HbA_{1C} reading between 5 and 8%. The conventional treatment regime provided the clinic's regular care. In the cohort without any sign of diabetes-associated complications, risk of developing retinopathy was reduced by 76% and neuropathy was reduced by 60% (Diabetes Control and Complications Trial Research Group, 1993). These effects were also seen in the cohort with mild diabetes-associated complications at the start of trial with a 47% reduction in development of severe retinopathy indicated. In both groups, a 10% lower Glycosylated Haemoglobin reading (HbA_{1C}) was associated with a 43-45% lower risk of retinopathy. Importantly, there was also found no significant difference in quality of life in patients in either the intensive treatment group or the conventional therapy group even considering the complexities of following the intensive treatment regime (DCCT Research Group, 1996).

1.6 Diabetes Control and Complications Trial (DCCT)

1.6.1 DCCT: The trial

The Diabetes Control and Complications Trial Research Group was set up in 1986 to conduct the first large scale multi-centre longitudinal study examining the effects of two different diabetes treatment regimes on the appearance and progression of complications associated with this disease. The Research Group published at every stage of this ambitious project and invited comment on their findings and recommendations. The selection criteria were discussed (DCCT Research Group, 1987b), as were the Quality of Life measures (DCCT Research Group, 1988) and other biomedical measures of blood glucose levels and electrolyte levels (DCCT Research Group, 1987a). 1441 patients were monitored for between 5 to 10 years, with a median of 7 years at the study's end in 1996 and were divided into two groups - a primary prevention group and a secondary intervention group. Patients in the primary prevention group had diabetes for more than one year and less than five, and had no evidence of retinopathy or other complications. Patients in the secondary intervention group had background diabetic retinopathy, had diabetes for one to fifteen years and were otherwise in good general health.

1.6.2 DCCT: Intensive versus conventional treatment regime

The participants of the primary prevention group and the secondary prevention group were randomly assigned to either of two treatment regimes - conventional therapy or 'intensive' therapy. The conventional therapy group were given standard diabetes education and nutrition information and basic advice on insulin administration. This information was not standardised, but was whatever the normal standard was in each clinic or research centre. The participants were instructed to inject insulin as normal - once or twice a day, test blood glucose once a day and to attend follow-up appointments every three months. The patient goals were to cease any symptoms of hypo or hyperglycaemia, to have no ketones in the urine and to maintain normal growth and development. There were no predefined targets for blood glucose levels and the insulin dose was not varied in response to the results of blood glucose testing unless the HbA_{1C} result was greater than 13.1%.

In the conventional therapy setting the dietician tailored meal plans to the needs and lifestyle of each individual with the goal of achieving or maintaining 90-120% of the patient's body weight. Physical exercise programmes were not required, but exercise was encouraged and advice given on adjusting insulin doses and diet change if the participant required.

In the intensive treatment regime, the goal was to achieve and maintain a blood glucose level as close to the non-diabetic range as possible without experiencing severe hypoglycaemia. Insulin was administered either by continuous subcutaneous insulin infusion (CSII pump) or with multiple (three or more) daily injections. Blood glucose was tested at least four times a day - before meals and before going to bed, and participants were asked to test at 3:00am once a week. Participants were closely monitored until they were comfortable with their regime and contact was maintained monthly throughout the study. The dieticians kept close contact with the patients in the intensive treatment group and in-depth individual meal plans were developed and provided. Guidance was also given on responding to low blood glucose levels, coping with activity and change in food intake. Exercise regimes were not provided, but the patients were taught to adjust their insulin dosages. Attempts were made to improve adherence by including motivational programmes, rewards for achieving goals and organised group activities within the study programme.

Outcome measures were HbA_{1C} readings as the principle measure of metabolic control, weight and height measurements, ketoacidosis was monitored by the level of ketones in urine, severe hypoglycaemia was described as episodes which required hospitalisation or the assistance of another person where the blood glucose level was found to be <50mg/dl, and catheter infections was described as any infection at the site of an insulin infusion catheter that required antibiotic treatment and/or surgical intervention.

1.6.3 DCCT: Main outcomes of the trial – physiological impact

The outcome of the trial can be divided into two areas - improvements and impairments in function. One of the main questions asked by the DCCT was whether following an intensive treatment regime would have any effect on the development and progression of long term complications associated with diabetes. Over the period of the study, patients in the primary-prevention cohort adhering to the intensive treatment regime reduced the risk of developing retinopathy by 76 % as compared to the conventional therapy group. In the secondary cohort already displaying some retinopathy at the start of the study, the patients adhering to the intensive treatment regime reduced the development of more severe retinopathy by 47%. With both cohorts combined, those adhering to the intensive treatment therapy reduced the occurrence of microalbuminuria by between 39% and 54%, and clinical neuropathy by 60% (Diabetes Control and Complications Trial Research Group. 1993). In each treatment group, mean HbA_{1C} during the trial was the most significant predictor of retinopathy progression. A 10% reduction in HbA_{1C} in both groups was associated with a 43-45% lower risk of retinopathy. Duration of Type 1 diabetes had a significant effect in the conventional therapy group with those having Type 1 diabetes for longer being at greater risk of developing retinopathy (31% increase per year), whilst there was no change in risk in the intensive therapy group (DCCT Research Group, 1995a). Similar effects were also found for the subgroup of adolescents (aged 13-17 years) taking part in the study. Those in the intensive treatment group demonstrated a 53% reduced risk of developing retinopathy (Cohen's $d = .45$, $N = 195$), a 70% reduced risk of developing severe retinopathy (Cohen's $d = .54$, $N = 195$) and a 55% reduced risk of microalbuminuria (Cohen's $d = .45$, $N = 195$) (DCCT Research Group, 1994).

The main impairment suffered by the patients in the intensive therapy group was an increased incidence of severe hypoglycaemic episodes. 65% of the patients in the intensive therapy group had at least one episode of hypoglycaemia compared with 35% of the conventional therapy group and the overall rates of hypoglycaemia were 61.2 per 100 patient years in the intensive therapy group and 18.7 per 100 patient years in the conventional therapy group (DCCT Research Group, 1997). The intensive therapy group experienced a 73% greater risk of becoming overweight

(Cohen's $d = .63$, N = 195)(DCCT Research Group, 1995b) and the relative risk for coma and/or seizure for patients in the intensive therapy group was twice that of the conventional therapy group controlling for baseline patient characteristics (DCCT Research Group, 1997). Particularly at risk were several subgroups of participants including male patients, adolescent patients and patients with a prior history of hypoglycaemic episodes. The adolescent subgroup of the intensive therapy group were three times as likely to experience severe hypoglycaemia (Cohen's $d = .63$, N = 195) (DCCT Research Group, 1994). Experience of prior glycaemic episodes was the strongest predictor of risk of further episodes even when adjusted for current HbA_{1C} (DCCT Research Group, 1997).

1.6.4 DCCT: Main outcomes of the trial – psychological impact

Quality of life measures were taken annually to assess the impact on the patient of the intensive diabetes treatment regime. Of all the patients taking part in the DCCT, 99% completed the study and >95% of tests were completed. At the end of the trial, there was found no significant difference in quality of life in patients in the intensive therapy group or in the conventional therapy group, indicating that patients undergoing intensive treatment regimes perceive no reduction in their quality of life even taking into account the complexities of the regime (DCCT Research Group, 1996).

1.6.5 DCCT: Summary of Main Findings

To summarise the findings of the Diabetes Control and Complications Trial, all participants demonstrating a 10% reduction in HbA_{1C} nearly halved the risk of developing eyesight deterioration. Those participants in the intensive treatment group more than halved their risk of developing eyesight problems and nearly eliminated their risk of experiencing rapid extreme eyesight deterioration in those participants starting the study with slight retina deterioration. The participants in the intensive treatment group also more than halved their likelihood of experiencing problems with the performance of their kidneys (as reflected by their reduced microalbuminuria levels) and reduced their likelihood of experiencing problems related to poor blood circulation (losing sensation in fingers and toes, poor healing of foot ulcers leading to possible amputations) by two-thirds. This all points to a dramatic improvement in health outlook for the participants.

The downside to the improved health and improved health outlook for the participants in the intensive treatment group was the increased experience of hypoglycaemia (low blood sugar levels) and weight gain. Although minor low blood sugar does not impair physical health and can be treated with ingestion of fast-acting carbohydrates, severe low blood sugar can place the body in hypoglycaemic coma requiring hospital treatment to raise blood sugar levels. The relative risk for experiencing low blood sugar levels severe enough to require hospital care was twice that in the intensive treatment group compared to the conventional treatment group. In particular, male adolescent participants of the intensive treatment group were more likely to experience severe hypoglycaemic episodes, but the main predictor for experiencing severe hypoglycaemic episodes in the intensive treatment group was previous experience of severe hypoglycaemic episodes and may reflect individual differences in the experience of diabetes and responsivity to the treatment programme for diabetes.

Unfortunately, daily experience of hypoglycaemia and moderate to large weight gain is likely to discourage people from following the intensive treatment regime. However, the experience of adhering to the intensive treatment programme, even with the increased incidence of hypoglycaemic episodes had no impact on the participant's perceived quality of life and when the health benefits of adhering to the intensive treatment programme are taken into consideration, implementing an intensive treatment programme is considered beneficial to people with diabetes.

1.7 Diabetes, Health and the Psychological Impact on the Young Person

Diabetes is a chronic, life-long condition with a complex treatment regime and severe possibility of diabetes-related health complications. The treatment is mulitfaceted and the person with diabetes must develop an understanding of their illness, develop skills to monitor and treat themselves and have an understanding of the implications of their diabetes. Currently there is no cure, although promising research into islet cell transplantation is ongoing, and once diagnosed the person (and often the whole family) has to adapt quickly both to survive in the short term and to prevent the development of long-term complications.

Good adaptation to diabetes and improved metabolic control has been associated with health beliefs related to the diabetes (such as perception of severity and vulnerability to diabetes and the long-term complications associated with diabetes) (Coates & Boore, 1998), health locus of control beliefs (Roth, 1999) and confrontive, supportive, optimistic and self-reliant coping strategies (Willoughby, Kee, Demi & Parker, 2000). It is therefore important to understand how a person develops their interpretation of what it is to be healthy and what it is about their health and illness beliefs that has a positive impact on diabetes metabolic control.

This thesis aims to consider these issues in diabetes and specifically investigates these in young people aged 16 to 25 years of age. People this age are experiencing a lot of change in their lifestyles (leaving home, starting new jobs or going to University, starting families of their own), the demands of the diabetes regime are still present and it can be difficult to balance the demands of a changing lifestyle with the demands of caring for themselves with a view to the long-term (and preventing diabetes-related complications of health). By understanding what young people believe about their health and diabetes, the issues related to metabolic control and adhering to the diabetes self-care regime in young people can be explored more thoroughly.

Health

2.1 Definitions of health

Definitions of health began by focusing on physical aspects and on the prevalence of germs or the absence of physical ailment (Millstein & Litt, 1990). However, current thinking looks at health as taking into account body, mind and social factors. According to Gochman (1988), a definition of health should incorporate three factors: the biological aspect of health; the social roles individuals are expected to perform and the psychological aspects such as an individual's attitudes and perceptions. As such, personal experience as well as cognitive factors may predict one's feelings of health. There are two further issues of health - first that one is responsible or in control of one's health, and second that of health as a biopsychosocial model.

2.1.1 Health Locus of Control

The notion that one is responsible or in control of one's health is called the Health Locus of Control (Wallston, Wallston & DeVellis, 1978). Those with internal locus of control believe that they are in control of their illness and are largely responsible for what happens to them health-wise. Those who have external locus of control tend to believe that illness and health is largely a result of external factors such as un-preventable catching illness from others. The issue of locus of control is discussed in more detail with respect to health models later in the chapter.

2.1.2 Biopsychosocial model of health

The biopsychosocial model interprets health within physical, psychological and sociological constructs (Engel, 1977) rather than within a pure biological medical model. Engel argues that the boundaries between 'wellness' and 'illness' are diffuse and cannot therefore be delineated with the medical model. Health and illness are determined by multiple causes that interact with each other and an accurate diagnosis cannot be made without contemplation of all causes. Consequently, change in one aspect of health is likely to have an impact on the other aspects - so change in psychological health is likely to impact on physical health and sociological health, for instance stress at work will impact on the physical health (eg sleeplessness, raised blood pressure) and on sociological health (eg partnerships, work relations) (Schwartz, 1982). Many health models used in research into health attitudes and behaviour incorporate the fundamental principles of the biopsychosocial model and are described in more detail later in the chapter.

2.2 Source of health beliefs

Older children and young people have very firm beliefs on what 'being healthy' means (Millstein & Litt, 1990). It is described as living up to one's potential; being able to function physically, mentally and socially; and experiencing positive emotional states. Two potential sources of health beliefs may explain these beliefs: first, the process of 'enduring family socialisation' where one's health beliefs are learned solely from the family environment through imitating beliefs and behaviour; and second, the processes of 'Lifelong Openness' during which a persons' peers and friends influence the learning of health beliefs and behaviours (Lau, Quadrel & Hartman, 1990). Lau, Quadrel & Hartman conducted a longitudinal study that tested 'enduring family socialisation' and 'lifelong openness' on the development of health beliefs and behaviours of young people from adolescence over three years into adulthood. Parents and young people completed questionnaires on the performance of a range of preventive health behaviours and were asked how effective they thought those behaviours were. The parents were also asked about their efforts in training the young people to perform these behaviours. The results showed, however, that as stand-alone models, neither enduring family socialisation or lifelong openness is particularly robust. Parents do appear to play an important part in the socialisation of young people's health beliefs, but their influence is not strong. Peers were found to have some influence, particularly if and when the young person went to college or university but again, the influence was not strong. As a result, the authors proposed the 'windows of vulnerability model'. In this model, the family plays an influential part in the development of health beliefs and health behaviour except during 'critical periods' of vulnerability. During these periods, for instance during adolescence, when leaving home or when setting up ones own home, the peer and friend group plays a large and important part in the process. The beliefs and behaviours learnt within the family system may be refined or lost dependent on the beliefs and behaviours of the peers in interaction with the young person or young adult. The period of adolescence in particular, is noted for being a period of health risk, and is considered a time when the young person is striving to achieve their personal identity and when they are potentially open to experimentation with behaviours different to the behaviours learnt within the home and family (Jessor, Donovan & Costa, 1991).

2.3 Development of Illness Beliefs

There is a strong developmental basis to illness beliefs (Campbell, 1975). A review of the cognitive-developmental literature (Burbach & Peterson, 1986) concluded that illness beliefs are strongly linked to life-span developmental processes. Cognitively mature children are more aware of the relationships between psychological, social and affective aspects of disease and are more aware of internal cues when determining illness than younger children. Older children are also more likely to feel that they have control over their illness and the healing process whereas younger children are more reliant on external cues and are more likely to view illness as an outcome of their bad behaviour and to interpret the illness as a form of punishment. This account of the change in conceptualisation of health and illness in more cognitively mature, rationally-thinking children is due to the older children functioning at the formal operations stage rather than the concrete operational stage of development and therefore using their increased powers of abstract reasoning in their interpretation of health and illness (Santrock, 1990). Older children are more able to view their illness in terms of having multiple causes when compared to the more simplistic and less sophisticated beliefs of younger children (Millstein, 1991).

2.4 Theory of Psychosocial Risk.

The Theory of Psychosocial Risk asserts that there are a range of factors which may predispose some young people to engage in problem behaviour and that some of these problem behaviours may have a direct effect on health status (Kagan, 1991). These factors can be 'Social Background' factors, for example the young person's educational level, family composition and experience of negative and positive life events; 'Social Psychological' factors, for example the young person's personality as defined by their values, beliefs and personal control, alongside the young person's perceived environment (parental control, role of social models and peer approval); and 'Behavioural System' factors defined in terms of both problem behaviours, for instance drug taking and smoking, and conventional behaviours, attending school, and adherence to a 'healthy diet'. In interpreting this model with a view to understanding why certain young people are more prone to engage in problem behaviours three behaviours were identified as sexual activity resulting in unplanned pregnancy, crime and drug taking. The five groups of young people at most risk for these behaviours were those who had experienced chronic school failure and those where the family environment was characterised by indifference, abuse and neglect ('social background'); those who were considered vulnerable to peer values and peer persuasion, those where there was a need to prove they are not fearful of risk; and finally those who live in families where stealing, drug use and pregnancy is acceptable behaviour ('social psychological' factors), (Kagan, 1991).

2.5 The Young Person's Perception of Risk

The concept of risk in adolescence has been investigated by a number of researchers. Elkind (1967) argued that young people have a certain egocentrism, that is they perform to an imaginary audience where the young person is the centre of attention. According to Elkind, the young person experiences life as a personal fable - they are special and experience events in a uniquely intense way. To this end, the young person tends to view him or herself as unique and invulnerable to risk. However, there appears to be only partial support for this point of view. Quadrel, Fischhoff and Davis (1993) tested this invulnerability hypothesis among groups of low-risk teenagers, their parents and high-risk teenagers from juvenile centres. Each participant was asked to evaluate their risk from eight possible adverse events – four of which were considered high in controllability (eg unplanned pregnancy) and four were considered low in controllability (eg exposure to radiation). Each event was also evaluated for an acquaintance and a friend, and in addition, the parents rated their teenagers and the teenagers rated their parents. The results showed that the adults rated themselves as equally vulnerable to risk as the acquaintance and friend. When the highly controllable events were compared with the less controllable events, the adults were more likely to perceive themselves as less vulnerable to the highly controllable events than the low-risk and high-risk teenagers (34.5%, 35.9% and 41.5% respectively), and when the parents and teenager scores were compared, the parents still exhibited higher scores of invulnerability to the risk events. The authors concluded that there was little support for the 'adolescent invulnerability' hypothesis.

A more detailed study examined the perceived costs and benefits of alcohol use and sexual behaviour in both male and female young people (Small, Silverberg & Kerns, 1993). Those young people who were non-sexually active and non-alcohol using perceived the costs of these behaviours to be far greater than did those who were engaging in the behaviour. Girls generally perceived a greater cost in both alcohol use and sexual behaviour, and older young people perceived fewer costs in both behaviours. Therefore, it would seem reasonable to conclude that the relationship of risk to behaviour is not a simple one and is indeed one that is affected by the young person's gender, age and degree of participation in the behaviour.

2.6 Health Behaviour and Health Status

The link between health behaviour and health status is difficult to extract. It has been argued that the health behaviour and health status must be conceptualised and measured accurately for the link between health behaviour and status to be demonstrated and tested (Bennett Johnson, 1994). For instance, patients undergoing antihypertensive drug therapy, only half (54%) of the participants fell into the categories where they demonstrated good health behaviour and showed a subsequent good health outcome, or conversely demonstrated poor health behaviour and then showed a subsequent poor health outcome (Taylor et al., 1978). More interestingly, 34% fell into the category of demonstrating good health behaviour but showed subsequently poor health outcome - indicating that their health behaviour had little or no effect on outcome.

In young people with diabetes, a similar effect of health behaviour on subsequent health outcome has been demonstrated (Bennett Johnson, 1994). In this study, 58% fell into good health behaviour/good outcome and poor health behaviour/poor outcome categories whilst 18% demonstrated good health behaviours yet still showed subsequently poor health outcome (Cohen's $d = .35$, N=103). This study raises the question of adherence with the health regime if 18% of the participants exhibited poor health outcome.

2.6.1 Adherence in health care

Adherence in health care could be defined as 'the extent to which a person's behaviour (in terms of taking medication, following diets or executing life style changes) coincides with medical or health advice.' (Haynes, Tyler & Sackett, 1979). As such, the patient's health behaviour is a function of how well the provider communicates what health behaviours are desired, the patients level of understanding of or skill at performing those health behaviours, the patient's motivation to comply and the patient's health beliefs. If the patient does not know what to do, s/he cannot do it, and conversely if the patient does know what to do, s/he needs the skills in order to carry out the behaviour. If the patient is motivated to comply, s/he is more likely to comply (Rogers, 1984). If the patient exhibits health beliefs as well as an internal health locus of control, the patient will also be more likely to comply (Wallston, Wallston & DeVellis 1978). It is important, however, to take into account that some people may not comply because they simply failed to remember to do so.

2.6.2 Patient skill and knowledge

Remembering the health advice given is particularly important in patients with diabetes. One study has shown that patients recalled only 18% of advice from their health provider and actually incorrectly recalled 40% of advice which the providers subsequently claimed had not been given to them in the first place (Page et al., 1981). Not only is there an issue of remembering the advice given, but also health providers need to learn to communicate more effectively or the patients will remain non-adherent. Patient skill and knowledge is particularly important in people with diabetes. The regimens involve knowledge of drugs and illness combined with complex timing and method of administering these drugs. Skill deficits in adults and children often go unrecognised by the patient or provider (Epstein, Figueroa, Farkas & Beck, 1981; Johnson, Pollak, Silverstein, Rosenbloom et al., 1982). In fact, the patient may believe s/he is performing the tasks correctly yet significant errors may be present when the patient is observed performing the task. In this situation, inadvertent non-adherence occurs as a result of insufficient skill and knowledge (Sergis-Deavenport & Varni, 1983). When working with young people with diabetes it is important to note that the relevant skills and knowledge are developmentally related. Younger children have fewer skills and knowledge to apply to the intricacies of the diabetes treatment regimen than older children and therefore need closer monitoring to develop good skills and knowledge to prevent long-term continuous incorrect task performance (Johnson et al., 1982; Gilbert et al., 1982).

2.6.3 Effectiveness of treatment

Linked to the concept of health status is the effectiveness of treatment. The more effective the treatment, the better the link between health behaviour and status even when perfect adherence is not necessary for optimal benefit (Bennett Johnson, 1944). There is a behavioural threshold to the link as a minimal amount of health behaviour is required before any impact on health status can occur. The level of treatment given also influences the relationship. A positive relationship between health behaviour and status can only occur if the correct level of medication is given however perfect the adherence - too little medication and the health behaviour will not elicit a good outcome, and conversely, too much medication and the health behaviour will not elicit a good outcome (Bennett Johnson, 1994).

2.6.3 Importance of health status

It has been argued that health status may not actually be so important (Kaplan, 1990). Health status may only be meaningful when related to morbidity (or dysfunction) and mortality (or death). Kaplan argued that both are actually quality of life outcomes rather than health outcomes and as such there is a need to know which behaviours are important to daily functioning rather than to projected long-term health outcomes. Certain health behaviours may not predict, for example, blood glucose levels in the patient with diabetes, but may influence the number of sick days that person takes, the number of hospital stays and perhaps performance at school.

2.7 Health Issues and Young People

A project commissioned by the Health Education Board for Scotland in 1994 investigated young peoples' perceptions of their own health needs (Schucksmith & Hendry, 1998). The qualitative study included both a literature review of existing data examining young person health issues as defined by adults, and a preliminary study of ten focus group discussions (comprising five or six people in each) to establish an initial agenda of young people health concerns. This was followed by 44 individual qualitative interviews to explore the issues raised in the initial discussions. The findings of the study mostly related to body image, appearance and weight which in turn was linked to the young people's concerns about their attractiveness and popularity. These concerns were expressed more extremely by the girls in the sample, but were also major concerns of the boys. Other concerns were parental control and supervision, leisure life and association with peers.

2.7.1 Parental control and supervision

The concerns of parental control and supervision directly influenced the readiness of the young person to undertake health risk activities. Whatever the social and cultural background of the young person, the young people would make their own choices in terms of health risk behaviours, but the list of choices was restricted according to structural constraints - their localised cultural development and norm-setting process. Norm-setting was related to social class and built environment - patterns of housing and planning impacted on the young people's general behaviour and health behaviour through the provision of leisure space and policing of activities by other community members.

2.7.2 Family influences

Family influences were strong in the group of young people interviewed. On the whole, the young people felt that they could talk to one or other parent about high risk issues such as sex, drugs, alcohol and smoking, but some were unable to speak to their parents at all. In those families where the young people felt that they could talk to one or other parent, the parents adopted a strategy of using news stories and relating them to the young person in their own terms. In this way, setting boundaries before any risk activity could take place.

2.7.3 Peer influences

Peer influences were important to the young people. Their relationships with peers and friends were crucial to adoption or otherwise of health-related behaviours. The peer networks provided important opportunities for practising new behaviours and developing the necessary social skills for interactions with same-sex and opposite-sex friends (Adams, 1983). These interactions develop skills in three areas of growth in social skills: firstly, by learning to adopt the appropriate emotion and behaviour in various social contexts (social knowledge); secondly, by learning to express empathy with others; and thirdly, by believing in the power of self-initiation. Acceptance to these networks was not an arbitrary process, acceptance had to be earned by conforming to the group norms of fashion, dress, personal appearance, musical tastes and leisure activities (Schucksmith & Hendry, 1998).

2.8 Health Issues and Diabetes

All these issues are relevant and important to the young person with diabetes. Peer influences and parental support will help the young person to balance the demands of living with diabetes with the demands of being a social young adult. The increasing effectiveness of the treatments available for diabetes combined with the increasing ease of use of blood glucose testing and insulin injecting equipment should help with the practical issues of adherence, whilst an increased understanding of the complex psychological issues surrounding diabetes should improve the ability of the researcher to gauge the impact diabetes has on the young person. Studies investigating the psychological impact of diabetes on the young person are discussed in greater detail in the next chapter.

Psychology and Diabetes

3.1 Psychosocial factors and diabetes

3.1.1 At diagnosis

At diagnosis, there are no significant differences in self-esteem, behavioural symptoms, or social functioning between children with newly diagnosed diabetes and children with other acute medical problems (Johnson et al., 1982) but around two thirds of children do exhibit mild symptoms of sadness, feelings of friendlessness, and social withdrawal. Mothers who demonstrated most distress immediately after diagnosis were more likely to remain emotionally upset over a long period of time following diagnosis (Kovacs, Goldston, Obrosky & Bonar, 1997). In the two years immediately after diagnosis, increased feelings of anger, depression and hostility in young people with diabetes are common as well as an increase in negative life experiences and psychiatric distress (Rubin & Peyrot, 1992).

3.1.2 Eating Disorders

During adolescence there is a particular problem of eating disorders, especially bulimia nervosa. A figure of around 30-40% of women with diabetes manipulate their insulin to promote weight loss or avoid weight gain, and there is a strong relationship between eating problems and poor adherence to non-diet aspects of the diabetes regimen (Rubin & Peyrot, 1992)

3.1.3 Stress

High levels of stress are associated with poorer glycaemic control in both adults and young people (Bradley, 1988). Why this is, is difficult to ascertain. It could be that stress affects glycaemic control by triggering a physiological state of arousal which in turn affects the output of certain counter-regulatory hormones. Alternatively, it may be that stress affects glycaemic control indirectly by disrupting the self-care routines, which in turn influence glycaemic control (Rubin & Peyrot, 1992). There appears to be no conclusive answer arising from the research literature at present and this may be clarified in the future. However, there is a certain amount of research investigating the effect stress-management training has on metabolic control and stress management training is offered as part of routine education packages for people with diabetes in the US (Bradley, 1994). Relaxation techniques have been shown to be beneficial for people experiencing poor metabolic control in conjunction with high levels of stress. Twenty minutes of relaxation can reduce blood glucose levels by up to 3 mmol/l in patients with HbA_{1C} levels above the normal 4-6 mmol/l (Bradley, 1994).

3.2 Social support and diabetes

The treatment regime for diabetes is very difficult to maintain especially for young people undergoing a series of social, psychological, emotional and physiological changes (Cerreto & Travis, 1984; Sills & Rapaport, 1994). Young people often feel forced to choose between adhering to their regimen or being a 'normal' young person. Young people with Type 1 diabetes tend to see the demands of adolescence as being more important than those of the disease and changes in family and peer relationships, which are common during adolescence, make managing diabetes even more complex. Family members provide more tangible support for regimen adherence and friends provided more emotional and companionship support. For older young people (aged 14-18 years), friends also provide assistance in the day-to-day management of diabetes. Friends begin to provide much of the emotional and social support that the family once provided, but the family still plays an instrumental role in the young person's life (La Greca, 1992).

3.2.1 Peers and friends as providers of social support

Peers and friends are an important source of emotional support for young people with diabetes (Meldman, 1987; La Greca, Auslander, Greco, Spetter et al., 1995) with friend support significantly related to adherence and metabolic control. The social support provided by peers and friends can be both structural and functional. Structural components include both sources of support (eg family, friends etc) and the density of this social network (eg extent to which members know one another). Functional components include many qualitative characteristics of these relationships (eg type of help provided, perceived helpfulness, communication effectiveness and cohesiveness). In diabetes, having a cohesive, supportive family is related to better cohesiveness). In diabetes, having a cohesive, supportive family is related to better adherence and metabolic control in young people (Anderson, Miller, Auslander & Santiago, 1981; Hauser, Jacobson, Lavori, Wolfsdort et al., 1990) and young people whose parents provide more diabetes-specific support exhibited better adherence behaviour than young people whose parents are less supportive of their child's regimen behaviours (Hanson, Henggeler & Burghen, 1987b; Hanson, DeGuire, Schinkel, Henggeler & Burghen, 1992). Supportive communication patterns have also been associated with better adherence and metabolic control (Wysocki, 1993; Bobrow, Avruskin & Siller, 1985).

3.2.2 Family members as providers of social support

Adjustment to diabetes is associated with family characteristics (Drotar, 1997). With young people from more supportive and cohesive families demonstrating better metabolic control and adherence (Burroughs, Harris, Pontious & Santiago, 1997). The presence of both family and friend support is predictive of better psychological outcomes (Wallander & Varni, 1989); reduced peer support, but not reduced family support, is associated with higher levels of both internalising and externalising behaviour problems in young people with Type 1 diabetes (Varni, Babani, Wallander, Roe & Frasier, 1989).

3.2.3 Age and gender differences in social support provision

In a study investigating age and gender differences in social support provision, Skinner & Hampson (1998) measured adherence to diabetes self-care tasks, social support, depression and anxiety in 74 young people (Mean age 15.14, SD 2.19). On the whole, older young people (aged 14-18 years) reported less support for dietary self-management than younger (aged 12-14 years) young people ($r=-.23$, $p<.05$). Girls reported higher levels of depression and anxiety but better dietary management and more support from friends. General family support was a significant predictor of perceived efficacy of the treatment regimen in controlling diabetes, and this perceived efficacy of the treatment regimen in controlling diabetes at least partially mediates the link between social support and dietary self-management (Skinner & Hampson, 1998).

3.2.4 Social support and metabolic control

Young people in good control report more cohesion and less conflict among family members; their parents encourage them to behave independently, express their feelings directly and act openly. Young people in good control may also describe family members as more committed, helpful and supportive of each other than young people in fair or poor control. In contrast, young people in poor control report that they are treated differently to their siblings and that family members are critical, distrustful or indifferent about their diabetes management (Anderson et al., 1981). However, further research has found that the longer the young person has lived with Type 1 diabetes, the weaker the association between family cohesion and disease control (Hanson, DeGuire, Schinkel & Kolterman, 1995; Hanson, Harris, Relyea, Cigrang et al., 1989; Kovacs, Goldston, Obrosky & Iyengar, 1992). One explanation for this may be that during adolescence, as the nature of family support goes through a period of transition, what is effective social support for a 12 year old young person will undoubtedly be qualitatively different from effective support for a 16 year old. High levels of general family affection, high levels of illness-specific family support, and low levels of illness-specific family non-support have been shown to predict the young person's general psychosocial adaptation. Families with high levels of disease-specific support are also high in flexibility and affection (Cohen's $d = .77$ and .63 respectively, N =157) (Hanson, DeGuire, Schinkel & Kolterman, 1995).

3.2.4 Social support and adherence to self-care regime

The effect of social support and other psychosocial variables on metabolic control appears not to be direct but instead mediated by regimen adherence. Social support has been found to influence metabolic control through regimen adherence, but chronic life stress has been found to have a direct link to metabolic control (Cohen's $d = .41$, N= 93) (Hanson et al., 1987b). The authors concluded that young people must develop certain basic skills to protect themselves from stress injury and these basic skills are best developed in the context of a supportive family. However, this has not always been found to be the case. Older young people with the strongest self-concepts, the most social support, the most knowledge about Type 1 diabetes and the fewest life stressors have been found to adhere the least well and have the poorest metabolic control (DCCT Research Group, 1994). Thus, the link between social support, adherence and metabolic control appears to be unclear.

3.3 Young people, developmental issues and diabetes

It is important to investigate the effect having Type 1 diabetes has on young people from a developmental perspective. The issues of self-care tasks and the treatment regime are complex and the impact of this in childhood and adolescence can be quite considerable (Grey, Kanner & Lacey, 1999). Grey et al., looked at this within the theoretical framework of Erickson's stages of Child Development (Erickson, 1968). Although diabetes is rare in infants and toddlers, the principles of child development can still be applied, for instance, the infant may have difficulty learning to trust, for example, when he or she is being injected with insulin and is being tested for blood glucose levels every day. The school-age child, the second most common period for diagnosis, may suffer feelings of inferiority if their diabetes interferes with their achievement at school, and the young person, whilst struggling to become autonomous and independent from their parents and other adults often exhibit less than ideal adherence to their medical regimen. Young people experience many social, psychological, emotional and physiological changes (Sills & Rapaport, 1994; Cerreto & Travis, 1984) and those with Type 1 diabetes tend to see the demands of adolescence as being more important than those of the disease regimen and changes in family and peer relationships, which are common during this period, make managing diabetes even more complex (La Greca, 1992).

Within the period of adolescence, the effect having diabetes has on a young person varies across age and gender (Hanna & Guthrie, 1999). Hanna & Guthrie found women were more likely to report significantly higher levels of diabetes mismanagement, and both men and women aged 18-24 years were more likely to report significantly higher levels of health compromising behaviours than their younger counterparts. However, every person reacts differently both to the diagnosis and the responsibility of diabetes and the issue of individual differences cannot be ignored.

3.4 Young people, psychosocial issues and diabetes

3.4.1 Body image, appearance and weight

The psychosocial issues of young people without a chronic illness are mostly related to body image, appearance and weight which in turn appear to be linked to concerns about their attractiveness and popularity (Schucksmith & Hendry, 1998). Parental control and supervision concerns directly influence the readiness of the young person to undertake health risk activities, but peer influences are important too and relationships with peers and friends are crucial to adoption or otherwise of health-related behaviours.

3.4.2 Following diagnosis

The psychosocial aspects of young people with diabetes are just the same as for those young people without diabetes, but the period immediately following diagnosis can be particularly difficult (Rubin & Peyrot, 1992). As mentioned previously, Kovacs, Iyengar, Goldston, Stewart et al., (1990) found that two thirds of young people responded to diagnosis with mild symptoms of sadness, feelings of friendlessness and social withdrawal. However this is not always the case, Jacobson, Hauser, Laroni, Wolfsdorf et al., (1990) found no significant differences in self-esteem, behavioural symptoms, or social functioning in newly diagnosed young people. Family stress appears to have a highly significant negative effect on HbA_{1C} levels at diagnosis ($r = 0.554$, $p<.001$), but family support had no significant effect at this time (Viner, McGrath & Trudinger, 1996).

3.5 Young people, social support and diabetes

In diabetes, having a cohesive, supportive family is related to better adherence and metabolic control in young people (Anderson et al., 1981; Hauser et al., 1990). As reported previously, young people whose parents provided more diabetes-specific support had better adherence than the young people whose parents were less supportive of their child's regimen behaviours (Hanson et al., 1987b; Hanson et al., 1992. Cohen's $d = .36$, $N = 93$) and supportive communication patterns have also been associated with better adherence and metabolic control (Wysocki, 1993; Bobrow, Avruskin & Siller, 1985).

3.5.1 Family and friends as providers of social support to young people with diabetes

La Greca et al., (1995) evaluated and compared the support provided by family members and friends for young people' diabetes care. Family and friend support were also examined in relation to other measures of social support, to demographic variables (age, gender, duration of diabetes) and to adherence. Using a structured interview, 74 young people with diabetes described the ways that family members and friends provided support for diabetes management (insulin shots, blood glucose monitoring, eating proper meals, exercise), and for helping them to 'feel good about their diabetes'. Families provided more support than friends for three management tasks (insulin injections, blood glucose monitoring, meals) and this support was largely instrumental. In contrast, friends provided more emotional support for diabetes than families. Greater family support was related to younger age (Cohen's $d = .95$), shorter disease duration (Cohen's $d = .77$), and better treatment adherence (Cohen's $d = .80$). Implications of the findings include encouraging parents to remain involved in young people' treatment management, and involving peers as supportive companions for meals and exercise.

3.5.2 Conflict and social anxiety in young people with diabetes

Wysocki, Hough, Ward & Green, (1992) investigated this relationship further in young people aged 18 – 22 years and concluded that early adjustment is predictive of regimen adherence. In contrast to these findings however, (Stenstrom et al., 1995) found that young people aged 16 – 19 years with the strongest self-concepts, the most social support, the most knowledge about Type 1 diabetes and the fewest life stressors adhered the least well and had the poorest metabolic control. Roth and Borkenstein (1989) also found that young people in good metabolic control were less assertive and had more problems with social anxiety than those young people in worse metabolic control. Young people aged 12 – 15 years had difficulty asserting themselves against others their own age and with the attitude towards their illness at school whilst young people aged 16 – 19 years described authority conflicts with parents and problems in dating relationships. Indeed, these young people often felt forced to choose between adhering to their regimen or being a normal young person.

3.6 Implications of Research into Psychological Issues of Diabetes

The studies reported thus far have raised awareness of the complex issues surrounding the experience of diabetes in the young person. However, few of the studies cited have investigated the psychological issues of diabetes within a health model-derived or theoretically driven framework. The next chapter seeks to discuss published research into the psychological issues of diabetes conducted within the realms of health psychology theory and models.

Theories and Models of Health Behaviour

4.1 Social Learning Theory

4.1.1 Social Learning Theory and health locus of control

There are a number of theories of health behaviour based on the principle of individual differences. The Locus of Control theory (Rotter, 1966) is based in Social Learning Theory (Bandura, 1977) and considers the expectations of individuals and how these are related to behavioural reinforcements. If the individual displays 'internal' locus of control, they are more likely to believe that the behavioural reinforcements received are directly a result of their own efforts of coping. If the individual displays 'external' locus of control however, they are more likely to believe that life is determined by external factors such as fate and/or 'powerful others' and the behavioural reinforcements they receive are in no way related to their own efforts. In the field of health psychology this theory has been developed into the Health Locus of Control Scale (Wallston, Wallston & DeVellis, 1978). Those individuals who display an internal locus of control are more likely to say that they are in control of their illness and its outcome, those with an external locus of control where 'powerful others' play a part are likely to believe that their illness can only be cured by consulting a doctor, and those with an external locus of control where fate plays a part in their illness behaviour are more likely to believe that luck plays a part in their illness and subsequent recovery.

4.1.2 Social Learning Theory and self-efficacy

Self-efficacy - an individual's confidence to carry out a behaviour - is a major factor in behaviour as it examines individual's confidence in their own abilities (Bandura, 1977; Bandura, 1986). Self-efficacy operates as a mediating variable between factors such as peer influence, knowledge and perceived vulnerability, and actual behaviour when related to condom use in adolescents (Wulfert & Wan,1993). There appears to be a gender bias to the notion of self-efficacy favouring men. Men tend to have stronger beliefs in their own abilities and incorporate more general optimism in making their decisions (Schwarzer, Basster, Kwiatek, Schroder & Zhang, 1997).

4.2 Optimism

Optimism, the belief that one is at lesser risk of developing health problems than one's cohort or peers, is a strong notion related to self-efficacy. In particular, adolescents demonstrate a strong feeling of invulnerability to illness and disease which makes for difficulties in health promotion campaigns (Quadrel, Fischoff & Davies, 1993). However, optimists often display better health and practice more health-promoting behaviours than pessimists, perhaps because they expect good outcomes and therefore cope better with short-term distress and discomfort (Scheier & Carver, 1985).

Optimism is a complex notion, and not all persons displaying 'optimism' may experience the concept of complete invulnerability (Scheier & Carver, 1985). Optimism may be 'cautious', the individual may be fairly confident that things will turn out alright, for instance, but still does everything in his or her power to ensure that it does, or the optimism may be 'cockeyed'. In this instance, the person does nothing to ensure a healthy outcome and merely sits back believing it will all 'sort itself out'. This person does nothing to change his or her lifestyle, neither introducing health-promoting behaviours into his or her lifestyle, nor avoiding unhealthy behaviours. Cautious optimism is related to a strong sense of self-efficacy, 'cockeyed' optimism is related to a poor sense of self-efficacy. Only cautious optimism predicts uptake and maintenance of health behaviours (Wallston, 1994). Optimism as a health behaviour predictor was investigated (Van der Velde, Van der Pligt & Hooykaas, 1994) in a population that varies in actual risk for contracting HIV - a heterosexual group with private partners (low risk), a homosexual group of single men and a heterosexual group with prostitute partners (high risk). Overall, higher levels of optimism and higher perceptions of risk were related to previous risk behaviour in the high-risk samples only. Pessimism was more pronounced in the high-risk sample but optimists had lower levels of previous risk behaviour and increased intentions to adopt safe sex practices.

The role of optimism has been studied in an adult population of women with diabetes (Willoughby, Kee & Demi, 2000). 115 women with diabetes (mean age 48, mean length of time diagnosed 10 years) completed measures of social support, a personal resource scale, the Jalowiec Coping Scale, the Psychosocial Adjustment to Illness Scale-Self-Report, and a self-report item for assessing household structure. The authors found that better adjustment to diabetes and more effective coping was associated with higher levels of social support and in particular, optimistic coping styles were associated with better psychosocial adjustment. Multiple regression analysis demonstrated that personal resources and social support accounted for 47% of the variance in adjustment to diabetes.

4.3 Health Belief Model (Rosenstock, 1966; Becker & Maiman, 1975)

The Health Belief Model (see figure 1) (Rosenstock, 1966; Becker & Maiman, 1975) proposes that a person's likelihood of engaging in health-related behaviours is a function of several dimensions. For a person to take preventative action against a disease that person must first feel personally susceptible to the disease (this is known as perceived susceptibility); then feel that the disease would have at least moderately serious consequences (known as perceived severity); feel that preventative behaviour would be beneficial either by preventing the disease, or by lessening its severity (otherwise known as perceived benefits); that barriers, such as pain, embarrassment or cost should not outweigh the perceived benefits of the proposed health action in order for the preventive health behaviour to occur; and that cues to action may trigger a consideration of the proposed health action. In a study conducted by Hyman, Baker, Ephraim, Moradel & Philip, (1994), the Health Belief Model was used to investigated women's attitudes to breast screening. Those found most at risk of under utilisation of screening resources were women who were white, women who had a family history of breast cancer and, in relation to the model, those who perceived fewer benefits of and greater barriers to mammography.

Protection Motivation Theory (Rogers, 1984)

The Protection Motivation Theory (figure 2) (Rogers, 1984) builds on the Health Belief Model by incorporating motivation as a factor. According to Rogers, a person has a motivation to protect him or herself from a threat to health and this motivation is based on four beliefs: that the threat is severe (the perceived magnitude of the threat); that one is vulnerable to the threat (there is a strong likelihood that one is susceptible to the threat); that one can perform the behaviour required to protect against the threat (a strong notion of self-efficacy); and that the response made will be effective (response efficacy). Rogers argues that it is not enough to address just one of these beliefs, more that all the health beliefs (magnitude of threat, susceptibility to threat, self-efficacy and response efficacy) have to be targeted for any change in behaviour which will protect against illness or disease. There is a certain amount of support for this theory. Abraham, Sheeran, Abrams and Spears, (1994) found evidence that a model based on Protection Motivation Theory accounted for 33% of anticipated condom use in a study aimed at investigating adolescents views on HIV infection risk and sexual behaviour. Coping appraisal measures were strongly associated with condom use, however threat appraisal did not predict perceived infection risk or use of preventative measures. In a study conducted by Van der Velde, Hooykaas & Van der Pligt (1996), the relationship between perceived risk and future health protective behaviour was investigated in a mixed population of low risk (stable partner relationship) and high risk (prostitute partner relationship) susceptibility for HIV infection. Their findings suggest that a significant positive relationship between perceived risk and intention to take preventative action was only found when the measure of risk was strongly related to the original concept of vulnerability or susceptibility (conditional risk) and was found to be more useful than a relatively general, unconditional measure of perceived risk. These study findings have been replicated since and it appears that perceived vulnerability is a necessary but not a sufficient condition for preventive action and the consensus of researchers' opinion is that a focus on conditional risk as opposed to unconditional risk is needed (Van der Pligt, 1998).

However, a recent study conducted by Orbell and Sheeran (1998) specified that in the case of cervical cancer screening, Protection Motivation Theory may well theoretically apply in describing motivation to act but it does not however, account for how intention is translated into action. In accordance with these findings, Block & Keller (1998) challenged the assumption made by Protection Motivation Theory that the issues of vulnerability, severity, response efficacy, and self-efficacy are equally weighted across individuals and incorporated aspects of the Transtheoretical Model of health behaviour (Prochaska & DiClemente, 1982; Prochaska & DiClemente, 1992).

4.4 Transtheoretical Model of illness behaviour (Prochaska & DiClemente, 1982)

The Transtheoretical model suggests that people move through a series of stages in changing their behaviour. The stages are categorised as the pre-contemplation phase (the person perceives no health problem); the contemplation phase (the person begins to think that they made need to take appropriate action); the preparation phase (the person begins to seriously plan the action required); the action phase (the person actively engages in the health behaviour) and finally the maintenance phase (the person continues to undertake the health action). Block and Keller (1998) proposed that people at different stages of readiness to change are affected by components of the Protection Motivation Theory. Results from their study indicated that vulnerability, severity, and efficacy (response and self) are the main motivations when the person is engaged at the pre-contemplation, contemplation, and action stages of health protective behaviour respectively. In response, a meta-analysis of research investigating health intentions and behaviour conducted by Milne, Sheeran & Orbell (2000) appears to clarify the relationships of the Protection Motivation Theory to the psychology of health behaviour. The authors of this paper concluded that the threat and coping appraisal components were found to be useful in the prediction of health-related intentions and the model was found to be useful in predicting concurrent behaviour. Where the model was found not to be so effective was in predicting future behaviour. Where it did have predictive validity, the coping-appraisal component of the model was more effective than the threat-appraisal component.

4.5 Leventhal's Self-Regulatory Model (Leventhal, Meyer & Nerenz, 1980)

Leventhal's Self-Regulatory Model (figure 3) is a model of illness behaviour and cognitions (Leventhal, Meyer & Nerenz, 1980). It is primarily a problem solving model where each person is an active problem solver whose behaviour reflects an attempt to close a perceived gap between current status and a goal or ideal state. The behaviour depends on the individual's cognitive representations of his or her current health status and the goal state, their plans for changing the current state and their techniques or rules for assessing progress. There are three stages that regulate behaviour: the interpretation of health threat - including symptom perception and social messages; an action plan or coping strategy (seeking medical attention would be an approach coping strategy, denial of the problem would be an avoidance coping strategy); and the utilisation of specific criteria to gauge the success of the coping actions - the appraisal stage. The perception of insufficient progress results in modifications to the coping actions, the individual returns to the appraisal stage to gauge the success of these modified coping actions and the process begins again.

4.6 Theory of Planned Behaviour (Ajzen, 1985)

The Theory of Planned Behaviour (see figure 5, Ajzen, 1985) was developed from the basics of the Theory of Reasoned Action (see figure 4, Fishbein & Ajzen, 1975) and suggests that people make decisions about their behaviour on the basis of a reasonable consideration of the available evidence. Behaviour is planned and planning is, in part, a function of an individual's intentions. Intentions are the most immediate determinants of behaviour and are a function of 3 elements. These elements are privately-held attitudes towards the behaviour; the perception of socially determined norms that represent the person's belief that others think she/he should behave in a certain way; and perceived behavioural control on the part of the individual - the belief that the individual can carry out the planned behaviour, that they have the necessary skills. Values are attached to each factor and are dependent on the individual's beliefs. In a study conducted by Agnew (1998), beliefs about condom use were examined in order to determine whether personal beliefs or modal (generalised) beliefs predicted one's attitudes to sexual behaviour and intention for condom use. Agnew's findings suggest that one's personal beliefs are stronger predictors of condom use although they are outweighed by the practical considerations of this method of contraception.

4.7 Theories of health: diabetes and metabolic control

The intended purpose of self-care activities is to normalise blood glucose levels and by doing so, reduce the probability of complications caused by the disease. Non-adherence is a prevalent problem in young people with diabetes so if good predictors can be identified, a better understanding of adherence difficulties may be achieved and techniques for encouraging adherence devised. A number of social psychological theories have been tested in the field of diabetes research and are described here in relation to adherence and metabolic control.

4.7.1 Social Learning Theory

Social Learning Theory emphasises both personal and environmental determinants of behaviour as well as any possible interactions between these variables. If any of the variables are shown to be predictive of adherence, then adherence might be improved by modifying those factors. Social Learning Theory was tested by McCaul, Glasgow & Schafer (1987) with young people aged 12 – 18 years. The authors found a strong relationship between expectancies and environmental support with higher skill levels associated with higher expectancies and greater environmental support which in turn were related to adherence. These skills were associated with adherence across all regimen areas and in particular, self-efficacy was the best individual predictor. Psychosocial variables including adolescent age, chronic life stress, social competence, family relations, and family knowledge about Type 1 diabetes have been investigated in relation to metabolic control (Hanson, Henggeler & Burghen, 1987b). This study concluded that knowledge about Type 1 diabetes, family relations and adolescent age had a direct effect on adherence and that adherence and stress were directly related to metabolic control.

4.8.2 Protection Motivation Theory

Protection Motivation Theory tests the relative contributions of adolescents' cognitions concerning diabetes treatment and predicts health behaviour to be a function of cognitions concerning adherence and non-adherence to treatment. Measures of the Threat Appraisal Process (issues of personal vulnerability and severity of risk) and measures of the Coping Appraisal Process (issues of response efficacy, self-efficacy and response costs) can illustrate adolescents' cognitions regarding their illness. With diabetes, personal vulnerability issues would be insulin reactions, ketoacidosis, gangrene, amputations, pregnancy complications and so on.

Severity of risk would be, for non-adherence to regime, the results of not injecting insulin, blood glucose monitoring, exercise and diet. Response efficacy and self efficacy would be related to the diabetes treatment regime and response costs would be the physical pain of say injecting insulin, personal dislike of the treatment process and other personal issues, such as embarrassment at having to inject or to eat a different meal to those around you.

Cognitive appraisals of adherence are related to treatment adherence as well as to the major components of treatment, insulin injection, blood glucose testing, diet and exercise maintenance. In a study conducted by Palardy, Greening, Ott, Holderby & Atchison (1998) response costs of adherence such as pain, inconvenience and embarrassment seemed to compromise the adolescents adherence and the perception of high response costs also decreased the likelihood of adherence to the individual components of treatment. However, without a longitudinal aspect to the study no conclusions can be drawn to whether adhering to the treatment regime had any effect on the young person's health status. Self-monitoring of blood glucose has been shown to have no significant impact on diabetic control (Wysocki, Green & Huxtable, 1989) and without a significant relationship between adherence and health status, it would seem reasonable to argue that treatment adherence is only important if it guarantees a reasonable health impact which, ultimately, is the goal of the diabetes regime.

4.9 Adherence and Diabetes

A great deal of research has been carried out into the issue of adherence to the treatment regime in adolescents with diabetes. Adherence is the extent to which a person's behaviour (medication-taking and lifestyle practices) coincides with medical or health advice and measuring it requires comparing a patient's self-care behaviour with a known standard (McNabb, 1997). Patients with diabetes are often described as largely non-adherent but the methodological problems in much adherence research makes it difficult to interpret the results of these studies. There is still no single definition for adherence and no 'gold standard' by which it can be measured (McNabb, 1997). This is further compounded by a lack of a clearly defined set of self-care behaviours that comprise the diabetes regimen and a lack of reliable, valid measures of adherence.

4.9.1 Measuring diabetes self-care regime

There are a number of difficulties inherent in identifying diabetes self-care behaviours, not least the complexity of the diabetes regimen that varies across patients and in different situations. This variability in diabetes regimen precludes the use of a standardised set of self-care recommendations. In practice, therefore, it may be more useful to measure effectiveness of treatment regimen from the individual patient's view of how good they feel and whether they are having a good day or a bad day. There is also considerable variability in the regimen prescribed by various health practitioners and how that regimen is communicated to the patient (Cotugna & Vickery, 1990). Instructions given to patients are also often not documented in their medical records so if there is no accurate record of what a particular patient is asked to do, there is no standard against which adherence may be assessed.

4.9.2 Measuring adherence to diabetes self-care regime

Once the diabetes self-care behaviours have been identified for the adolescent with diabetes, there are more problems incurred in assessing their adherence to these behaviours. There is a lack of reliable measures of adherence, most rely on self-report from patients and as such self-reports of low adherence are more likely to be accurate than self-reports of very high levels of adherence (Johnson, 1992). There is also no common approach to quantifying levels of adherence. Studies vary in measuring adherence in terms of relative frequency with which behaviours are performed, measuring the number of times a behaviour is performed and measuring the percentage of time patients adhere to their treatment regime. Any instrument developed to measure adherence needs to be flexible enough to take into account each individual's prescribed regime and allow for adherence scores for each aspect of the treatment regime to be collected. Each aspect of the regime represents quite different skills, for instance skills of injecting, blood-glucose testing, diet adherence and exercise upkeep, and requires different levels of patient motivation (McNabb, 1997).

4.10 Young people's adherence to regime and subsequent health status

A longitudinal analysis of adherence in diabetes would demonstrate whether treatment regimen adherence does indeed have any effect on health status in young people with diabetes. Early studies demonstrated that young adults are generally less adherent than younger children, with boys being more compliant on injection regularity and exercise frequency (Bennett Johnson, Freund & Silverstein, 1990), but the links between regimen adherence and health status were unclear. 194 young people and their mothers measured their injection frequency, diet type, blood glucose testing-eating frequency, calories consumed and so on in 24 hour recall interviews (Bennett Johnson & Kelly, 1992). The conclusions of the study were broad. There were weak associations between adherence behaviours and diabetes control measures, and testing-eating frequency and injecting demonstrated greater power over glycaemic control. An issue raised by the authors linked the hormonal changes of puberty to the changes found in insulin resistance and therefore, change in metabolic control. The hormonal changes in puberty may be strong enough to obscure the true association between adherence and diabetic control (Amiel, Sherwin, Simonson, Lauritano & Tamborlane, 1986). The standard glycosylated haemoglobin readings (HbA_{1c}) used in these studies also measure an average blood glucose level, they do not give information on daily blood glucose variability and it is on this variability that adherence behaviours have their primary influence (Bennett Johnson, Freund & Silverstein, 1990). Following the Diabetes Control and Complications Trial, it has been established that strict adherence to an intensive regime results in improved metabolic control and better health status, however, most people do not have the necessary high level of support available to them to follow such a complex regime so thoroughly. Therefore, models of health behaviour can contribute to our understanding of the process underpinning adherence in the population with diabetes following a conventional treatment regime.

4.10.1 Social Learning Models and adherence to regime

Social Learning Models, when applied to diabetes, state self efficacy (a persons belief in his/her own capacity to perform the behaviour) as predictive of adherence to treatment. The strength of efficacy beliefs determine the degree of effort that an individual will expend and how long they will persist in their coping methods. One study has shown self-efficacy to predict adherence to diet, exercise and blood-glucose testing in people with diabetes (Kavanagh, Gooley & Wilson, 1993). However, this relationship may not be consistent over time, indeed a relationship found at one time between efficacy and behaviour may not actually apply at another subsequent point of time (Skelly, Marshall, Haughey, Davis & Dunford, 1995). Self-efficacy is not always related to behaviour in adults with diabetes. Coping strategies vary across different situations and often behavioural strategies are suppressed in work settings where visible coping strategies carry some psychosocial cost (Drapkin, Wing & Schiffman, 1995).

4.10.2. Health Belief Model and adherence to regime

The Health Belief Model (Rosenstock, 1966) states that an individual's level of self-care is related to a combination of variables: perceived vulnerability to disease; perceived seriousness of disease; and the perceived costs and benefits of action. All these variables are influenced by internal and external cues to action. In diabetes, the internal cue may be feeling unwell due to high blood sugar and the external cue may be advice and information about diabetes. The Health Belief Model does not demonstrate cause and effect and may not, therefore, be an appropriate model for diabetes (Harris & Linn, 1985). Indeed, the Health Belief Model is unlikely to predict behaviour due to the continually changing relationship between beliefs, behaviour and outcome over time (Shillitoe & Miles, 1989). However, the Health Belief Model has been tested in young people with diabetes (Bond, Aiken & Somerville, 1992). The authors found that increasing age was associated with decreases in adherence to three aspects of regimen; exercise, injection regularity and glucose testing frequency. Increasing age was also associated with an increase in perceived threat whilst cues were most closely associated with adherence.

4.11 Extended Health Belief Model and adherence to regime

The Health Belief Model has since been extended to include other health measures (Aalto & Uutela, 1997). In their study investigating glycaemic control, self-care behaviours and psychosocial factors in adult insulin treated diabetics, the authors supplemented the Health Belief Model with measures of locus of control, self-efficacy, health value and social support. In a sample of 423 adults (aged 20-64 years) with type I diabetes, Aalto and Uutela found significant associations between diet adherence and diabetes-related social support, and significant associations between blood glucose testing and self-efficacy. Both diet adherence and blood glucose testing were significantly related to HbA_{1c} reading. Previous research has found that the original Health Belief model explained 9%-25% of the variance in adherence to the treatment regime in young people (Bond, Aiken & Somerville, 1992) and in adults, health beliefs have been found to account for 41%-52% of the variance in adherence (Brownlee-Duffeck, Peterson, Simonds, Goldstein et al., 1987). In the study by Aalto and Uutela, the Extended Health Belief Model was found to account for 14% of the variation in diet adherence and 21% of the variation in blood glucose testing. More generally, the study did find that higher perceived benefits of adherence were related to stricter adherence to both diet and blood glucose testing, but that perceived threat of disease was not. The authors suggest that to perceive positive benefits of adherence, the patient has to perceive that diabetes is a controllable disease and that they have confidence in their ability to carry out the self-care tasks. Those who had a stronger belief in controllability of diabetes and who had more social support also perceived their diabetes as less threatening. Cues had a direct effect on diet adherence and blood glucose testing. The authors conclude that treatment regimens for patients should be planned individually, in relation to their life circumstances and to their personal capacity to accomplish the self-care tasks.

These are the two main studies looking into psychological factors affecting adherence within the theoretical framework of the Health Belief Model. Most research has however, focused mainly on investigating single paths to adherence incorporating one or more of the social psychological factors of the Extended Health Belief Model.

4.11.1 Social Support

La Greca et al., (1995) investigated a measure for looking at the impact family and peer social support has on the young person's adherence to regime. La Greca and colleagues developed the Diabetes Social Support Interview asking in what way family and friends helped support adherence to four diabetes-care tasks (insulin injections, blood glucose testing, diet adherence and adherence to a regular exercise plan), how often this support took place and how supportive the young person thought this support was. Looking specifically at diabetes-related social support, the authors concluded that families provide mostly instrumental support for diabetes-related tasks whereas friends provide more emotional support. The relationship between family and friend support changed as the adolescent grew older with younger adolescents experiencing greater family support and older adolescents reporting greater friend support. The authors (La Greca et al, 1995) conclude that it is important to encourage both types of support – family for the tasks of treatment management and friends for support during meal times and exercise sessions.

In adults, however, the pattern of social support is less clear. Trief, Grant, Elbert and Weinstock (1998) investigated family and peer social support in young adults with diabetes. The participants completed the Family Environment Scale, the Diabetes Family Behaviour Checklist, the Diabetes Quality of Life Scale, the Medical Outcomes Study Health Survey and the Appraisal of Diabetes Scale. Glycaemic control was measured by HbA_{1C} readings. The authors found that none of the family system scales predicted medical outcome. However, when family members acted in a way that supported the diabetes regimen, psychosocial adaptation of the participant improved. The participants reported greater satisfaction with adaptation to diabetes (Cohen's $d = .75$, N = 150) and reported less interference in role function due to emotional problems (Cohen's $d = .52$, N = 150). Family cohesion was related to better physical function (Cohen's $d = .63$, N = 150) and women reported higher levels of diabetes satisfaction (Cohen's $d = .75$, N = 150). The Appraisal of Diabetes Scale predicted both metabolic control (Cohen's $d = .75$) and better psychosocial adaptation (Cohen's $d = .75$, N = 150). Thus, for young adults in this study, levels of family support did not predict metabolic control, but did however predict better psychosocial outcome.

Burroughs, Harris, Pontious & Santiago (1997) provided a comprehensive review of psycho-social research into social support and adherence in diabetes. The authors summarised the findings that supportive, cohesive families were more likely to have adolescents with strong adherence and good metabolic control than families without such cohesion. Social support appeared to be critical during the early years after diagnosis and early adjustment is predictive of regimen adherence in later adolescence. Both positive and negative support behaviours from the family were linked to dietary adherence. The research to date seems contradictory with studies reporting both behaviours to either support or interfere with diet adherence. In terms of communication style, adolescents with good adherence had interactions with their parents that were characterised as open and empathic, whereas those adolescents with poor adherence had interactions described as emotionally charged and confrontational. These interactions in particular were more common in later adolescence.

Hanson, Henggeler, Harris, Burghen & Moore (1989) looked at the relationship between two coping styles (use of personal and interpersonal resources; ventilation and avoidance) and two health outcomes (adherence and metabolic control) in 135 young people with Type 1 diabetes. Poor adherence to treatment, older adolescent age and long duration of diabetes were correlated with ventilation and avoidance coping, whilst those with short duration of diabetes were more likely to cope using personal and interpersonal resources, although this was not related to health outcome. Multiple regression analysis demonstrated that high ventilation and avoidance coping was predicted by high stress, low family cohesion and older adolescent age. The interaction between family adaptability and duration of diabetes significantly predicted ventilation and avoidance coping.

4.11.2 Locus of Control

Murphy, Thompson and Morris, (1997) conducted a study based on 40 young people with Type 1 diabetes theoretically grounded in a transactional stress and coping model. Multiple regression analyses indicated that esteem related to physical appearance, perceived control when ill and attributional style for negative events explained 32 percent of the variance in adherence to blood glucose testing behaviour. The authors suggest that young people with diabetes who have a negative perception of their bodies; perceive little internal control over health when ill; and have an external attributional style for negative events were at greatest risk for poor adherence for blood glucose testing.

The relationship of diabetes locus of control to diabetes metabolic control was investigated by Stenstrom, Wikby, Andersson & Ryden, (1998). 312 outpatients with Type 1 diabetes completed the Diabetes Locus of Control Scale (DCCT, 1993) and their HbA_{1C} scores were collected. Stenstrom et al., (1998) demonstrated that those patients with a strong internal locus of control combined with weak chance locus of control was related to a better HbA_{1C} score than those with other locus of control scores (Cohen's $d = .35$, $N = 312$), suggesting that knowing the patient's locus of control beliefs may be beneficial in constructing their specific diabetes treatment regime. However, a study conducted by Weist, Finney, Barnard, Davis & Ollendick (1993) contradicted this finding. The authors investigated a range of psychosocial variables related to metabolic control in children with diabetes. The children completed measures on anxiety, coping, family environment, health locus of control and the parents completed parallel measures plus the Child Behaviour Checklist. Metabolic control was measured by HbA_{1C} readings which were classified either optimal or non-optimal. The authors found that children in optimal control of their diabetes had more structured and controlling family environments and had a strong belief in 'significant others' for locus of control. The children in poorer metabolic control demonstrated a slightly higher level of knowledge about diabetes and its management. Weist and colleagues conclude that parental involvement with the diabetes regime has a positive effect on metabolic control in children with diabetes.

Schwartz, Coulson, Toovy, Lyons & Flaherty, (1991) investigated the relationship between recent life stress, social support, locus of control and change in control of blood glucose in patients with diabetes over two time points. The study found that the number of recent life events experienced and social support was related to blood glucose control. External locus of control was also associated with poor blood glucose control at both time one and time two.

4.11.2 Quality of life

Quality of life has recently been argued as an important health outcome, being the ultimate goal of all health interventions. Rubin & Peyrot (1999) reviewed the published literature on quality of life in adults with diabetes and concluded that although adults with diabetes had worse quality of life scores than adults without a chronic illness, they did have better quality of life than adults with other chronic illness. Duration and type of diabetes is not consistently associated with quality of life, intensive treatment (as discussed in the DCCT, 1988) does not impair quality of life and having better glycaemic control is associated with better quality of life scores. The most important determinant of low quality of life scores in diabetes is the experience of complications and demographic factors (lower demographic scores indicating lower quality of life), whilst determinants of high quality of life scores are improved health status and perceived ability to control diabetes.

Lloyd, Matthews, Wing & Orchard (1992) investigated which psychosocial variables are associated with diabetic complications in patients with child onset Type 1 diabetes. 175 patients took part and completed questionnaires on quality of life, depressive symptomatology and personality type and a clinical assessment of the patient taken. Compared with those with no complications, those with macrovascular disease ($p<0.01$) or nephropathy ($p<0.05$) reported significantly worse quality of life scores. Those with microvascular disease also reported greater depressive symptomatology ($p<0.05$) and those with more than four complications reported much worse quality of life scores ($p<0.001$). The authors concluded that quality of life scores and depression are related to the number and type of diabetic complications present, however the direction of effect is unknown.

Guttmann Bauman, Strugger, Flaherty and McEvoy (1998) investigated the relationship between quality of life scores and metabolic control in young people aged 10 - 20 with Type 1 diabetes. Diabetes Quality of Life (DQOL) score was correlated with mean HbA_{1C} (mean of past years scores) and latest HbA_{1C} score (taken at time of clinic visit). The Worries sub-scale of the DQOL correlated with the occurrence of acute events but not with either HbA_{1C} score. The authors concluded that those young people in better metabolic control reported better quality of life.

Stenstrom, Wikby, Hornquist and Andersson (1995) looked at recent life events and gender differences on the control of Type 1 diabetes over a period of 1 year. At time 1, males who reported mostly negative life-events and had poorer levels of social support had worse HbA_{1c} scores than those with few or no negative life events. For females, more life events, particularly positive life events, was associated with better metabolic control. At the one-year follow-up, the results were the same for the males but there was found no association between life events and metabolic control for the females. The authors suggest this could be a reflection of differences in psychosocial environment and coping strategies between the genders.

4.11.3 Benefits and Costs

Palardy, Greening, Ott, Holderby and Atchison (1998) investigated the psychosocial aspects of adherence from the theoretical stance of Protection Motivation Theory. 101 young people (aged 12-18 years) with diabetes were assessed on threat appraisal (measures included personal vulnerability and severity of risk); coping appraisal (response efficacy, measures of self-efficacy and response costs); and adherence (the Summary of Self-Care Activities Scale was used and covered areas of self-care including insulin injection, blood glucose testing, dietary plan, exercising and being prepared for insulin reactions). The study revealed that coping appraisals were significantly related to treatment adherence as well as adherence to the individual components of treatment. Response costs (such as pain, inconvenience and embarrassment) were negatively related to adherence and to the individual components of treatment. The authors concluded that appraisals of adherence were far more effective in influencing adherence to treatment regime than appraisals of non-adherence and suggest that practitioners focus on the positive aspects of adherence rather than the negative aspects of non-adherence.

4.11.4 Self Efficacy

Drapkin, Wing and Schiffman (1995) applied Bandura's (1982) Self-Efficacy Theory to adherence in young people with diabetes. 143 participants completed measures of adherence to regime, self-efficacy for diabetes care, personal responsibility for diabetes care and a measure of supportive and non-supportive diabetes-specific behaviours exhibited by parents. Regression analysis demonstrated that self-efficacy is a mediator between the paths of personal responsibility for diabetes care and adherence and non-supportive parent behaviours and patient non-adherence to the blood glucose testing part of the regime. Self-efficacy was found not to be a significant mediator between supportive parental behaviours and adherence.

4.12 Summary

To summarise this chapter, internal locus of control and belief in powerful others locus of control has been demonstrated to be beneficial towards health behaviour (Wallston, Wallston & DeVellis, 1978). Self-efficacy appears to act as a mediator between peer influence, knowledge, perceived vulnerability and actual health behaviour (Wulfert & Wan, 1993). Self-efficacy has also been found to be a predictor of adherence to diabetes self-care regime (McCaul, Glasgow & Schafer, 1987). Cautious optimism influences the uptake of health behaviour (Wallston, 1994) and optimistic coping styles increase adaptation to diabetes (Willoughby, Kee & Demi, 2000). Family support is an important factor in adherence to self-care regime in young people (Hanson, Henggeller & Burghen, 1987).

Protection Motivation Theory incorporates motivation as a factor protecting against threat of illness or health problem and is a concept linked to perceived vulnerability towards health problem (Rogers, 1984). However, motivation does not account for how intentions are translated into action. The person's notion of vulnerability, severity and self-efficacy are important factors in translating threat to health into health protective behaviours. This is supported by Palardy et al., (1998) who tested the viability of the Protection Motivation Theory with young people with diabetes and the main factor affecting adherence was the perceived costs of doing so.

The Transtheoretical Model of illness describes a progression through phases from perceiving no health problems, to feeling the need to take action, to maintaining that action. The Transtheoretical Model also specifies the importance of the person's perceived notion of vulnerability, severity and self-efficacy (Milne, Sheeran & Orbell, 2000). This progression through phases touches on the theoretical background of the Self-Regulatory Model (Leventhal, Meyer & Nerenz, 1980). Here the person tries to close the gap between their current health status and their ideal state of health. In order to do so, the person needs to interpret the health threat, cope with that threat and then appraise their success at coping with the health threat. Again, the notion of person perception of severity and vulnerability to health threat, as well as their efficacy at dealing with the health threat come to the fore.

The Theory of Planned Behaviour builds on the fundamental issues of responding to health threat by incorporating intentions based on the person's private beliefs, the beliefs of others and their perceived behavioural control (Ajzen, 1985). In this sense, the Theory of Planned Behaviour is very similar to the Health Belief Model (Rosenstock, 1966) which takes into account patient perceived severity and vulnerability to the illness, cues to act (from family or health professionals, or from symptom recognition) and the benefits and barriers to taking the required action to deal with the health threat. When the Health Belief Model is augmented to include specific measures of social support, self-efficacy, locus of control and quality of life (Aalto & Uutela, 1997), the Extended Health Belief Model pulls together the models and theories of health behaviour into one larger model and incorporates all the factors considered important in influencing health threat appraisal and coping processes. With a specific view to diabetes management, the Extended Health Belief Model provides a structure for and seeks to understand what factors affect the person's adherence to the diabetes self-care regime and how these factors interact to provide a model of the person's experience of diabetes. It is this model which will be tested in the first stage of the empirical work of this thesis.

Study 1: The Extended Health Belief Model Applied to the Experience of Diabetes in Young People

5.1 Abstract

The experience of diabetes in young people was investigated within the theoretical framework of the Extended Health Belief Model (EHBM). 197 Participants registered with the Southampton University Hospitals Trust aged 16 to 25 years with Type 1 Diabetes Mellitus were sent a set of questionnaires incorporating previously published scales measuring aspects of the EHBM. 64 sets (40.25%) were returned. Participants' mean age was 21.45 years and they had been diagnosed for between 6 months and 22 years (M= 9.36, SD = 5.49). None of the participants were experiencing physical health complications associated with their diabetes, 21 had HbA_{1C} readings within the 'normal' range (5-8%) and 39 had readings within the 'high' range (8.01% plus). The participants did not differ significantly from the non-participants on age or HbA_{1C} readings but there was a difference in gender split, with more women taking part in the study than men. Pearson product moment correlations were calculated and the subsequent matrix subjected to path analysis. The results of the path analysis for the EHBM indicated poor fit (CFI = .48). The model was augmented with additional paths until the final model was accepted (CFI = .92). High levels of family support and low locus of control beliefs in powerful others to control their diabetes reduce the young person's perception of severity and vulnerability to diabetes-related complications. High levels of family support and high quality of life scores predicted low life threat due to diabetes. High internal locus of control beliefs and high levels of diabetes-related empowerment predicted that the young person would see the benefits of adhering to the self-care regime as outweighing the costs of doing so and finally, adherence to self-care regime was predicted largely by high levels of family support. The final model proposed explained 18.5% of the variance in the young person's adherence to diabetes self-care regime, which was supported by the findings of Aalto & Uutela (1997).

5.2 Introduction

The Health Belief Model (see figure 1, Appendix A) has been applied to the understanding of the experience of diabetes. Harris, Linn and Pollack (1984) investigated the relationship between various health beliefs and psychological variables in patients with diabetes and found that although several health belief model variables correlated with adherence, the model failed to predict adherence although it did predict metabolic control. More specifically, Brownlee-Duffeck et al., (1987) investigated the role of these health beliefs with regard to adherence to medical regime and metabolic control in both adults and adolescents. The authors took scores on measures of diabetes risk and complications severity and susceptibility, costs and benefits of adhering to regime and cues to action. These variables were found to explain 52% of the variance in self-reported adherence with regime and 20% of variance in HbA_{1C} values in the adolescent sample aged 13-26 years. The costs of adhering (in terms of difficulty of injecting, embarrassment in front of friends, forward planning on long trips and so on) had the only statistically significant influence on patient self-reported adherence with this age group and patient susceptibility and severity scores had the only statistically significant influence on HbA_{1C} values.

However, it was not until Bond, Aiken & Somerville in1992 that the Health Belief Model was specifically tested with young people with diabetes. The authors tested the ability of the health belief model to predict adherence in a sample of 56 young people with Type 1 diabetes. The young people completed a Child Self-Administered Questionnaire (CSAQ) comprising the Diabetes Health Belief Scale (sub-scales Severity/Vulnerability and Benefits/Barriers), Barriers to Adherence Questionnaire, Diabetes Health Belief Questionnaire, Diabetes Regimen Compliance Questionnaire and the Summary of Diabetes Self-Care Activities. They also completed a Child Compliance Telephone Interview (CCTI) - a 20 minute, subjective 24 hour recall of regimen-related events - exercise, insulin injection, diet type, frequency of eating and blood glucose testing and diet amount. The study found that generally the sample was well-motivated to comply, perceived relatively low susceptibility but high severity of complications, perceived greater benefits than costs to adherence, and had a sensitivity to and willingness to act on cues. Increasing age was associated with decreases in adherence to three aspects of regimen - exercise, injection regularity and glucose testing frequency. Increasing age was also associated with an increase in perceived threat. The part most closely associated with adherence was willingness and ability to act on cues.

The Health Belief Model was augmented by Aalto & Uutela (1997) to include measures of locus of control, self-efficacy, health value and social support (see figure 6, Appendix A). Social support was measured by adapting Cronenwett's measure of social support (1985) developed for use measuring social psychological outcomes of pregnancy. Scores were obtained for each participant on four types of social support received: emotional, informational, tangible and appraisal. Health value was measured by a brief version of the Rokeach Value Survey (Nagy & Wolfe, 1984). Locus of control was measured using the Diabetes Locus of Control Scale (Ferraro, Price, Desmond and Roberts, 1987). The Diabetes Locus of Control Scale (DLoCS) contains four sub-scales: belief in diabetes control is internally driven; by chance; by significant others; and by health care professionals. Belief in diabetes control by health care professionals is considered external locus of control, but of positive, beneficial effect to the patient (not relying on chance or significant others) and as such the score on this sub-scale is combined with belief in internal diabetes control to form one score of controllability of diabetes. Self-efficacy was measured by a scale previously used by the authors (Aalto & Kangas, 1993) assessing 13 items on perceived competence in self-care. In this study, the data from the self-efficacy scale was subjected to factor analysis with varimax rotation and three main factors were disclosed – General Self Efficacy (8 items); Efficacy in Self-Monitoring of Blood Glucose(3 items); and Exercising Efficacy (2 items).

The 'cues to action' portion of the HBM was conceptualised in terms of internal cues (frequency of hypoglycaemic symptoms and perceived diabetic control) and external cues (supportive participation of significant others in self-care). Aalto and Uutela devised their own single question measures of the internal cues and the participation of significant others was measured by a revised version of the Diabetes Family

Behaviour Checklist (Schafer, McCaul & Glasgow, 1986). Severity of complications and susceptibility to complications was measured by a simple question assessing five possibly diabetes-related complications: eye diseases; amputation; foot pain at rest; kidney disease and heart conditions. Costs and benefits of adhering with treatment regime were measured with single item questions on diet adherence and self-monitoring of blood glucose. Life threat of diabetes was measured by a single question. Outcome measures were HbA_{1C} readings and measures of diet adherence (3 item self-report) and self-monitoring of blood glucose (single item self-report).

423 participants completed all measures for both diet adherence and self-monitoring of blood glucose. Path analysis using structural equation modelling techniques (LISREL) revealed the EHBM as formulated by Aalto & Uutela explained 14% of the variance in diet and 21% of the variance in adherence to self-monitoring of blood glucose. In neither case did perception of life threat of diabetes predict adherence with either aspect of the regimen. The authors conclude that the EHBM is a valid theoretical framework for understanding adherence to diabetes regime, and that to perceive the benefits of adherence to the diabetes regime, the patient must have good internal locus of control and to have confidence in their ability to carry out the tasks required. Physiological cues to action (such as experience of hypoglycaemic symptoms) predicted self-monitoring of blood glucose, and diabetes-related social support predicted diet adherence.

The Extended Health Belief Model (EHBM) has been further tested by Wdowik, Kendall & Harris (1997) using focus groups and interviews to determine the psychosocial issues of diabetes and the barriers to control as part of a long term study of young people's experience of diabetes. The authors conducted focus groups and fifteen interviews with College students with diabetes covering aspects of the EHBM. The main barriers to successful diabetes management were time management stress, hypoglycaemic reactions, diet management constraints and inadequate finances. The psychological issues were identified and collated into three categories: the inconveniences of diabetes management (or 'barriers' to adherence); motivators to managing diabetes (or 'benefits' to adherence), and social support. The second stage of the study involved the use of intervention programmes aimed at improving young people's knowledge of their diabetes, changing their attitudes towards their diabetes and changing their self-care behaviour (Wdowik, Kendall, Harris & Keim, 2000). As a result, the young people showed improved diabetes knowledge and reported more support. This coincided with an increase in blood glucose testing – particularly when the young people felt their blood glucose was low – and an improvement in metabolic control (as measured by HbA_{1C} values).

5.3 Rationale for Study

Adolescence is a time when peers become very important and influential and conformity to the social group is desirable. It is a time when the young person is more likely to be open to experimentation with behaviours different to those learnt in the family environment. There is a developmental basis to the generation of health beliefs, older adolescents believe they have more control over illness and that it is likely to have multiple causes. The actual health status of the adolescent is influenced by their social background, their personality and environment, and their behavioural system (whether they actually engage in the 'problem behaviours' or not). The adolescent's perception of risk resulting from these 'problem behaviours' is influenced by gender, age and degree of participation in the behaviours, with women perceiving greater risk, but older and participating adolescents generally perceiving less risk to younger, non-participating adolescents. The adolescent makes their own choices in terms of health risk behaviour, but the list of 'problem behaviours' they have to choose from is restricted according to their localised cultural environment.

It is not just important to understand why the adolescent is or is not carrying out their health-promoting behaviours, particularly in diabetes their adherence to medical regime, but a more detailed understanding is necessary of the link between these health behaviours and actual health outcome. Adherence is only an important measure of health if it guarantees metabolic control which in turn guarantees a good health outcome.

5.3.1 Aims of the study

This study aims to investigate the experience of diabetes in young people aged 16 to 25 years within the Extended Health Belief Model framework. On the basis of previously published work, it is anticipated that participant reports of high internal locus of control, high diabetes-related empowerment, coping with hypoglycaemia and diabetes-related social support will indicate good patient adherence to the self-care regime.

5.4 Method

5.4.1 Participants

Participants were aged between 16 and 25 years (mean = 21.47, 22 = male) and registered with either the Southampton General Hospital Diabetes Unit or the Royal South Hants Hospital Diabetes Resource Centre. The total number approached was 197. Following the approach letter, 38 could be discounted as either deceased (4), unable to complete the questionnaires (for instance, being learning disabled or other communication problem, 4), not having diabetes (4) and not resident at the address (26). This left a sample of 159, of which 64 completed and returned the questionnaires. The response rate was therefore 40.25%.

5.4.2 Materials

Questionnaires were used to investigate each variable of the Extended Health Belief Model. Where possible brief versions of the measures were used to encourage completion by the participants. All measures used are standard scales employed in the experimental investigation of the experience of diabetes. The survey is included in Appendix B. The rational for using each is presented below:

5.4.2.1 Individual perceptions

Susceptibility to and severity of illness

The Diabetes Specific Health Beliefs: Susceptibility and Seriousness Scale (Lewis & Bradley, 1994) was used. This is a 60 item measure consisting of two sub-scales. The severity of illness sub-scale has 31 items: 10 items measuring severity of developing long term and short term complications associated with diabetes (eg high blood pressure, numbness of the feet); six items measuring general diabetes measurement problems (eg weight gain, high blood sugars); and 15 items measuring severity of other non-diabetes related illness (eg bronchitis, influenza, arthritis). The vulnerability to illness sub-scale consists of items essentially measuring the same illnesses. It has 29 items: 10 items measuring patients perceived vulnerability to long term and short term complications associated with diabetes; four items measuring general diabetes management problems; and 15 items measuring patient perceived vulnerability to other non-diabetes related illness. Answers are scored on a 6-point Likert-type scale where a score of '0' indicates that the patient considers the illness to be 'not at all serious' or 'very unlikely to develop the problem' and a score of '5' indicates the patient considers the illness to be 'serious' or 'very likely to develop the problem' (depending on the scale being completed). The use of this scale had a mixed response from researchers and there are no published figures denoting scale reliability and validity. It is however widely used and, as the only published scale available to test this section of the Health Belief Model, included in this study.

5.4.2.2 Modifying factors

Social-psychological variables

Social support

The Diabetes Family Behaviour Checklist (DFBC)(Schafer, McCaul & Glasgow, 1986) was used to measure diabetes-specific family support (described later) and one sub-scale of that scale measures general family support. For the purpose of this study the DFBC was kept complete as a measure of diabetes-specific family support and as such no separate score of general family support was included in the analysis.

Locus of control

The Diabetes Locus of Control Scale (Ferraro, Price, Desmond & Roberts, 1987) was developed for use on participants aged 18 to 80 years. The scale consists of 18 items: six items measuring Internal locus of control; six items measuring Powerful Others locus of control; and six items measuring Chance locus of control. Participants score their answers on a 7-point Likert-type scale where a score of '0' indicates they 'strongly disagree with the statement' and a score of '6' indicates they 'strongly agree with the statement'. Internal consistency for these sub-scales was high (Cronbach alphas of .75, .72 and.77 respectively). Test-retest reliabilities for the sub-scales were high (r_{int}= .77, r_{pow}= .66 and r_{chan}= .72) as were the internal reliabilities of the sub-scales (r_{int}= .75, r_{pow}= .72 and r_{chan}= .77 (Ferraro et al., 1987)). Content validity was provided by three authors of previously published locus of control scales. Criterion-related validity was measured by correlating participants' responses to the Diabetes Locus of Control sub-scales with responses to the corresponding sub-scales of the Multidimensional Health Locus of Control scale (Wallston, Wallston & DeVellis, 1978). The correlations were high (r_{int}= .57, r_{pow}= .64 and r_{chan}= .71). Although the Diabetes Locus of Control scale was developed on a population aged 18 to 80 years, it has been used with success on younger people as part of the Diabetes Control and Complications Trial (1993) and was considered appropriate for use with the participants of this study.

Quality of life

The Audit Diabetes-Dependent Quality of Life Scale (Bradley, Todd, Gorton, Symonds et al., 1999) was developed to determine individual patients' perceived impact of diabetes on their quality of life. This scale is unique in providing a measure of the impact diabetes has on specific aspects of daily life as well as how important that aspect of life is to the patient. There are 18 items related to aspects of daily life (eg employment/ career opportunities, social life, friendships) and two overview items: one measuring current general quality of life and one measuring what the participant believes their quality of life would be without diabetes. The 18 domain-specific questions are scored in two parts. First the participant marks on a scale from –3 to +3, where a score of '-3' indicates that if the patient did not have diabetes, that aspect of their life would be 'a great deal better' and a score of '+3' indicates that the participant considers that aspect of their life to be 'a great deal worse' if they did not have diabetes. The second part of the domain-specific questions asks the participant to indicate on a scale of 0 to 3 how important that aspect of their life is. A score of '3' indicates that this aspect of their life is 'very important' and a score of '0' indicates that this is 'not at all important'. The response options for the two overview items follow the same pattern but without the 'importance' section. Bradley et al., (1999) tested the ADDQoL reported that internal consistency for each domain was high (Cronbach alphas of .81 to .84) as well as construct validity – mean scores on the ADDQoL correlate significantly with number of reported complications ($r=-.2141$, $n=141$, $p<.005$) and with perceptions of hypoglycaemia ($r=-.3237$, $n=90$, $p<.001$). No test-retest reliability figures were published.

Self-efficacy

The Diabetes Empowerment Scale (Anderson, Funnell, Fitzgerald & Marrero, 2000) measures diabetes-specific self-efficacy and is a 28-item scale comprising three sub-scales: managing the psychosocial aspects of diabetes; assessing dissatisfaction and readiness to change; and setting and achieving diabetes goals. The participant scores their answers to each question on a 5-point Likert-type scale where a score of '1' indicates the participant 'strongly agrees' with the statement and a score of '5' indicates the participant 'strongly disagrees' with the statement. The Diabetes Empowerment Scale shows moderate construct validity when compared with three sub-scales of the well-used Diabetes Care Profile and, as it evolved from the authors' previous work in self-efficacy and diabetes-specific empowerment, shows content validity. Test-retest reliability is good ($r= .79$) when participants are tested at a six-week interval and the correlations between scores on each sub-scale are high ($r= .67$, $r= .75$, $r= .64$).

<u>5.4.2.3 Life threat of diabetes</u>

This was measured by the item: 'How much shorter do you think your life expectancy is due to diabetes?' with response options 'not at all' (score = 1); 'a little shorter' (score = 2), and 'very much shorter' (score = 3) as published in Aalto & Uutela (1997). A high score on this item indicates higher life threat due to diabetes.

<u>5.4.2.4 Cues to action</u>

Perceived metabolic control

This was measured by a single item as published in Aalto & Uutela (1997) 'How well do you think you are managing to control your diabetes?'. The participant scores their response on a 5-point Likert-type scale where a score of '1' indicates a response of 'not very well' and a score of '5' indicates a response of 'very well'.

Hypoglycaemic symptoms

The Hypoglycaemia Fear Survey (Cox, Irvine, Gonder-Frederick, Nowacek & Butterfield, 1987) is a 23-item self-report measure of two aspects of hypoglycaemia. The first part consists of 10 items measuring how often a particular behaviour is carried out daily to prevent hypoglycaemia occurring and the second part consists of 13 items measuring patient worry about aspects of hypoglycaemia eg not recognising the signs, not having the resources to cope and others' reaction to the outward signs of hypoglycaemia such as 'appearing stupid or drunk' and 'embarrassing myself or my friends in a social situation'. Answers are scored on a 6-pont Likert-type scale where a score of '0' indicates the patient 'never' carries out the preventive behaviour or 'never' worries about that aspect of hypoglycaemia, and a score of '5' indicates the patient 'always' carries out the preventive behaviour or 'always' worries about that aspect of hypoglycaemia. Scores are totalled to provide sub-scale scores of hypoglycaemia worry and behaviour and these scores can be combined to provide a total hypoglycaemia fear score. The Hypoglycaemia Fear Survey demonstrates a high level of internal consistency (Cronbach's alpha = .87) and high levels of reliability for the worry sub-scale (Cronbach's alpha = .89 to .96) and for the behaviour sub-scale (Cronbach's alpha = .60 to .84). Test-retest reliabilities are also high (Worry sub-scale, $r = .64$ to .76; Behaviour sub-scale, $r = .59$ to .68).

Diabetes-specific social support

The Diabetes Family Behaviour Checklist (Schafer, McCaul & Glasgow, 1986) was designed to be used with people aged 12 to 64 years and is composed of 16 items assessing family support for: diet adherence (4 items); blood glucose testing (3 items); insulin injecting (3 items); exercise adherence (3 items) and general support for diabetes care (3 items). Half the items indicated behaviours considered of 'positive support' and half the items indicated behaviours considered of 'negative support'. The participant records their score on a 5-point Likert-type scale where a score of '1' indicates that the family members do this 'never' and a score of '5' indicates that the family members do this 'at least once a day'. Test-retest reliability of the Diabetes Family Behaviour Checklist is high ($r=.84$ to $.95$ for positive support items, $r=.69$ to $.77$ for negative support items (Schafer, McCaul & Glasgow, 1986)). The validity of the scale was measured by comparing patient-completed scores and family member scores. For the participants aged 19 to 64 years the validity of the scale was supported ($r=.27$, $p<.05$ to $r=.68$, $p<.001$), although the correlations were insignificant for the participants aged 12 to 18 years. The Diabetes Family Behaviour Checklist has, since publication, been used extensively as a measure of diabetes-specific family support with older adolescents and young adults and was considered appropriate for use with the age group of participants of this study (16 to 25 years). None of the participants aged 16 to 18 years expressed difficulties answering any of the items of the scale.

5.4.2.5 Likelihood of action

Benefits and costs of adhering to regime

Perceived benefits of following the treatment regime and the perceived costs of doing so were measured using the Diabetes Specific Health Beliefs (DSHB): Benefits and Barriers sub-scales (Lewis & Bradley, 1994). The DSHB: Benefits and Barriers scale is a 12 item measure incorporating six items measuring the perceived barriers to diabetes self-care and six items measuring the perceived benefits to diabetes self-care. Participants score their answers on a 7-point Likert-type scale where a score of '0' indicates the patient 'strongly disagrees' with the statement and a score of '6' indicates the patient 'strongly agrees' with the statement. To obtain total scores on each sub-scale, the scores are added together. A measure of perceived 'cost-effectiveness' of adhering to the diabetes self-care regime can be obtained by subtracting the 'barriers' sub-scale score from the 'benefits' sub-scale score. Internal reliability scores for the sub-scales are high (Cronbach's alpha for the 'benefits' sub-scale = .67 and for the 'barriers' sub-scale = .79) (Lewis & Bradley, 1994).

Adherence with regimen

Adherence with regimen was measured using the Summary of Diabetes Self-Care Activities Scale (Toobert & Glasgow, 1994). This is an 12 item self-report recall measure of adherence over the past seven days to five aspects of the diabetes self-care regime: healthy diet (4 items), insulin injecting (1 item), blood glucose testing (2 items), exercise (2 items), foot care (2 items) and smoking behaviours ('0' = non-smoker, '1' = smoker, number of cigarettes smoked per day). The participants circle how many of the past 7 days they have adhered to their prescribed regime on each of the above behaviours. Mean scores are collected for each self-care behaviour and a total adherence score can be obtained by summing the mean scores on each subscale (Toobert, Hampson & Glasgow, 2000).

5.4.2.6 Metabolic control

Each participant had the option of submitting a blood sample for an HbA_{1C} test to be carried out. The HbA_{1C} test (or glycosylated haemoglobin test) provides an average rating of metabolic control over the previous 8-12 weeks and is used as a standard measure of metabolic control in studies of diabetes.

5.4.3 Design

Cross-sectional independent measures postal survey design Participant selection criteria were a diagnosis of diabetes mellitus, registered with Southampton University Hospitals Trust, of age 16-25 years and not registered learning disabled.

5.4.4 Procedure

Participants were approached via a letter from their Consultant Endocrinologist inviting them to participate in the study. This letter was followed by a pack of questionnaires as detailed above accompanied by a cover letter, consent form, an HbA_{1C} testing kit request slip and a pre-paid return envelope. This first mailing resulted in 44 completed sets of questionnaires and 16 respondents excluded from the study for reasons detailed above. Six weeks later, a second pack of questionnaires was sent to those participants who had not replied to the first mailing. This second mailing resulted in 64 completed sets of questionnaires. All data was entered into an SPSS database and analysed as sub-scale and full-scale scores. A correlation matrix for the full-scale scores was subjected to path analysis for modelling onto the Extended Health Belief Model as proposed by Aalto and Uutela (1997). All participants requesting HbA_{1C} testing kits were sent complete kits which were analysed by the Haematology Laboratories at Southampton General Hospital.

5.5 Results

5.5.1 Participant details

Table 5.1 Comparison of participants and non-participants age, gender and HbA1C scores.

		Participants (N=64)	*Non-Participants (N=143)*
Age	Mean	21.47	20.92
	SD	2.62	3.08
	Min.	16	15
	Max.	25	25
Gender	Mean	1.66	1.44
	SD	.48	.5
	Min.	1	1
	Max.	2	2
HbA_{1C}	Mean	8.78	8.49
	SD	1.97	1.97
	Min.	5.10	4.70
	Max.	14.30	12.80

The participants were aged 16 – 25 years (M = 21.45 years) and 22 were male. The participants had been diagnosed for between 6 months and 22 years (Mean = 9.36, SD = 5.49) with Type 1 diabetes (insulin-dependent diabetes mellitus). 27 lived at home with their parents, 1 lived with other members of family, 9 lived in shared / student accommodation, 21 lived with partners /spouse and 6 lived alone. None of the participants was experiencing recognised physical health complications associated with their diabetes. The HbA_{1C} readings (N=60) ranged from 5.1% to 14.30% of which 21 participants were within the 'normal' range (5 – 8%) and 39 participants had readings within the 'high' range (8.01% and over). The participants did not differ significantly from the non-participants on age ($t_{(205)} = 1.248$, $p= .213$) and latest HbA_{1C} readings ($t_{(140)} = .390$, $p= .140$) but there was a difference in gender split ($Chi^2 = .8229$, $p<.01$).

5.5.2 Summary of findings: Sub-scale scores

Diabetes Specific Health Beliefs (DSHB): Severity and Vulnerability Scores

Table 5.2 Subscale scores on the DSHB: Severity and Vulnerability Scale

Measure Sub-Scale	*N*	*Min.*	*Max.*	*Mean*	Mean publ.	*SD*	SD publ.
Severity of non-diabetes illness	61	1.47	4.67	2.95	3.05	.64	.69
Severity of diabetes complications	61	1.88	5.00	3.77	3.37	.62	.62
Vulnerability to non-diabetes illness	60	.13	3.27	1.73	2.04	.71	.52
Vulnerability to diabetes complications	60	.29	4.36	2.65	2.17	.91	.81

Participants rated the severity of experiencing diabetes-related complications greater than the severity of contracting non-diabetes illness and considered themselves more at risk of experiencing diabetes-related complications than non-diabetes illness. Bond, Aiken & Somerville (1992) investigated health beliefs in a group of 56 young people aged 10-19 with Type 1 diabetes. The authors findings were very similar to the findings of this study for severity of non-diabetes illness (Cohen's $d = .15$) although participants in this study reported severity of diabetes complications as much greater (Cohen's $d = .64$). Participants scores for vulnerability to non-diabetes illness were similar to the published scores (Cohen's $d = .50$) and slightly higher for diabetes complications (Cohen's $d = .56$).

Diabetes Family Behaviour Checklist

Table 5.3 Subscale scores on the Diabetes Family Behaviour Checklist

Measure Sub-Scale	*N*	*Min.*	*Max.*	*Mean*	*SD*
Family support for diet	63	-5	7	.11	2.63
Family support for blood glucose testing	64	-9	1	-3.06	2.13
Family support for insulin injecting	63	-2	9	2.54	2.47
Family support for exercising	63	-3	9	2.25	2.08
Family support for diabetes	64	-3	7	1.44	1.97

Family support for all the diabetes care behaviours (Mean = 3.24, SD = 6.93) when compared with the findings of Schafer, McCaul & Glasgow (1986), is quite low (Cohen's $d = .32$ to $.74$). Mean scores for the young people in that study aged 12-19 years were 8.39 at time 1 and 8.24 after a six month interval and mean scores for the adults aged 20 – 64 were 5.47 at time 1 and 7.75 after a six month interval.

Diabetes Locus of Control Scale

Table 5.4 Subscale scores on the Diabetes Locus of Control Scale

Measure Sub-Scale	*N*	*Min.*	*Max.*	*Mean*	*SD*
Internal Locus of Control	64	19	36	30.22	4.25
Powerful Others Locus of Control	62	8	29	16.87	5.74
Chance Locus of Control	63	7	29	19.14	4.76

The participants reported relatively high 'internal' locus of control with respect to their diabetes. The internal locus of control score was higher than that relating to 'powerful others' ($t=17.92$, $df= 61$, $p<.001$) and to 'chance' ($t=12.47$, $df= 62$, $p<.001$) indicating that these participants consider themselves to be the greatest influence on their metabolic control. Scores indicating 'chance' locus of control were greater than scores indicating a belief in 'powerful others' ($t=-2.66$, $df= 60$, $p<.01$) indicating that chance is considered by the participants to be a greater factor in the control of their diabetes than the influence of the medical team over-seeing their care regime.

Diabetes Empowerment Scale

Table 5.5 Subscale scores on the Diabetes Empowerment Scale

Measure Sub-Scale	*N*	*Min.*	*Max.*	*Mean*	Mean publ.	*SD*	SD publ.
Empowerment: Psychosocial aspects	63	1	5	2.26	3.91	.81	.70
Empowerment: Dissatisfaction	63	1	3.22	2.03	3.96	.52	.53
Empowerment: Setting and achieving goals	63	1	4.20	2.32	3.96	.72	.62

The participants mean score on the Diabetes Empowerment Scale sub-scales was 2.26 (SD = .81) for 'psychosocial aspects', for 'dissatisfaction', mean = 2.03, SD = .52 and for 'setting and achieving goals', mean = 2.32, SD = .72, indicating the participants feel more empowered for setting and achieving goals and psychosocial aspects of diabetes relative to dissatisfaction with their diabetes self efficacy. Compared with scores published by Anderson, Funnell, Fitzgerald & Marrero (2000), these scores (lower score indicates greater empowerment) reflect the young people in this study consider themselves more empowered for psychosocial aspects (Cohen's $d = 2.18$), for dissatisfaction (Cohen's $d = 3.67$) and feel more empowered for setting and achieving goals (Cohen's $d = 2.47$).

Audit of Diabetes-Dependent Quality of Life

Table 5.6 Subscale scores on the Audit of Diabetes-Dependent Quality of Life

Measure Sub-Scale	*N*	*Min.*	*Max.*	*Mean*	*SD*
Quality of Life now	64	-3	3	1.34	1.21
Quality of Life without diabetes	64	-3	3	-1.16	1.31

Quality of life scores for 'now' suggest that these participants consider their current quality of life to be 'good' although scores for quality of life 'without diabetes' suggest that these participants feel their quality of life would be 'a little better' without diabetes.

Life Threat and Perceived Metabolic Control

Table 5.7 Scores on Life Threat and Perceived Metabolic Control

Measure Sub-Scale	*N*	*Min.*	*Max.*	*Mean*	*Mean publ.*	*SD*	*SD publ.*
Life Threat	63	1	3	2.20	1.80	.61	.58
Perceived Control of Diabetes	64	1	5	1.59	2.70	.56	.55

The participants see their life expectancy due to diabetes as being 'somewhat shorter' than that of a person without diabetes and consider the control of their diabetes to be 'moderate' to 'poor'. The scales of each were re-coded to match the scoring used by Aalto & Uutela (1997). Each measure then had a maximum possible score of 2 and a minimum possible score of 0. Participants' notion of life threat was similar to Aalto & Uutela's published findings (Cohen's $d = .42$) but participants' notion of perceived metabolic control (Cohen's $d = .96$) was considerably worse.

Hypoglycaemia Fear Survey

Table 5.8 Sub-scale scores on the Hypoglycaemia Fear Survey

Measure Sub-Scale	*N*	*Min.*	*Max.*	*Mean*	*Mean publ.*	*SD*	*SD publ.*
Hypoglycaemia Behaviour Score	62	4	33	20.47	33.06	6.74	6.51
Hypoglycaemia Worry Score	61	3	52	23.75	28.34	12.02	6.40

On the Hypoglycaemia Fear Survey the participants have high scores on the 'hypoglycaemia worry' section and moderate scores on the 'hypoglycaemia behaviour' section. Cox et al., (1987) used the HFS with a sample of 108 people aged 15 – 35 years and published total mean scores on the HFS of 64 (SD = 17). Compared with total mean scores on the HFS with this sample (Cohen's $d = 1.26$), these scores are low for this group. The mean sub-scales scores published in Cox et al., (1987) for hypoglycaemia worry and hypoglycaemia behaviour are much higher than those obtained in this study suggesting that the study participants worry less about hypoglycaemia (Cohen's $d = 1.90$) than the participants in the Cox et al., (1987) study, but also that the study participants are less prepared to counteract the effects of possible hypoglycaemic episodes (Cohen's $d = .50$).

Diabetes Specific Health Beliefs: Benefits and Barriers

Table 5.9 Sub-scale scores on the DSHB: Benefits and Barriers

Measure Sub-Scale	*N*	*Min.*	*Max.*	*Mean*	Mean publ.	*SD*	SD publ.
Benefits of adhering to regime	64	13	36	27.09	3.10	5.65	.64
Barriers to adhering to regime	64	0.00	34	13.59	2.17	9.25	.62

Scores reflecting the benefits of and barriers to adherence indicate that this participant group see the benefits of adhering to their diabetes care regime as outweighing the costs of doing so. Compared with the published findings of Bond, Aiken & Somerville (1992), the results of this study show higher scores for the benefits of adhering to the diabetes self-care regime (Cohen's $d = 1.77$) but there is little difference in scores indicating perceived barriers to the diabetes self-care regime (Cohen's $d = .03$).

Summary of Diabetes Self-Care Activities Scale

Table 5.10 Sub-scale scores on the Summary of Diabetes Self-Care Activities Scale

Measure Sub-Scale	*N*	*Min.*	*Max.*	*Mean*	*SD*
Self care: diet	63	.25	7	4.17	1.29
Self care: exercise	64	0	7	3.43	2.03
Self care: blood glucose testing	64	0	7	3.41	2.72
Self care: insulin injecting	64	2	7	6.73	.89
Self care: foot care	64	0	7	1.57	1.80
Self care: smoking	64	0	7	1.57	1.80

Scores on this seven-day recall of actual adherence to their prescribed diabetes care regime demonstrate that although on the whole participants are injecting insulin as prescribed, they are not following their diet and exercise programmes regularly or testing their blood glucose levels as frequently as advised. There is low adherence to foot care and few patients smoke. The figure below provides comparison figures collected from seven studies (no mean figures for smoking behaviour were published) from Toobert, Hampson & Glasgow (2000).

Table 5.11 Comparison of study data to published findings for use of the SDSCA (Toobert, Hampson & Glasgow, 2000)

Domain	Mean (%) Publ.	Mean (%) *This study*	SD (%) Publ	SD (%) *This study*	N Publ	N *This study*	Effect sizes
Diet	63.05	*59.57*	22.8	*18.42*	1191	*64*	*.17*
Exercise	34.3	*49.0*	31.9	*29.0*	883	*64*	*-.48*
Blood glucose testing	69.0	*48.71*	34.9	*38.85*	685	*64*	*.58*
Insulin injecting	95.0	*96.14*	15.4	*12.7*	218	*64*	*.08*
Foot care	47.1	*22.42*	21.4	*25.7*	407	*64*	*1.05*

There is no published data on the use of the SDSCA with participants aged between 16 and 25 with Type 1 diabetes but the table above provides figures for older participants (aged 45 to 60) with Type 2 diabetes. Although the participants are older and have Type 2 diabetes, there are remarkable similarities between the data obtained in this study and the data published by Toobert, Hampson & Glasgow (2000). Adherence to diet and to insulin injection is similar in the two groups. Exercise activity is low in both groups but the young participants in this study are taking more exercise than the older participants. Perhaps younger people tend to be more active compared to an inactive, older more obese population who have developed Type 2 diabetes. The young group are much worse at adhering to their prescribed blood glucose testing regime and their foot care regime. Perhaps the older group may be experiencing complications related to their diabetes and/or may be more health aware than the young group. Foot care and blood glucose testing among younger people with diabetes is notoriously poor. For total adherence scores, published means and standard deviations do not include the (optional) sub-scale of smoking behaviour. When the participants scores were adjusted to exclude smoking behaviour, no difference was found between published and participant scores on total adherence to the diabetes self-care regime (Cohen's $d = .26$).

Table 5.12 Correlations between HbA_{1C} and self-care activities as measured by the Summary of Diabetes Self-Care Activities Scale (Toobert, Hampson & Glasgow, 1994).

Self-care task	*r*	*df*	*p*
HbA_{1C}	1.00	58	
Diet	-0.20	58	NS
Exercise	0.08	58	NS
Insulin injection	-0.17	58	NS
Blood glucose testing	-0.19	58	NS
Foot care	0.18	58	NS
Smoking	0.18	58	NS

Adherence for this group was not significantly correlated with metabolic control. This appears to contradict the findings of the Diabetes Control and Complications Trial (1993), however, some patients were not able to supply recent HbA_{1C} readings so a mean HbA_{1C} reading was formed based on readings taken over the past 2 years and used as an indicator of current HbA_{1C}. The strength of relationship between current report of adherence to self-care activities and current metabolic control may therefore be weakened. A relationship between adherence and actual metabolic control has however, been found by a number of authors, including the study conducted by Lloyd, Wing, Orchard, and Becker (1993) who found that metabolic control was related to age, income and educational attainment (correlations coefficients between -0.1 and -0.2; $P < 0.01$), and adherence to self-care regime (r = -0.11; P < 0.01). This is supported by Johnson & Kelly (1992) who investigated the link between adherence and metabolic control more rigidly and found a correlation between the two (r= .05 to .10, Cohen's *d* = .30).

Although when looking at the participant pool as a whole, adherence was not directly correlated with metabolic control, on splitting the pool into two groups – those exhibiting normal HbA1C scores (up to 10%) and those exhibiting high HbA1C scores (10% above) – differences are found on certain measures. People with diabetes are encouraged to obtain and sustain an HbA1C scores between 5 and 8% for optimal control, although scores up to 10% are considered reasonable control. Scores above 10% place the person at risk for developing complications such as nephropathy, neuropathy, retinopathy, difficulties in pregnancy and impotence.

Table 5.13 Comparison of total scores by reported good and poor metabolic control.

Variable	*Latest HbA1C*	*N*	*Mean*	*SD*	*t*	*df*	*P*	*Effect Size*
DSHB: Severity & Vulnerability score	≥ 10.0	12	2.80	.48	.020	50	.984	.006
	<10.0	40	2.80	.40				
DFBC	≥ 10.0	12	1.17	6.74	-1.242	57	.219	-.40
	<10.0	47	3.77	6.41				
Internal locus of control	≥ 10.0	13	29.23	4.78	-.765	58	.447	-.25
	<10.0	47	30.26	4.13				
Powerful others locus of control	≥ 10.0	12	16.00	5.88	-.586	56	.560	-.19
	<10.0	46	17.04	5.39				
Chance locus of control	≥ 10.0	13	19.31	4.35	.315	57	.754	.10
	<10.0	46	18.85	4.73				
Quality of life total score	≥ 10.0	13	-1.70	1.26	-.291	58	.772	-.09
	<10.0	47	-1.56	1.63				
Empowerment	≥ 10.0	13	2.11	.56	-.419	57	.677	-.13
	<10.0	46	2.19	.55				
Life threat due to diabetes	≥ 10.0	13	.84	.55	1.711	58	.092	.54
	<10.0	47	.55	.54				
Perceived metabolic control	≥ 10.0	13	1.92	.64	-2.569	58	.013	-.80
	<10.0	47	2.44	.65				
Hypoglycaemia: Fear and Worry	≥ 10.0	13	39.23	15.13	-1.634	58	.108	-.53
	<10.0	47	46.26	13.33				
DSHB: Benefits & Barriers score	≥ 10.0	13	11.46	10.91	-.688	58	.494	-.21
	<10.0	47	14.02	12.10				

The sample of participants in Study 1 had HbA_{1C} scores between 5.1% and 14.30% (Mean = 8.60, SD =1.97, N=60), with 47 (78%) falling between the range 5-10% considered 'good' metabolic control and scores of 14 to 15% indicate the person is treading a very thin line between being able to function barely adequately and entering into a state of ketoacidosis (indicated by HbA_{1C} readings of 15 to 6% and greater). Ketoacidosis is serious condition caused by insufficient insulin levels in the bloodstream which requires hospitalisation to avert coma and death. With 78% with scores in the range of 6-10%, this leaves 22% of the sample with HbA_{1C} readings outside this range (hence 22% of the sample population are at high risk for experiencing problems with their diabetes). Splitting the sample into two groups – those with HbA_{1C} readings below 10% and those with HbA_{1C} readings greater than 10% - created a sub-sample of participants in good control and a sub-sample of participants in poor control. Further analysis of the data revealed significant differences in the sub-group's scores on the measures demonstrated to be the main indicators of adherence.

In study one, participants in good metabolic control reported higher diabetes-specific family support scores compared with participants in poor metabolic control (Mean = 3.77 and 1.17 respectively, SD = 6.41, N=59, Cohen's d = -.40). Participants exhibiting good metabolic control also perceived their metabolic control to be better compared with participants exhibiting poor metabolic control (Mean = 2.44 and 1.92 respectively, SD = .65, N= 60, Cohen's d = -.80) and engaged in less hypoglycaemic worry and fewer preventive behaviours to avoid hypoglycaemia (Mean = 46.26 and 39.23 respectively, SD = 13.33, N= 60, Cohen's d = -.53). Thus the main indicators of poor metabolic control were low levels of reported diabetes-specific social support, greater perceived life threat due to diabetes, worse reported perceived metabolic control and poorer scores on the hypoglycaemia worry and behaviour measure.

Comparing the groups on the sub-scales of the Hypoglycaemia Fear Survey, scores on the Worry sub-scale indicated that there were differences between the groups with those participants exhibiting good metabolic control reporting greater worry scores that those in poor metabolic control (Mean = 21.42 and 19.23 respectively, SD = 5.95, N= 60 Cohen's d =-.43). A similar finding is revealed for scores on the Behaviour sub-scale with those participants exhibiting good metabolic control reporting fewer hypoglycaemia prevention behaviours than those participants exhibiting poor metabolic control (Mean = 24.8 and 20.0 respectively, SD = 11.20, N = 60, Cohen's $d = -.37$). Thus, those participants with high HbA_{1C} readings were much less likely to adopt behaviours to counteract the effects of hypoglycaemia than those participants with low HbA_{1C} readings. In terms of worry about hypoglycaemia, the participants with high HbA_{1C} scores were less likely to report high levels of worry than those participants with low HbA_{1C} scores. With HbA_{1C} scores above 10%, the participant is unlikely to experience many hypoglycaemic episodes (hypoglycaemia being a possible draw-back to intensive therapy aimed at maintaining a low HbA_{1C} score) and may in fact be running their blood sugars high so they can avoid the possible embarrassments associated with experiencing a hypoglycaemic episode (appearing drunk, slurring their speech, trouble concentrating and so on) that the young person finds distressing in front of their friends, so their worry score is likely to indicate the reduced (and possibly purposefully avoided) likelihood of the participant experiencing hypoglycaemia in a day-to-day setting.

Thus those participants exhibiting poor metabolic control reported lower levels of diabetes-specific social support, higher levels of life threat due to diabetes, reported being in worse metabolic control and reported less worry about hypoglycaemia and less hypoglycaemia preventive behaviours.

Summary of results

The findings of this study generally follow the pattern of other published studies indicating that the participants of this study are representative of other populations being researched. Scores on the DFBC are much lower in this sample however reflecting that the participants of this study perceive less social support from the family than similarly aged participants in other studies. However, their notion of perceived metabolic control is better and their scores on the DSHB: Severity & Vulnerability and DSHB: Benefits & Barriers scales are similar to other published findings. The adherence to self-care activities scores show differences, but the published findings are for an adult population and as yet, no figures are available for young people aged 16-25 years. Overall, this suggests that the data obtained in this study reflects the findings of other studies being conducted both in the UK and in the US.

5.5.3 Summary of findings: Full-scale scores

Table 5.14 Summary of findings: Total scores on each of the behaviour measures with minimum and maximum possible scores in parentheses.

Measurement Scale	*N*	*Min.*	*Max.*	*Mean*	*SD*
DSHB Severity / Vulnerability Score	58	0	3.88	2.44	1
Diabetes Family Behaviour Checklist	63	-12	22	3.24	6.93
Diabetes L.o.C. Scale Internal	63	19	36	30.22	4.25
Diabetes L.o.C. Scale Powerful Others	62	8	29	16.87	5.74
Diabetes L.o.C. Scale Chance	63	7	29	19.14	4.76
Audit of Diabetes Dependent Quality of Life	63	-6.89	1.12	-1.59	1.69
Diabetes Empowerment Scale	63	1.00	4.14	2.20	.61
Life Threat	63	1	3	1.59	.56
Perceived Control of Diabetes	64	1	5	3.47	1.01
Hypoglycaemia Fear Survey	64	12	74	44.13	14.38
DSHB Benefits / Barriers Score	64	-10	36	13.50	11.85
Summary of Diabetes Self-Care Activities Scale (z-scored)	63			-8.18E-18	1.000
Valid N (listwise)	55				

5.5.4 Correlation Matrix

The Pearson's product moment correlations were calculated to construct a correlation matrix for the score totals for the following measures: Life Threat, Quality of Life now and Quality of Life without diabetes, DSHB Benefits and Barriers, DSHB Severity and Vulnerability, Diabetes Empowerment Scale, Hypoglycaemia Fear Survey, Diabetes Family Behaviour Checklist, Locus of Control sub-scales (Internal, Powerful Others and Chance), Quality of Life total score and the Summary of Diabetes Self-Care Activities Scale.

		Severity / Vulnerability	*DFBC*	*Internal L.o.C.*	*Powerful Others L.o.C*	*Chance L.o.C*	*Quality of Life Score*	*Empower-ment Score*	*Life Threat Score*	*Perceived Control*	*Hypoglyc-aemia Score*	*Benefits / Barriers*	*Adherence*
Severity / Vulnerability Score	Pearson Cor.	-											
	N												
Diabetes Family Behaviour Checklist Score	Pearson Cor.	-.210	-										
	N	55											
Internal Locus of Control	Pearson Cor.	-.051	.196	-									
	N	56	63										
Powerful Others Locus of Control	Pearson Cor.	-.120	-.003	-.002	-								
	N	54	61	62									
Chance Locus of Control	Pearson Cor.	.022	.001	-.275*	.165	-							
	N	55	62	63	61								
Quality of Life Score	Pearson Cor.	-.129	.030	.245	-.167	-.158	-						
	N	56	63	64	62	63							
Empowerment Score	Pearson Cor.	.055	-.103	-.210	.160	.358**	-.467**	-					
	N	56	62	63	61	62	63						
Life Threat Score	Pearson Cor.	.426**	-.345**	-.150	-.089	.052	-.208	.102	-				
	N	56	63	64	62	63	64	63					
Perceived Control of Diabetes Score	Pearson Cor.	-.201	.360**	.395**	-.049	-.313*	.248*	-.609**	-.244	-			
	N	56	63	64	62	63	64	63	64				
Hypoglycaemia Worry and Behaviour Score	Pearson Cor.	.257	.115	-.229	.084	-.061	-.301*	.144	.094	-.006	-		
	N	56	63	64	62	63	64	63	64	64			
Benefits and Barriers Score	Pearson Cor.	-.372**	.184	.415**	.021	-.252*	.634**	-.591**	-.289*	.587**	-.194	-	
	N	56	63	64	62	63	64	63	64	64	64		
Adherence Score	Pearson Cor.	-.087	.338**	.052	.018	.146	.037	-.252*	-.120	.305*	.229	.222	-
	N	56	62	63	61	62	63	62	63	63	63	63	

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

*. Correlation is significant at the 0.05 level (2-tailed)

<u>Table 5.15 Correlation matrix of full scale scores</u>

Diabetes Specific Health Beliefs (DSHB): Severity and Vulnerability Scores

Participant scores on the Diabetes Specific Health Beliefs (DSHB): Severity and Vulnerability measures positively correlated with perceived life threat due to diabetes, and with DSHB: Benefits and Barriers scores.

Diabetes Family Behaviour Checklist

Scores reflecting diabetes-specific family support positively correlated with adherence scores (as measured by the Summary of Diabetes Self-Care Activities Scale) and perceived metabolic control, and negatively correlated with life threat.

Diabetes Locus of Control Scale

Participants' 'internal' locus of control scores correlated positively with their perceived control of diabetes and with their DSHB: Benefits and Barriers score and negatively with participants' 'chance' locus of control scores.

Participants' scores corresponding with 'chance' locus of control positively correlated with diabetes-related empowerment scores and negatively with perceived control of diabetes scores and with their DSHB: Benefits and Barriers score. A high score on the Diabetes Empowerment Scale indicates low participant empowerment, therefore strong beliefs in 'chance' playing a part in their control of diabetes was related to low personal diabetes-related empowerment scores.

Audit of Diabetes-Dependent Quality of Life

Participant quality of life scores negatively correlated with diabetes-related empowerment scores and Hypoglycaemia Fear Survey (worry and behaviour) scores, and positively correlated with perceived metabolic control and DSHB: Benefits and Barriers score.

Diabetes Empowerment Scale

Diabetes-related empowerment scores negatively correlated with perceived metabolic control, DSHB: Benefits and Barriers scores and SDSCA scores.

Life Threat and Perceived Metabolic Control

Participant perceived life threat scores were negatively correlated with their DSHB: Benefits and Barriers score. Participant perceived metabolic control was positively correlated with their DSHB: Benefits and Barriers scores and their adherence scores on the Summary of Diabetes Self-Care Activities Scale.

Diabetes Specific Health Beliefs (DSHB): Benefits and Barriers

Participant scores on the DSHB: Benefits and Barriers scale were not correlated with any of the variables of the EHBM.

5.5.5 Path Analysis

EQS and Structural Equation Modelling

Structural equation modelling is based upon two main assumptions. First that the relationships between variables are considered causal and are represented by a series of regression (or 'structural') equations, and second, that these relationships can be shown in a pictorial representation that mirrors the theoretical concepts connecting the variables under study (Byrne, 1994). This allows all the variables within the hypothesised model to be analysed concurrently and the fit of data to this model to be computed. Structural equation modelling is different from other multivariate analyses by being confirmatory in nature rather than exploratory with respect to the data analysis. It is also a process that will provide explicit estimates of measurement error and can incorporate both unobserved (or 'latent') and observed variables. Good fit of a prescribed model to the data is indicated by a Comparative Fit Index (CFI) of greater than .90 and a Root Mean Square Error of Application (RMSEA) of less than .05. In this context, the Extended Health Belief Model as proposed by Aalto & Uutela (1997) is tested using the total scale scores for each variable under investigation There are no latent variables in the model.

The Extended Health Belief Model (Aalto & Uutela, 1997)

Figure 2 (Appendix A) shows the Extended Health Belief Model as tested by Aalto & Uutela (1997). Figure 6 (Appendix A) shows a diagrammatically simplified Extended Health Belief Model.

The correlation matrix (as per table 15) was entered into the structural equation modelling programme (EQS/Windows) and the method of covariance analysis performed (EQS print out attached, Appendix D). Table 16 shows how the model was modified and the paths added to improve the fit of the data to the model.

Table 5.16 Results of Path Analysis for Extended Health Belief Model and Final Proposed Model

Iteration	*Chi Square*	*df*	*Sig.*	*AIC*	*CFI*	*RMSEA*	*Paths added*
Initial Model	120.47	40	.001	40.46	.48	.18	
Final Model	23.87	17	>.05	-10.13	.94	.08	V12, V2 V7, V6 V7. V4 V6, V3

Path analysis of the Extended Health Belief Model as tested by Aalto & Uutela (1997) demonstrated poor fit with the data from these participants. The Largest Standardised Residuals matrix indicated paths where possible misfit of the model may occur. Confirming these paths using the Lagrange Multiplier Test (for adding parameters) the following paths were added:

A path corresponding to a relationship between quality of life scores and diabetes-related empowerment scores.

This path is supported by research by Aalto, Uutela & Aro (1997) who investigated the impact diabetes locus of control, diabetes health beliefs, self-efficacy and social support had on quality of life in 385 adults with Type 1 diabetes and concluded that the most important factors involved in patient quality of life was positive social support and patient self-efficacy.

A path corresponding to a relationship between empowerment and 'powerful others' locus of control.

This path indicates that high empowerment scores correlate with high 'powerful others' locus of control scores. As high empowerment scores indicate low participant diabetes-related empowerment, this indicates that low participant empowerment predicts participant belief in 'powerful others' to obtain and maintain metabolic control. Interestingly, Aalto & Uutela (1997) combined the scores for 'powerful others' locus of control with scores for 'internal' locus of control as their argument was that a belief in 'powerful others' to control the diabetes was a positive belief and indicated the person's belief in the medical staff to offer a treatment regime that would control their diabetes. However, if belief in 'powerful others' is predicted by low diabetes-related empowerment, this does not bode well for the patient in developing the skills necessary to respond to their own diabetes needs on a daily basis. Combining the scores for the locus of control measures, the authors did not find a relationship between locus of control and empowerment (Aalto & Uutela, 1997).

A path corresponding to a relationship between diabetes-specific family support with participant 7-day recall of adherence with prescribed regime.

Research carried out by Skinner & Hampson (2000) with 43 young people aged 12-18 years found strong support for diabetes-specific family support predicting adherence to self-care tasks over a six month period ($t_{(42)} = 2.75, p<.01$). This is also supported by research conducted by Lloyd, Wing, Orchard & Becker (1993) with 592 people with diabetes aged 18 –60 investigating psychosocial correlates of glycaemic control. The authors found a strong correlation between scores on the DFBC and adherence to self-care tasks ($r=.14, p<.001$).

A path corresponding to a relationship between quality of life and 'internal' locus of control.

High scores on the Audit of Diabetes-dependent Quality of Life measure were predicted by high scores on the 'internal' locus of control sub-scale. This path is supported by research conducted by Aalto, Uutela & Aro (2000) in an adult population of people with Type 1 diabetes (n=385). The authors used hierarchical logistic regression analysis to investigate the predictors of health-related quality of life in adults with diabetes. High internal locus of control was a significant predictor of low pain experience which in turn predicted better reported health-related quality of life.

Paths removed corresponding to a relationship between perceived metabolic control and perceived life threat, and hypoglycaemia fear survey scores and perceived life threat

The paths constituting the 'cues to action' part of the EHBM were removed as these reduced the goodness of fit of the data to the model. These paths were between perceived metabolic control and perceived life threat, and Hypoglycaemia Fear Survey scores and perceived life threat. This mirrors the findings of Aalto & Uutela (1997) with adherence to diet. However, on their analysis of variables predicting adherence to blood glucose testing, the authors found direct paths from perceived metabolic control and hypoglycaemic symptoms to adherence (path values = .13 and .24 respectively) which were not mediated by participant's perception of life threat due to diabetes.

This revised model demonstrated good fit to the data with these participants and no further amendments were considered necessary or theoretically appropriate (EQS print out attached, Appendix E). The final model explained 16.2% of participant variance in adherence to their self-care regime. This compares well with the findings of Aalto & Uutela (1997) whose path models explained 14% of the variance in diet adherence and 21% of the variance in blood glucose testing.

Summary of significant paths for the revised version of the Extended Health Belief Model

Figure 7 (Appendix A) shows the diagrammatically simplified final model with path values. Therefore, the revised version of the Extended Health Belief Model suggests that for this participant group:

Perceived Life Threat of Diabetes

High life threat was predicted as proposed by the Extended Health Belief Model (Aalto & Uutela, 1997) and was predicted by participants exhibiting low family support (DFBC Scores) (path value $\beta = -.273$) and by high DSHB: Severity and Vulnerability scores (path value $\beta = .422$).

DSHB: Benefits and Barriers

High DSHB: Benefits and Barriers score was predicted by participants exhibiting high 'internal' locus of control (path value $\beta = .203$), and high 'powerful others' locus of control (path value $\beta = .244$), by good quality of life scores (path value $\beta = .425$) and by participants exhibiting high diabetes-related empowerment scores (path value $\beta = -.413$).

Diabetes Empowerment Scale

High diabetes-related empowerment scores were predicted by high quality of life scores (path value $\beta = -.434$) and low 'powerful others' locus of control scores (path value $\beta = .285$).

Audit of Diabetes-Dependent Quality of Life

Participants diabetes-dependent quality of life scores were predicted by high internal locus of control scores (path value $\beta = .245$).

Summary of Diabetes Self-Care Activities Scale

Good participant 7-day recall of adherence to their prescribed medical regime was predicted by high family support (as measured by the DFBC) (path value $\beta = .329$).

5.6 Discussion

5.6.1 Summary of main findings

The participants see their life expectancy due to diabetes as being 'somewhat shorter' than that of a person without diabetes and consider the control of their diabetes to be moderate to poor. Participants consider their current quality of life to be 'good' but feel their quality of life would be 'a little better' without diabetes. High life threat scores were predicted by high participant DSHB: Severity and Vulnerability scores and low diabetes-specific social support scores. High DSHB: Benefits and Barriers scores were predicted by participants high quality of life scores, high empowerment scores, high internal locus of control scores and high powerful others locus of control scores. Participant adherence to their diabetes self-care regime was predicted by high diabetes-specific social support scores. Those participants exhibiting poor metabolic control reported lower levels of diabetes-specific social support, higher levels of life threat due to diabetes, reported being in worse metabolic control and reported less worry about hypoglycaemia and less hypoglycaemia preventive behaviours.

5.6.2 Comparison of Findings to those of Aalto & Uutela, (1997) and Wdowik, Kendall & Harris, (1997)

The findings of this study are very similar to those of Aalto and Uutela (1997). The Aalto & Uutela study patient adherence was measured only in two fields: self-monitoring of blood glucose and diet adherence. The analysis conducted by Aalto & Uutela (1997) kept the adherence items separate, thus the analysis was re-run to predict a model based on diet adherence and a model based on adherence to the diabetes self-care task of self-monitoring of blood glucose in order for direct comparisons to be made. The final models for diet adherence and self-monitoring of blood glucose are enclosed in Appendix A, figures 8 and 9).

The models for diet adherence compare well, the patients exhibited high life threat of diabetes and considered their control of diabetes to be moderate to poor. High family support predicted severity and vulnerability to diabetes-related complications (path values = -.14; -.15 (Aalto & Uutela (1997); this study respectively throughout) and severity and vulnerability scores (path values = .37 ; .42); social support (path values

= -.14; -.27); locus of control scores (path values = -.18; -.02 to -.04) and empowerment scores (path values = -.24; -.22) predicted participant-perceived life threat due to diabetes. Participant locus of control scores (path values = .27; -.027 to .21) and participant empowerment scores (path values = .18; .44 (high scores on the Diabetes Empowerment Scale used in this study indicate low participant empowerment scores)) predicted participant benefit and barrier scores. Participant benefit and barrier scores (path values = .27; .05) and diabetes-specific social support (path values = .35; .23) predicted patient adherence to diet. The final model predicted 12.4% of the variance in adherence to diet (compared with 14% , Aalto & Uutela, (1997)).

The model suggested for adherence to self-monitoring of blood glucose also compared well to the model proposed by Aalto & Uutela (1997). High family support predicted severity and vulnerability to diabetes-related complications (path values = -.14; -.15 (Aalto & Uutela (1997); this study respectively throughout) and severity and vulnerability scores (path values = .37 ; .42); social support (path values = -.14; -.27); locus of control scores (path values = -.18; -.02 to -.27) and empowerment scores (path values = -.24; -.018) predicted participant-perceived life threat due to diabetes. Participant locus of control scores (path values = .27; .20 to .24) and participant empowerment scores (path values = .18; -.41 (high scores on the Diabetes Empowerment Scale used in this study indicate low participant empowerment scores) predicted participant benefit and barrier scores. Participant benefit and barrier scores (path values = .27; .04) and diabetes-specific social support (path values = .35; .27) predicted patient adherence to diet. The final model explained 13.1% of the variance in adhering to the self-care task of blood glucose testing (compared with 21%, Aalto & Uutela, (1997)).

In addition to the findings presented here, Aalto and Uutela did not find a relationship between participant-perceived metabolic control and adherence. However, although Aalto & Uutela (1997) did not find a significant relationship between diabetes-specific social support and adherence, the study conducted by Wdowik, Kendall & Harris (1997) did find a relationship between diabetes-specific social support and patient adherence to regime as well as supporting the finding that there is a relationship between participant scores on a benefits and barriers to regime measure and adherence.

5.6.3 Comparison of findings in relation to other published studies

The main indicators of adherence to self-care regime in this study were patient-perceived higher benefits to costs ratio of adhering to regime and high diabetes-specific social support. These findings are supported by previously published work.

The relationship between the benefits and costs measure of adhering to regime and patient reports of actual adherence to the diabetes self-care regime is supported by Bond, Aiken & Somerville (1992) and Coates & Boore (1998). Bond, Aiken & Somerville (1992) tested the predictive utility of the Health Belief Model with participants with Type 1 diabetes aged 10 to 19 years. The DSHB: Benefits and Barriers scale was used to assess the benefits and costs of adhering to regime. Results indicated that participant adherence to regime was correlated with DSHB: Benefits and Barriers ($r= .33$ to $.43$). Coates & Boore (1998) used the DSHB: Benefits and Barriers scale to investigate the influence of the perceived benefits and costs of adhering to regime on participant metabolic control. The participants in this study were aged 18 to 35 diagnosed with Type 1 diabetes. The results indicate that the participants considered the benefits to following the self-care regime as outweighing the costs of doing so. Coates & Boore (1998) also gave the participants the DSHB: Severity and Vulnerability scale to complete and found that the participants considered the severity of diabetes-related complications to be high and considered themselves moderately vulnerable to them. However, path analysis found no predictive ability of either scale on metabolic control as measured by HbA_{1C} readings. Unfortunately, Coates & Boore (1998) did not take a measure of adherence and, as indicated in previous chapters, the link between adherence and metabolic control is complicated. It would therefore be impossible to state whether this lack of impact on metabolic control can be explained by extraneous variance or through lack of effect on participant adherence.

5.6.4 Implications of Poor Metabolic Control

Long-term poor metabolic control is a serious issue with diabetes. As mentioned before, high HbA_{1C} readings result in retinopathy leading to blindness, neuropathy leading to poor blood flow in the extremities (fingers and toes) resulting in amputations, nephropathy leading to kidney failure, reproductive difficulties and coronary heart disease. Having diabetes reduces the life expectancy of a person in good metabolic control by 20 years and is the main contributor to the primary cause of death in this country through heart disease, so the effect on life expectancy on a person in poor metabolic control is dramatic and costly for the health service. The Diabetes Control and Complications Trial demonstrated that reducing HbA_{1C} readings by 1% resulted in reductions of between 40 and 70% in developing and/or the progression of health-related complications. It is also important for good metabolic control to be attained as soon as possible after diagnosis of diabetes. The sooner good metabolic control is attained, the better a person's metabolic control tends to be in the future and the fewer the diabetes-related health complications experienced.

For 22% of the sample in study one to be in such poor metabolic control is a difficult issue for the Diabetes teams working in the Southampton hospitals as both the Nurses and the Consultants are well aware that a person's HbA_{1C} reading is a strong indicator of the problems these young people are going to experience in the near future. Although the problems associated with poor metabolic control were repeated during each clinic visit, many young people continued to keep their HbA_{1C} readings high. Discussion with the Diabetes Specialist Nurses at the Southampton hospitals revealed some of the reasons young people give to support purposefully keep their HbA_{1C} readings high. Young people who were interested in sport were more likely to keep their HbA_{1C} readings high as, even though they were aware of the health costs of doing so, they were extremely unlikely to want to experience a hypoglycaemic episode during either training periods or competition events. Another main reason appeared to do with academic success. Young people studying for and taking GCSE and A Level examinations keep their HbA_{1C} levels high to avoid hypoglycaemic episodes affecting their memory during revision periods and examination periods as well as avoiding experiencing a hypoglycaemic episode requiring medical care during an examination. However, whatever the reason given, the opinion of the medical staff is that once a person's HbA_{1C} reading went beyond 10%, it is extremely difficult to persuade the person to work to reduce that reading.

As mentioned previously, high HbA_{1C} readings of 15% and above place the person at risk of experiencing ketoacidosis. Diabetic Ketoacidosis (DKA) occurs in approximately 10% of people with diabetes and results from severe insulin deficiency (from not taking the required insulin dose) and /or insulin resistance and displays as severe hyperglycaemia, ketoacidosis, dehydration and electrolyte losses which result in dehydration and shock in the person and loss of consciousness (Silink, 1998). DKA accounts for most hospitalisations in paediatric departments and is the most common cause of death – mostly due to the effect DKA has causing cerebral oedema (Rosenbloom & Harvas, 1996). Women experience more episodes of DKA requiring hospitalisation than men (Cohn et al., 1997) and in adults, DKA accounts for approximately 2% of deaths due to diabetes (Malone, Gennis & Goodwin, 1992). DKA needs to be treated within 30 minutes of presentation at hospital to reduce morbidity and mortality but the treatments administered (insulin and hydrating agents) need to be administered slowly in order to prevent cerebral oedema, of which the survival rates are approximately 50% (Brink, 1999). DKA has an important effect on young people, in particular in being associated with lower IQ and less good general cognitive function (Holmes & O'Brien, 1995).

Limited research has been conducted on young people experiencing DKA. Social psychological factors related to DKA include adherence, social support and attendance at clinic. A study conducted by Morris et al., (1997) indicated that DKA was related to poor adherence to self-care regime and poor glycaemic control in young people with Type 1 diabetes. Liss, Walker et al., (1998) investigated family support in 25 young people who were hospitalised with DKA and 25 young people without a history of DKA and discovered a strong link between poor social support and occurrence of DKA. Poor attendance at clinic has also been associated with DKA. In a study conducted by Jacobson et al., (1997), the young person's poor attendance at clinic was associated with lower socio-economic status, parental separation or divorce, poorer family support, worse metabolic control and subsequently experience of DKA. Therefore, incidence of DKA is predicted by low levels of social support and previous occurrence of DKA episodes. These findings tie in well with the findings of study one with good metabolic control characterised by high levels of social support, internal locus of control and high levels of psychosocial adaptation to diabetes.

5.6.5 Limitations

There are a number of limitations to this study. First, the response rate was low (N= 64, response rate = 40.25%) and therefore the conclusions one can draw from this study are restricted. Running this study again with participants from other NHS regions would help to increase the numbers and hence increase the power of the results. The participant group was not significantly different to the non-participant group on age and HbA_{1C} readings, so it may be presumed that the participants are representative of the larger population with diabetes in the South Hampshire region. Second, some of the data was not normally distributed and was skewed to either extreme on some of the scales. There was also quite a large distribution of some of the data on some of the scales (eg scores reflecting barriers to adhering with the diabetes self-care regime and scores on the Hypoglycaemia Fear Survey). However, on comparing the findings of this study with other published findings (presented in the results section), the scores were generally reflective of the larger diabetic population. The scores on the variables which were not normally distributed were not transformed to standardised scores as they were considered indicative of the scores normally found for this population. A third limitation of this study with regard to the participants is the large variation in number of years since diagnosis of diabetes. It would seem reasonable to expect a different experience of diabetes in those participants diagnosed in the first few years from birth to the experience of diabetes in those participants diagnosed in the late teen years to early twenties. Unfortunately, the low number of participants precludes any meaningful analysis of this effect to be undertaken.

A further limitation of this study could be within the coding of the ADDQoL. Participant scores on each ‘quality of life’ item are multiplied by their scores on the corresponding 'importance' item. If the participant scores '0' on the 'quality of life' items (indicating that this aspect of their life would be no different if they did not have diabetes) then the participant consequently scores '0' overall for the question. However, the participant may score the importance of that aspect of their life as '3' (indicating that this is very important to the participant) but this is not reflected in the overall score for the question. The situation can also be reversed if the participant scores the importance of that aspect of their life as '0' when in turn the indicate that the aspect would be very different if they did not have diabetes (indicated by a score between –3 to +3). The final score for the ADDQoL for each participant may not necessarily reflect the importance of the items contained or equally, not reflect the impact of that item.

Re-coding the ADDQoL scores was performed where scores on the domain-specific questions scores from –3 through 0 to +3 were re-coded as scores from 7 to 1 and scores on the 'importance' part of each domain question were re-coded from 3 to 0 as scores from 4 to 1. This created a new maximum score obtainable on each question of 21 and a minimum score available of 1. Analysis of these revised scores produced mean scores of 14.42 with a standard deviation of 3.73. The correlation matrix was reconstructed using the revised ADDQoL scores and path analysis conducted starting with the Extended Health Belief Model structure. The findings suggest that changing the values attributable to the scores on the ADDQoL had little effect on the fit of the data (and indeed worsened it slightly) to the final model (Chi Square = 24.25, df = 17, Model AIC = -9.57, CFI = .93, RMSEA = .08) and therefore the original scoring of the measure was kept for all analysis with this data set.

The coding of the Diabetes Locus of Control scale may also present a problem. In this study, the participant scores for 'internal' locus of control, 'powerful others' locus of control and 'chance' locus of control were kept as separate scores and treated as covariances in the path analysis. In the Aalto & Uutela (1997) paper, the scores were treated quite differently. Aalto & Uutela considered both the 'internal' locus of control scores and the 'powerful others' locus of control scores to be important to the management of diabetes and combined the scores to form an overall 'control' locus of control score. The participant scores on the 'chance' locus of control sub-scale were then taken away from the 'control' locus of control score to provide the authors with a 'control' locus of control score relative to the 'chance' locus of control score. However, the results of both this study and Aalto & Uutela (1997) were very similar in that they both found significant pathways between the locus of control scores and life threat, and between the locus of control scores and the benefits and barriers to adherence scores. In this study only, significant paths were found between locus of control scores and DSHB: Severity and Vulnerability scores, providing evidence for the link presented in the Extended Health Belief Model.

Diabetes-specific social support was measured by the Diabetes Family Behaviour Checklist (Schafer, McCaul & Glasgow, 1986). Looking at the living arrangements of the participants it appears that approximately half lived within the family environment (27 of the 64 participants). This suggests that the DFBC was not an appropriate measure of social support for the remaining 37 participants, especially for those living independently or within a shared house environment. Social support is an important factor in adherence to the diabetes self-care regime both in the final model presented here and in the Aalto & Uutela study, so a more accurate measure of social support for those participants not living within the family environment would be more suitable.

A final limitation of this study became apparent on receipt of the completed surveys. The participants had difficulties completing some of the items of the Summary of Diabetes Self-Care Activities Scale. All participants were aware of the need for insulin injecting and blood glucose testing, but some wrote on their surveys that they were not aware of their prescribed self-care regime for diet and exercise adherence and foot care. Many requested further information and leaflets purporting to describe the appropriate care regime for these aspects, but participant self-report adherence to these was understandably low. This highlights an area for attention in the clinic setting for these young people. In conjunction with this, the measure of metabolic control (HbA_{1C} reading) was, for many participants, not a recent reading. That there was no relationship found between adherence to self-care regime and actual metabolic control is not surprising when the measure for adherence was based on a 7-day recall of events and, for some, the latest reading available for metabolic control dated anything up to two years previous to the study.

Common Method Variance

One limitation of research conducted purely with the target population is that of common method variance. Without measures from the parents, spouse or siblings of the participants, it is difficult to obtain any notion of how reliable and valid the scores obtained from the measures are in representing a true picture of the social psychological factors at issue. This study has used self-report measures throughout – including self-report of diabetes-specific family support and adherence to self-care regime. Therefore, all that is available for analysis is the participant's perception of, for example, what supportive behaviours are exhibited by the family and how supportive these behaviours may be. Often parental support for health behaviours may not be interpreted as supportive, or may indeed not be recognised as present by the young person. The self-report measure of adherence too is likely to be at risk for inaccuracy. Possibly the young person may consider over-reporting their adherence to the self-care regime if they feel it would present an image of a 'better behaved' person with diabetes to the person scoring the survey. If the reports of adherence to self-care regime could be combined with parental or spouse reports of adherence to self-care regime, a more realistic score might be obtained.

A further issue with the common method variance problem is that of finding correlations between variables that may be spurious yet are present because all measures are completed by the same person at the same sitting. Any inflections of mood and/or circumstance are hence going to affect the self-report measures to the same degree. It is well documented that a side-effect of experiencing poor metabolic control (which 20% of the sample were experiencing) is feelings of mild depression and anxiety which in turn are going to affect how the participant interprets their experience of diabetes at that time – in particular scores of severity and vulnerability to diabetes and its complications, notion of benefits and costs to adhering to the self-care regime and possibly scores on the quality of life and empowerment scales. A study conducted by Lloyd, Dyer & Barnett (2000) found 28% of the young people with diabetes (aged over 18 years, N=109) reported moderate to severe levels of depression or anxiety or both on the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1993). A study conducted with younger people with diabetes (aged 12-18 years, N = 42) revealed that girls were in worse metabolic control than boys (Mean HbA_{1c} girls = 10.17, SD= 2.5, Mean HbA_{1c} boys = 8.59, SD= 1.9, $F_{ratio} = 4.74$, $p<.05$) and reported more symptoms of depression measured by the Beck Depression Inventory – Revised version (Mean scores girls = 5.04, SD= 4.3, Mean scores boys = 1.27, SD= 1.2, $F_{ratio} = 11.06$, $p<.01$) and anxiety measured by the State-Trait Anxiety Inventory – Revised version (Mean scores girls = 35.00, SD= 8.8, Mean scores boys = 28.73, SD= 5.2, $F_{ratio} = 6.17$, $p<.05$) (La Greca et al., 1995).

5.7 Conclusions

The EHBM provided a good theoretical starting point to understanding the experience of diabetes in young people. However, the final model indicates that the processes underlying adherence to the diabetes self-care regime is far more complex than previously indicated. The models proposed for total adherence to diabetes self-care tasks, adherence to prescribed diet and to the self-care task of blood glucose testing explained 18.5%, 12.4% and 13.1% of the variance in each outcome respectively and each model was supported well by the published work of Aalto & Uutela (1997) and others.

An overview of the main findings of this study indicate that high levels of family support and low locus of control beliefs in powerful others to control their diabetes reduce the young person's perception of severity and vulnerability to diabetes-related complications. High levels of family support and high quality of life scores predicted low life threat due to diabetes. High internal locus of control beliefs and high levels of diabetes-related empowerment predicted that the young person would see the benefits or adhering to the self-care regime as outweighing the costs of doing so and finally, adherence to self-care regime was predicted largely by high levels of family support.

An interesting finding was the lack of support for paths between participant perceived metabolic control and hypoglycaemic worry and behaviour scores with participants perceived life threat due to diabetes or adherence to self-care regime. Aalto & Uutela (1997) found these paths only with participant adherence to the self-care task of blood glucose testing but again, these paths were direct and not mediated by participant perceived life threat due to diabetes. Indeed, only participant perceived metabolic control influenced participant perceived life threat due to diabetes in the model for adherence to the self-care task of blood glucose testing, but the authors found no path between participants perceived life threat due to diabetes and actual adherence with the self-care task of blood glucose testing. In fact, the authors found no path between participant perceived life threat due to diabetes and participant adherence with diet recommendations either. The consistent path to adherence for both self-care behaviours was an appraisal of the severity of and vulnerability to diabetes-related complications which predicted participant's perceived life threat due to diabetes which in turn was predicted by the participant's locus of control. These scores predicted the participant's appraisal of the benefits and costs of adhering to the self-care regime which, in combination with diabetes-specific social support, predicted participant adherence with diet.

The issue of common method variance is problematic in this study. Parental or spouse/partner reports on certain of the measures would help reduce the effect this has on the findings. A possible measure to use could be a revised version of the Diabetes Family Behaviour Checklist – written from the parent /spouse viewpoint– to indicate the level of support the parent or spouse consider they are providing to the young person with diabetes. Another could be a version of the Summary of Diabetes Self-Care Activities scale - again written from the parent /spouse viewpoint – to indicate the level of adherence to self-care routine occurring. This measure could be problematic however if the parent or spouse is unsure what the activities are and the frequency with which the young person undertakes with respect to their diabetes. There will be intrinsic difficulties in obtaining parent /spouse measures on aspects of the Extended Health Belief Model with respect to diabetes as the measures used to assess each variable are so diabetes-specific as to render a parent /spouse appraisal near impossible. It would be difficult to appraise the young person's experience of diabetes from the viewpoint of a person without diabetes who, in the case of the parent, may also be much older.

The way forward would be, therefore multifaceted. This study needs repeating to try and replicate these findings in a different, matched population of young people with diabetes and see if the models proposed for adherence to diabetes self-care activities hold. Replicating these findings will not only lend validity to the use of the measures with young people aged 16-25, but also to the model proposed explaining the variance in adherence in this population. Replication will also indicate whether the finding that participant perceived metabolic control and hypoglycaemia worry and behaviour scores do not predict participant's perceived life threat due to diabetes, is consistent with young people with diabetes. This finding is supported by the work of Aalto & Uutela (1997) and more recent work published by the authors (Aalto, Uutela & Aro, 2000) also supports the influence of social psychological factors affecting adherence to the diabetes self-care regime within the framework of the Extended Health Belief Model.

The issues raised by participants taking part in this study also need to be further investigated. Some participants added personal comments to the questionnaires reflecting on their experience of diabetes. To do this, a qualitative semi-structured interview study will determine any specific areas not covered by the quantitative study 1 and its replication (presented as study 3). The findings of the qualitative study combined with the findings of study 1 and study 3 will inform the progression of research into the fourth and final study of this thesis.

This study has demonstrated the effectiveness of investigating the experience of diabetes in the young person within the theoretical framework of the Extended Health Belief Model and on consideration of the alternative theoretical models to explain health behaviour, it is proposed that the Extended Health Belief Model is an adequate model for understanding the social psychological factors present in the young person's appraisal of their diabetes which in turn influence the young person's adherence to the diabetes self-care regime. Unfortunately, adherence to the self-care regime did not predict outcome in terms of metabolic control but, as discussed previously, there was such variation in the date of HbA_{1C} testing that meaningful analysis could not be made. The participants were encouraged to apply for HbA_{1C} testing on completion of the survey but could not be pressed to do so for ethical reasons. The level of support for the study from the paediatric and adult diabetes centres was very strong but perhaps greater collaboration with the paediatric and adult diabetes services may have resulted in obtaining more recent measures of metabolic control but time and work pressures of the staff, as well as the on-going problem of non-attendance at clinic in each centre precluded this.

Study 2: Qualitative Investigation of the Experience of Diabetes in Young People

6.1 Rationale for Study 2

Although the previous study has provided a large amount of information describing the psychological experience of young people with diabetes, questionnaires can only tap into limited aspects of the young person's lives. The Extended Health Belief Model provides a comprehensive, holistic view of personal and social factors influencing the young person's beliefs about the seriousness of their diabetes and their ability and willingness to adhere to the current medical regime to control their condition, however, it does not cover aspects of the day-to-day living with diabetes considered important by young people. It is a model useful for appraising the social and cognitive processes involved in assessing one's health status and consideration of the need and effectiveness of activating health behaviour in response to health status, but, as many of the participants pointed out, there is more to living with diabetes than a continuous appraisal of health status and carrying out health behaviours.

Participants were given the option to include comments and statements indicating areas which they considered had not been covered by the questionnaires. In study 1, six participants included details of their experience of diabetes which they felt had not been covered by the study. These comments were noted and the issues raised formed the basis of Study 2. Details about these comments are given below. It was considered important to investigate these issues by semi-structured interviews with the young people. As discussed in the previous study, the Extended Health Belief Model appears to explain the experience of those young people in good metabolic control more than it does young people in poor metabolic control. To investigate further why this was the case, the interviews were arranged so that patients in poor metabolic control ($HbA_{1C} > 10.0\%$) were approached with a matched sample (matched for age, gender and duration of diabetes) in good metabolic control (HbA_{1C} 5-8%).

6.2 Method

6.2.1 Participants

Participants were aged between 16 and 25 years (mean = 21.47, 22 = male) and registered with either the Southampton General Hospital, the Royal South Hants Hospital, Royal Hampshire County Hospital or the North Hampshire Hospital. All participants were selected from the pool who had responded to the questionnaire studies. The number of patients in poor metabolic control (HbA_{1C} > 10.0%) was 15 and the number of patients in good metabolic control (HbA_{1C} 5.0-8.0%) was 18. Patients in good metabolic control were matched to the patients in poor metabolic control by age, gender and duration of diabetes. The number of patients in each group who responded as willing to participate in the interviews was 11. The response rate was therefore 33%.

6.2.2 Materials

The extra comments added to the questionnaire study by participants were thematically analysed to provide structure for the proposed interviews. The comments were typed and identification codes added. Codes were considered necessary to aid future location of the original comments from within the pool of data provided by this series of studies. The comments were then subjected to thematic analysis. The interviews were read through twice, the comments made in response to each question asked were kept together and each comment was coded once only. Themes were assigned to each comment and comments collected from different participants with the same theme were grouped together. The comments were coded according to their theme and the themes identified and the allocation of comments to these themes were agreed upon by two researchers. Examples of the comments and themes are included below:

Themes identified from comments/correspondence attached to completed returned questionnaires

1. Depression

'I don't think I will ever come to terms with diabetes, I do try to just get on with life but it can be very hard… the main thing that keeps my chin up is my boyfriend and my two children. I get very depressed at least once a month about having diabetes…' (E.L.C)

'I wouldn't wish it on anyone…' (P.F.)

'All my life I have felt isolated due to not knowing enough… diabetes with a visual impairment…' (E.M.)

'I hate my diabetes and what it has done to my life. Last year I was put on anti-depressants and have recently come off them. My diabetes was not the only reason I was on them, but it was certainly a main contributor… I hate my life since being diagnosed and often cry and get angry with myself for becoming diabetic. I cannot describe the effect it has on my life, it is just terrible and I hate myself completely for it and wish that it would just go away…' (H.K.S)

2. Fear

'I hate injections… I also forget to do my blood tests… I miss my hospital appointments … I am always worried about what might happen to me because of diabetes…' (E.L.C)

3. Positive points

'I love exercise but I also love my food (and sweets which is not good!)… I do eat healthy food and I love walking etc.' (E.L.C)

'I think the key to good diabetes control is following some sort of routine ie meals at the same time, but routines don't have to be restrictive!…' (C.A.)

4. Diabetes management

'… it just does my head in all the timing of things and making sure I do everything… as far as going out is concerned I always worry about my blood… I can't relax and get on as normal.' (E.L.C)

'My diabetes does, as far as I am concerned, restrict my life. The only regime that seems to work for me is four injections… I also feel really frustrated by my blood sugar levels…' (E.M.)

5. Relationships

'I get chatting to girls, I mention diabetes and all of a sudden they are gone… it's happened time and time again, now I just don't bother.' (P.F)

6. Others' response to diabetes

'People hear all these stories of legs, fingers, toes falling off and all the diabetic fits shaking on the floor, that's all they think about the moment I mention it... well of course, they don't wanna know...' (P.F)

'Some of my friends I didn't tell for a year, you should have seen their faces when I told them – 'looked like someone beat them cross the face with a bar'

'You never see a diabetic on TV in a good light, always bad...' (P.F.)

7. Parents' response to diabetes

'when you're little, you're wrapped up in cotton-wool to the point you can't move... that killed my social life at school... that hurt! The others all went off to Longleat, I stayed home because mum didn't wanna risk it and the teachers didn't want to take me either because they classed me a risk themselves.' (P.F.)

8. Medical profession's response to patients with diabetes

'The medical profession never really understand what it is like actually living with it...' (E.M.)

'I feel that the service at... at the moment is appalling... find it a complete bore to sit in their waiting room for over an hour and a half just to be told everything is ok!...' (H.K.S)

'When I was first diagnosed with diabetes, my mum and I were not at all happy about the way we were treated by the hospital consultant and nurse specialist...' (R.H.)

'I think that it is wrong to scare-monger young people into controlling their diabetes by telling them horrific and worrying stories...' (R.H.)

patient	*age as of Nov 2000*	*HbA_{IC}*	*duration of diabetes*
E.L.C.	*19*	*6.4%*	*duration 9 years*
P.F.	*19*	*14.3%*	*duration 17 years*
E.M.	*23*	*8.49%*	*duration 22 years*
H.K.S.	*16*	-	*duration 4 ½ years*
C.A.	*21*	-	*duration 10 years*
R.H.	*16*	*6.5%*	*duration 3 years*

HbA_{IC} : 5-8% = good metabolic control / 8-10% = moderate / 10-15 = very poor

From these important comments and themes, a structure for the proposed interview was developed to investigate further the psychological experience of young people with diabetes:

Interview Themes Schedule

1. Diabetes management

How do you go about managing your diabetes?
What do you find easy / hard to do?

Do you have a daily routine for managing your diabetes?
How do you manage to keep to this routine?
What makes it easy/difficult to do so?

2. Family involvement

How do you family get involved in the care of your diabetes?
What helps / What deters you from managing your diabetes?

How do you parents in particular get involved in the care of diabetes?
What helps / What deters you from managing your diabetes?

3. Others response

Similar questions as before but relate to:
Work colleagues / College friends / Love relationships

4. Medical profession

Would you describe your experience of coming to clinics for help with your diabetes care
What do you find beneficial / not beneficial?
What would you like to see?

5. Fears

What are your fears related to diabetes?
What would help alleviate your fears?
What, if anything, are you doing to help this situation?

6. Emotions – depression, anxiety, well-being etc..

What moods do you experience related to your diabetes?
Do you feel sad or angry / Do you feel generally well?
Do you feel positive moods?

7. Positive points

Can you think of any good points about having diabetes?
Do you feel you achieve perhaps to 'prove a point'?
Do you feel you can still live a normal life whilst having diabetes?

8. Hopes and fears for the future

What are your feelings about your future?
How do you think having diabetes is going to affect your future?
Life threat / Mobility / Close relationships

9. Any other issues

Do you have anything else you would like to say about having diabetes?

6.2.3 Procedure

Participants were selected according to their latest HbA_{1C} reading. Those with a high HbA_{1C} (great than 10.0%) were selected for the group of participants exhibiting poor metabolic control (group 1) and those with a low HbA_{1C} (between 5.0 and 8.0%) were selected for the group of participants exhibiting good metabolic control (group 2). Those participants in group 2 who matched those in group 1 for age, gender and duration of diabetes remained in the second group. Those who did not were not approached to participate in this study.

Participants were approached by introductory letter explaining the rationale behind the study and requesting permission to contact the participants to engage in the interviews. Participants returned a consent slip to be contacted and interviews were set up at the participant's convenience. Interviews were conducted either at home or at work or by telephone. Consent was obtained for the interviews to be tape-recorded to aid facilitation of later transcription. Interviews were begun by asking participants the question 'How do you feel about having diabetes?' and continued with prompting by the researcher until all the themes indicated on the interview schedule were covered. The interview was brought to a close by asking the last question 'Is there anything else you would like to say on how you feel about having diabetes?' and when the participant agreed they had covered what they wanted to disclose about having diabetes, the interview was considered finished.

On completion of the interviews, the tapes were transcribed and the participant's comments clustered under each question and sub-question indicated on the interview schedule. Comments were sub-grouped by whether they came from a participant in group 1 (poor metabolic control) or from a participant in group 2 (good metabolic control). The comments were then thematically analysed.

6.3 Results

Reading through the comments made by the participants in response to the questions it was difficult to say whether the participants in group 1 (good metabolic control) were encountering different situations or describing a different experience to those participants in group 2 (poor metabolic control). Thematic analysis was applied to all the comments generated and the proposed themes and example supporting comments are presented below.

1. Diabetes management

How do you feel about having diabetes?

Theme 1: Acceptance

e.g. '… just kind of get on with it…' [RS]

'…it's part of my life now…' [EM]

Theme 2: Non-acceptance

e.g. '… it's a bit of a pain and I get fed up with it…' [SS]

'I don't like having diabetes.' [PH]

How do you go about managing your diabetes?

Theme 1: Routine

e.g. 'I just take my insulin, I check it [blood sugars] and I just sort of try and make sure I eat a healthy diet…' [PW]

' … it really is just one routine…' [GB]

Theme 2: Responsive

e.g. 'I'll test if I think I'm very [blood sugars] low… or if I think I'm a bit high…' [LF]

'… when I did start injecting, I did test everyday, but yeah, I've got used to it now and I'm like… inject now.' [LM]

Theme 3: No routine

e.g. '… there is no routine…' [PH]

Do you have a daily routine for managing your diabetes?

Theme 1: Routine

e.g. '... most of the time I keep to a regular routine...' [PW]

'I check my blood sugars every time I do an injection... and then I adjust my insulin accordingly.' [EM]

Theme 2: Responsive

e.g. '...I know what I'm feeling like, like what my blood sugar is, what to take and when I need it, what to control and I just get on with it...' [RS]

'I can tell if I'm going a bit high by the taste in my mouth and I'll see, yeah I've gone a bit high and try and sort it...' [LG]

2. Family involvement

How do your family get involved in the care of your diabetes?

Theme 1: Practical help

e.g. '... my mum writes to me and tells me to control my sugars better!' [AC]

'... she'll [mum] quickly remind me or if I like, don't appear well, she'll remind me to test my sugar level.' [AT]

Theme 2: Lack of understanding

e.g. '... my brother-in-law doesn't really understand...' [LF]

How do your parents in particular get involved in the care of diabetes?

Theme 1: Practical help

e.g. '... they're a bit like... you've got to take your insulin every day...' [RS]

'My mum, she's really, really good, she reads up on everything and reads all the latest Balance [Diabetes UK magazine] books.' [GB]

Theme 2: Emotional support

e.g. 'Yeah, they phone to have a chat, not about the diabetes because they know I'm fine with it, but they keep in touch.' [EM]

Theme 3: Negative interactions

e.g. '... my mum was very like... wrap her in cotton wool, she's got diabetes... and wouldn't let me take control...' [SS]

'... all I get is a lecture every time I go round...' [PH]

3. Others response

How do your work colleagues get involved in the care of your diabetes?

Theme 1: Supportive

e.g. '... lots of my friends at work... they've all had to bring me round... [they're] very good, switched on...' [AC]

'... everyone's cool...' [LM]

Theme 2: Negative – work opportunities

e.g. '... I haven't been able to get the jobs...' [RS]

'... they say you know, you're physically fit but not medically fit...' [RS]

Theme 3: Negative – difficult social outcomes

e.g. 'I've made quite a few friends... but it's always come on out for a drink and it's always loads... they're always drinking in rounds... I don't know how bad it is for me...' [LG]

How do your college friends get involved in the care of your diabetes?

Theme 1: Acceptance

e.g. 'They're fine... they don't have a problem with it really.' [EM]

'Yeah, they don't really mind.' [AT]

How do your love partners get involved in the care of your diabetes?

Theme 1: Acceptance

e.g. 'She's fine, just the same as everyone else.' [RS]

Theme 2: Active support

e.g. 'He's been brilliant... really, really good... took time off work to look after me...' [LF]

'... he says to me – have you done your injections - and things like that' [SS]

Theme 3: Not understanding

e.g. 'umm... not really...I mean, if I feel high or low, he does understand, but not really he doesn't...' [GB]

Theme 4: Avoidance

e.g. 'I don't tell girlfriends until about 2 weeks in to the relationship...' [PH]

How do other people get involved in the care of your diabetes?

Theme 1: Not actively supportive

e.g. '... most of the instructors [at the gym] know I'm diabetic, but... I know probably half an hour to an hour before I get to the falling on the floor stage [hypo] so...' [RS]

Theme 2: Not understanding

e.g. '... they look at you as if to say oh, I thought you were better. I am, but well, this is what I've got to do...' [LF]

'I say I'm diabetic and people freak...' [PH]

Theme 3: Avoidance

e.g. 'I try to avoid telling people if at all possible, I don't want to explain it.' [PH]

4. **Medical profession**

Would you describe your experience of coming to clinics for help with your diabetes care

Theme 1: Personal dissatisfaction

e.g. '… no, I go to see my doctor… I had a bit of a disagreement with the consultant…' [RS]

'… it was a really scary experience…'

' … they've been so rude and patronising towards me.. I just think, I've had this for 13 years, I know what I'm doing, I'm not stupid…' [EM]

Theme 2: Feel in wrong clinic

e.g. '… they're [patients] all old…really old people… I want to be in a clinic with young people…' [SS]

'… it's usually filled with old people, in fact, I don't know anyone in the whole are who's diabetic…' [AC]

Theme 3: Obligation

e.g. '… they do the job they're supposed to, but I find it a bit of waste of my time… it's a bit of a chore…' [PW]

'I'm only here because I have to be here… I don't get anything out of it you know…' [LF]

Is there anything you would like to see at a clinic that you're not getting now?

Theme 1: Clinic style

e.g. 'It's quite strange at times… I'm getting used to it now…' [AC]

'It's just scary! I would prefer my own age group to go to clinic with…'[SS]

Theme 2: More information – health related

e.g. '… no-one's ever discussed the future with me… like 10, 15, 20 years down the line…' [LF]

'I don't know…frighten the youngsters or something… more flyers…' [LG]

Theme 3: More information – product related

e.g. '… they don't sort of tell you…like a new product on the market…' [PW]

Theme 4: Emotional support

e.g. '… you need a little bit of reassuring, am I going to be alright?' [LF]

'… they're not actually… your emotional side of anything is not actually… 'how are you?' means have you been a good girl and not eaten the wrong things…' [LF]

Theme 5: Age-specific clinic

e.g. 'I would prefer my own age group to go to clinic with…' [SS]

5. Fears

What are your fears related to diabetes?

Theme 1: Acceptance of risk of complications

e.g. '… I just get on with it…' [RS]

'… I'm not going to worry about the complications yet…' [EM]

Theme 2: Physical complications

e.g. 'I have concerns about your sight…' [LM]

'My feet… I'm paranoid about my feet…' [SS]

'… my eyes are desperately deteriorating…' [LG]

Theme 3: Restriction of future activity due to complications

e.g. 'It worries me the fact that I'm going to deteriorate and not probably going to be able to do what I want to…' [PW]

Theme 4: Mortality

e.g. '… I'm always thinking about one day if I'm going to die or not…' [AT]

6. Emotions – depression, anxiety, well-being etc..

What moods do you experience related to your diabetes?

Theme 1: Lethargy

e.g. '… if my blood sugars up high I feel very lethargic…' [RS]

'… if I'm high [blood sugars] then I'm tired and I don't do so well at work…' [LG]

Theme 2: Aggression / Anger

e.g. '… I was quite short-tempered…' [RS]

'… I get really ratty with people…' [SS]

Theme 3: Frustration

e.g. 'I get frustrated at others people's attitudes towards me…' [AC]

'… it's slightly frustrating… generally the sort of things you can't do…' [PW]

Theme 4: Depression

e.g. '… you get a bit depressed about it and think, 'why me?' …' [SS]

'… sometimes it really bugs me… I can absolutely hate it…' [EM]

Theme 5: Tiredness

e.g. '… I feel tired… I don't feel like doing anything… I just want to lie there…' [LG]

7. Positive points

Can you think of any good points about having diabetes?

Theme 1: Free prescriptions and medical care

e.g. '… free prescriptions!' [RS]

'… they tend to pick up on lots of small health problems… which I wouldn't know about or things about…' [PW]

Theme 2: Self-aware – health related

e.g. 'I think you gain a better understanding of your body…' [LF]

'… you tend to know yourself a bit better…' [GB]

Theme 3: Adhere to healthy life-style

e.g. 'I think it makes you eat healthily and it makes you eat as well…' [EM]

'… I do eat healthier…' [LG]

Theme 4: No good points

e.g. '…no… it's a burden on your shoulders… I wouldn't give it to my worst enemy to be honest…' [RS]

'Good points.. no.' [PH]

8. Hopes and fears for the future

What are your feelings about your future?

Theme 1: Mortality

e.g. '… it will shorten my life span…' [RS]

Theme 2: Physical health complications

e.g. '… you have to have absolutely perfect blood sugar before you even get pregnant and then … the whole concept of my baby being diabetic…' [LM]

Theme 3: Denial / avoidance

e.g. '… I hope not to have any complications… hopefully there will be something soon that will make it all a bit easier to manage… that's what I'm hoping for…' [EM]

Theme 4: Guilt

e.g. 'One thing that does bother me is my little boy. I'd feel ever so guilty [if he got diabetes], ever so guilty…' [LF]

Theme 5: Acceptance

e.g. 'I just take each day as it comes… there's no miracle cure for it.. that's going to help me now… carry on and do the best you can…' [SS]

Theme 6: Frustration

e.g. '… they [other people] can go out and drink and it doesn't mean that in 20 years time they're going to lose their eye-sight or a limb or something like that..' [LG]

9. Any other issues

Do you have anything else you would like to say about having diabetes?

Theme 1: Career prospects

e.g. '… the career is the main thing… somebody turning around and saying no because of something that's out of your control…' [RS]

Theme 2: Maintaining / establishing good metabolic control

e.g. 'I find it really hard…' [AC]

'I've always had trouble with diabetes…' [PH]

Theme 3: Meet people own age

e.g. 'I've never met anyone my own age with diabetes…' [LF]

Theme 4: Counselling

e.g. 'I've been offered counselling for my diabetes. I think in some ways, that would be good for some people, get a few things off their chest…' [SS]

Theme 5: Knowledge

e.g. 'I think they just generally don't understand…' [PH]

Theme 6: Minimise impact of diabetes

e.g. '… I feel diabetes is like asthma… every so often it'll give you a hard time, and then after you've seen to it, you're alright. You can live with it.' [PH]

The frequency of each comment was then recorded by the experimenter for participants reporting good metabolic control and poor metabolic control. A second person also completed the task to provide reliability for the frequency scores. The frequencies recorded by the experimenter and the second scorer (scores provided in parentheses) are indicated in the table below:

Table 6.1 Frequency of comments within themes by group membership – group 1 (good metabolic control), group 2 (poor metabolic control)

Question / Theme	Group 1 No. responses	Group 2 No. responses
How do you feel about having diabetes?		
Theme 1: Acceptance	5 (5)	3 (3)
Theme 2: Non-acceptance	0 (0)	2 (2)
How do you go about managing your diabetes?		
Theme 1: Routine	1 (1)	2 (1)
Theme 2: Responsive	2 (2)	0 (0)
Theme 3: No routine	0 (0)	2 (3)
Do you have a daily routine for managing your diabetes?		
Theme 1: Routine	2 (2)	1 (1)
Theme 2: Responsive	1 (1)	2 (2)
How do your family get involved in the care of your diabetes?		
Theme 1: Practical help	3 (3)	1 (1)
Theme 2: Lack of understanding	1 (1)	1 (1)
How do your parents in particular get involved in the care of your diabetes?		
Theme 1: Practical help	2 (2)	1 (1)
Theme 2: Emotional support	1 (1)	0 (0)
Theme 3: Negative interactions	0 (0)	2 (2)
How do your work colleagues get involved in the care of your diabetes?		
Theme 1: Supportive	4 (4)	1 (1)
Theme 2: Negative – work opportunities	2 (2)	0 (0)
Theme 3: Negative – difficult social outcomes	0 (0)	2 (2)
How do your college friends get involved in the care of your diabetes?		
Theme 1: Acceptance	1 (1)	1(1)

How do your love partners get involved in the care of your diabetes?		
Theme 1: Acceptance	2 (2)	0 (0)
Theme 2: Active support	3 (3)	1 (1)
Theme 3: Not understanding	0 (0)	1 (1)
Theme 4: Avoidance	0 (0)	1 (1)
How do other people get involved in the care of your diabetes?		
Theme 1: Not actively supportive	1 (1)	0 (0)
Theme 2: Not understanding	2 (2)	1 (1)
Theme 3: Avoidance	0 (0)	1 (1)
Would you describe your experience of coming to clinics for help with your diabetes care?		
Theme 1: Personal dissatisfaction	3 (3)	2 (2)
Theme 2: Wrong clinic	1 (1)	1 (1)
Theme 3: Obligation	1 (1)	0 (0)
Theme 4: Satisfied	2 (2)	2 (2)
Is there anything else you would like to see at a clinic that you're not getting now?		
Theme 1: Clinic style	2 (2)	3 (3)
Theme 2: More information – health related	1 (1)	1 (1)
Theme 3: More information – product related	1 (1)	0 (0)
Theme 4: Emotional support	2 (2)	0 (0)
Theme 5: Age-specific clinic	0 (0)	2 (2)
Theme 6: Nothing	2 (2)	1 (1)
What are your fears related to diabetes?		
Theme 1: Acceptance of risk	2 (3)	0 (0)
Theme 2: Physical complications	3 (3)	4 (4)
Theme 3: Restriction of future activities	1 (1)	1 (1)
Theme 4: Mortality	0 (0)	1 (1)
What moods do you experience related to your diabetes?		
Theme 1: Lethargy / tiredness	1 (1)	2 (2)
Theme 2: Aggression / anger	3 (3)	2 (2)
Theme 3: Frustration	2 (2)	0 (0)
Theme 4: Depression	2 (2)	2 (2)
Can you think of any good points about having diabetes?		
Theme 1: Free medical care	3 (3)	1 (1)
Theme 2: Self aware	3 (3)	1 (1)
Theme 3: Healthy life style	1 (1)	1 (1)
Theme 4: No good points	1 (1)	4 (4)

What are your feelings about your future?		
Theme 1: Mortality	1 (1)	0 (0)
Theme 2: Health complications	2 (2)	1 (1)
Theme 3: Denial / avoidance	2 (2)	0 (0)
Theme 4: Guilt	1 (1)	0 (0)
Theme 5: Acceptance	0 (0)	1 (1)
Theme 6: Frustration	0 (0)	1 (1)
Do you have anything else you would like to say about having diabetes?		
Theme 1: Career prospects	1 (1)	0 (0)
Theme 2: Metabolic control	1 (1)	0 (0)
Theme 3: Meet people own age	1 (1)	0 (0)
Theme 4: Counselling	0 (0)	1 (1)
Theme 5: Knowledge	0 (0)	1 (1)
Theme 6: Minimise diabetes	0 (0)	1 (1)

6.4 Inter-rater Reliability

The comments collected during the interviews were then made totally anonymous and, with the coding sheet, given to another researcher in the field for duplicate coding. Agreement between researchers for the coding of the comments was 98.2% for the participants in good metabolic control, 96.4% for the participants in poor metabolic control and 97.3% overall. Agreement was reached on the few areas of dispute and it was accepted that agreement between the researchers for the coding was high and the coding categories accepted.

6.5 Summary of Findings

Although participant numbers were low, some differences can be seen between the two groups. Those participants in good metabolic control were more accepting of their diabetes, had both a daily routine for managing it and felt able to respond to their insulin requirements if necessary. The family were more likely to offer them support both in practical terms and emotional needs. Participants in good metabolic control were more likely to discuss their diabetes with their work colleagues and love partners and found them accepting and actively supportive. Participants in both groups indicated dissatisfaction with the diabetes clinics they attended and expressed a desire for change. This was expressed in terms of wanting a more age-specific clinic and more emotional support. Participants in both groups feared the limitations that future physical complications would have on their physical functioning and lifestyle choices and many were not prepared to think about the future in too much detail, preferring to focus on the present. Emotions experienced by participants related to their diabetes were lethargy and tiredness, aggression and anger, frustration and depression. Participants in the poor metabolic control group were less likely to perceive any positive points to having diabetes, although participants in the good metabolic control group were more positive and indicated increased health care and greater awareness of health generally as the main points. For participants in both groups there was frustration expressed at the way they were perceived by other people without diabetes. Career prospects and understanding of the diabetes were factors where the young people felt they had been misjudged.

6.6 Discussion

A review of current research conducted with young people with poor metabolic control reveals that there are certain characteristics associated with hyperglycaemia. Richardson, Adner & Nordstrom (2001) found that adults exhibiting poor metabolic control were characterised by low acceptance of diabetes and a poor sense of coherence. Surgenor, Horn, Hudson, Lunt & Tennent (2000) found that poor metabolic control was associated with self-report of the experience of loss of psychological control, feelings of inadequacy, reduced control in interpersonal relationships and reduced control of bodily function. Poor metabolic control has also been linked to reports of poor quality of life (Wikblad, Leksell & Wibell, 1996) and disordered eating behaviour (Rydall, Rodin, Olmstead, Devenyi & Daneman, 1997). Poor metabolic control has been associated with poor adherence to diabetes self-care regime, less cohesive family structure and more family conflict (Hanson, DeGuire, Schinkel & Kolterman, 1995). Poor metabolic control is also more common in women and is associated with high levels of depression and anxiety (LaGreca, Swales, Klemp et al., 1995) and with a poorer physical self-image (Boeger & Seiffgekrenke, 1994; Ryden et al., 1994).

A brief review of the literature investigating family responses to chronic illness suggest a number of areas where the family's response to the chronic illness affects the adaptation to and management of the chronic illness in the young person. The transference of care from the parents to the young person needs to be made at a developmentally appropriate time (Coffen, 1999). The benefits of appropriate transfer of care is relief of burden for the parents and increased confidence, freedom, independence and control of their diabetes in the young person as well as parents' increased pride in the young person. However, a negative aspect to transference of care from the parents to the young person was a perception of loss of control, authority and supervision reported by the parents (Hanna & Guthrie, 2000). There appears to be no effect of family composition (intact families, single parent, blended families) on health status, treatment adherence and the parent-adolescent relationship (Harris, Greco, Wysocki et al., 1999) but there does appear to be an impact on the family dynamics when there is a child with a chronic illness present. Families are likely to become more structured and less emotionally warm and communicative (Wamboldt & Wamboldt, 2000). Families with high levels of criticism are also more likely to have difficulty adapting to the diagnosis of chronic illness (Wamboldt & Wamboldt, 2000). Adjustment to the diagnosis of chronic illness has been demonstrated to be related to lower parenting stress, higher husband marital satisfaction and higher levels of and helpfulness of social support (Sheeran, Marvin & Pianta, 1997). Both parents are likely to have the same perception of severity of chronic illness, however their coping strategies used are different. Fathers are more likely to use reasoning strategies to cope, whereas mothers tend to use releasing and relating strategies (Copeland & Clements, 1993).

Parent distress is also related to sibling adjustment problems (Fisman, Wolf, Ellison & Freeman, 2000). Parents tend to display low involvement in social activities (mothers) and extended family (fathers) (Stewart, Stein, Forrest & Clark, 1992). Siblings of chronically ill children also tend to express more negative emotion towards fathers (Stewart, Stein, Forrest & Clark, 1992) and can present more behaviour problems particularly if the sibling is older than the ill child (Stawski, Auerbach, Barasch, Lerner et al., 1997). These behaviour problems may be related to the amount and quality of maternal involvement with the healthy sibling at play and mealtimes (Quittner & Opipari, 1994) or related to the mother's role in the family and the healthy child personality characteristics (Thompson, Curtner & O'Rear, 1994). All these concerns can impact on the success of the young person coping with the responsibility of the care for their chronic illness and with the demands of clinic and hospital visits (DiGirolamo, Quittner, Ackerman & Stevens, 1997).

The participants in this study however were either living independently or with their spouse/partner so the levels of family support available to them is less than for the participants still living at home. Partners are also an important source of social support with many adults (in particular, women) reporting more support from spouse and partner than from any other source (Primomo, Yates & Wood, 1990). Penninx, van Tilburg, Boeke, Deeg et al., (1998) looked at the spouse support on coping in adults with chronic illness and found that adults who had a romantic partner, had many close friendships, high levels of empowerment and self-esteem expressed lower levels of depression. However, receiving instrumental support was associated with higher levels of depression in adults with diabetes. Social support from the romantic partner does not seem to actually alter the incidence or course of chronic illness (Kriegsmna, Penninx & van Eijk, 1995) but a shift in responsibilities (especially household and family) to the spouse can prove adaptive for the person with the chronic illness in the short term (post-diagnosis) (Helgeson, 1993).

6.7 Conclusions

Although this study has limited number of participants, it appears that there is evidence for a number of factors distinguishing good and poor metabolic control in young adults with diabetes. The findings of this study as well as the supporting evidence presented above indicate that good metabolic control is characterised by acceptance of diabetes, practical social support and the young person's ability to cope with the day-to-day demands of diabetes as well as responding to changing needs on unique occasions. Young people in poor metabolic control appear to have difficulty accepting the diagnosis of diabetes and are unwilling to admit to others that they have diabetes. The role of spouse/partner in the young peoples' lives was cited as important providers of social support. Therefore, this finding needs further investigation to determine the extent of this.

Study 3: The Extended Health Belief Model Applied to the Experience of Diabetes in Young People: Replication

7.1 Summary of findings from study 1

This is the first time the Extended Health Belief Model (EHBM) has been specifically tested with young people aged 16-25 years with Type 1 diabetes. As a model for explaining adherence to diabetes self-care behaviour the results have indicated that the EHBM is an acceptable framework for investigating the experience of diabetes in this age group.

The findings of study 1 showed that the main influence on adherence to self-care regime was diabetes-specific social support. This relationship was mediated by perceived low life threat due to diabetes, participant report of lesser severity of risk and lower susceptibility to the complications associated with diabetes and the participant perceiving that the benefits of adhering to the self-care regime outweighed the personal costs of doing so. This 'weighing-up' of the costs and benefits of adhering to the self-care regime was itself influenced by participant internal locus of control beliefs and greater participant empowerment.

7.2 Proposed design of Study 3

As this is the first time the EHBM has been specifically tested with young people aged 16-25 years with Type 1 diabetes, study 3 will replicate study 1 using the same measures in the same format but with different participants. This study aims to investigate the experience of diabetes in young people aged 16 to 25 years within the Extended Health Belief Model framework. On the basis of study 1, it is anticipated that participant reports of high internal locus of control, high diabetes-related empowerment and diabetes-related social support will indicate good patient adherence to the self-care regime and be related to good metabolic control.

7.3 Method

7.3.1 Participants

Participants were aged between 16 and 25 years (mean = 20.83, 28 = male) and registered with either the Royal Hampshire County Hospital or the North Hampshire Hospital. The total number approached was 154 (77 from the Royal Hampshire

County Hospital and 77 from the North Hampshire Hospital) of which 54 completed and returned the questionnaires. The response rate was therefore 35%.

7.3.2 Materials

The same questionnaires used in study 1 were used to investigate each variable of the Extended Health Belief Model. Where possible brief versions of the measures were again used to encourage completion by the participants. All measures used are standard scales employed in the experimental investigation of the experience of diabetes. The survey is included in Appendix A. The rational for using each was presented in Study 1.

The measures used were:

Individual perceptions

Susceptibility to and severity of illness

The Diabetes Specific Health Beliefs: Susceptibility and Seriousness Scale (Lewis Bradley, 1994).

Modifying factors

Social-psychological variables

Social support

The Diabetes Family Behaviour Checklist (DFBC)(Schafer, McCaul & Glasgow, 1986)

Locus of control

The Diabetes Locus of Control Scale (Ferraro, Price, Desmond & Roberts, 1987)

Quality of life

The Audit Diabetes-Dependent Quality of Life Scale (Bradley, Todd, Gorton, Symonds et al., 1999).

Self-efficacy

The Diabetes Empowerment Scale (Anderson, Funnell, Fitzgerald & Marrero, 2000).

Life threat of diabetes

This was measured by the item: ‘How much shorter do you think your life expectancy is due to diabetes?’ with response options ‘not at all’; ‘a little shorter’, and ‘very much shorter’ as published in Aalto & Uutela (1997).

Cues to action

Perceived metabolic control

This was measured by a single item as published in Aalto & Uutela (1997) 'How well do you think you are managing to control your diabetes?'. The participant scores their response on a 5-point Likert-type scale where a score of '1' indicates a response of 'not very well' and a score of '5' indicates a response of 'very well'.

Hypoglycaemic symptoms

The Hypoglycaemia Fear Survey (Cox, Irvine, Gonder-Frederick, Nowacek & Butterfield, 1987).

Likelihood of action

Benefits and costs of adhering to regime

Perceived benefits of following the treatment regime and the perceived costs of doing so were measured using the Diabetes Specific Health Beliefs (DSHB): Benefits and Barriers sub-scales (Lewis & Bradley, 1994).

Adherence with regimen

Adherence with regimen was measured using the Summary of Diabetes Self-Care Activities Scale (Toobert & Glasgow, 1994).

Metabolic control

Each participant had the option of submitting a blood sample for an HbA_{1C} test to be carried out. The HbA_{1C} test (or glycosylated haemoglobin test) provides an average rating of metabolic control over the previous 8-12 weeks and is used as a standard measure of metabolic control in studies of diabetes.

7.3.3 Design

Cross-sectional independent measures postal survey design. Participant selection criteria was a diagnosis of Type 1 diabetes mellitus, registered with the Royal Hampshire County Hospital and the North Hampshire Hospital, of age 16-25 years and not registered learning disabled.

7.3.4 Procedure

Participants were approached via a letter from their Consultant Endocrinologist inviting them to participate in the study. This letter was followed by a pack of questionnaires as detailed above accompanied by a cover letter, consent form, an HbA_{1C} testing kit request slip and a pre-paid return envelope. This resulted in 54 completed sets of questionnaires. All data was entered into an SPSS database and analysed as sub-scale and full-scale scores. A correlation matrix for the full-scale scores was subjected to path analysis for modelling onto the Extended Health Belief Model as proposed by Aalto and Uutela (1997). All participants requesting HbA_{1C} testing kits were sent complete kits which were analysed by the Haematology Laboratories at the Royal Hampshire County Hospital and the North Hampshire Hospital.

7.4 Results

25 participants (Mean age = 21.04 years, SD = 2.62; 14 males; mean latest HbA_{1C} = 8.55%; mean duration of diabetes = 7.9 years) responded from the North Hampshire Hospital and 29 participants (Mean age = 20.66 years, SD = 2.35; 14 males; mean latest HbA_{1C} = 7.82%; mean duration of diabetes = 8.55 years) responded from the Royal Hampshire County Hospital. As expected, statistical analysis of participants from the North Hampshire Hospital and the Royal Hampshire County Hospital found no significant difference of age, gender split, latest HbA_{1C} or duration of diabetes and the groups were combined to form a larger group comprising 54 participants.

7.4.1 Participant details

The participants were aged 16 – 25 years (M = 20.83 years) and 28 were male. The participants had been diagnosed for between 6 months and 22.5 years (Mean = 8.24 years, SD = 6.04) with Type 1 diabetes (insulin-dependent diabetes mellitus). 27 lived at home with their parents, 13 lived in shared / student accommodation, 12 lived with partners /spouse and 2 lived alone. None of the participants were experiencing physical health complications associated with their diabetes. The HbA_{1C} readings (N=43) ranged from 5% to 11.9% of which 21 participants were within the 'normal' range (5 – 8%) and 22 participants had readings within the 'high' range (8.01% and over). The participants did not differ significantly from the non-participants on age, gender split or latest HbA_{1C} readings .

7.4.2 Summary of findings: Sub-scale scores

Diabetes Specific Health Beliefs (DSHB): Severity and Vulnerability Scores

Table 7.1. Subscale scores on the DSHB: Severity and Vulnerability Scale

Measure Sub-Scale	*N*	*Min.*	*Max.*	*Mean*	*SD*
Severity of non-diabetes illness	52	17	67	40.73	10.03
Severity of diabetes complications	52	24	50	38.55	5.94
Vulnerability to non-diabetes illness	52	0	52	27.85	10.14
Vulnerability to diabetes complications	53	2	44	25.55	8.27

Participants rated the severity of experiencing diabetes-related complications as being greater than the severity of contracting non-diabetes related illness and considered themselves more at risk of experiencing diabetes-related complications than non-diabetes related illness.

Diabetes Family Behaviour Checklist

Table 7.2. Subscale scores on the Diabetes Family Behaviour Checklist

Measure Sub-Scale	*N*	*Min.*	*Max.*	*Mean*	*SD*
Family support for diet	53	-4	7	.69	2.34
Family support for blood glucose testing	53	-7	2	-2.30	2.15
Family support for insulin injecting	53	-2	9	2.00	2.30
Family support for exercising	53	-1	8	2.43	2.22
Family support for diabetes	53	-1	8	2.26	1.98

Family support for diet behaviours, glucose testing, insulin injecting, exercise and general diabetes care was low.

Diabetes Locus of Control Scale

Table 7.3. Subscale scores on the Diabetes Locus of Control Scale

Measure Sub-Scale	*N*	*Min.*	*Max.*	*Mean*	*SD*
Internal Locus of Control	54	12	36	29.89	4.88
Powerful Others Locus of Control	54	6	36	18.24	6.46
Chance Locus of Control	54	6	25	17.26	3.99

The participants reported relatively high 'internal' locus of control with respect to their diabetes. The internal locus of control score was greater than that relating to 'powerful others' (t=11.426, df= 53, p=.000) and to 'chance' (t=13.626, df= 53, p=.000) indicating that these participants consider themselves to be the main influence on their metabolic control. Scores indicating 'chance' locus of control were no different to scores indicating a belief in 'powerful others' (t=-.879, df= 53, p=.383) indicating that chance and the influence of the medical team over-seeing their care regime are considered equally important by the participants of this study.

Diabetes Empowerment Scale

Table 7.4. Subscale scores on the Diabetes Empowerment Scale

Measure Sub-Scale	*N*	*Min.*	*Max.*	*Mean*	*SD*
Empowerment: Psychosocial aspects	53	1	3.78	2.16	.67
Empowerment: Dissatisfaction	53	1	3.22	2.09	.48
Empowerment: Setting and achieving goals	52	1	4.00	2.36	.69

The participants have mean scores lower than the scale mid-point on the Diabetes Empowerment Scale sub-scales indicating slightly elevated diabetes-related self efficacy.

Audit of Diabetes-Dependent Quality of Life

Table 7.5. Subscale scores on the Audit of Diabetes-Dependent Quality of Life scale

Measure Sub-Scale	*N*	*Min.*	*Max.*	*Mean*	*SD*
Quality of Life now	53	-1	3	1.55	.91
Quality of Life without diabetes	53	-3	1	-1.30	1.05

Quality of life scores for 'now' suggest that these participants consider their current quality of life to be 'good' although scores for quality of life 'without diabetes' suggest that these participants feel their quality of life would be 'a little better' without diabetes.

Life Threat and Perceived Metabolic Control

Table 7.6. Subscale scores on life threat and perceived metabolic control

Measure Sub-Scale	*N*	*Min.*	*Max.*	*Mean*	*SD*
Life Threat	53	0	2	.70	.54
Perceived Control of Diabetes	53	0	4	2.51	.99

The participants see their life expectancy due to diabetes as being 'a little shorter' than that of a person without diabetes and consider the control of their diabetes to be 'ok' to 'poor'.

Hypoglycaemia Fear Survey

Table 7.7. Subscale scores on Hypoglycaemia Fear Survey

Measure Sub-Scale	*N*	*Min.*	*Max.*	*Mean*	*SD*
Hypoglycaemia Behaviour Score	53	12	32	21.58	5.08
Hypoglycaemia Worry Score	53	2	49	25.52	11.17

On the Hypoglycaemia Fear Survey the participants have high scores on the 'hypoglycaemia worry' section (Mean = 25.52, SD = 11.17) and moderate scores on the 'hypoglycaemia behaviour' section (Mean = 21.58, SD = 5.07).

Diabetes Specific Health Beliefs: Benefits and Barriers

Table 7.8. Subscale scores on DSHB: Benefits and Barriers scale

Measure Sub-Scale	*N*	*Min.*	*Max.*	*Mean*	*SD*
Benefits of adhering to regime	54			26.94	.67
Barriers to adhering to regime	54			13.54	1.02

Scores reflecting the benefits of and barriers to adherence indicate that this participant group see the benefits of adhering to their diabetes care regime as outweighing the costs of doing so ($t = 11.283$, $df = 53$, $p = .000$).

Summary of Diabetes Self-Care Activities Scale

Table 7.9. Subscale scores on Summary of Diabetes Self-Care Activities Scale

Measure Sub-Scale	*N*	*Min.*	*Max.*	*Mean*	*SD*
Self care: diet	54	0	6.75	3.73	1.70
Self care: exercise	54	0	7	3.55	1.95
Self care: blood glucose testing	53	0	7	4.36	2.74
Self care: insulin injecting	54	2	7	6.75	.91
Self care: foot care	54	0	7	1.49	1.99
Self care: smoking	54	0	7	1.49	1.99

Scores on this seven-day recall of actual adherence to their prescribed diabetes care regime demonstrate that although on the whole participants are injecting insulin as prescribed, they are not following their diet and exercise programmes regularly or testing their blood glucose levels as frequently as advised. There is low adherence to foot care and few patients smoke. Comparing the adjusted mean scores (to exclude smoking behaviour) there was no difference between published scores and participants scores on total adherence to the diabetes self-care regime (Cohen's d = .18).

Adherence to the self-care regime for this group was not significantly correlated with metabolic control (Pearson's r = , p).

Summary of results

The findings of this study follow the pattern of both Study 1 and other published studies indicating that the participants of this study are representative of other populations being researched.

7.4.3 Summary of findings: Full-scale scores

Table 7.10. Summary of findings: Total scores on each of the behaviour measures with minimum and maximum possible scores in parentheses.

Measurement Scale	*N*	*Min.*	*Max.*	*Mean*	*SD*
DSHB Severity / Vulnerability Score	52	1.25	14.68	7.23	2.45
Diabetes Family Behaviour Checklist	53	-10	29	5.09	7.46
Diabetes Locus of Control Scale Internal	54	12	36	29.89	4.88
Diabetes Locus of Control Scale Powerful Others	54	6	36	18.24	6.46
Diabetes Locus of Control Scale Chance	54	6	25	17.26	3.99
Audit of Diabetes Dependent Quality of Life	47	-3.89	.33	-1.26	1.05
Diabetes Empowerment Scale	52	1.00	3.32	2.20	.53
Life Threat	53	0	2	.70	.54
Perceived Control of Diabetes	53	0	4	2.50	.99
Hypoglycaemia Fear Survey	52	21	73	47.48	13.33
DSHB Benefits / Barriers Score	54	-4	36	13.41	8.73
Summary of Diabetes Self-Care Activities Scale (z-scored)				-4.9E-16	1.000
Valid N (listwise)	42				

Participants' mean scores on the Diabetes Family Behaviour Checklist, internal locus of control, perceived metabolic control and the DSHB: Benefits and Barriers scales were higher than the relevant scale's midpoint indicating that these participants perceived elevated levels of family support, internal locus of control, perceived metabolic control and the benefits of adhering to the regime as outweighing the costs of doing so. Participants' mean scores on powerful others locus of control, chance locus of control and diabetes–related quality of life were lower than the relevant scale's midpoint indicating that these participants had lower perceived belief in chance and powerful others in relation to diabetes-specific locus of control and perceived their quality of life to be worse than a person without diabetes. Participants' mean scores on the Diabetes Empowerment Scale were lower than the scale's midpoint indicating that participants have good diabetes-related empowerment.

7.4.4 Correlation Matrix

The Pearson's product moment correlations were calculated to construct a correlation matrix for the score totals for the following measures: Life Threat, Quality of Life now and Quality of Life without diabetes, DSHB Benefits and Barriers, DSHB Severity and Vulnerability, Diabetes Empowerment Scale, Hypoglycaemia Fear Survey, Diabetes Family Behaviour Checklist, Locus of Control sub-scales (Internal, Powerful Others and Chance), Quality of Life total score and the Summary of Diabetes Self-Care Activities Scale. The scores on the last measure were standardised.

Diabetes Specific Health Beliefs (DSHB): Severity and Vulnerability Scores

Participant scores on the Diabetes Specific Health Beliefs (DSHB): Severity and Vulnerability measures positively correlated with perceived life threat due to diabetes (Pearsons $r= .301$, $p<.001$), and negatively with ADDQoL scores (Pearsons $r= -.303$, $p<.001$).

Diabetes Family Behaviour Checklist

Scores reflecting diabetes-specific family support positively correlated with adherence scores (Pearsons $r= .524$, $p<.001$) , DSHB: Benefits and Barriers scores (Pearsons $r= .435$, $p<.001$) and negatively correlated with diabetes-related empowerment scores (Pearsons $r= -.337$, $p<.001$) (negative scores on which indicate high empowerment).

		Severity / Vulnerability	*DFBC*	*Internal L.o.C.*	*Powerful Others L.o.C*	*Chance L.o.C*	*Quality of Life Score*	*Empower-ment Score*	*Life Threat Score*	*Perceived Control*	*Hypoglyc-aemia Score*	*Benefits / Barriers*	*Adherence*
Severity / Vulnerability Score	Pearson Cor.	-											
	N												
Diabetes Family Behaviour Checklist Score	Pearson Cor.	.240	-										
	N	51											
Internal Locus of Control	Pearson Cor.	-.024	-.026	-									
	N	52	53										
Powerful Others Locus of Control	Pearson Cor.	.068	.218	.151	-								
	N	52	53	54									
Chance Locus of Control	Pearson Cor.	-.036	-.216	-.170	-.184	-							
	N	52	53	54	54								
Quality of Life Score	Pearson Cor.	-.303**	.270	.137	-.108	-.199	-						
	N	45	47	47	47	47							
Empowerment Score	Pearson Cor.	.018	-.337**	-.208	-.070	.230	-.586**	-					
	N	50	52	52	52	52	46						
Life Threat Score	Pearson Cor.	.301**	-.146	-.173	.027	.214	-.232	.184	-				
	N	51	52	53	53	53	46	51					
Perceived Control of Diabetes Score	Pearson Cor.	-.194	.096	.264	.028	-.112	.395	-.583**	-.379	-			
	N	51	52	53	53	53	47	51	52				
Hypoglycaemia Worry and Behaviour Score	Pearson Cor.	.248	.132	.072	.226	.045	-.436**	.288*	-.015	-.201	-		
	N	50	52	52	52	52	46	51	51	51			
Benefits and Barriers Score	Pearson Cor.	-.192	.435**	.298**	.146	-.331**	.629**	-.487**	-.311*	.520**	-.234	-	
	N	52	53	54	54	54	47	52	53	53	52		
Adherence Score	Pearson Cor.	.250	.524**	.080	.013	-.149	.060	-.127	.059	.114	.075	.221	-
	N	51	52	53	53	53	46	52	52	52	51	53	

**. Correlation is significant at the 0.01 level (2-tailed).
*. Correlation is significant at the 0.05 level (2-tailed)

Table 7.11 Correlation matrix of full scale scores

Diabetes Locus of Control Scale

Participants' 'internal' locus of control scores correlated positively with DSHB: Benefits and Barriers score (Pearsons r= .298, p<.001).

Participants' scores corresponding with 'chance' locus of control negatively correlated with DSHB: Benefits and Barriers scores (Pearsons r= -.331, p<.001).

Audit of Diabetes-Dependent Quality of Life

Participant quality of life scores negatively correlated with diabetes-related empowerment scores (Pearsons r= -.586, p<.001) and Hypoglycaemia Fear Survey (worry and behaviour) scores (Pearsons r= -.436, p<.001), and positively correlated with DSHB: Benefits and Barriers score (Pearsons r= .629, p<.001).

Diabetes Empowerment Scale

Diabetes-related empowerment scores negatively correlated with perceived metabolic control (Pearsons r= -.583, p<.001) and DSHB: Benefits and Barriers scores (Pearsons r= -.487, p<.001) and positively with Hypoglycaemia Fear Survey (worry and behaviour) scores (Pearsons r= .288, p<.001).

Life Threat and Perceived Metabolic Control

Participant perceived life threat scores were negatively correlated with their DSHB: Benefits and Barriers score (Pearsons r= -.311, p<.001). Participant perceived metabolic control was positively correlated with DSHB: Benefits and Barriers scores (Pearsons r= .520, p<.001).

7.4.5 Path Analysis

EQS and Structural Equation Modelling

The Extended Health Belief Model (Aalto & Uutela, 1997)

Figure 6 (Appendix A) shows the diagrammatically simplified Extended Health Belief Model as tested by Aalto & Uutela (1997). The correlation matrix (as per table 7.11) was entered into the structural equation modelling programme (EQS/Windows) and the method of covariance analysis performed.

Table 7.12 shows how the model was modified and the paths added to improve the fit of the data to the model.

Table 7.12. Results of Path Analysis for Extended Health Belief Model and Final Proposed Model

Iteration	Chi Square	df	Sig.	AIC	CFI	RMSEA	Paths added	
Initial Model	204.89	40	<.001	124.89	.406	.19		
Final Model	22.83	17	>.05	-11.17	.938	.08	V12, V2 V7, V6	V7, V4 V6, V3

Path analysis of the Extended Health Belief Model as tested by Aalto & Uutela (1997) demonstrated poor fit with the data from these participants. The Largest Standardised Residuals matrix indicated paths where possible misfit of the model may occur. Confirming these paths using the Lagrange Multiplier Test (for adding parameters) the following paths were added:

- *A path corresponding to a relationship between quality of life scores and diabetes-related empowerment scores.*
- *A path corresponding to a relationship between diabetes-specific family support with participant 7-day recall of adherence with prescribed regime.*
- *A path corresponding to a relationship between empowerment and 'powerful others' locus of control.*
- *A path corresponding to a relationship between quality of life and 'internal' locus of control.*
- *Paths removed corresponding to a relationship between perceived metabolic control and perceived life threat, and hypoglycaemia fear survey scores and perceived life threat*

This revised model demonstrated good fit to the data with these participants and no further amendments were considered necessary or theoretically appropriate. Figure 10 shows the diagrammatically simplified final model with path values. The final model was exactly the same as proposed in study 1 and explained 29.4% of participant variance in adherence to their self-care regime. This compares well with the findings of Aalto & Uutela (1997) whose path models explained 14% of the variance in diet adherence and 21% of the variance in blood glucose testing and the findings of Study 1 which found the final model explained 16.2%.

Combination of Data Sets from Study 1 and Study 3

Table 7.13. Summary of findings: Total scores on each of the behaviour measures

Measurement Scale	*Study*	*N*	*Mean*	*SD*	*t*	*df*	*P*	*Effect size*
Age	1	32	21.16	2.42	-.953	77	.344	-.22
	3	47	21.68	2.39				
Gender	1	32	1.47	.51	-1.698	77	.094	-.38
	3	47	1.66	.48				
HbA_{1C}	1	32	8.29	1.67	-.788	77	.433	-.18
	3	47	8.64	2.13				
Duration of diabetes(years)	1	32	7.72	6.26	-.978	77	.331	-.22
	3	47	9.02	5.48				
DSHB Severity / Vulnerability Score	1	32	7.09	2.38	-.596	76	.553	-.14
	3	47	7.45	2.66				
Diabetes Family Behaviour Checklist	1	32	6.69	8.11	1.783	77	.079	.40
	3	47	3.85	6.02				
Diabetes L.o.C. Scale Internal	1	32	30.41	3.54	-.022	77	.982	.00
	3	47	30.43	3.88				
Diabetes L.o.C. Scale Powerful Others	1	32	17.34	6.45	.459	77	.647	.10
	3	47	16.72	5.48				
Diabetes L.o.C. Scale Chance	1	32	17.00	4.57	-1.884	77	.063	-.43
	3	47	18.96	4.51				
Audit of Diabetes Dependent Quality of Life	1	32	-1.02	.86	1.461	77	.148	.34
	3	47	-1.39	1.28				
Diabetes Empowerment Scale	1	32	2.19	.50	.875	77	.384	.20
	3	47	2.09	.48				
Life Threat	1	32	.65	.60	.792	77	.431	.17
	3	47	.55	.54				
Perceived Control of Diabetes	1	32	2.65	.86	1.739	77	.086	.39
	3	47	2.36	.64				
Hypoglycaemia Fear Survey	1	32	47.41	12.74	1.127	77	.263	.26
	3	47	43.85	14.41				
DSHB Benefits / Barriers Score	1	32	15.81	9.13	.658	77	.512	.15
	3	47	14.21	11.49				
Summary of Diabetes Self-Care Activities Scale	1	32	3.76	.91	1.213	77	.229	.28
	3	47	3.48	1.07				

There was found no significant difference in age, gender split, latest HbA_{1C} and duration of diabetes between participants of Study 1 and participants of Study 3. There was also found no significant difference between participants of Study 1 and participants of Study 3 on all the measure total scale scores bar one. There was a significant difference found in chance locus of control scores (M, Study 1 = 19.14, SD = 4.76; M, Study 3 = 17.25, SD = 3.99), $t_{(115)} = -2.29$, $p<.05$. For the measure sub-scale scores, there was found no significant difference between participants of Study 1 and Study 3 on all sub-scale scores bar one. Study 3 participant scores were significantly different from Study 1 participant scores on the 'general support' sub-scale of the Diabetes Family Behaviour Checklist (M, Study 1 = 1.43, SD, 1.96; M, Study 3 = 2.26, SD = 1.98) $t_{(115)} = 2.255$, $p<.05$.

The limitations of the work previously had been mainly due to low participant numbers and the studies comprised participants from different hospitals whom may have experienced different levels of care at each site from different Consultant Diabetologists and their medical teams. Therefore, to increase the statistical power of the findings and to test the model on a larger data set, the data for all participants in studies 1 and 3 was combined to form one large data set and path analysis conducted using the final version of the revised Extended Health Belief Model. The participants scores on the full scale scores and the sub-scale scores as well as the correlation matrix are included below.

Table 7.14. Total scores on each of the behaviour measures

Measurement Scale	*N*	*Min.*	*Max.*	*Mean*	*SD*
DSHB Severity / Vulnerability Score	110	1.32	15.67	8.15	2.75
Diabetes Family Behaviour Checklist	117	-12	29	4.09	7.17
Diabetes L.o.C. Scale - Internal	118	12	36	30.07	4.53
Diabetes L.o.C. Scale - Powerful Others	118	6	36	17.48	6.10
Diabetes L.o.C. Scale - Chance	118	6	29	18.36	4.57
Audit of Diabetes Dependent Quality of Life	110	-6.89	.33	-1.43	1.36
Diabetes Empowerment Scale	116	1	4.14	2.20	.57
Life Threat	117	0	2	.64	.55
Perceived Control of Diabetes	118	0	4	2.47	1.00
Hypoglycaemia Fear Survey	116	12	74	45.52	13.83
DSHB Benefits / Barriers Score	118	-10	36	13.46	10.50
Summary of Diabetes Self-Care Activities Scale (Zscore)	116	1.96	2.87	2.88E-16	1.000
Valid N(listwise)	106				

Table 7.15. Subscale scores on each of the behaviour measures

Measure Sub-Scale	*N*	*Min.*	*Max.*	*M*	*SD*
Severity of non-diabetes illness	114	1.13	4.67	2.84	.66
Severity of diabetes complications	114	1.77	5.00	3.59	.63
Vulnerability to non-diabetes illness	113	.00	3.47	1.79	.69
Vulnerability to diabetes complications	115	.50	4.40	2.77	.80
Family support for diet	117	-5	7	.37	2.50
Family support for blood glucose testing	117	-9	2	-2.72	2.16
Family support for insulin injecting	117	-2	9	2.30	2.39
Family support for exercising	117	-3	9	2.33	2.13
Family support for diabetes	117	-3	8	1.81	2.01
Internal Locus of Control	118	12	36	30.07	4.53
Powerful Others Locus of Control	118	6	36	17.48	6.10
Chance Locus of Control	118	6	29	18.36	4.57
Empowerment: Psychosocial aspects	116	1	5	2.21	.75
Empowerment: Dissatisfaction	116	1	3.22	2.06	.50
Empowerment: Setting and achieving goals	116	1	4.20	2.33	.70
Quality of Life now	117	-3	3	1.44	1.09
Quality of Life without diabetes	117	-3	3	-1.22	1.20
Life Threat	117	0	2	.64	.55
Perceived Control of Diabetes	118	0	4	2.47	1.00
Hypoglycaemia Behaviour Score	117	4	33	21.04	5.99
Hypoglycaemia Worry Score	117	2	52	24.33	11.61
Benefits of adhering to regime	118	13	36	27.02	5.30
Barriers to adhering to regime	118	0	34	13.57	8.47
Self care: diet	117	0	7	3.97	1.50
Self care: exercise	118	0	7	3.49	1.99
Self care: blood glucose testing	117	0	7	3.84	2.76
Self care: insulin injecting	118	2	7	6.74	.89
Self care: foot care	118	0	7	1.54	1.88
Self care: smoking	118	0	26	3.34	6.45
Valid N (listwise)	106				

		Severity / Vulnerability	*DFBC*	*Internal L.o.C.*	*Powerful Others L.o.C*	*Chance L.o.C*	*Quality of Life Score*	*Empower-ment Score*	*Life Threat Score*	*Perceived Control*	*Hypoglyc-aemia Score*	*Benefits / Barriers*	*Adherence*
Severity / Vulnerability Score	Pearson Cor.	-											
	N												
Diabetes Family Behaviour Checklist Score	Pearson Cor.	-.012	-										
	N	109											
Internal Locus of Control	Pearson Cor.	-.035	.077	-									
	N	110	117										
Powerful Others Locus of Control	Pearson Cor.	-.015	.130	.092	-								
	N	110	117	118									
Chance Locus of Control	Pearson Cor.	-.072	-.128	-.233*	.001	-							
	N	110	117	118	118								
Quality of Life Score	Pearson Cor.	-.165	.128	.180	-.145	-.289**	-						
	N	102	110	110	110	110							
Empowerment Score	Pearson Cor.	.001	-.203*	-.206*	.057	.313	-.533**	-					
	N	109	115	116	116	116	108						
Life Threat Score	Pearson Cor.	.385**	-.236*	-.164	-.023	.072	-.195*	.135	-				
	N	109	116	117	117	117	109	115					
Perceived Control of Diabetes Score	Pearson Cor.	-.224*	.171	.386**	.022	-.233*	.369*	-.548**	-.278**	-			
	N	110	117	118	118	118	110	116	117				
Hypoglycaemia Worry and Behaviour Score	Pearson Cor.	.297**	.135	-.095	.164	-.040	-.292*	.199*	.062	-.082	-		
	N	108	116	116	116	116	109	114	115	116			
Benefits and Barriers Score	Pearson Cor.	-.300**	.272**	.358**	.059	-.280**	.631**	-.551**	-.294	.578**	-.207*	-	
	N	110	117	118	118	118	110	116	117	118	116		
Adherence Score	Pearson Cor.	-.007	.280**	.062	.006	.062	-.133	-.023	-.071	.087	-.042	-.067	-
	N	109	115	116	116	116	108	115	115	116	114	116	

**. Correlation is significant at the 0.01 level(2-tailed).
*. Correlation is significant at the 0.05 level(2-tailed)

Table 7.16 Correlation matrix for full scale scores

Summary of Paths for the Revised Version of the Extended Health Belief Model

The fit of the data to the model was moderate ($Chi^2 = 43.07$, $df = 17$, $p<.001$, model AIC = 9.07, CFI = .86, RMSEA = .11) and explained 12% of the variance in adherence to the diabetes self-care regime. Therefore, the revised version of the Extended Health Belief Model statistically significant path values offer support to suggest that for the entire participant group:

DSHB: Severity and Vulnerability

High DSHB: Severity and Vulnerability score was predicted by low participant quality of life scores (path value $\beta = -.252$).

Perceived Life Threat of Diabetes

High life threat was predicted as proposed by the Extended Health Belief Model (Aalto & Uutela, 1997) and was predicted by participants exhibiting low family support (DFBC Scores) (path value $\beta = -.206$) and by high DSHB: Severity and Vulnerability scores (path value $\beta = .373$).

DSHB: Benefits and Barriers

High DSHB: Benefits and Barriers score was predicted by high family support (DFBC) (path value $\beta = .136$), by participants exhibiting high 'internal' locus of control (path value $\beta = .207$), by good quality of life scores (path value $\beta = .470$) and by participants exhibiting high diabetes-related empowerment scores (path value $\beta = -.243$).

Audit of Diabetes-Dependent Quality of Life

Quality of life scores were predicted by participant high levels of internal locus of control (path value $\beta = .180$).

Diabetes Empowerment Scale

Diabetes-related empowerment scores were predicted by good quality of life scores (ADDQoL) (path value $\beta = -.535$, DES is reverse scored).

Summary of Diabetes Self-Care Activities Scale

Good participant 7-day recall of adherence to their prescribed medical regime was predicted by high reported diabetes-specific family support (as measured by the DFBC) (path value $\beta = .311$).

7.4.6 Amendment to the Final Model

Overall fit to the model could be improved by adding a path indicating that participant reported quality of life scores are predicted by low chance locus of control scores (path value $\beta = -.261$). This changes the fit of the data ($Chi^2 = 43.07$, $df = 17$, $p < .001$, model AIC = 9.07, CFI = .86, RMSEA = .11) to a more acceptable fit ($Chi^2 = 34.99$, $df = 16$, $p < .01$, model AIC = 2.99, CFI = .90, RMSEA = .10). This amended model explains exactly the same amount of variance in the young person's adherence to the diabetes self-care regime as the final model (12%) but increases the amount of variance in explaining what factors may predict diabetes-specific quality of life from 4% to 10%.

7.5 Discussion

7.5.1 Summary of main findings

High participant perceived susceptibility to and severity of diabetes-related complications was predicted by low quality of life scores and by low reported diabetes-specific social support. High life threat due to diabetes was predicted by high participants perceived susceptibility to and severity of diabetes-related complications. Perceiving the benefits of adhering to the diabetes self-care regime as outweighing the psychological costs of doing so was predicted by high levels of diabetes-specific social support, high internal locus of control, good quality of life and high diabetes-related empowerment. Participant high levels of adherence to the diabetes self-care regime was predicted by high levels of diabetes-specific social support.

7.5.2 Comparison of findings to those of study 1

Participants in study 3 find low quality of life scores predicted high perceived severity of and susceptibility to diabetes-related complications. High DSHB: Severity & Susceptibility scores in turn predict high life threat due to diabetes. High diabetes-related empowerment and high health value both predict participants' perceiving the benefits of adhering to the diabetes self-care regime as outweighing the psychological costs of doing so and good participant adherence to the diabetes self-care regime was predicted by high levels of diabetes-specific social support. High participants scores on health value predicted high diabetes-related empowerment. The previously strong path between quality of life scores and life threat (study 1, path value - .219) became negligible in study 3 (study 3, path value β = -.065) as did the path between powerful others locus of control and DSHB: Benefits & Barriers (study 1, path value β = .244; study 1, path value β = .105). Diabetes-specific social support exerted much greater influence within the model with the data collected in study 3 and the final EHBM explained 29.4% of the variance in behaviour compared with 16.2% in study 1. Diabetes-specific social support has more than twice the influence on DSHB: Severity and Susceptibility scores (study 1, path value β = -.147; study 3, path value β = .322) and nearly twice the influence directly on adherence to diabetes self-care regime (study 1, path value β = .329; study 3, path value β = .527) for participants of study 3. On combining the data sets however, the path values between diabetes-specific social support and DSHB: Severity and Susceptibility scores is reduced to -.008 yet social support is nevertheless a significant factor in adherence to the diabetes self-care regime for young people (path value $\beta = .311$). Thus social support is still a significant predictor of good adherence to the diabetes self-care regime within the revised Extended Health Belief Model.

At the end of study 1 it was suggested that perhaps the model explained the experience of young people with diabetes in *good* metabolic control better than it did the experience of young people with diabetes in *poor* metabolic control. To test if this was the case the entire data set was split to form two groups – one consisting people in good metabolic control (HbA_{1C} below 10.0%) and one consisting people in poor metabolic control (HbA_{1C} above 10.01%). Summary statistics for these groups are included in table 7.17.

Table 7.17 Participants in good and poor metabolic control full scale scores.

Variable	*Control*	*N*	*Mean*	*SD*	*t*	*df*	*P*	*Effect Size*
DSHB: Severity & Vulnerability	Good	36	7.49	2.09	-2.082	85	.040	-.48
	Poor	51	8.72	3.07				
DFBC	Good	36	4.75	6.80	-.046	85	.963	.00
	Poor	51	4.82	7.60				
Locus of Control: Internal	Good	36	30.47	3.75	.329	85	.743	.07
	Poor	51	30.19	3.92				
Locus of Control: Power Others	Good	36	16.89	4.77	-.191	85	.849	-.04
	Poor	51	17.14	6.71				
Locus of Control: Chance	Good	36	17.67	3.83	-1.075	85	.285	-.24
	Poor	51	18.78	5.34				
QOL Total	Good	36	-.95	.89	2.302	85	.024	-.52
	Poor	51	-1.51	1.24				
DES Total	Good	36	2.03	.37	-1.848	85	.070	-.42
	Poor	51	2.23	.58				
Life threat due to diabetes	Good	36	.64	.59	.575	85	.567	.12
	Poor	51	.57	.54				
HFS Total	Good	36	45.56	13.51	.102	85	.919	.02
	Poor	51	45.25	13.64				
DSHB: Benefits & Barriers	Good	36	16.86	10.39	1.771	85	.080	.38
	Poor	51	12.70	11.04				
Adherence	Good	36	3.94	1.17	.471	85	.639	.09
	Poor	51	3.82	1.26				

Path analysis was run for the two groups testing the final revised Extended Health Belief Model and the results confirmed the predictions. Path analysis for those participants in good metabolic control revealed that high participant perceived susceptibility to and severity of diabetes-related complications was predicted by low quality of life scores. High life threat due to diabetes was predicted by high participants perceived susceptibility to and severity of diabetes-related complications and by low reported diabetes-specific social support. Perceiving the benefits of adhering to the diabetes self-care regime as outweighing the psychological costs of doing so was predicted by high internal locus of control, good quality of life and high diabetes-related empowerment. High levels of internal locus of control, good quality of life and high diabetes-related empowerment predicted participant DSHB: Benefits and Barriers scores. Participant high levels of adherence to the diabetes self-care regime was predicted by high levels of diabetes-specific social support.

The data fit for the participants in good metabolic control to the model was greater than that for the participants in poor metabolic control (Participants in good control: $Chi^2 = 33.90$, df = 17, model AIC = -.09, CFI = .87, RMSEA = .11. Participants in poor control: $Chi^2 = 26.17$, df = 17, model AIC = -7.83, CFI = .71, RMSEA = .18). The amount of variance explained by the model for those participants in good metabolic control was 16% compared with 4% for those participants in poor metabolic control.

7.6 Conclusions

Study 3 did replicate the findings of study 1. There was found no significant difference in scores on measure total scores or measure sub-scale scores, age, gender split, HbA_{1C} or duration of diabetes. The data fit to the proposed final Extended Health Belief Model was excellent and explained 29.4% of variance in behaviour for the participants of study 3. The data fit to the proposed final Extended Health Belief Model was good for the combined data set and explained 11.5% of the variance in behaviour for the participants of this research. There were changes to the values of paths between certain variables however, social support was still indicated as a strong predictor in the young person's adherence to the diabetes self-care regime. The revised version of the Extended Health Belief Model appears to explain the experience of young people with diabetes exhibiting good metabolic control better that it does the experience of young people with diabetes in poor metabolic control but it is suggested that the final revised version of the Extended Health Belief Model is acceptable for use with all young people with diabetes within this age group.

Chapter 8: Further Analysis of the Data Collected

8.1. The Extended Health Belief Model

The previous studies have demonstrated the suitability of the Extended Health Belief Model (EHBM) as a model for explaining the experience of young adults with diabetes and in particular, have demonstrated the validity of the model in explaining some of the processes involved in the young adult choosing to adhere to their diabetes self-care regime.

Using path analysis techniques to test the revised version of the EHBM (as proposed at the end of the previous chapter) allows path values to be assigned to the directional paths between the variables and it may possibly identify those paths which have the most predictive value and therefore, which paths significantly predict the young adults' adherence to the diabetes self-care regime.

The paths of the revised EHBM which have statistically significant values are presented in figure 10 Appendix A.

High DSHB: Severity & Vulnerability scores are predicted by low ADDQoL (quality of life) scores (path value = -.165), perceiving the benefits of adhering to the diabetes self-care regime as outweighing the costs of doing so is predicted by high levels of diabetes-specific social support (path value = .154), high internal locus of control (path value = .223), good quality of life (path value = .457) and high reported levels of diabetes-related empowerment (path value = -.244). High levels of diabetes-related empowerment are predicted by good quality of life scores (path value = -.533) and good quality of life scores is predicted by high levels of internal locus of control (path value = .180). High life threat due to diabetes is predicted by high DSHB: Severity & Vulnerability scores (path value = .383) and low levels of diabetes-specific social support (path value = -.232). Interestingly, the only significant path predicting adherence to the diabetes self-care regime is that from diabetes-specific social support (path value = .280). Path analysis conducted on a model displaying only these significant paths revealed good fit of the data to this model ($Chi^2 = 32.31$, df = 18, $p>.05$, model AIC = -3.69, CFI = .92, RMSEA = .08). This model explains 7.84% of the variance in the young persons' adherence to the diabetes self-care regime.

It has been suggested that the revised version of the EHBM is believed to explain the experience of young adults exhibiting good metabolic control better than that of those young adults exhibiting poor metabolic control. Path analysis of the revised version of the EHBM using data collected only from the participants in good metabolic control (those whose HbA_{1C} was below 10%) revealed exactly the same significant paths in the model as it did when tested using data collected from all participants. Path analysis was conducted on only the significant paths of the model using only the data collected from those participants in good metabolic control. This revealed good fit of the data to the model (model (Chi^2 = 33.77, df = 20, model AIC = -6.23, CFI = .89, RMSEA = .09). This model explains 13.3% of the variance in the young persons' adherence to the diabetes self-care regime. When compared to the fit of the data to the model for the participants in poor control, although participant numbers are low, the differences become clear (Chi^2 = 33.13, df = 20, model AIC = -6.86, CFI = .59, RMSEA = .19). This model explains 2% of the variance in the young persons' adherence to the diabetes self-care regime. Thus there is support for the notion that the significant paths of the revised EHBM explain the variance in the young persons' adherence to the diabetes self-care regime for those in good metabolic control better than those in poor metabolic control.

8.2 Participants in good and poor reported metabolic control

Participants in good metabolic control ($HbA_{1C} < 10\%$) and poor metabolic control ($HbA_{1C} > 10\%$) were compared on the total scales scores. Significant differences between the groups were found for diabetes-dependent quality of life and results approaching significance were found for life threat due to diabetes and the DSHB: benefits and barriers scale. Thus compared to the participants in good metabolic control, the participants in poor metabolic control reported worse quality of life scores, reported worse life threat due to diabetes and worse DSHB: benefits and barriers scores.

Table 8.1 Participants in good and poor metabolic control full scale scores.

Variable	*Control*	*N*	*Mean*	*SD*	*t*	*df*	*P*	*Effect Size*
DSHB: Severity	Good	64	7.23	2.43	-.520	76	.605	.14
& Vulnerability	Poor	14	7.62	3.10				
DFBC	Good	64	5.55	7.01	1.504	76	.137	.44
	Poor	14	2.43	7.08				
Diabetes L.o.C.	Good	64	30.61	3.67	.810	76	.420	.23
Internal	Poor	14	29.71	4.10				
Diabetes L.o.C.	Good	64	17.11	5.83	.596	76	.553	.17
Powerful Others	Poor	14	16.07	6.27				
Diabetes L.o.C.	Good	64	18.00	4.71	-.624	76	.534	.19
Chance	Poor	14	18.86	4.38				
QOL Total	Good	64	-1.09	1.06	2.320	76	.023	**.65**
	Poor	14	-1.84	1.26				
DES Total	Good	64	2.11	.46	-.483	76	.630	-.13
	Poor	14	2.18	.62				
Life threat due to	Good	64	.55	.56	-1.888	76	.063	**.57**
diabetes	Poor	14	.86	.53				
HFS Total	Good	64	45.92	13.20	.995	76	.323	.27
	Poor	14	41.86	16.59				
DSHB: Benefits	Good	64	15.91	10.35	1.866	76	.066	**.54**
& Barriers	Poor	14	10.14	11.02				
Adherence	Good	64	3.56	.98	-.415	76	.679	-.12
	Poor	14	3.69	1.22				

Table 8.2 Participants in good and poor metabolic control sub scale scores.

Variable	*Control*	*N*	*Mean*	*SD*	*t*	*df*	*P*	*Effect Size*
QoL now	Good	64	2.88	1.44	.497	76	.620	**1.13**
	Poor	14	1.40	1.18				
QoL without	Good	64	.26	1.76	.740	76	.461	**1.68**
diabetes	Poor	14	-2.00	.93				
DSHB: Benefits	Good	64	27.79	5.29	.596	76	.553	.18
	Poor	14	26.93	3.94				
DSHB: Barriers	Good	64	12.36	8.28	-2.152	76	.034	**.61**
	Poor	14	17.40	8.21				

To investigate this further, the participants' scores on the sub-scales were compared and the specific areas where the two groups differed became apparent. Participants in good metabolic control reported much better quality of life now whilst participants in poor metabolic control reported much better quality of life if they did not have diabetes

For the DSHB: Benefits and Barriers scores, the groups again showed differences on the sub-scale scores. Both the participants in good metabolic control and the participants in poor metabolic control had high scores on the benefits of adhering to the diabetes self-care regime sub-scale. However, when rating the costs or barriers of adhering to the diabetes self-care regime, participants in poor metabolic control had a significantly higher score than participants in good metabolic control. Therefore, the participants in poor metabolic control rate the costs of adhering to the self care regime more highly and see these costs as more of a barrier to adhering to the diabetes self-care regime and to the process needed for achieving and maintaining good metabolic control.

Therefore, significant differences were found between those participants in good metabolic control and those participants in poor metabolic control. Those in poor metabolic control reported poorer quality of life, the costs or barriers to them carrying out their diabetes self-care tasks were much greater than those reported by the participants in good metabolic control and worse life threat due to diabetes

The implications for adherence to the diabetes self-care regime become more apparent when a correlation matrix is drawn for total scale scores (table 8.3). Good adherence to the diabetes self-care regime correlated highly with high levels of diabetes-specific social support for the participants in good metabolic control ($r = .486$, $P = .001$), but not for participants in poor metabolic control. Indeed, there are no significant correlations between adherence to the diabetes self-care regime and any of the health belief variables for the participants in poor metabolic control. When the sub-scale scores for diabetes specific social support are investigated there are significant correlations between all the sub-scales and the sub-scales of the adherence to diabetes self-care regime measure ($r= .252$-$.285$, $p \leq .01$) for participants in good metabolic control but none for participants in poor metabolic control. This lends further support to the notion that the revised version of the Extended Health Belief Model explains the experience of young adults with diabetes in good metabolic control better than the experience of young adults with diabetes in poor metabolic control.

		Severity / Vulnerability	*DFBC*	*Internal L.o.C.*	*Powerful Others L.o.C*	*Chance L.o.C*	*Quality of Life Score*	*Empower-ment Score*	*Life Threat Score*	*Perceived Control*	*Hypoglyc-aemia Score*	*Benefits / Barriers*	*Adherence*
Severity / Vulnerability Score	Pearson Cor.	-											
	N												
Diabetes Family Behaviour Checklist Score	Pearson Cor.	.057	-										
	N	76											
Internal Locus of Control	Pearson Cor.	-.006	.102	-									
	N	77	84										
Powerful Others Locus of Control	Pearson Cor.	.125	.151	.128	-								
	N	75	82	83									
Chance Locus of Control	Pearson Cor.	.056	-.024	-.267*	-.062	-							
	N	76	83	84	82								
Quality of Life Score	Pearson Cor.	-.236*	.220	.236*	-.105	-.175	-						
	N	71	79	79	77	78							
Empowerment Score	Pearson Cor.	.124	-.217	-.366**	-.108	.287**	-.447**	-					
	N	75	82	82	80	81	77						
Life Threat Score	Pearson Cor.	.243*	-.237*	-.093	.060	.168	-.232*	.205	-				
	N	76	83	84	82	83	78	81					
Perceived Control of Diabetes Score	Pearson Cor.	-.370**	.130	.422**	.069	-.210	.318**	-.647**	-.343**	-			
	N	76	83	84	82	83	79	81	83				
Hypoglycaemia Worry and Behaviour Score	Pearson Cor.	.292*	.161	-.071	.142	.040	-.319**	.205	.016	-.194	-		
	N	76	84	84	82	83	79	82	83	83			
Benefits and Barriers Score	Pearson Cor.	-.312**	.263*	.443**	.051	-.261*	.624**	-.606**	-.288**	.587**	-.242*	-	
	N	77	84	85	83	84	79	82	84	84	84		
Adherence Score	Pearson Cor.	-.022	.486**	.094	.028	.113	.057	-.189	-.129	.135	.134	.218*	-
	N	76	83	84	82	83	78	82	83	83	83	84	

**. Correlation is significant at the 0.01 level(2-tailed).
*. Correlation is significant at the 0.05 level(2-tailed)

Table 8.3 Correlation matrix for full scale scores: good metabolic control (poor metabolic control condition yielded no significant results)

8.3 Social Support and Adherence to the Diabetes Self-Care Regime

Table 8.4 Social support scores by participant gender

Variable	*Gender*	*N*	*Mean*	*SD*	*t*	*df*	*P*	*Effect Size*
Total	Male	49	2.41	6.02	-2.179	114	.031	**-.42**
	female	67	5.31	7.78				
Diet	male	49	-.02	2.47	-1.476	114	.143	-.28
	female	67	.67	2.51				
Glucose	male	49	-2.84	1.93	-.512	114	.610	-.09
	female	67	-2.63	2.35				
Insulin	male	49	1.67	2.08	-2.429	114	.017	**-.47**
	female	67	2.75	2.52				
Exercise	male	49	2.10	1.83	-1.009	114	.315	-.19
	female	67	2.51	2.33				
General	male	49	1.49	2.04	-1.398	114	.165	-.26
	female	67	2.01	1.97				

Females reported higher levels of total diabetes-specific social support than males and higher levels of support for the task of insulin injecting than males. Decreasing levels of reported support for insulin injecting was associated with increasing age of the participant ($r = -.192$, $P<.05$) but not with increasing duration of diabetes ($r = -.148$ to $.140$, $p = NS$). High levels of reported support for insulin injecting were highly correlated with support for exercise, general support and total diabetes support ($r = .334, .319, .561$ respectively, all $p<.001$) and high reported levels of total diabetes support were related to high levels of support for all the diabetes support sub-scales - diet, blood glucose testing, insulin injecting, exercise and general support ($r = .513$ to $.742$, $p = <.001$).

To explore the effect of social support further, the participants' living location was investigated to see whether there was a difference between those who lived in a high available support environment and those who lived in a low available support environment. The participants indicated at the beginning of the questionnaire whether they lived with a parents ($N = 55$), with spouse/partner ($N =33$), in shared (college) house ($N = 22$), independently ($N = 8$)or other ($N = 0$). There was no difference in gender of the participants living in any of these categories ($Chi^2 = 1.622$, $df = 3$, $p = NS$). The participants living with parents or spouse/partner were combined to form a 'high environmental support' set and the participants living in a shared house or living independently were combined to form a 'low environmental support' set. These sets thus reflect the level of diabetes-specific social support available to the participant on a day-to-day basis.

Greater numbers of participants lived in the 'high environmental support (HES)' set (N = 88) than the 'low environment support (LES)' set (N = 30). When the effects of living environment were tested against diabetes-specific social support, the HES set reported higher levels of support for insulin injecting only than the LES set ($t_{(115)}$ = 2.536, p<.05), and there was no difference of gender (Chi^2 = 1.346, df = 1, p = NS) between the sets. Therefore, the high levels of social support for insulin injecting and total support reported by the female participants cannot be explained by living environment alone. Of the participants living in the LES set, 60% were female compared with 54% female participants in the HES set and there was no difference in HbA_{1C} between males and females ($t_{(101)}$ =.309, p = NS). However, participants in poor metabolic control (HbA_{1C} > 10.0) were more likely to reside in a 'high environmental support' situation and participants in good metabolic control (HbA_{1C} < 10.0) were more likely to reside in a 'low environmental support' situation (Chi^2 = 5.034, df = 1, p <.05). No difference was found in duration of diabetes between participants in the HES set and participants in the LES set ($t_{(111)}$ =-.528, p = NS)

To provide a more comprehensive measure of social support, participants' scores on the Diabetes Family Behaviour Checklist sub-scales were split at the median score to form two sets of participants – those reporting high levels of diabetes-specific social support and those reporting low levels of diabetes-specific social support. These two sets were then combined with the HES and LES sets in a matrix to form 3 'support' groups, see table 8.5 below:

Table 8.5 Matrix to show allocation of participants to total 'support' groups

		Environmental Support	
		High	Low
Diabetes-Specific Social Support	High	HH	M
	Low	M	LL

Thus group HH reside in a highly supportive environment and report high levels of diabetes-specific social support, group LL reside in a low support environment and report low levels of diabetes-specific social support and the third group M report a mix of the two.

There was no difference between the 'support' groups in age ($F_{(2)} = 1.169$, p = NS), gender ($Chi^2 = 2.443$, df = 2, p = NS), or whether the participants exhibited good or poor metabolic control ($Chi^2 = .469$, df = 2, p = NS). However there were differences in reported adherence to the diabetes self-care activities. (See table 8.6 below).

Table 8.6 Scores on the self-care activities of diet, insulin and total adherence for each of the 'support' groups.

Self-Care Activity	*'Support' Gp*	*N*	*Mean*	*SD*
Diet	HH	40	2.600	1.16
	M	61	4.590	1.20
	LL	16	5.031	.63
Insulin	HH	40	6.475	1.30
	M	61	6.855	.62
	LL	16	7.000	.00
Adherence	HH	40	3.383	.93
	M	61	4.071	1.35
	LL	16	4.151	1.05

Participants in the LL group reported significantly higher adherence to diet than participants in the M group or participants in the HH group ($F_{(2, 118)} = 45.673$, P<.001). Participants in the LL group reported higher adherence to insulin injecting than participants in the M group or participants in the HH group ($F_{(2, 118)} = 3.017$, P= .053). Participants in the LL group reported significantly higher adherence to total adherence to the diabetes self-care regime than participants in the M group or participants in the HH group ($F_{(2, 118)} = 4.720$, P=.01). Post-hoc analysis revealed the group divide: for adherence to diet, participants of the HH group consist one group whereas the M and LL groups form the second group; and for total adherence to the diabetes self-care regime, participants of the HH group consist one group and participants of the LL group form the second group. This indicates that members of the HH group are distinguished from the M group and the LL group in adherence to diet and in total adherence to the diabetes self-care regime. Therefore, those participants experiencing low levels of support are actually adhering to their diabetes self-care regime better than those experiencing high levels of support.

The 'support' groups also demonstrated differences in their perception of the life threat of diabetes. The group means (and standard deviations) for the groups are as follows : HH group = .5385 (.50), M group = .6290 (.55) and the LL group = .9375 (.57). Analysis of variance revealed the difference between the scores ($F_{(2)} = 3.144$, $p < .05$) and post hoc tests indicated that participants of the HH group consisted one group and participants of the LL group formed the second. This indicates that those participants with a high 'support' group rating report less life threat than those in the mixed 'support' group and those in the 'low' support group. Therefore, those participants reporting lower levels of support experience greater life threat due to the diabetes.

Review of findings

Thus the analysis presented indicates that as the young person with diabetes gets older, their perceived level of support reported for their diabetes decreases. Generally, the young people who were older had been diagnosed with diabetes for longer, which may explain the reduction in social support on the basis that as the young person has diabetes for longer so they become more proficient at controlling their diabetes and their need for diabetes-related support is reduced. However, the analysis presented also indicates that the longer-term diagnosed reported more diabetes-related support than those who were recently diagnosed. This may suggest that families are unable to provide the support the young person needs when newly diagnosed – perhaps due to the family's initial need to adjust to the diagnosis and to determine what support the young person actually needs – or perhaps as the young person adjusts to their diabetes their support needs become more apparent to the family or the young person realises that what the family does is 'support' which is reflected in their higher scores on the family support measure (DFBC). The implications for this appear to be that the older adults with a new diagnosis of diabetes appears to be experiencing a lower level of support than the younger adults or those with a longer diagnosis of diabetes.

One reason that the older adults appear to report less diabetes-related support could be due to the finding that they are more likely to live in a low support environment and therefore have lower levels of contact with supportive family members. Low levels of support is important to the young person as it appears to predict greater perceived life threat due to the diabetes in the young adults. Thus, those adults living in a low support environment, reporting lower levels of diabetes-related support consider themselves at greater risk from their diabetes than those living with their parents or with spouse/partner and reporting higher levels of diabetes-related support.

The analysis shows that females report greater levels of diabetes-related support than males, and in particular, report a greater level of support for insulin injecting. The reason for this gender bias in support is unclear, either women report more support for insulin injecting than men, or women are receiving more support for insulin injecting than men. As there was no gender difference in young adults living in high environment support or low environment support conditions, the analysis seems to suggest that women are not actually receiving any more support than the men, so it would seem reasonable to suggest that women are over-reporting the support for insulin injecting compared with the men. High levels of support for insulin injecting are extremely important, not only for adherence to the main task in the diabetes self-care regime, but also because support for insulin injecting is highly correlated with support for general diabetes care and total diabetes-related support.

The analysis has shown that support for the diabetes self-care tasks is highly correlated with adherence to the diabetes self-care regime for those young people reporting good metabolic control. However, those reporting good metabolic control are also more likely to live in low environment support conditions yet those reporting poor metabolic control are more likely to live in high environment support conditions and the analysis shows no correlation between levels of diabetes-related support received and actual adherence to the diabetes self-care tasks for the young people in poor metabolic control. Those young people reporting good metabolic control also consider the quality of life *without* diabetes to be much better than those who reported poor metabolic control. Perhaps the daily effort of high adherence to the diabetes self-care tasks results in the relative impact of *not* having diabetes for the young people in good metabolic control to be much greater than for those young people in poor metabolic control reporting lower adherence to the diabetes self-care tasks.

Interestingly, those young people living in high environment support conditions and reporting high levels of diabetes-related support report worse adherence to diabetes self-care tasks than the young people living in low environment support conditions. Perhaps the presence of family members or partner/spouse actually inhibits the young person from assuming full adherence to the diabetes self-care tasks and indeed, living in a low environment support condition promotes independence and good adherence to the diabetes self-care tasks when there is no-one to fall back on and no-one to act as reminder for the various tasks. This corresponds with the young person living in a low environment support condition reporting greater life threat. If the young person does not live with the safety buffer of they family or partner/spouse and has to constantly responsible for their own care, perhaps this results in a heightened awareness of the personal risks of poor metabolic control and hence greater life threat due to diabetes. However, although the young people living in low environment support conditions report great adherence to the diabetes self-care tasks, there was no effect on metabolic control. No statistical difference was found in reported metabolic control for those living in high or low environment support conditions.

Summary

Therefore, further analysis of the data has shown that females reported greater levels of diabetes-related support than males and in particular, reported a greater level of support for insulin injecting. High levels of support for insulin injecting are extremely important as support for insulin injecting is highly correlated with support for general diabetes care and total diabetes-related support. Support for the diabetes self-care tasks is highly correlated with adherence to the diabetes self-care regime for those young people reporting good metabolic control. As the young person gets older, their perceived level of support reported for their diabetes decreases. Adults living in a low support environment, reporting lower levels of diabetes-related support consider themselves at greater risk from their diabetes than those living with their parents or with spouse/partner and reporting higher levels of diabetes-related support. Older adults with a new diagnosis of diabetes appeared to be experiencing a lower level of support than the younger adults or those with a longer diagnosis of diabetes. Those reporting poor metabolic control are more likely to live in high environment support conditions – there was no correlation between levels of diabetes-related support received and actual adherence to the diabetes self-care tasks for the young people in poor metabolic control. Those young people living in high environment support conditions and reporting high levels of diabetes-related support reported worse adherence to diabetes self-care tasks which may suggest that the presence of family members or partner/spouse actually inhibits adherence to the diabetes self-care tasks. No statistical difference was found in reported metabolic control for those living in high or low environment support conditions.

Study 4: The Role Of Partner Relationships In The Young Person's Adherence To The Diabetes Self-Care Regime

9.1 Abstract

The role of partner relationships in the young person's adherence to the diabetes self-care regime was investigated. Advertisements were placed for the study on diabetes-specific web pages on the internet for young adults with diabetes and their spouse/partner to take part in an electronic format questionnaire located on the University of Southampton web page. 50 couples responded (mean age participants with diabetes = 28.68 years, SD = 4.08, 23 were male; mean age spouse/partner = 28.12, SD = 3.43, 25 were male). Participants with diabetes completed the Relationship Assessment Scale (Hendrick, 1988), the Diabetes Family Behaviour Checklist (Schafer, McCaul & Glasgow, 1986), a question measuring life threat due to diabetes and the Summary of Adherence to Diabetes Self-Care Activities Scale (Toobert & Glasgow, 1994). The spouse/partner completed spouse/partner versions of the scales. Spouse/partner reports were matched to participants with diabetes' reports by unique identifying codes. The results indicate that the participants with diabetes reported a better quality relationship, more diabetes-specific social support, more life threat due to the diabetes and worse adherence to the diabetes self-care regime than did their partner/spouse. A better quality relationship correlated with high reported levels of diabetes-specific social support which in turn was correlated highly with reported adherence to the diabetes self-care regime for both the participant with diabetes and for the partner/spouse. Gender analysis revealed that the female participants with diabetes in *longer* term relationships and male participants with diabetes in *shorter* term relationships reported better quality relationships, more diabetes-specific support and more adherence to the diabetes self-care tasks. This discrepancy appeared to be explained by overall relationship length with females reporting much shorter relationships than males. Path analysis demonstrated that diabetes-specific social support predicts adherence to the diabetes self-care regime for all but the male participants with diabetes for whom the reported quality of relationship predicted adherence to the diabetes self-care regime. Further analysis demonstrated that for male participants with diabetes, relationship quality acts as a mediator between reported diabetes-specific social support and adherence to the diabetes self-care regime.

9.2 Introduction

9.2.1 Summary of Previous Studies

The previous studies (Studies 1 and 3) have demonstrated the important role of social support in the young person's adherence to the diabetes self-care regime and some indication of the source of this support has been made (Study 2). The findings of Study 1 showed that the main influence on adherence to the diabetes self-care regime was diabetes-specific social support. This relationship was mediated by perceived life threat due to diabetes. The findings of Study 3 supported this relationship and allowed for analysis to be conducted between those participants in good metabolic control and those in poor metabolic control. The revised version of the Extended Health Belief Model appeared to explain the experience of young people with diabetes exhibiting good metabolic control better than it did the experience of young people with diabetes in poor metabolic control, but for both groups, social support was the main predictor of adherence to the self-care regime and again, this relationship was mediated by participant reported life threat due to diabetes. Study 2 demonstrated that good metabolic control was characterised by acceptance of diabetes, availability of practical social support and the young person's ability to cope with the day-to-day demands of diabetes as well as responding to changing needs on unique occasions. Young people in poor metabolic control appear to have difficulty accepting the diagnosis of diabetes and are unwilling to admit to others that they have diabetes.

Further analysis of the data collected from studies 1 and 3 has shown that women reported more support for insulin injecting which in turn correlated with more total support for diabetes self care activities. Life threat due to diabetes and adherence to the diabetes self-care regime was greater in the older participants who reported low levels of diabetes-specific support and lived in a low support environment. However, there was no correlation with levels of adherence in those participants living in a high support environment and reporting high levels of diabetes-specific social support. The participants reporting worse metabolic control tended to live in high support environments but there was no statistical difference in HbA_{1C} between those living in high support environments and reporting high levels of diabetes-specific social support and those living in low support environments and reporting low levels of diabetes-specific social support.

Many of the participants of the studies were no longer living at home and were living with partners or their spouse (32.8% of participants in Study 1 and 22% of participants in Study 3). In these studies it would seem reasonable to suggest that the young person receives most social support for their diabetes from the people they currently reside with thus the partner/spouse would be the main provider of social support rather than parents or other family members in these cases. Therefore, the role of partners as providers of social support needs investigating.

9.2.2 The Role of the Partner as Provider of Social Support

The role of partners in the lives of young adults is important. Connolly & Johnson (1996) conducted research looking at the experiences of 535 young men and 514 young women aged 13-19 years. The authors found that young adults with boy or girlfriends reported larger social networks, more opposite-sex friends and more non-school friends. Those young adults in more long term romantic relationships reported more social support from the boy or girlfriend than those in shorter term romantic relationships and these long term relationships were viewed more favourably than pre-existing and/or current friend and parent relationships. The strength of these relationships was tested by Gurung, Sarason & Sarason (1997). 52 young women and 34 young men (aged 18-22 years) and their romantic partners took part in a videotaped interaction that included a familiar task and a stress-inducing task. The observed mutually supportive behaviour from the couples in the familiar task was related to the personal characteristics of both partners and their view of the relationship quality. However, following the stress-inducing task, the supportive behaviour was predicted only by the personal characteristics of both partners and not by their view of the relationship quality. The authors conclude that the introduction of a stress-inducing task demonstrates the fallibility of the young adults' view of what constitutes a good quality relationship and what constitutes a poor quality relationship. In a study of older adults (52 participants aged 18-25 years old and 38-51 years old), Argyle & Furnham (1983) asked participants to rate 15 sources of satisfaction and 15 sources of conflict in 9 types of relationships located within 3 domains – the family, friends and work colleagues. The sources of satisfaction and sources of conflict were subjected to factor analysis. For the sources of satisfaction, 3 main factors emerged – instrumental reward, emotional support and shared interests. For the sources of conflict, one main factor – emotional conflict - and a minor factor – criticism – emerged. For the relationship with spouse, the participants gave the highest ratings on both the sources of conflict and satisfaction. The women reported greatest satisfaction in the area of emotional support and reported most support coming from members of the family and their friends. The men reported greatest satisfaction from their spouses and their work superiors. Thus the presence of a romantic relationship in young people indicates greater availability of social support generally and can be considered more important than the relationship with friends or parents (Connolly & Johnson, 1996). The relationship with the partner or spouse is a highly important source of both conflict and support in both young people and adults with women reporting most support in the arena of emotional support (Argyle & Furnham, 1983). However, the study conducted by Gurung, Sarason & Sarason (1997) indicates that how a couple copes with the introduction of a stress-inducing event depends on the personal characteristics of the individuals making up that couple rather than on the couple's reported view of their relationship.

Research has investigated the effect of a health threat as a stress-inducing event on both the couple's and the individual's perception of the relationship. Gale, Bennett, Tallon, Munnoch et al., (2001) investigated the experience of 158 women experiencing fears over their breast health as they attended a 'one-stop' breast clinic. Measures of stress, anxiety and depression, social support, self-esteem and quality of partnership (for those participants with romantic partners). The authors found that there was no effect of romantic relationship on the women's scores on stress anxiety and depression, however, those women reporting a low quality relationship experienced greater amounts of distress and reported less support from their partner than those women in high quality relationships, an effect that could not be explained by self esteem alone. When the health threat or illness is confirmed, the contribution of the spouse to the relationship and to the care of the ill partner becomes more apparent. A study by Helgeson (1993) investigated 77 adults aged 31-69 years and their spouses following hospitalisation after their first coronary event. The couples were followed up at 3 months and 12 months following the event. Helgeson reported that a shift in household responsibilities from the patient to the spouse occurred following the event. This was reported as supportive and adaptive for the patients initially but after 3 months, this was reported negatively by the patients. Interestingly, this shift in responsibilities was always reported negatively by the spouse. The study found that although spouse support did not predict patient adjustment to the coronary event, *spouse* adjustment to this event predicted spouse provision of support. Those patients where the spouse was distressed by the event reported less support than those patients where the spouse adjusted well. The role of spouse as provider of social support following onset of illness has been compared with the role of the primary health care provider. Yates (1995) compared the contribution of both spouse and health care providers on the outcome of 93 adults 2 months after a coronary event. Yates reported that practical support from the spouse was associated with better short term psychological adjustment for the patient. Interestingly, both the spouse and the health care provider had an important role to play in the recovery of the patient. Greater satisfaction with and more emotional support from the spouse was associated with better short term and long term *psychological* recovery and greater satisfaction with the health care provider was associated with better short term and long term *physical* recovery. Thus it would appear that when presented with a health threat, a high quality relationship with the spouse reduces the amount of distress experienced by the patient (Gale, Bennett, Tallon, Munnoch et al., 2001). However, once onset of illness has occurred, the adjustment of the spouse to this illness predicts higher levels of support (Helgeson, 1993) which in turn is related to better short and long term psychological recovery for the patient whilst greater satisfaction with the health care provider indicates better short and long term physical recovery (Yates, 1995).

The role of the spouse is still important in the first year following diagnosis of illness. Alferi, Carver, Antoni, Weiss & Duran (2001) reported the experience of 51 Hispanic women with early stage breast cancer. Measures of different types of social support were taken pre-surgery, post surgery and at 3, 6 and 12 month intervals post surgery. Emotional support from friends and instrumental support from the spouse at pre-surgery predicted lower levels of emotional distress post surgery. This study demonstrated that both the role of the spouse and the role of friends was important in predicting levels of emotional distress in the women with breast cancer. This finding is also supported by previous work by Hoskins (1995). Hoskins investigated how emotional and physical adjustment to a diagnosis of and surgery for breast cancer was predicted by levels of marital support, other sources of social support, women's role function within and outside of the family, and the women's satisfaction with health care provision. 128 women with breast cancer and 121 partners or spouses were interviewed at 7-20 days, 6months and 12 months post surgery. Hoskins found that the women's good emotional adjustment to the diagnosis and surgery was predicted by high levels of marital support, support from other adults and by good role function at each time point. However, as is the case following onset of illness, in the year following onset, it appears that the spouse's experience of the illness is indicative of the outcome for the patient. Northouse, Mood, Templin, Mellon & George (2000) investigated 56 couples aged 25-80 years where one member of the couple had a diagnosis of cancer of the colon. The couples were interviewed at 1 week post surgery, 60 days and 1 year post surgery. The authors found that the healthy spouses reported more emotional distress and reported receiving less social support than the patients and for women this finding was more profound than for the men, irrespective of whether they were the patient or the healthy spouse. Both patients and spouse reported a reduction in family functioning and external social support following surgery but they also reported a reduction in emotional distress experienced as time passed. Indeed, the type of support the partner/spouse provides as well as how mutually supportive the relationship is reported to be predicts the ability, particularly of women patients, to cope (Sormanti & Kayser, 2000). Thus, in the year following onset of illness, a highly supportive relationship with friends and partner/spouse *pre-surgery* predicts lower patient distress post-surgery (Alferi, Carver, Antoni, Weiss & Duran, 2001; Hoskins, 1995) but this relationship is possibly mediated by spouse adjustment and perception of received social support (Northouse, Mood, Templin, Mellon & George, 2000).

With respect to chronic ill health, the literature can be divided into research investigating the impact of the support offered by the partner/spouse on the patients' health outcome and the impact of the chronic illness on the spouses' health outcome. Looking first at the effect on the patient's health outcome, a study by Primomo, Yates & Woods (1990) investigating the role of social support on 125 women (mean age 41.3 years) with a diagnosis of chronic illness revealed that the women reported more support from their romantic partner/spouse than from any other source. Family members provided mostly emotional support whilst friends provided mostly affirmatory support. After their spouses, the women were more likely to confide in the various health care providers or counsellors (both psychological and religious) than to their family members or friends. However, all sources of support had an important role to play in reducing levels of depression reported by the women and in turn was related to higher levels of spouse relationship quality and better family functioning. High levels of spouse-provided support were also reported in a study by Revenson & Majerovitz (1990) of 42 patients with rheumatoid arthritis and their healthy spouses. When the patients were experiencing high levels of pain and depressed mood, the spouses were able to provide the most social support and the most problem-solving support, particularly when the rheumatoid arthritis was in a more advanced stage. When the disease was in a more advanced stage, the spouses reported higher levels of depression, however this effect was moderated by the spouses reporting a good support network available to them outside of the spouse/patient relationship. (Revenson & Majerovitz, 1991). The ability of the partner/spouse to cope with their partner's chronic ill health can be reflected in their reported attitude to the spouse. Manne & Zautra (1989) investigated 103 women with rheumatoid arthritis (aged 25-80 years) and their spouses. Manne & Zautra found that the women's adjustment to their rheumatoid arthritis was predicted by the attitude of the spouse. Those women who had a highly critical spouse demonstrated greater maladaptive coping behaviours and poorer psychological adjustment than those women whose spouse exhibited low criticism. More adaptive coping behaviours were demonstrated by the women who perceived their spouse as being more supportive to their chronic ill health. Therefore, people experiencing chronic illness report their partner/spouse as being the greatest provider of social support although support provided by family, friends and counsellors predicted a reduction in the patient's depressed mood and an increase in role and family functioning (Primomo, Yates & Woods, 1990). Spouses appear to offer the most support when the patient is distressed or in the advanced stages of chronic illness (Revenson & Majerovitz, 1990) but the spouses can experience difficulties themselves. Depression in the spouse is more prevalent when the patient is in the advanced stages of the chronic illness (Revenson & Majerovitz, 1991) and when this is expressed as criticism, this affects the patient's ability to adopt adaptive coping behaviours (Manne & Zautra, 1989). However, depression experienced by the spouse appears to be positively affected by a supportive social group extraneous to the patient/spouse relationship (Revenson & Majerovitz, 1991).

The spouse's response to their partner's chronic health problem has been investigated further. Manne & Zautra (1990) followed up their 1989 study of the role of spouse's criticism on their partner's health outcome. Manne & Zautra returned to their sample of 103 women with rheumatoid arthritis (age 25-80 years) and their husbands. Both the spouse's and the chronically ill partner's psychological adjustment to the rheumatoid arthritis was predicted by how well the couple adjusted to the illness. The spouse's mental health was most affected by their own perceived vulnerability to rheumatoid arthritis and their poor coping efficacy. The chronically ill partner's psychological adjustment was most affected by pain severity and their ability to cope with their rheumatoid arthritis. Thus for both the spouse and the chronically ill partner, coping efficacy and therefore illness impact was an important factor in their psychological adjustment to the illness. This finding has been supported by research by Bigatti & Cronan (2002) in their study of the effect of having a partner with fibromyalgia syndrome on spouse's mental health. 135 spouses with partners with fibromyalgia syndrome were compared with 153 spouses with healthy partners. The spouses of chronically ill partners reported worse health and affective states, higher levels of depression and loneliness, and higher levels of stress than spouses of healthy partners. This effect on mental health in spouses was moderated by the degree of reported illness impact between the couples. Those husbands who reported their chronically ill wives experienced worse sleep quality and worse coping efficacy, reported worse mental health than any other of the spouses. This effect is not restricted to husbands however, Hafstrom & Schram (1984) reported the effect of chronic illness on 43 families where the husband was ill and 26 families where the wife was chronically ill (age range of the women was 28-60 years, for the men, 28-64 years) and compared them with 147 families where neither partner was chronically ill. Hafstrom and Schram found that when the husband was chronically ill, the wife reported worse marital satisfaction and worse husband-wife interactions than when the wife was ill, or when neither were ill. Therefore, for both the spouse and the chronically ill partner, coping efficacy and illness impact appear to be an important factor in the spouse's psychological adjustment to the illness (Manne & Zautra, 1990; Bigatti & Cronan (2002). Although research suggests this effect on mental health may be more prevalent in husbands of chronically ill wives, wives of chronically ill husbands are affected by the presence of the illness but this is expressed in terms of worsened marital satisfaction and husband-wife interaction (Hafstrom & Schram, 1984).

Although there is a body of research into the effects illness and chronic illness have on the mental health of the patient and their spouse, little research has been carried out into the role of the romantic partner with direct reference to diabetes mellitus. Jensen (1985) interviewed 51 couples where one partner had a diagnosis of Type 1 diabetes mellitus. The group where the male partner had Type 1 diabetes mellitus was aged 32-52 years, and the group where the female partner had Type 1 diabetes mellitus was aged 32-51 years. Overall, the partner with Type 1 diabetes mellitus (irrespective of their gender) complained more than their spouse of fears and anxiety for the future, reported more fluctuations in mood, were more tired and reported more troublesome aspects to daily life. The male partners with Type 1 diabetes mellitus reported greater concerns about issues related to sex and sexual functioning than the female partners with Type 1 diabetes mellitus and spouses. In 1986, Jensen followed up this research by publishing findings that the male partners with Type 1 diabetes mellitus reported reduced body-related self-esteem, more sexual dysfunction, greater fears that their children would inherit diabetes than the female partners with Type 1 diabetes mellitus, and reported that they felt their partners would benefit from more information regarding the influence of diabetes on their relationship and the future effect the diabetes could have on their children. Thus there appears to be that the partner with diabetes reports worse mental health than their spouse and has greater concerns about the future, both for themselves and their children (Jensen, 1985; Jensen, 1986).

Therefore, the literature presented indicates that for young adults the presence of a romantic relationship is important as both an indicator of general social and as a provision of greater support than family or friends support (Connolly & Johnson, 1996). How this relationship provides support depends on the personal characteristics of the individuals however (Gurung, Sarason & Sarason ,1997), and this relationship can be both a source of support and conflict (Argyle & Furnham, 1983). When the couple are presented with a health threat to one of their members, the quality of that relationship affects the level of distress experienced by the ill partner (Gale, Bennett, Tallon, Munnoch et al., 2001). If the spouse adjusts well to the onset of illness, the increased level of support provided by them is related to better short term and long term psychological recovery for the ill partner (Helegeson, 1993; Yates, 1995). In the year following onset of illness, a highly supportive relationship, indicated by good spouse adjustment and spouse reported high level of social support, predicts better psychological adjustment in the ill partner (surgery (Alferi, Carver, Antoni, Weiss & Duran, 2001; Hoskins, 1995; Northouse, Mood, Templin, Mellon & George, 2000). When the partner is chronically ill, all sources of support reduced levels of depression in the ill partner which in turn was related to higher levels of spouse relationship quality and better family functioning (Primomo, Yates & Woods, 1990) . The impact the illness has and the coping efficacy of both the spouse and the ill partner predict both the ill partner's health outcome and the spouse's health outcome (Bigatti & Cronan, 2002; Manne & Zautra, 1990). The spouse is worse affected when the chronic illness is in its advanced stages (Revenson & Majerovitz, 1991) and this can affect the ability of the ill partner to cope adaptively with their illness (Manne & Zautra, 1989). Husbands of chronically ill wives may find their mental health more affected than wives of chronically ill husbands (Haufstrom & Schram, 1984), but the mental health problems experienced appear to be positively affected by a supportive social group extraneous to the patient/spouse relationship (Revenson & Majerovitz, 1991). With diabetes, the chronically ill partner reports worse mental health than their spouse and has greater concerns about the future, both for themselves and their children (Jensen, 1985; Jensen, 1986).

9.2.3 The use of the internet as a data collection tool

It has been estimated that by the year 2005, 1 billion people will have access to and be accustomed to the internet (Sheehan & Hoy, 1999b). Certainly the current estimate of people using the internet is approximately 50 million (Cook, Heath & Thompson, 2000). The first forms of electronic survey conducted were in email format which respondents indicated were easy to use and, similar to paper based surveys, could be completed in the respondents own time and at their own pace (Parker, 1992). Recent developments in HTML and java script programming have allowed more interactive interfaces between the respondent and the data collector (Schillewaert, Langerak & Duhamel, 1998) which respondents generally find more appealing (University of Colorado, 1996).

A meta-analysis of web-based and internet-based surveys conducted by Cook, Heath & Thompson (2000) used 2 search engines: 'web of science' and 'google'. Surveys were coded on 15 variables including topic salience and whether the survey collected attitudinal data, factual data or a combination of both. The meta-analysis concerned 56 surveys reported in 39 articles. The results indicated that response rates to the surveys ranged from approximately 30-50%. Response to the survey was increased by the inclusion of a personalised letter introducing the study, when the respondent had previously been contacted for research purposes, when the topic of the survey was coded 'somewhat salient' (covered important issues but which were not necessarily 'current or timely'), and interestingly, when no incentive was offered to complete the study.

The response rates are similar to those of paper mail surveys of which published response rates of 40-50% have been reported (Kerlinger, 1986). The response rate did not depend on questionnaire length, there being no correlation between number of questions in the survey and response rate (Cook, Heath & Thompson, 2000). Thus the use of web-based surveys appears to produce the same response rate as mailed paper based surveys. However, what must be considered is that the number of people who regularly access the internet is relatively low. Yet the representativeness of the sample may not necessarily be affected. With targeted advertising on internet message boards of web-groups for the sample population under investigation, it is possible to approach a precise population from which the respondents may be considered a representative sample. The use of electronic surveys for psychological research via the internet is therefore considered a useful method by which data can be collected.

Summary:

The role of the romantic partner as provider of social support has been investigated in young people without illness as the focus, in adults with the threat of illness, in adults following the onset of illness and also in adults coping with chronic illness. Both the spouse and the partner who is ill appears to be detrimentally affected by the presence of both short term illness and chronic illness, but this effect appears to be reduced by the presence of a strong supportive social network beyond the spousal relationship and by the efficacy of both spouse and ill partner to cope with the illness. The use of the internet to collect data for research purposes warrants more investigation, however, the evidence seems to suggest that response rates and sample representativeness to a web-based survey will be similar to those achieved in a mailed paper based survey.

9.3 Rationale for Study 4

As the previous studies have shown, social support appears to be the main factor influencing the young person's adherence to the diabetes self-care regime. However, this thesis has so far only investigated the young person's family of origin as providers of that support, yet for this age group (16-25 years), the review of research just presented suggests that partners and spouses have a contribution to make in providing support for the young person with diabetes. Study 4 therefore has been designed specifically to address this neglected area by investigating the effect social support provided by the partner has on the young person's adherence to the diabetes self-care regime. This study will also have a novel approach both in obtaining data from both the young person with diabetes and their partner plus using an electronic-format questionnaire accessible from and advertised on the internet.

9.3.1 Aims for the Study

The aims of this study are to investigate further the effect of social support on adherence to the diabetes self-care regime by investigating the contribution the young person's partner has as provider of social support and to obtain information on this from both the young person with diabetes and from their partner. It is predicted that those participants reporting a better quality relationship (indicated by higher scores on the Relationship Assessment Scale (Hendrick, 1988) will report more available social support and greater adherence to the diabetes self-care regime. Participant scores are predicted to correlate highly with partner scores on all measures. The previous studies indicated that women report more diabetes-specific social support and it is therefore predicted that women will report more diabetes-specific social support in this study.

9.4 Method

9.4.1 Participants

Participants were recruited by advertising in web-based diabetes support group message boards. These were identified as those support groups registered with current (May 1st, 2002) web servers ('Yahoo', 'Google', 'Lycos', 'Vizzavi', 'aol', 'excite', 'btinternet' and 'askjeeves'). The participants targeted were aged 18-30 years with a diagnosis of diabetes mellitus and their partners. 50 participants with diabetes mellitus responded aged 22-35 years (Mean age 28.68, SD 4.08), 26 were female and their HbA_{1C} scores ranged from 5.90 to 9.00 (Mean = 7.04, SD = 1.17). The mean length of relationship with the partner was 6.58 years (range 3-13 years, SD = 3.15). Consequently, 50 partners aged 22-34 years (Mean age = 28.12, SD = 3.43), 24 were female reporting a mean length of relationship with the young person with diabetes of 6.54 years (range 3-13 years, SD = 3.19) completed the questionnaires. All participants' partners responded creating a sample of 50 matched pairs.

9.4.2 Materials

Electronic version web-based questionnaires were used to investigate each variable of the portion of the Extended Health Belief Model under investigation. Where possible brief versions of the measures were used to encourage completion by the participants. All measures used were standard scales employed in Study 1 and Study 3. The survey is included in Appendix B. The Diabetes Family Behaviour Checklist (Schafer, McCaul & Glasgow, 1986), the question measuring life threat and the Summary of Diabetes Self-Care Activities Scale (Toobert & Glasgow, 1994) are all the same measures used in the previous studies. For the partners, the wording for each of these questionnaires was changed slightly so that the questions focus was what the partner thought the young person with diabetes did/thought/experienced etc., with regard to their perceived levels of social support, life threat and adherence to diabetes self-care activities. A copy of the revised questionnaires is included in Appendix B. The Relationship Assessment Scale was used to provide an indication of the satisfaction and quality of the relationship experienced by both the young person with diabetes and their partner. This measure is described below:

The Relationship Assessment Scale (Hendrick, 1988)

The Relationship Assessment Scale (RAS) is a 7 item Likert scale based on the Marital Assessment Questionnaire (Hendrick, 1981). Each item is scored from '1' indicating low satisfaction to '5' indicating high satisfaction. Two items, items 4 and 7, are reverse scored. It is unique in offering a measure not only of marital relationship but includes any other style relationship. Published data for this measure provide means and standard deviation scores as well as reliability and validity results, presented below:

Table 9.1. Items, means and standard deviations for the Relationship Assessment Scale (RAS): Study N = 125 (Hendrick, 1988).

Item No.	Content	Mean	SD
1.	How well does your partner meet your needs?	4.224	.869
2.	In general, how satisfied are you with your relationship?	4.256	.924
3.	How good is your relationship compared to most?	4.280	.912
4.	How often do you wish you hadn't gotten into this relationship?	4.136	.970
5.	To what extent has your relationship met your original expectations?	3.944	1.080
6.	How much do you love your partner?	4.792	.528
7.	How many problems are there in your relationship?	3.512	1.126

The RAS correlates well with other relationship measures, notably the Love Attitudes Scale (Hendrick and Hendrick, 1986), the Sexual Attitudes Scale (Hendrick, Hendrick, Slapion-Foote & Foote, 1985) and measures of commitment, beliefs about one's ability to attract another partner and level of investment in the relationship (Lund, 1985) indicating good scale validity.

For the Love Attitudes Scale (Hendrick and Hendrick, 1986), the RAS correlated with a measure of 'Eros' (passionate love): $r = .60$, $p<.05$; 'Ludus' (game playing love): $r = -.30$, $p<.05$; and 'Agape' (altruistic love): $r = .36$, $p<.05$; but not with 'Storge' (friendship love), 'Pragma' (practical love) or 'Mania' (possessive, dependent love) $r = -.05$ to $.14$, $p = NS$.

For the Sexual Attitudes Scale (Hendrick, Hendrick, Slapion-Foote & Foote, 1985) the RAS correlated only with 'Communion' (idealistic sex): $r = .24$, $p<.05$; but not with 'permissiveness' (casual sex), 'sexual practices' (responsible sex) or 'Instrumentality' (utilitarian sex) $r = -.14$ to $.15$, $p = NS$.

The RAS also correlated highly with measures of commitment: $r = .55$, $p<.05$; beliefs about one's ability to attract another partner: $r = -.21$, $p<.05$; and level of investment in the relationship: $r = .45$, $p<.05$.

The RAS has also been tested against the Dyadic Adjustment Scale (Spanier, 1976). The Dyadic Adjustment Scale (DAS) is a widely used 32 item scale originally designed for married couples. It has 4 subscales: Dyadic Satisfaction, Cohesion, Consensus and Affectional Expression. The RAS correlated highly with all four subscales of the DAS when tested on 57 University undergraduate couples (Hendrick, 1988). The correlations were all significant ($p<.05$) and were: RAS and Dyadic Consensus, $r = .62$, with Dyadic Satisfaction, $r = .83$, with Dyadic Cohesion, $r = .57$ and with Affectional Expression, $r = .80$. The RAS also correlated highly with the Total DAS, $r = .80$, $p<.05$ (Hendrick, 1988).

The RAS demonstrates good test-retest reliability ($r = .49$, $\alpha = .86$) on this University Undergraduate population ($N = 114$) and correlations between partners on each item were also good ($r = .27$ to $.67$, $p<.05$) bar on question 5 ('To what extent has your relationship met your original expectations?'), $r = .24$, $p = NS$. Total RAS score correlation between partners was also high, $r = .62$, $p<.05$. The RAS also demonstrated good discriminant validity of couples who had either stayed together or broken up 6 months later. ANOVA revealed a statistically significant difference between the groups of couples of stayed together and couples who had broken up ($F(1,29) = 28.41$, $p<.001$), the mean RAS scores for each group were 4.34 and 3.33 respectively (Hendrick, 1988). Total scores for the RAS and DAS for the University Undergraduate population were used as separate predictors for discriminant analysis.

The RAS correctly discriminated 91% of the couple who had stayed together and 57% of the couples now separated. This compares well with the DAS which correctly discriminated 93% of the couples who had stayed together and 50% of the couples now separated.

In conclusion, the Relationship Assessment Scale appears to be a useful, brief measure of the love relationship existing between two people, married or not, same or mixed gender couples and it is accepted as an appropriate measure for use in this study.

9.4.3 Design

Cross-sectional matched pairs electronic web-based survey design. Participant selection criteria for the young person with diabetes were a diagnosis of diabetes mellitus and currently in a relationship. The partners were elected by the young person with diabetes and gave their consent to take part in the study.

9.4.4 Procedure

Advertisements for this study were placed on diabetes support groups located on the internet (date: May 1st 2002). Search engines 'Yahoo', 'Google', 'Lycos', 'Vizzavi', 'aol', 'excite', 'btinternet' and 'askjeeves' were used to locate these diabetes support groups. The groups were general 'message board' type sites where members would share anecdotes, tips and medical information relating to their experience of diabetes. A total of 25 diabetes support groups accepted the advertisement and displayed it on their message boards. Contained within the message was a hyperlink that the person could click on to take them to the electronic study page located on the University of Southampton, Department of Psychology webpage. From this page the participant could view information about the study and elect to take part.

Young people with diabetes were asked to take part if they were involved in a relationship and to ask their partner to take part in the study. After couples gave their consent to take part in the study they were asked to provide a unique identifier code so that when the data came to be analysed the sets of scores could be correctly paired.

The participants completed demographic questions followed by a measure of life threat (as used previously in Studies 1 and 3), the Relationship Assessment Scale (Hendrick, 1988), the Diabetes Family Behaviour Checklist (Schafer, McCaul & Glasgow, 1986) and the Summary of Diabetes Self-Care Activities Scale (Toobert & Glasgow, 1994). The young person with diabetes completed these questions as normal, the partner completed the partner-version questions with the focus being what they *believed* the young person's experience of their diabetes was. On completion of the measures each participant was automatically asked if they would be happy to take part in further research and were then forwarded to the debrief page.

All data was collected anonymously. The data was received in the form of an email message which had no identifying information on it other than information the participant had provided if they had agreed to be contacted further. The messages were automatically given the subject 'person with diabetes' or 'person without diabetes' dependent on which set of questionnaires the person had completed. These messages were then saved into a text format which could be interpreted by the Microsoft Excel statistical programme. This database was then converted for SPSS analytic use and all analysis was completed using this programme.

9.5 Results

9.5.1 Participant details

The participants with diabetes were aged 22-35 years (Mean age = 28.68 years, SD = 4.08) and 23 were male. The participants had been diagnosed for between 2 and 33 years (Mean = 13.55 years, SD = 10.81) with Type 1 diabetes (insulin-dependent diabetes mellitus). 46 lived with partners /spouse and 4 lived in shared accommodation. The HbA_{1C} readings (N=31) ranged from 5.9% to 9.0% (Mean = 7.04%) of which 24 participants were within the 'normal' range (5 – 8%) and 7 participants had readings within the 'high' range (8.01% and over). The reported duration of relationship with partner/spouse ranged from 3 – 13 years (Mean = 6.58 years, SD = 3.15). 4 participants indicated their ethnicity as 'black'. The partners/spouses of the participants with diabetes were aged 22-34 years (Mean = 28.12 years, SD = 3.43) and 25 were male. The reported duration of relationship with partner/spouse with diabetes was 3-13 years (Mean = 6.54 years, SD = 3.19). All partners/spouses of participants with diabetes indicated their ethnicity as 'white/caucasian'.

9.5.2 Summary of findings: Sub-scale scores

Relationship Assessment Scale

Table 9.2. Subscale scores for the person with diabetes for the Relationship Assessment Scale

Item no.	*Content:*	*N*	*Min.*	*Max.*	*Mean*	*SD*
1.	How well does your partner meet your needs?	50	4	5	4.70	.463
2.	In general, how satisfied are you with your relationship?	50	3	5	4.32	.621
3.	How good is your relationship compared to most?	50	4	5	4.84	.370
4.	How often do you wish you hadn't gotten into this relationship?	50	1	2	1.16	.370
5.	To what extent has your relationship met your original expectations?	50	3	5	4.38	.635
6.	How much do you love your partner?	50	4	5	4.92	.274
7.	How many problems are there in your relationship?	50	3	5	3.68	.621

Table 9.3. Subscale scores for the spouse/partner for the Relationship Assessment Scale

Item No.	*Content:*	*N*	*Min.*	*Max.*	*Mean*	*SD*
1.	How well does your partner meet your needs?	50	2	5	4.28	.97
2.	In general, how satisfied are you with your relationship?	50	1	5	3.96	1.23
3.	How good is your relationship compared to most?	50	1	5	4.04	1.26
4.	How often do you wish you hadn't gotten into this relationship?	50	1	5	1.92	1.30
5.	To what extent has your relationship met your original expectations?	50	2	5	3.92	.944
6.	How much do you love your partner?	50	2	5	4.52	.99
7.	How many problems are there in your relationship?	50	1	5	3.44	1.07

The participants with diabetes scores on the Relationship Assessment Scale were all higher than the published scores from a matched healthy population (Hendrick, 1988) (see table 9.4). The participants with diabetes were more satisfied with how well their partner met their needs (Cohen's d = -.71) and thought their relationship was better compared to most than the matched comparison sample (Cohen's d = -.87). However, the participants with diabetes were more likely to wish that they had not got into the relationship than the matched comparison sample published by Hendrick (1988)(Cohen's d = -1.05) although they rated their relationship high in meeting their original expectations (Cohen's d = -.51).

When the participant with diabetes' scores were compared with their partner/spouse scores again the participants with diabetes scored higher on each question in the scale. The participants with diabetes felt their partner met their needs more than did their spouse ($t_{(49)} = 3.364$, $P<.001$, Cohen's $d = .59$) , were generally more satisfied with their relationship ($t_{(49)} = 2.168$, $P<.05$, Cohen's $d = .38$)and thought their relationship was better compared to most than did their partner/spouse ($t_{(49)} = 4.802$, $P<.001$, Cohen's $d = .98$). The participants with diabetes wished they had not got into the relationship more than the partner/spouse did ($t_{(49)} = -4.007$, $P<.001$, Cohen's $d = .91$) but felt the relationship had met their original expectations more than the partner/spouse did ($t_{(49)} = 3.342$, $P=.001$, Cohen's $d = .58$). Interestingly, the participant with diabetes rated their love for their partner/spouse higher than their partner/spouse did ($t_{(49)}$ = 3.130, P<.005, Cohen's *d* = .63) although both groups indicated about the same number of problems occurring within the relationship ($t_{(49)}$ = 1.519, P>.05, Cohen's *d* = .28).

Table 9.4. Effect sizes (Cohen's *d*) for responses to each question of the Relationship Assessment Scale for the participants with diabetes and spouse scores compared with published results for a matched healthy population, and participant with diabetes compared with spouse.

Item No.	Content	Diabetes vs published	Spouse vs published	Diabetes vs Spouse
1.	How well does your partner meet your needs?	**-.71**	-.06	**.59**
2.	In general, how satisfied are you with your relationship?	-.08	.27	.38
3.	How good is your relationship compared to most?	**-.87**	.22	**.98**
4.	How often do you wish you hadn't gotten into this relationship?	**-1.05**	.05	**.91**
5.	To what extent has your relationship met your original expectations?	**-.51**	.02	**.58**
6.	How much do you love your partner?	-.32	.36	**.63**
7.	How many problems are there in your relationship?	-.19	.06	.28

When the partner/spouse scores were compared with published scores from a matched healthy sample there was no difference found between them on any of the questions (Cohen's *d* = range -.06 to .36 (*d* = .36 for how much do you love your partner)). This suggests that the partner/spouse group in this study are representative of healthy adults of this age and demographics as per the Hendricks study (1988).

Diabetes Family Behaviour Checklist

Table 9.5. Subscale scores for the person with diabetes for the Diabetes Family Behaviour Checklist

Sub scale	*N*	*Min.*	*Max.*	*Mean*	*SD*
diet	50	0	7	2.64	1.93
blood glucose testing	50	-3	0	-1.26	1.06
insulin injecting	50	-3	5	3.28	2.18
exercising	50	1	8	3.06	2.03
diabetes	50	2	9	5.6	1.96

Table 9.6. Subscale scores for the spouse/partner for the Diabetes Family Behaviour Checklist

Sub scale	*N*	*Min.*	*Max.*	*Mean*	*SD*
diet	50	-3	8	1.76	3.02
blood glucose testing	50	-4	1	-1.04	1.54
insulin injecting	50	0	7	3.58	2.13
exercising	50	1	6	3.58	1.55
diabetes	50	-1	9	4.38	2.88

The combined data set from Studies 1 and 3 was used as a comparison data set. The participant with diabetes' scores on each of the sub-scales of the Diabetes Family Behaviour Checklist (table 9.5 and table 9.6) revealed that they generally reported more support for the various sub-scales than did the combined comparison data set (family support for diet $t_{(165)} = 5.731$, $P<.001$; insulin injecting $t_{(165)} = 2.490$, $P<.05$; exercise $t_{(165)} = 2.046$, $P<.05$; general support $t_{(165)} = 11.245$, $P<.001$). Only on blood glucose testing were the participant with diabetes' scores lower than for the combined comparison data set (blood glucose testing $t_{(165)} = 4.528$, $P<.001$). Comparing the partner/spouse data to the participant with diabetes scores showed that generally the partner/spouse reported higher levels of support than the person with diabetes.

Table 9.7: Effect size calculations (Cohen's *d*) for Diabetes Family Behaviour Checklist Scores for Person with diabetes compared with Study1 & 3 combined scores and person with diabetes compared with partner/spouse.

DFBC scale	Diabetes vs study 1& 3	Diabetes vs Partner/Spouse
diet	**-1.02**	.35
blood	**-.91**	-.17
insulin	-.43	-.14
exercise	-.35	-.29
general	**-1.91**	.50

Effect sizes (see table 9.7) calculated for the scores indicates that when compared with the combined comparison data set, the participants with diabetes reported more support for diet (Cohen's $d = -1.02$), for blood glucose testing (Cohen's $d = -.91$) and for general diabetes support (Cohen's $d = -1.91$). When the participant with diabetes' scores are compared with their partner/spouse scores, there are no significant effects present. This demonstrates that this study's participant group and partner/spouses are reporting more diabetes-specific support than the participants from studies 1 and 3 and the limitations of comparing the two groups (participants from this study and participants from study 1 and 3) on this measure.

Summary of Diabetes Self-Care Activities Scale

Table 9.8. Subscale scores for the person with diabetes for the Summary of Diabetes Self-Care Activities Scale

Sub scale	*N*	*Min.*	*Max.*	*Mean*	*SD*
diet	50	1.75	7	4.43	1.74
exercise	50	.50	6	3.32	2.27
blood glucose testing	50	1	7	6.44	1.64
insulin injecting	50	7	7	7	0
foot care	50	0	4.5	1.47	1.48
smoking	50	0	5	.52	1.42

Table 9.9. Subscale scores for the spouse/partner for the Summary of Diabetes Self-Care Activities Scale

Sub scale	*N*	*Min.*	*Max.*	*Mean*	*SD*
diet	50	2	6.5	4.61	1.32
exercise	50	0	7	2.70	2.54
blood glucose testing	50	1	7	5.30	2.63
insulin injecting	50	0	7	6.36	1.93
foot care	50	0	4.5	2.08	1.55
smoking	50	0	45	4.94	12.21

The adherence to the diabetes self-care regime scores for the participants with diabetes were slightly different to the ones reported in the combined comparison data set with the participants with diabetes reporting slightly greater adherence to diet ($t_{(165)} = 1.725$, $P>.05$) and insulin injecting ($t_{(165)} = 1.998$, $P<.05$), and much greater adherence to blood glucose testing ($t_{(165)} = 6.185$, $P<.001$) but lower adherence to exercise ($t_{(165)} = -.489$, $P>.05$) and foot care ($t_{(166)} = -.213$, $P>.05$) whilst also reporting lower rates of smoking ($t_{(165)} = -3.053$, $P<.05$). Interestingly, the partner/spouse reports of the participant's adherence to the self-care regime revealed generally worse accounts of adherence than the participants with diabetes reported, apart from smoking behaviour where the scores were very much greater ($t_{(49)} = -2.508$, $P=.01$).

Table 9.10: Effect size calculations (Cohen's *d*) for Summary of Diabetes Self-Care Activities Scale Scores for Person with diabetes compared with Study1 & 3 combined scores and person with diabetes compared with partner/spouse.

SDSCA scale	Diabetes vs published	Partner/Spouse vs combined	Diabetes vs Partner/Spouse
diet	-.01	-.28	-.12
exercise	-.41	.08	.26
blood	**-.79**	**-1.18**	.53
insulin	**-.65**	.58	**.66**
foot	**1.22**	.04	-.45
Smoking		**.72**	**-.65**

Effect size calculations (see table 9.10) revealed that the participants with diabetes reported adherence to blood glucose testing and insulin injecting was significantly higher than the combined comparison group (Cohen's d = -1.18 and .58 respectively) whilst the partner/spouse scores of adherence to insulin injecting were significantly lower (Cohen's d = .66). For smoking behaviour, the difference in reporting between the participants with diabetes and their partner/spouse was significant (Cohen's d = -.65). This demonstrates that the participants in this study differ from the participants from studies 1 and 3. This may present a problem in interpreting any analysis comparing the data with previous data from this thesis or with published data as the published data presented in this thesis has been collected on younger adults (aged 16-25 years) and any data published for older adults tends to be presented as part of a larger dataset describing the experience of adults aged 20-60 or more years with a mix of type 1 and type 2 diabetes. Without precise sample-matched published data for adults aged up to 30 years with type 1 diabetes available on the measures used in this study, the best comparison that can be made at present is with the data published for younger adults that has been cited in the previous studies of this thesis.

Although every attempt was made to collect data from a population with diabetes (advertisements specifically asked for the participation of young adults with diabetes and were placed on diabetes-specific group message boards), it is not known exactly how many of the participants actually had diabetes. By examining the scores of the participants in this study with those of other published studies and with the data collected in the previous studies, not only can the similarities between the data sets be determined, but also the differences. The results presented so far suggest that as there are similarities between this data set and the data collected either in published studies and/or in the previous studies of this thesis, the participants in this study *did* have diabetes, yet the occasional substantial differences between the data sets whilst supported by spouse/partner data suggest that the experience of this slightly older group of young people with diabetes is significantly different from those young people aged 16-25 years old.

9.5.3 Summary of findings: full-scale scores

When scores are compared with published scores these published scores are the same as reported in Study 1.

Table 9.11. Summary of findings: Total scores for both person with diabetes and their partner on each of the behaviour measures with minimum and maximum possible scores in parentheses.

Measurement Scale	*N*	*Min.*	*Max.*	*Mean*	*SD*
Relationship Assessment Scale Total Score	50	3.71	4.71	4.33	.25
Diabetes Family Behaviour Checklist	50	4	27	13.32	5.26
Summary of Diabetes Self-Care Activities Scale	50	2.67	4.79	3.86	.61
Life threat due to diabetes	50	0	2	1.22	.85
Relationship Assessment Scale Total Score – **Partner Score**	50	2.00	4.57	3.91	.77
Diabetes Family Behaviour Checklist – **Partner Score**	50	-1	27	12.26	8.64
Summary of Diabetes Self-Care Activities Scale – **Partner Score**	50	.75	11.88	4.33	2.48
Life threat due to diabetes – **Partner Score**	50	0	2	.93	.90
Valid N (listwise)	50				

Table 9.12: Effect size calculations (Cohen's *d*) for each of the measures for person with diabetes compared with Study1 & 3 combined scores and person with diabetes compared with partner/spouse.

Total Scale	Diabetes vs published	Spouse/partner vs published	Diabetes vs combined	Diabetes vs Partner/Spouse
RAS	.20	-.52	-	**.82**
DFBC	**1.49**	**.78**	**1.48**	.15
SDSCA			.02	-.30
Life threat	.58	**.81**	**.83**	.25

Relationship Assessment Scale

The total scale scores on the Relationship Assessment Scale for the participants with diabetes (Mean = 4.33, SD = .25) were higher than the total scale scores for the partners/spouse (Mean = 3.91, SD = .77) $t_{(49)} = 4.326$, P<.001, Cohen's *d* = .82. These scores compare well for 'white/caucasian' people where mean scores have been published as 4.31 (SD = .51) for women and 4.19 (SD = .57) for men (Contreras, Hendrick & Hendrick, 1996).

Diabetes Family Behaviour Checklist

The total scale scores on the Diabetes Family Behaviour Checklist for the participants with diabetes (Mean = 13.32, SD = 5.26) were a little higher than the total scale scores reported by the partners/spouse (Mean = 12.26, SD = 8.64) $t_{(49)} =1.007$, P=.32, Cohen's *d* = .15. However, the total scale scores for the participants with diabetes were very much higher than those collected in Studies 1 and 3 (Mean combined dataset = 4.09, SD = 7.17) $t_{(165)} =8.191$, P<.001, Cohen's *d* = 1.48.

Summary of Diabetes Self-Care Activities Scale

The total scale scores on the Summary of Diabetes Self-Care Activities Scale for the participants with diabetes (Mean = 3.86, SD = .61) were a little lower than the total scale scores reported by the partners/spouse (Mean = 4.33, SD = 2.48) $t_{(49)} =-1.423$, P=.16, Cohen's *d* = -.30. The total scale scores for the participants with diabetes were very similar to those collected in Studies 1 and 3 (Mean combined dataset = 3.845, SD = 1.21) $t_{(164)} = .101$, P=.92, Cohen's *d* = .02). When the adjusted total scores (to exclude smoking behaviour) participant scores in this study did not differ from published scores (Cohen's $d = .13$) (Toobert & Hampson, 1994).

Measure of Perceived Life Threat

Mean scores for the participants with diabetes were 2.18 (SD = .72) which were higher, indicating greater life threat of diabetes, than the scores reported by their partner/spouse (Mean = 1.98, SD = .59) $t_{(49)} = 1.278$, P=.21, Cohen's $d = .30$. The score for life threat was significantly greater for the participants with diabetes than for the participants in Studies 1 and 3 (Mean combined dataset = 1.64, SD = .55) $t_{(161)} = 5.144$, P<.001, Cohen's $d = .72$.

9.5.4 Correlation Matrix – full-scale scores

Table 9.16. Correlation matrix of full scale scores

		DFBC Score	*RAS Score*	*SDSCA Score*	*Life threat*	*DFBC Score partner score*	*RAS – partner score*	*SDSCA Score – partner score*	*Life threat partner score*
DFBC Score	Pearson Cor.	-							
	N								
Relationship Assessment Scale	Pearson Cor.	-.177	-						
	N	46							
Adherence Score	Pearson Cor.	.017	-.223	-					
	N	46	46						
Life threat	Pearson Cor.	.279	.315*	.008	-				
	N	46	46	46					
DFBC Score partner score	Pearson Cor.	.353*	-.070	.151	.233	-			
	N	46	46	46	46				
RAS – partner score	Pearson Cor.	.343*	.462**	-.043	.654**	.061	-		
	N	46	46	46	46	46			
Adherence Score – partner score	Pearson Cor.	.379**	.158	.358*	-.111	.674**	-.035	-	
	N	46	46	46	46	46	46		
Life threat – partner score	Pearson Cor.	.143	-.081	.019	.000	.234	.016	.162	-
	N	46	46	46	46	46	46	46	

**. Correlation is significant at the 0.01 level (2-tailed).
*. Correlation is significant at the 0.05 level (2-tailed)

Participant with diabetes full-scale scores were highly correlated with partner/spouse full scale scores on the Diabetes Family Behaviour Checklist, on the Relationship Assessment Scale and on the Summary of Adherence to Diabetes Self-Care Activities

Scale. Both participants with diabetes full-scale score and their partner/spouse full scale score on the Diabetes Behaviour Checklist were highly correlated with partner/spouse reported full scale score on the Summary of Adherence to Diabetes Self-Care Activities Scale. Partner/spouse full scale scores on the Relationship Assessment Scale were highly correlated with participant with diabetes full scale score on the Diabetes Family Behaviour Checklist. Participant with diabetes and their spouse/partners' rating of the relationship quality correlated positively with participant notion of life threat due to diabetes.

Therefore, participant with diabetes and their partner/spouse correlated highly on their reports of diabetes-specific social support, strength of relationship and on the participant with diabetes' adherence to their self-care regime. Adherence to this self-care regime as reported by the partner/spouse (NOT by the participant with diabetes themselves) is highly correlated to social support reported by both participant with diabetes and their partner/spouse. Higher quality relationships as reported by both participant with diabetes and their spouse/partner correlated with participant with diabetes' greater reported life threat due to diabetes.

9.5.5 Correlation Matrix – sub-scale scores

Relationship Assessment Scale

For the participants with diabetes, responses on each of the seven questions on the Relationship Assessment Scale were highly correlated with each other (See table 9.13). The number of problems in the relationship was the poorest indicator of how well their partner/spouse met their needs, their general satisfaction with the relationship and how often they wished they had not got into the relationship (Pearson's $r = -.128$ to $.271$, $p = NS$).

For the partner/spouse scores, all responses on each of the 7 questions of the Relationship Assessment Scale were highly correlated with each other (Pearson's $r = -.980$ to $.935$, $p<.05$). Participant with diabetes scores on question 1 – how well does your partner meet your needs? – were highly correlated (inversely for the reverse scored questions 4 and 7) with spouse/partner responses to all the questions (Pearson's $r = -.412$ to $.615$, $p<.05$). Participant with diabetes scores of general satisfaction with the relationship correlated highly with partner/spouse response of satisfaction with the relationship, how good the relationship was compared to others and how much the partner/spouse loves their partner (Pearson's r = .338 to .518, p<.05). Participant with diabetes and spouse/partner scores were highly correlated for how good the relationship was compared to others, how well the relationship had met their original expectations and how much they loved each other (Pearson's r = .290 to .455, p<.05). Participant with diabetes scores for how much they loved their partner/spouse were highly correlated with partner/spouse responses to all the 7 questions (Pearson's r = .393 to .482, p<.05).

Therefore, inter-item correlations were high when the Relationship Assessment Scale was completed by the participant with diabetes and when the Relationship Assessment Scale was completed by their partner/spouse. The correlations between participant with diabetes and their partner/spouse scores on each item (e.g. the correlation between participant score on question 1 and partner/spouse score on question 1 of the Relationship Assessment Scale) was also high. How much the participant with diabetes loved their partner and how much they felt their partner met their needs was highly correlated with their partner/spouse scores on all items. Partner/spouse general satisfaction with the relationship, how good the relationship is compared with others and how much they love their partner was highly correlated with participant with diabetes scores on most items of the scale.

Diabetes Family Behaviour Checklist

Participant with diabetes scores on the Diabetes Family Behaviour Checklist (see table 9.14) were generally highly correlated with each other (Pearson's r = .291 to .564, p <.05). Spouse/partner scores were also highly correlated with each other (Pearson's r = .300 to .642, p<.05). Participant with diabetes scores for general diabetes support were highly correlated with spouse/partner scores on all sub-scales other than blood glucose testing (Pearson's r = .400 to .632, p <.01). Participant with diabetes scores of support for diet were highly correlated with their partner/spouse scores of support for diet (Pearson's r = .739, p<.01) also, Participant with diabetes scores of support for exercise were highly correlated with their partner/spouse scores of support for exercise (Pearson's r = .447, p<.01).

		Rel. Scale Q1	*Rel. Scale Q2*	*Rel. Scale Q3*	*Rel. Scale Q4*	*Rel. Scale Q5*	*Rel. Scale Q6*	*Rel. Scale Q7*	*Rel. Scale Q1P*	*Rel. Scale Q2P*	*Rel. Scale Q3P*	*Rel. Scale Q4P*	*Rel. Scale Q5P*	*Rel. Scale Q6P*	*Rel. Scale Q7P*
Relationship Scale Q1	Pearson Cor.	-													
	N														
Relationship Scale Q2	Pearson Cor.	.341*	-												
	N	50													
Relationship Scale Q3	Pearson Cor.	.667*	.227	-											
	N	50	50												
Relationship Scale Q4	Pearson Cor.	-.190	-.582*	-.405*	-										
	N	50	50	50											
Relationship Scale Q5	Pearson Cor.	.465*	.306*	.611*	.083	-									
	N	50	50	50	50										
Relationship Scale Q6	Pearson Cor.	.450*	.633*	.676*	-.676*	.78	-								
	N	50	50	50	50	50									
Relationship Scale Q7	Pearson Cor.	.227	.271	.483*	-.128	.522*	.326*	-							
	N	50	50	50	50	50	50								
Relationship Scale Q1 – partner response	Pearson Cor.	.418*	.255	.127	-.127	.056	.393*	.016	-						
	N	50	50	50	50	50	50	50							
Relationship Scale Q2 – partner response	Pearson Cor.	.589*	.338*	.345*	-.165	.308*	.475*	.197	.935*	-					
	N	50	50	50	50	50	50	50	50						
Relationship Scale Q3 – partner response	Pearson Cor.	.615*	.400*	.364*	-.364*	.261	.482*	.121	.825*	.923*	-				
	N	50	50	50	50	50	50	50	50	50					
Relationship Scale Q4 – partner response	Pearson Cor.	-.412*	-.219	-.111	.111	-.036	-.360*	-.083	-.980*	-.917*	-.791*	-			
	N	50	50	50	50	50	50	50	50	50	50				
Relationship Scale Q5 – partner response	Pearson Cor.	.458*	.254	.313*	-.079	.290*	.448*	.304	.872*	.912*	.826*	-.832*	-		
	N	50	50	50	50	50	50	50	50	50	50	50			
Relationship Scale Q6 – partner response	Pearson Cor.	.567*	.518*	.230	-.230	.295*	.455*	.011	.904*	.919*	.862*	-.878*	.784*	-	
	N	50	50	50	50	50	50	50	50	50	50	50	50		
Relationship Scale Q7 – partner response	Pearson Cor.	.477*	.397	.181	-.387*	.079	.400*	.216	.861*	.851*	.862*	-.877*	.721*	.814*	-
	N	50	50	50	50	50	50	50	50	50	50	50	50	50	

Table 9.13. Correlation matrix of scores on the Relationship Assessment Scale – person with diabetes and partner.
** Correlation is significant at the 0.01 level (2-tailed).
*. Correlation is significant at the 0.05 level (2-tailed)

		Diet	Glucose	Insulin	Exercise	General	Diet – P	Glucose – P	Insulin – P	Exercise – P	General – P
Family support for diet	Pearson Cor.	-									
	N										
Family support for glucose testing	Pearson Cor.	.379**	-								
	N	50									
Family support for insulin injecting	Pearson Cor.	-.043	.058	-							
	N	50	50								
Family support for exercise	Pearson Cor.	.291*	-.473**	-.100	-						
	N	50	50	50							
Family support general	Pearson Cor.	.564**	.262	.351*	.109	-					
	N	50	50	50	50						
Family support for diet- partner score	Pearson Cor.	.739**	.488**	-.045	.016	.632**	-				
	N	50	50	50	50	50					
Family support for glucose testing- partner score	Pearson Cor.	-.101	-.231	-.252	-.012	-.005	.244	-			
	N	50	50	50	50	50	50				
Family support for insulin injecting- partner score	Pearson Cor.	.314*	.122	.249	-.140	.585**	.530**	.331*	-		
	N	50	50	50	50	50	50	50			
Family support for exercise- partner score	Pearson Cor.	.159	-.240	-.211	.447**	.400**	.300*	.642**	.353*	-	
	N	50	50	50	50	50	50	50	50		
Family support general- partner score	Pearson Cor.	.652**	.352*	.129	.142	.491**	.832**	.372**	.639**	.324*	-
	N	50	50	50	50	50	50	50	50	50	

Table 9.14. Correlation matrix of scores on the Diabetes Family Behaviour Checklist – person with diabetes and partner.
** Correlation is significant at the 0.01 level (2-tailed).
*. Correlation is significant at the 0.05 level (2-tailed)

		Diet	Exercise	Blood	Insulin	Feet	Smoking	Diet P	Exercise P	Blood P	Insulin P	Feet P	Smoking P
Self Care Diet	Pearson Cor.	-											
	N												
Self Care Exercise	Pearson Cor.	.611**	-										
	N	50											
Self Care Blood	Pearson Cor.	.407**	.268	-									
	N	50	50										
Self Care Insulin	Pearson Cor.	+	+	+	-								
	N	50	50	50									
Self Care Feet	Pearson Cor.	-.019	-.496**	.345*	+	-							
	N	50	50	50	50								
Self Care Smoking	Pearson Cor.	-.398**	-.364**	-.924**	+	-.109	-						
	N	50	50	50	50	50							
Self Care Diet Partner scores	Pearson Cor.	.526**	.200	.568**	+	.331*	-.596**	-					
	N	50	50	50	50	50	50						
Self Care Exercise Partner scores	Pearson Cor.	.286*	.205	.135	+	-.038	-.251	615**	-				
	N	50	50	50	50	50	50	50					
Self Care Blood Partner scores	Pearson Cor.	.343*	.252	.455**	+	.266	-.415*	.202	.136	-			
	N	50	50	50	50	50	50	50	50				
Self Care Insulin Partner scores	Pearson Cor.	.434**	.271	.963**	+	.335*	-.918**	.630**	.159	.455**	-		
	N	50	50	50	50	50	50	50	50	50			
Self Care Feet Partner scores	Pearson Cor.	.417**	.089	.339*	+	.408*	-.159	.478**	-.030	.262	.358*	-	
	N	50	50	50	50	50	50	50	50	50	50		
Self Care Smoking scores	Pearson Cor.	.299*	-.357*	.141	+	.321*	-.116	.365**	-.096	.075	.136	.285*	-
	N	50	50	50	50	50	50	50	50	50	50	50	

Table 9.15. Correlation matrix of scores on the Summary of Diabetes Self-Care Activities Scale – person with diabetes and partner.
** Correlation is significant at the 0.01 level (2-tailed).
*. Correlation is significant at the 0.05 level (2-tailed)

Therefore, partner/spouse reported support for all diabetes self-care activities were highly correlated. The participants with diabetes' reported support for diet was highly correlated with most other aspects of the diabetes self-care regime. There were few correlations between participant with diabetes reported support and partner/spouse reported support for diabetes activities. Only scores of general diabetes support, insulin injecting and support for diet were correlated.

Summary of Diabetes Self-Care Activities Scale

Participants with diabetes reported scores of adherence to diet (see table 9.15) were highly correlated with their scores on adherence to exercise, blood glucose testing and smoking behaviour (Pearson's $r = -.398$ to $.611$, $p<.01$). Participants with diabetes reported scores of adherence to exercise and blood glucose testing were both inversely correlated with reported adherence to foot care and smoking behaviour (Pearson's $r = -.496$ to $-.924$, $p<.05$). Partner/spouse scores of their partner's adherence to the diabetes self-care regime for diet were highly correlated with scores of their partner's adherence to exercise, insulin injecting, foot care and smoking scores (Pearson's $r = .365$ to $.630$, $p<.01$).

Participants with diabetes scores of adherence to diet were highly correlated with partner/spouse scores of their reported adherence to all aspects of the diabetes self-care regime (Pearson's $r = .286$ to $.526$, $p<.050$ and participant with diabetes scores of adherence to blood glucose testing were highly correlated with partner/spouse reports of their adherence to blood glucose testing, insulin injecting and foot care (Pearson's $r = .339$ to $.963$, $p<.05$). Participant with diabetes reports of their smoking behaviour was inversely correlated with their partner/spouse reports of their adherence to diet, blood glucose testing and insulin injecting (Pearson's $r = -.415$ to $-.918$, $p<.05$).

Therefore, participant with diabetes reports of adherence to diet, blood glucose testing and foot care correlates highly with partner/spouse reports of their adherence to the self-care regime. High levels of participant with diabetes reports of smoking is correlated with low partner/spouse reported adherence to the diabetes self-care regime.

Results of correlations between measure subscales

See table 9.16. Participants with diabetes who felt their partner met their needs reported greater support for insulin injecting (Pearson's $r = .347$, $p<.05$). Participants with diabetes reporting greater satisfaction with the relationship also reported low support for glucose testing (Pearson's $r = -.612$, $p<.01$) and high support for exercise behaviour (Pearson's $r = .502$, $p<.01$). Those participants with diabetes who thought their relationship was better compared to others reported high levels of support for diet (Pearson's $r = .374$, $p<.01$) and for glucose testing (Pearson's $r = .306$, $p<.05$). Participants with diabetes whose relationships met their original expectations reported greater support for diet (Pearson's $r = .495$, $p<.01$) although participants reporting high levels of love for their spouse/partner reported low levels of general support (Pearson's $r = -.365$, $p<.01$). Whereas those participants with diabetes reporting fewer numbers of problems in the relationship (item reverse scored) reported high levels of support for diet (Pearson's $r = .854$, $p<.01$), exercise (Pearson's $r = .339$, $p<.05$) and general support (Pearson's $r = .430$, $p<.01$) but low levels of support for insulin injecting (Pearson's $r = -.354$, $p<.05$).

Low participant with diabetes reported adherence to exercise behaviour correlated with high scores of their partner meeting their needs (Pearson's $r = -.363$, $p<.01$), high scores of satisfaction with the relationship (Pearson's $r = -.306$, $p<.05$), felt their relationship was better compared to most (Pearson's $r = -.326$, $p<.05$), felt their relationship met their original expectations (Pearson's $r = -.461$, $p<.01$), but also that

		Relationship Q1	Relationship Q2	Relationship Q3	Relationship Q4	Relationship Q5	Relationship Q6	Relationship Q7	Relationship Total	DFBC Diet	DFBC Glucose	DFBC Insulin	DFBC Exercise
Relationship Q1 Meet needs	Pearson Cor.	-											
	N												
Relationship Q2 satisfaction	Pearson Cor.	.300*	-										
	N	46											
Relationship Q3 good compared to others	Pearson Cor.	.660**	.198	-									
	N	46	46										
Relationship Q4 wish not got into this	Pearson Cor.	-.170	-.576**	-.395**	-								
	N	46	46	46									
Relationship Q5 Met your expectations	Pearson Cor.	.435**	.234	.604**	.127	-							
	N	46	46	46	46								
Relationship Q6 love your partner	Pearson Cor.	.444**	.643**	.673**	-.673**	.160	-						
	N	46	46	46	46	46							
Relationship Q7 number of problems	Pearson Cor.	.138	.088	.523**	-.060	.456**	.352*	-					
	N	46	46	46	46	46	46						
Relationship Total Score	Pearson Cor.	.729**	.746**	.714**	-.585**	.548**	.741**	.129	-				
	N	46	46	46	46	46	46	46					
Diabetes Family Behaviour Checklist Diet	Pearson Cor.	.185	-.270	.391**	.229	.423**	.054	.747**	-.059	-			
	N	46	46	46	46	46	46	46	46				
Diabetes Family Behaviour Checklist Glucose	Pearson Cor.	.032	-.675**	.300*	.118	-.024	-.080	.094	-.230	.447**	-		
	N	46	46	46	46	46	46	46	46	46			
Diabetes Family Behaviour Checklist Insulin	Pearson Cor.	.336*	-.042	-.160	-.044	-.004	-.245	-.540**	.160	-.148	.051	-	
	N	46	46	46	46	46	46	46	46	46	46		
Diabetes Family Behaviour Checklist Exercise	Pearson Cor.	-.337*	.407**	-.433**	.275	.061	-.079	-.224	-.030	-.380**	-.763**	-.249	-
	N	46	46	46	46	46	46	46	46	46	46	46	

Table 9.17. Correlation matrix of scores on all sub scales – person with diabetes and partner.

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

*. Correlation is significant at the 0.05 level (2-tailed)

		DFBC General	*DFBC Total*	*Self Care Diet*	*Self Care Exercise*	*Self Care Blood*	*Self Care Insulin*	*Self Care Foot Care*	*Self Care Smoking*	*Self Care Total*	*Life Threat*	*Relationship Partner Q1*	*Relationship Partner Q2*
Relationship Q1 Meet needs	Pearson Cor.	-.065	.134	-.039	-.424**	-.141	-	.130	.079	-.290	.461**	.392**	.569**
	N	46	46	46	46	46	46	46	46	46	46	46	46
Relationship Q2 satisfaction	Pearson Cor.	-.242	-.309*	-.153	-.410**	-.440**	-	.115	.326*	-.387**	.060	.198	.280
	N	46											
Relationship Q3 good compared to others	Pearson Cor.	-.317*	-.183	.039	-.367*	-.030	-	.425**	.178	.010	.396**	.102	.325*
	N	46	46	46	46	46	46	46	46	46	46	46	46
Relationship Q4 wish not got into this	Pearson Cor.	.184	.316*	-.174	.216	.166	-	-.014	-.178	.058	-.396**	-.102	-.138
	N	46	46	46	46	46	46	46	46	46	46	46	46
Relationship Q5 Met your expectations	Pearson Cor.	-.031	.182	-.316*	-.563**	-.223	-	.598**	.417**	-.225	-.011	-.009	.253
	N	46	46	46	46	46	46	46	46	46	46	46	46
Relationship Q6 love your partner	Pearson Cor.	-.481**	-.437**	.139	-.247	-.111	-	.286	.120	.018	.452**	.385**	.470**
	N	46	46	46	46	46	46	46	46	46	46	46	46
Relationship Q7 number of problems	Pearson Cor.	.154	-.018	-.271	-.586**	-.212	-	.561**	.341*	-.261	.229	-.164	.050
	N	46	46	46	46	46	46	46	46	46	46	46	46
Relationship Total Score	Pearson Cor.	-.337*	-.177	-.031	-.451**	-.266	-	.267	.280	-.223	.315*	.319*	.495**
	N	46	46	46	46	46	46	46	46	46	46	46	46
Diabetes Family Behaviour Checklist Diet	Pearson Cor.	.342*	.489**	-.114	-.566**	.342*	-	.793**	-.149	-.006	.166	.021	.210
	N	46	46	46	46	46	46	46	46	46	46	46	46
Diabetes Family Behaviour Checklist Glucose	Pearson Cor.	.263	.356*	.662**	.293*	.565**	-	.203	-.363*	.744**	..329*	.118	.086
	N	46	46	46	46	46	46	46	46	46	46	46	46
Diabetes Family Behaviour Checklist Insulin	Pearson Cor.	.352*	.678**	.010	-.202	.035	-	-.010	.002	-.118	.371*	.514**	.500**
	N	46	46	46	46	46	46	46	46	46	46	46	46
Diabetes Family Behaviour Checklist Exercise	Pearson Cor.	-.449**	-.374*	-.455**	.069	-.163	-	-.059	.037	-.274	-.672**	-.143	-.186
	N	46	46	46	46	46	46	46	46	46	46	46	46

Table 9.17. Correlation matrix of scores on all sub scales – person with diabetes and partner (cont'd).
** Correlation is significant at the 0.01 level (2-tailed).
*. Correlation is significant at the 0.05 level (2-tailed).

		Relationship Partner Q3	*Relationship Partner Q4*	*Relationship Partner Q5*	*Relationship Partner Q6*	*Relationship Partner Q7*	*Relationship Partner Total*	*DFBC Partner diet*	*DFBC Partner Gluc*	*DFBC Partner Insul*	*DFBC Partner Exer*	*DFBC Partner Gen*	*DFBC Partner Tot*
Relationship Q1 Meet needs	Pearson Cor.	.598**	-.387**	.425**	.556**	.445**	.520**	.080	.079	-.068	-.113	.101	.037
	N	46	46	46	46	46	46	46	46	46	46	46	46
Relationship Q2 satisfaction	Pearson Cor.	.355*	-.163	.160	.504**	.301*	.284	-.085	.356*	.109	.394**	-.079	.111
	N	46	46	46	46	46	46	46	46	46	46	46	46
Relationship Q3 good compared to others	Pearson Cor.	.346*	-.087	-.289	.216	.140	.254	.104	-.134	-.116	-.204	-.048	-.071
	N	46	46	46	46	46	46	46	46	46	46	46	46
Relationship Q4 wish not got into this	Pearson Cor.	-.346*	.087	-.038	-.216	-.370*	-.129	-.023	-.013	-.417**	-.119	-.040	-.154
	N	46	46	46	46	46	46	46	46	46	46	46	46
Relationship Q5 Met your expectations	Pearson Cor.	.209	.026	.212	.267	-.054	.191	-.035	-.148	-.271	-.111	-.314*	-.232
	N	46	46	46	46	46	46	46	46	46	46	46	46
Relationship Q6 love your partner	Pearson Cor.	.476**	-.351*	.447**	.449**	.404**	.452**	.097	.206	.065	.080	.175	.160
	N	46	46	46	46	46	46	46	46	46	46	46	46
Relationship Q7 number of problems	Pearson Cor.	-.030	.067	.121	-.105	-.084	-.025	.400**	.137	.186	.105	.161	.284
	N	46	46	46	46	46	46	46	46	46	46	46	46
Relationship Total Score	Pearson Cor.	.585**	-.260	.349*	.606**	.397**	.462**	-.090	.059	-.054	.031	-.130	-.070
	N	46	46	46	46	46	46	46	46	46	46	46	46
Diabetes Family Behaviour Checklist Diet	Pearson Cor.	.145	-.089	.226	-.025	.123	.116	.681**	.033	.249	-.232	.508**	.430**
	N	46	46	46	46	46	46	46	46	46	46	46	46
Diabetes Family Behaviour Checklist Glucose	Pearson Cor.	-.024	-.165	.016	-.132	.138	.027	.505**	-.222	-.110	-.310*	.363*	.224
	N	46	46	46	46	46	46	46	46	46	46	46	46
Diabetes Family Behaviour Checklist Insulin	Pearson Cor.	.630**	-.485**	.378**	.545**	.611**	.517**	-.095	-.239	.236	-.291*	.094	-.037
	N	46	46	46	46	46	46	46	46	46	46	46	46
Diabetes Family Behaviour Checklist Exercise	Pearson Cor.	-.210	.239	-.065	-.013	-.358*	-.121	-.457**	.180	-.419**	.183	--.335*	-.311*
	N	46	46	46	46	46	46	46	46	46	46	46	46

<u>Table 9.17. Correlation matrix of scores on all sub scales – person with diabetes and partner (cont'd).</u>
** Correlation is significant at the 0.01 level (2-tailed).
*. Correlation is significant at the 0.05 level (2-tailed).

		Self Care Partner Diet	*Self Care Partner Exer*	*Self Care Prtner Blood*	*Self Care Partner Insul*	*Self Care Partner foot*	*Self Care Partner Smk*	*Self Care Partner Tot*	*Life Threat Partner*
Relationship Q1 Meet needs	Pearson Cor.	-.006	-.073	-.482**	-.150	-.367*	.243	.046	-.062
	N	46	46	46	46	46	46	46	46
Relationship Q2 satisfaction	Pearson Cor.	.109	.090	-.321*	-.283	-.268	.389**	.222	.048
	N	46	46	46	46	46	46	46	46
Relationship Q3 good compared to others	Pearson Cor.	-.033	-.373*	-.318*	-.045	.136	.197	.052	-.153
	N	46	46	46	46	46	46	46	46
Relationship Q4 wish not got into this	Pearson Cor.	-.104	-.150	.318*	.045	-.136	-.197	-.146	.153
	N	46	46	46	46	46	46	46	46
Relationship Q5 Met your expectations	Pearson Cor.	-.147	-.476**	-.238	-.306*	.003	.372*	.136	.046
	N	46	46	46	46	46	46	46	46
Relationship Q6 love your partner	Pearson Cor.	.146	-.043	-.214	.047	-.009	.132	.082	-.103
	N	46	46	46	46	46	46	46	46
Relationship Q7 number of problems	Pearson Cor.	-.175	-.376**	.149	-.219	.375*	.194	.120	.058
	N	46	46	46	46	46	46	46	46
Relationship Total Score	Pearson Cor.	.071	-.106	-.532**	-.195	-.235	.379**	.158	-.081
	N	46	46	46	46	46	46	46	46
Diabetes Family Behaviour Checklist Diet	Pearson Cor.	.103	-.261	.342*	.268	.426**	.321*	.367*	.039
	N	46	46	46	46	46	46	46	46
Diabetes Family Behaviour Checklist Glucose	Pearson Cor.	.218	-.095	.327*	.468**	.529**	.122	.273	-.026
	N	46	46	46	46	46	46	46	46
Diabetes Family Behaviour Checklist Insulin	Pearson Cor.	.004	.296*	-.322*	-.005	-.325*	.051	-.001	-.026
	N	46	46	46	46	46	46	46	46
Diabetes Family Behaviour Checklist Exercise	Pearson Cor.	-.008	.000	.015	-.089	-.383**	-.153	-.173	.060
	N	46	46	46	46	46	46	46	46

Table 9.17. Correlation matrix of scores on all sub scales – person with diabetes and partner (cont'd).
** Correlation is significant at the 0.01 level (2-tailed).
*. Correlation is significant at the 0.05 level (2-tailed).

		DFBC General	*DFBC Total*	*Self Care Diet*	*Self Care Exercise*	*Self Care Blood*	*Self Care Insulin*	*Self Care Foot Care*	*Self Care Smoking*	*Self Care Total*	*Life Threat*	*Relationship Partner Q1*	*Relationship Partner Q2*
Diabetes Family Behaviour Checklist General	Pearson Cor.	-											
	N												
Diabetes Family Behaviour Checklist Total	Pearson Cor.	.776**	-										
	N	46											
Adherence to Self Care Diet	Pearson Cor.	.167	.061	-									
	N	46	46										
Adherence to Self Care Exercise	Pearson Cor.	-.255	-.382**	.585**	-								
	N	46	46	46									
Adherence to Self Care Blood	Pearson Cor.	-.115	.224	.397**	.253	-							
	N	46	46	46	46								
Adherence to Self Care Insulin	Pearson Cor.	-	-	-	-	-	-						
	N	46	46	46	46	46							
Adherence to Self Care Foot Care	Pearson Cor.	.066	.409**	-.168	-.658**	.334	-	-					
	N	46	46	46	46	46	46						
Adherence to Self Care Smoking	Pearson Cor.	.156	-.084	-.385**	-.350*	-.923**	-	-.071	-				
	N	46	46	46	46	46	46	46					
Adherence to Self Care Total	Pearson Cor.	-.051	.017	.866**	.677**	.613**	-	.020	-.492**	-			
	N	46	46	46	46	46	46	46	46				
Life Threat	Pearson Cor.	.286	.279	.241	-.249	-.277	-	.085	.366*	.008	-		
	N	46	46	46	46	46	46	46	46	46			
Relationship Partner Q1 meet needs	Pearson Cor.	.038	.342*	.232	-.114	.028	-	.200	.005	.139	.638**	-	
	N	46	46	46	46	46	46	46	46	46	46		
Relationship Partner Q2 Satisfaction	Pearson Cor.	.039	.386**	.064	-.380**	-.038	-	.397**	.114	-.031	.667**	.931**	-
	N	46	46	46	46	46	46	46	46	46	46	46	

Table 9.17. Correlation matrix of scores on all sub scales – person with diabetes and partner (cont'd).

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

*. Correlation is significant at the 0.05 level (2-tailed).

		Relationship Partner Q3	*Relationship Partner Q4*	*Relationship Partner Q5*	*Relationship Partner Q6*	*Relationship Partner Q7*	*Relationship Partner Tot*	*DFBC Partner Diet*	*DFBC Partner Gluc*	*DFBC Partner Insul*	*DFBC Partner Exer*	*DFBC Partner Gen*	*DFBC Partner Tot*	*Self Care Partner Diet*
Diabetes Family Behaviour Checklist General	Pearson Cor.	-.191	-.131	.041	.274	.535**	-.006	.108	.575**	.211	.324*	.498**	-.019	-.019
	N	46	46	46	46	46	46	46	46	46	46	46	46	46
Diabetes Family Behaviour Checklist Total	Pearson Cor.	-.403**	.256	.318*	.486**	.468**	.343**	-.082	.409**	-.206	.417**	.353*	.104	.104
	N	46	46	46	46	46	46	46	46	46	46	46	46	46
Adherence to Self Care Diet	Pearson Cor.	-.070	-.265	-.157	.069	.277	.039	.465**	.134	.155	.142	.352*	.366*	.466**
	N	46	46	46	46	46	46	46	46	46	46	46	46	46
Adherence to Self Care Exercise	Pearson Cor.	-.508**	.144	-.359*	-.354*	-.329*	-.323*	-.222	-.045	-.354*	.064	-.154	-.217	.131
	N	46	46	46	46	46	46	46	46	46	46	46	46	46
Adherence to Self Care Blood	Pearson Cor.	-.012	.039	-.068	-.185	.058	-.072	.487**	-.056	.029	-.414**	.550**	.270	.547**
	N	46	46	46	46	46	46	46	46	46	46	46	46	46
Adherence to Self Care Insulin	Pearson Cor.	-	-	-	-	-	-	-	-	-	-	-	-	-
	N	46	46	46	46	46	46	46	46	46	46	46	46	46
Adherence to Self Care Foot Care	Pearson Cor.	.394**	-.183	.405**	.261	.271	.325*	.474**	-.036	.187	-.279	.366*	.275	.213
	N	46	46	46	46	46	46	46	46	46	46	46	46	46
Adherence to Self Care Smoking	Pearson Cor.	.084	-.068	.172	.200	-.029	.133	-.444**	-.126	.001	.257	-.570**	-.316*	-.602**
	N	46	46	46	46	46	46	46	46	46	46	46	46	46
Adherence to Self Care Total	Pearson Cor.	-.186	-.122	-.116	-.103	.047	-.043	.333*	-.059	-.069	-.097	.255	.151	.440**
	N	46	46	46	46	46	46	46	46	46	46	46	46	46
Life Threat	Pearson Cor.	.628**	-.713**	.620**	.546**	.707**	.654**	.167	-.041	.394**	-.050	-.273	.233	-.165
	N	46	46	46	46	46	46	46	46	46	46	46	46	46
Relationship Partner Q1 meet needs	Pearson Cor.	.816**	-.980**	.869**	.904**	.870**	.963**	.095	.022	.129	-.168	.386**	.165	.203
	N	46	46	46	46	46	46	46	46	46	46	46	46	46
Relationship Partner Q2 Satisfaction	Pearson Cor.	.919**	-.914**	.908**	.922	.850**	.987**	.127	-.111	.064	-.309*	.291*	.079	.107
	N	46	46	46	46	46	46	46	46	46	46	46	46	46

Table 9.17. Correlation matrix of scores on all sub scales – person with diabetes and partner (cont'd).
** Correlation is significant at the 0.01 level (2-tailed).
*. Correlation is significant at the 0.05 level (2-tailed).

		Self Care Partner Exer	*Self Care Prtner Blood*	*Self Care Partner Insul*	*Self Care Partner Foot*	*Self Care Partner Smk*	*Self Care Partner Tot*	*Life Threat Partner*
Diabetes Family Behaviour Checklist General	Pearson Cor.	.141	.249	-.191	.267	.421**	.411**	.251
	N	46	46	46	46	46	46	46
Diabetes Family Behaviour Checklist Total	Pearson Cor.	.122	.173	.128	.112	.358*	.379**	.143
	N	46	46	46	46	46	46	46
Adherence to Self Care Diet	Pearson Cor.	.189	.303*	.427**	.363*	.357*	.505**	.080
	N	46	46	46	46	46	46	46
Adherence to Self Care Exercise	Pearson Cor.	.133	.219	.256	.030	-.342*	-.173	-.006
	N	46	46	46	46	46	46	46
Adherence to Self Care Blood	Pearson Cor.	.104	.446**	.963**	.325*	.155	.426**	-.120
	N	46	46	46	46	46	46	46
Adherence to Self Care Insulin	Pearson Cor.	-	-	-	-	-	-	-
	N	46	46	46	46	46	46	46
Adherence to Self Care Foot Care	Pearson Cor.	-.232	.210	.324*	.338*	.408**	.427**	.000
	N	46	46	46	46	46	46	46
Adherence to Self Care Smoking	Pearson Cor.	-.227	-.403**	-.917**	-.135	-.131	-.396**	.099
	N	46	46	46	46	46	46	46
Adherence to Self Care Total	Pearson Cor.	.043	.438**	.611**	.449**	.139	.358*	.019
	N	46	46	46	46	46	46	46
Life Threat	Pearson Cor.	.096	-.221	-.224	.007	-.056	-.111	.000
	N	46	46	46	46	46	46	46
Relationship Partner Q1 meet needs	Pearson Cor.	.423**	-.171	.078	-.313*	-.012	.023	.059
	N	46	46	46	46	46	46	46
Relationship Partner Q2 Satisfaction	Pearson Cor.	.172	-.333*	-.002	-.257	.112	.044	.000
	N	46	46	46	46	46	46	46

Table 9.17. Correlation matrix of scores on all sub scales – person with diabetes and partner (cont'd).
** Correlation is significant at the 0.01 level (2-tailed).
*. Correlation is significant at the 0.05 level (2-tailed).

		Relationship Partner Q3	*Relationship Partner Q4*	*Relationship Partner Q5*	*Relationship Partner Q6*	*Relationship Partner Q7*	*Relationship Partner Tot*	*DFBC Partner Diet*	*DFBC Partner Gluc*	*DFBC Partner Insul*	*DFBC Partner Exer*	*DFBC Partner Gen*	*DFBC Partner Tot*
Relationship Partner Q3 Good compared to most	Pearson Cor.	-											
	N												
Relationship Partner Q4 Wish not got into	Pearson Cor.	-.780**	-										
	N	46											
Relationship Partner Q5 Met your expectations	Pearson Cor.	.817**	-.828**	-									
	N	46	46										
Relationship Partner Q6 How much do you love?	Pearson Cor.	.860**	-.876**	.790**	-								
	N	46	46	46									
Relationship Partner Q7 How many problems?	Pearson Cor.	.870**	-.893**	.677**	.843**	-							
	N	46	46	46	46								
Relationship Partner Total Score	Pearson Cor.	.905**	-.936**	.934**	.938**	.846**	-						
	N	46	46	46	46	46							
Diabetes Family Behaviour Checklist Partner Diet	Pearson Cor.	.041	-.186	-.058	.026	.327*	.035	-					
	N	46	46	46	46	46	46						
Diabetes Family Behaviour Checklist Partner Glucose	Pearson Cor.	-.197	-.063	-.086	.069	.075	-.066	.360*	-				
	N	46	46	46	46	46	46	46					
Diabetes Family Behaviour Checklist Partner Insulin	Pearson Cor.	.206	-.237	-.015	.109	.512**	.066	.502**	.382**	-			
	N	46	46	46	46	46	46	46	46				
Diabetes Family Behaviour Checklist Partner Exercise	Pearson Cor.	-.414**	.105	-.302*	-.047	-.126	-.256	.132	.837**	.300*	-		
	N	46	46	46	46	46	46	46	46	46			
Diabetes Family Behaviour Checklist Partner General	Pearson Cor.	.256	-.436**	.244	.209	.546**	.278	.793**	.535**	.632**	.131	-	
	N	46	46	46	46	46	46	46	46	46	46		
Diabetes Family Behaviour Checklist Partner Total	Pearson Cor.	.041	-.261	-.015	.109	.416**	.061	.825**	.734**	.766**	.501**	.887**	-
	N	46	46	46	46	46	46	46	46	46	46	46	

Table 9.17. Correlation matrix of scores on all sub scales – person with diabetes and partner (cont'd).
** Correlation is significant at the 0.01 level (2-tailed).
*. Correlation is significant at the 0.05 level (2-tailed).

		Self Care Partner Diet	*Self Care Partner Exer*	*Self Care Prtner Blood*	*Self Care Partner Insul*	*Self Care Partner Foot*	*Self Care Partner Smk*	*Self Care Partner Tot*	*Life Threat Partner*
Relationship Partner Q3 Good compared to most	Pearson Cor.	.009	.141	-.416**	.023	-.336*	.107	.007	-.091
	N	46	46	46	46	46	46	46	46
Relationship Partner Q4 Wish not got into	Pearson Cor.	-.134	-.402**	.105	.000	.279	-.036	-.057	-.110
	N	46	46	46	46	46	46	46	46
Relationship Partner Q5 Met your expectations	Pearson Cor.	.010	.190	-.265	-.019	-.284	-.231	-.236	-.032
	N	46	46	46	46	46	46	46	46
Relationship Partner Q6 How much do you love?	Pearson Cor.	.167	.345*	-.356*	-.137	-.405**	.220	.128	.085
	N	46	46	46	46	46	46	46	46
Relationship Partner Q7 How many problems?	Pearson Cor.	.184	.399*	-.107	.107	-.219	.264	.268	.058
	N	46	46	46	46	46	46	46	46
Relationship Partner Total Score	Pearson Cor.	.093	.265	-.316*	-.029	-.340*	.010	-.035	.016
	N	46	46	46	46	46	46	46	46
Diabetes Family Behaviour Checklist Partner Diet	Pearson Cor.	.543**	.116	.496**	.496**	.559**	.674**	.821**	.133
	N	46	46	46	46	46	46	46	46
Diabetes Family Behaviour Checklist Partner Glucose	Pearson Cor.	.348*	.422**	.511**	.066	-.117	.226	.366*	.278
	N	46	46	46	46	46	46	46	46
Diabetes Family Behaviour Checklist Partner Insulin	Pearson Cor.	.013	.348*	.438**	.054	.095	.285	.382**	.161
	N	46	46	46	46	46	46	46	46
Diabetes Family Behaviour Checklist Partner Exercise	Pearson Cor.	.203	.386**	.307*	-.309*	.012	.208	.262	.306*
	N	46	46	46	46	46	46	46	46
Diabetes Family Behaviour Checklist Partner General	Pearson Cor.	.505**	.446**	.585**	.601*	.160	.281	.538**	.122
	N	46	46	46	46	46	46	46	46
Diabetes Family Behaviour Checklist Partner Total	Pearson Cor.	.455**	.423**	.626**	.337*	.250	.478**	.674**	.234
	N	46	46	46	46	46	46	46	46

Table 9.16. Correlation matrix of scores on all sub scales – person with diabetes and partner (cont'd).
** Correlation is significant at the 0.01 level (2-tailed).
*. Correlation is significant at the 0.05 level (2-tailed).

		Self Care Partner Diet	*Self Care Partner Exer*	*Self Care Prtner Blood*	*Self Care Partner Insul*	*Self Care Partner Foot*	*Self Care Partner Smk*	*Self Care Partner Tot*	*Life Threat Partner*
Self Care Partner Diet	Pearson Cor.	-							
	N								
Self Care Partner Exercise	Pearson Cor.	.551**	-						
	N	46							
Self Care Partner Blood	Pearson Cor.	.143	.068	-					
	N	46	46						
Self Care Partner Insulin	Pearson Cor.	.642**	.132	.447**	-				
	N	46	46	46					
Self Care Partner Foot Care	Pearson Cor.	.422**	-.153	.222	.346*	-			
	N	46	46	46	46				
Self Care Partner Smoking	Pearson Cor.	.444**	-.054	.101	.150	.333*	-		
	N	46	46	46	46	46			
Self Care Partner Total	Pearson Cor.	.684**	.173	.359*	.439**	.467**	.917**	-	
	N	46	46	46	46	46	46		
Life Threat Partner	Pearson Cor.	.017	.132	.239	-.131	-.057	.148	.162	-
	N	46	46	46	46	46	46	46	

Table 9.17. Correlation matrix of scores on all sub scales – person with diabetes and partner (cont'd).
** Correlation is significant at the 0.01 level (2-tailed).
*. Correlation is significant at the 0.05 level (2-tailed).

their relationship had higher levels of problems in it (Pearson's $r = -.302$, $p<.05$). High participant reported adherence to foot care was positively correlated with feeling their relationship was better compared to most (Pearson's $r = .437$, $p<.01$), feeling that the relationship met their original expectations (Pearson's $r = .641$, $p<.01$), feeling high levels of love for their spouse/partner (Pearson's $r = .295$, $p<.05$) and high levels of problems in the relationship (Pearson's $r = .655$, $p<.01$). Low levels of adherence to blood glucose testing were correlated with high levels of satisfaction with the relationship (Pearson's $r = -.381$, $p<.01$) and high levels of smoking correlated with the feeling that the relationship met their original expectations (Pearson's $r = .365$, $p<.01$).

Scores on the Diabetes Family Behaviour Checklist for the participants with diabetes indicated that high levels of support for diet correlated with high adherence to foot care (Pearson's $r = .811$, $p<.01$), high levels of support for blood glucose testing correlated with high adherence to diet (Pearson's $r = .650$, $p<.01$), exercise (Pearson's $r = .301$, $p<.05$), blood glucose testing (Pearson's $r = .568$, $p<.01$) and negatively to smoking behaviour (Pearson's $r = -.368$, $p<.01$). High levels of reported general support correlated with high levels of adherence to diet (Pearson's $r = .297$, $p<.05$).

Spouse/partners reported their partner receiving greater levels of general support when they felt their partner met their needs (Pearson's $r = .436$, $p<.01$), when they reported greater satisfaction with the relationship (Pearson's $r = .368$, $p<.01$), when they thought their relationship was better compared to others (Pearson's $r = .328$, $p<.05$), when they did not wish they had not got into the relationship (Pearson's $r = -.475$, $p<.01$), when they thought their relationships met their original expectations (Pearson's $r = .364$, $p<.01$) and when they reported fewer problems in the relationship (Pearson's $r = -.639$, $p<.01$). Fewer problems in the relationship also correlated with high levels of spouse/partner reported support available to their partner for diet (Pearson's $r = -.449$, $p<.01$) and insulin (Pearson's $r = -.539$, $p<.01$).

High spouse/partner reported adherence to exercise behaviour for their partner correlated with high scores of their partner meeting their needs (Pearson's $r = .466$, $p<.01$), felt their relationship met their original expectations (Pearson's $r = .296$, $p<.05$), had low scores on wishing they had not got into the relationship (Pearson's r =

-.444, $p<.01$) and that their relationship had fewer of problems with it (Pearson's $r = -.499$, $p<.01$). High spouse/partner reported adherence to foot care was negatively correlated with feeling high levels of love for their spouse/partner (Pearson's $r = -.346$, $p<.05$). Low levels of spouse/partner reported adherence to blood glucose testing were correlated with feeling the relationship was better compared to others (Pearson's $r = -.54$, $p<.05$) and high levels of feeling in love with their partner (Pearson's $r = -.318$, $p<.05$) and high levels of spouse/partner reported adherence to diet correlated with fewer problems in the relationship (Pearson's $r = -.314$, $p<.05$).

Scores on the Diabetes Family Behaviour Checklist indicated that the spouse/partner reported high levels of support for diet correlated with high adherence to diet (Pearson's $r = .613$, $p<.01$), blood glucose testing (Pearson's $r = .523$, $p<.01$), insulin injecting (Pearson's $r = .490$, $p<.01$), foot care (Pearson's $r = .603$, $p<.01$), and also high levels of smoking (Pearson's $r = .557$, $p<.01$). High levels of spouse/partner reported support for blood glucose testing correlated with high adherence to exercise (Pearson's $r = .310$, $p<.05$) and blood glucose testing (Pearson's $r = .457$, $p<.01$). High levels of spouse/partner reported support for insulin injecting correlated with high adherence to exercise (Pearson's $r = .391$, $p<.01$) and blood glucose testing (Pearson's $r = .460$, $p<.01$). High levels of spouse/partner reported support for exercise behaviour correlated with high adherence to diet (Pearson's $r = .339$, $p<.05$), exercise (Pearson's $r = .495$, $p<.01$) and blood glucose testing (Pearson's $r = .356$, $p<.05$). High levels of spouse/partner reported general support for diabetes correlated with high adherence to diet (Pearson's $r = .589$, $p<.01$), exercise (Pearson's $r = .547$, $p<.01$), blood glucose testing (Pearson's $r = .596$, $p<.01$) and insulin injecting (Pearson's $r = .572$, $p<.01$).

Therefore, for both the participant with diabetes and their spouse/partner, greater support for diabetes self-care activities generally correlates with a greater quality of relationship with their spouse/partner and high levels of support for the diabetes tasks is generally correlated with high levels of adherence to the diabetes self-care tasks. Fewer problems reported in the relationship correlates with the participant with diabetes reporting greater support for various diabetes tasks, namely diet, exercise and general support. Greater relationship quality however, is correlated with low adherence to the diabetes self-care tasks except for foot care.

For the participants with diabetes, scores of relationship satisfaction were highly correlated with partner reports of support for exercise (Pearson's r = .481, $p<.01$), low scores on wishing they had not got into the relationship were correlated with high levels partner reports of support for insulin injecting (Pearson's r = -.431, $p<.01$), and fewer numbers of problems with the relationship were correlated with high levels of partner reports of support for diet (Pearson's r = .546, $p<.01$) exercise (Pearson's r = .366, $p<.01$) and general support for diabetes (Pearson's r = .412, $p<.01$).

With reference to partner reports of adherence to the diabetes self-care regime, participant with diabetes' scores of how well their partner met their needs were negatively correlated with partner reports of adherence to blood glucose testing (Pearson's r = -.427, $p<.05$) and foot care (Pearson's r = -.294, $p<.05$), high satisfaction with the relationship was correlated with high levels of partner reports of smoking (Pearson's r = .326, $p<.05$). Thinking the relationship was better compared to most was negatively correlated with partner reports of exercise behaviour (Pearson's r = -.291, $p<.05$) and blood glucose testing (Pearson's r = -.285, $p<.05$). High participant with diabetes' scores on wishing they had not got into the relationship was correlated (this question reverse scored) with low partner reports of adherence to blood glucose testing (Pearson's r = .285, $p<.05$). High participant with diabetes' scores of how well the relationship met their original expectations correlated highly with partner reports of adherence to foot care (Pearson's r = .425, $p<.05$).

For the participants with diabetes, their scores of social support for insulin injecting correlated with all partner responses on the relationship measure - indicating that if the participants felt their partner met their needs, there was high satisfaction in the relationship, their relationship was better than most, they did not wish they had not got into the relationship, the relationship had met their original expectations and they were very much in love with their partner, then the participants with diabetes were more likely to report high levels of support for insulin injecting (Pearson's r = -.492, 387 to 633, $p<.05$). High levels of support for adhering to their recommended diet was correlated with high levels of partner satisfaction with the relationship (Pearson's r =.320, $p<.05$), the partners felt their relationship meets their needs (Pearson's r = .386, $p<.05$) and also that there were fewer problems in the relationship (Pearson's r

=-.373, p<.05). High levels of participant with diabetes' scores of general support for diabetes were correlated with fewer reported problems in the relationship (Pearson's r = -.435, p<.05).

With reference to the participant with diabetes' scores of adherence to the diabetes self-care regime, adherence to diet was correlated with how well the spouse/partner felt their partner met their needs (Pearson's r = .284, p<.05), negatively with how often the spouse/partner wished they had not got into the relationship (Pearson's r = -.312, p<.05) and how many problems the partner thought there were in the relationship (Pearson's r = -.372, p<.01). Adherence to exercise was negatively correlated with spouse/partner satisfaction with the relationship (Pearson's r = -.303, p<.05), spouse/partner thinking the relationship was better than most (Pearson's r = -.432, p<.01) and how much the spouse/partner love their partner (Pearson's r = -.310, p<.05). Participant with diabetes adherence to foot care was positively correlated with how satisfied the spouse/partner is with the relationship (Pearson's r = .453, p<.01), the spouse/partner thinking the relationship was better than most (Pearson's r = .443, p<.01), the spouse/partner thinking the relationship met their original expectations (Pearson's r = .487, p<.01), high scores of the spouse/partner loving their partner (Pearson's r = .294, p<.05) and low scores on the number of problems in the relationship reported by the spouse/partner (Pearson's r = -.400, p<.01).

Therefore, for the participants with diabetes, their report of a good quality relationship and reporting lower numbers of problems in the relationship is associated with high levels of diabetes-related support reported by their spouse/partner. Supporting this, high reports of diabetes-related support reported by the participant with diabetes is associated with generally good reported quality of relationship by the spouse/partner as well as low numbers of problems in the relationship.

Good reported adherence to the diabetes self-care regime for blood glucose testing, foot care and exercise reported by the spouse/partner is correlated with low levels of relationship quality in the participant with diabetes. Low levels of problems reported in the relationship by the participant with diabetes is associated with high adherence to foot care. Good reported adherence to the diabetes self-care regime for diet and foot care reported by participant with diabetes is correlated with generally high levels of relationship quality, only adherence to exercise is associated with low levels of spouse/partner reported relationship quality. Again, low levels of problems reported in the relationship by the spouse/partner is associated with high adherence to diet and foot care.

9.5.6 Analysis of Results by Participant with Diabetes' Gender

Table 9.18. Participant with diabetes age, duration of diabetes and relationship for males and females.

	Female participants (N=25)			Male participants (N=23)		
	M	SD	Range	M	SD	Range
Age	27.33	3.90	22-33	30.26	3.78	23-35
Duration of Diabetes	10.24	7.44	2-30	17.36	11.26	4-33
Duration of Relationship	5.33	2.42	3-12	8.04	3.32	3-13

Age, duration of diabetes and duration of relationship for male and female participants with diabetes is presented in table 9.18. The participants with diabetes differed significantly on age (t=2.688, df = 47, p<.01), duration of diabetes (t=2.327, df = 39, p<.01) and duration of relationship (t=3.247, df = 40, p<.001).

Table 9.19. Comparison of sub- scale scores on the Relationship Assessment Scale by gender of person with diabetes.

Variable	*Gender*	*N*	*Mean*	*SD*	*t*	*df*	*P*	*Effect Size*
Q1 – meet your needs?	Male	23	.174	.72	1.164	22	.257	-.54
	Female	27	.629	.97	3.384	26	.002	
Q2 – how satisfied?	Male	23	-.130	.92	-.680	22	.503	-.85
	Female	27	.778	1.22	3.314	26	.003	
Q3 – how good?	Male	23	.348	.49	3.425	22	.002	-.87
	female	27	1.185	1.44	4.270	26	.000	
Q4 – wish not got into relationship?	Male	23	-.174	.72	-1.164	22	.257	.97
	female	27	-1.259	1.51	-4.337	26	.000	
Q5 – met expectations?	Male	23	.043	1.02	.204	22	.840	-.85
	female	27	.815	.786	5.385	26	.000	
Q6 – love them?	Male	23	.174	.39	2.152	22	.043	-.54
	female	27	.593	1.15	2.672	26	.013	
Q7- how many problems?	Male	23	-.174	.72	-1.164	22	.257	-.77
	female	27	.593	1.28	2.408	26	.023	

When the participant with diabetes is female, they report significantly much greater scores on all 7 items of the Relationships Assessment scale than their partner/spouse (see table 9.19 below). However, when the participant with diabetes is male, they report similar scores throughout the scale to their partner/spouse apart from reporting statistically significantly greater scores on how good the relationship is compared to others and how much they love their partner. Female participants with diabetes report higher scores on all items of the Relationship Assessment Scale than male participants with diabetes (Cohen's d range = -.54 to .97).

Table 9.20. Comparison of sub- scale scores on the Diabetes Family Behaviour Checklist by gender of person with diabetes.

Variable	*Gender*	*N*	*Mean*	*SD*	*t*	*df*	*P*	*Effect Size*
Diet	Male	23	-.348	1.97	-.848	22	.406	.91
	Female	27	1.926	1.49	6.709	26	.000	
Glucose	Male	23	-.522	2.54	-.986	22	.335	-.27
	Female	27	.037	1.55	.124	26	.903	
Insulin	Male	23	-.522	2.61	-.959	22	.348	-.15
	female	27	-.111	2.71	-.213	26	.833	
Exercise	Male	23	-.783	1.38	-2.719	22	.013	-.26
	female	27	-.296	2.30	-.669	26	.509	
General	Male	23	.043	1.58	.132	22	.896	-.99
	female	27	2.222	2.83	4.076	26	.000	

Table 9.21. Comparison of sub- scale scores on the Summary of Diabetes Self-Care Activities Scale by gender of person with diabetes.

Variable	*Gender*	*N*	*Mean*	*SD*	*t*	*df*	*P*	*Effect Size*
Diet	Male	23	-.196	1.72	-.544	22	.592	0
	Female	27	-.176	1.38	-.659	26	.515	
Exercise	Male	23	.196	3.72	.252	22	.803	-.26
	Female	27	.981	2.33	2.188	26	.038	
Blood	Male	23	1.52	2.78	2.627	22	.015	.29
	female	27	.815	1.99	2.126	26	.043	
Insulin	Male	23	-	-	-	-	-	-
	female	27	1.185	2.53	2.437	26	.022	
Foot care	Male	23	-.456	1.43	-1.532	22	.140	.17
	female	27	-741	1.83	-2.102	26	.045	
Smoking	Male	23	-9.22	17.05	-2.591	22	.017	-.89
	female	27	-.333	2.935	-.590	26	.560	

Scores on most items of the Diabetes Family Behaviour Checklist are not statistically significant for both the participant with diabetes and their partner/spouse (see table

9.20). When the participant with diabetes is female, they report statistically significant greater scores for support for diet and for general diabetes care than their partner/spouse. The male participant with diabetes only reports statistically significant greater support for exercise behaviour. Female participant with diabetes' reports of support for diet and general diabetes care are greater than male participants with diabetes' reports (Cohen's d = .91 and -.99 respectively).

Scores on the Summary of Diabetes Self-Care Activities Scale were generally not statistically significantly different between the participants with diabetes and their partner/spouse reports (see table 9.21). Female participants with diabetes reported statistically significant greater adherence to the self-care activity of exercise, blood glucose testing but worse foot care than their partner/spouse reported. When the participant with diabetes was male, they reported statistically significant greater scores on blood glucose testing and on smoking behaviour. For the participants with diabetes, those who were male were much more likely to smoke than those who were female (Cohen's d = -.89).

Table 9.22. Comparison of full- scale scores on all measures by gender of person with diabetes

Variable	*Gender*	*N*	*Mean*	*SD*	*t*	*df*	*P*	*Effect Size*
Relationship Assessment Scale	Male	23	.14	.42	4.371	26	.000	-1.26
	Female	27	.67	.79				
DFBC	Male	23	-2.13	7.47	3.088	26	.005	-.79
	Female	27	3.78	6.36				
Adherence to Self Care Regime	Male	23	-1.36	3.16	2.043	26	.051	-.52
	Female	27	.29	.73				
Life threat due to diabetes	Male	23	1.47	.51	2.191	44	.05	.68
	Female	17	.95	1.02				

For total scale scores, participants with diabetes who were female reported statistically significant greater scores on the Relationship Assessment Scale, the Diabetes Family Behaviour Checklist and the Summary of Adherence to Diabetes Self-Care Activities Scale than their partner/spouse (see table 9.22). On the Summary of Adherence to Diabetes Self-Care Activities Scale the male participants with diabetes reported statistically significant worse scores of total adherence than their partner/spouse. Overall, female participants with diabetes reported greater relationship scores, greater diabetes-specific social support and greater adherence to the diabetes self-care regime than male participants with diabetes (Cohen's *d* range = -.52 to –1.26).

9.5.7 Analysis of Results by Participants Reported Metabolic Control

Unfortunately there were too few participants reporting poor metabolic control (HbA_{1C} above 8.0%) for meaningful analysis to be undertaken (HbA_{1C} below 8.0%, N = 23, HbA_{1C} above 8.0%, N = 8, no HbA_{1C} figure provided, N = 19, Total N for study = 50). Although the data from studies 1 and 3 could have provided greater numbers of participants reporting good and poor metabolic control, the participants in this study did not match the participants of studies 1 and 3 for age, duration of diabetes or HbA_{1C} results and so the data set was not pooled.

9.5.8 Analysis by duration of relationship and participant gender

Although not specified in the aims of the study, it was considered that perhaps duration of relationship may influence perception of social support and thus adherence to the diabetes self-care regime. With a greater duration of relationship comes greater interdependence between the two partners and this may be expressed in terms of greater provision of emotional and practical support. If greater duration of relationship does indeed result in greater provision of support, then as social support has been demonstrated throughout this thesis to result in greater adherence to the diabetes self-care regime, then greater duration of relationship should also result in greater reported adherence to the diabetes self-care regime.

The data set was first split into two – those reporting the duration of relationship as equal to or shorter than the statistical median of 6 years and those reporting the duration of relationship as longer than 6 years. This formed two groups of participants, those in shorter term relationships (ST relationship) and those in longer term relationships (LT relationship) descriptives presented in tables 9.23, and 9.24. 2 x 2 ANOVAs were conducted on all sub-scale and full scale scores.

Table 9.23. Descriptives for participants full scale scores.

		Relationship duration	*Mean*	*SD*	*N*
RAS	Male	Short term	4.500	.076	8
		Long term	4.247	.065	15
	Female	Short term	4.333	.379	18
		Long term	4.228	.078	5
DFBC	Male	Short term	14.000	2.138	8
		Long term	12.400	1.723	15
	Female	Short term	11.333	3.850	18
		Long term	11.200	6.573	5
Adherence (SDSCA)	Male	Short term	4.208	.311	8
		Long term	3.583	.328	15
	Female	Short term	3.606	.693	18
		Long term	4.333	.114	5
Life threat due to diabetes	Male	Short term	1.500	.534	8
		Long term	1.467	.516	15
	Female	Short term	.889	1.023	18
		Long term	1.200	1.095	5

ANOVAs revealed that there was no significant effect of gender on participants' Relationship Assessment Scale scores although there was for duration of relationship. Participants in short term relationships reported better quality relationships than those in long term relationship ($F_{(1,46)} = 4.653$, $p<.05$). There was no significant effect of gender or duration of relationship for total scores on the Diabetes Family Behaviour Checklist (DFBC) or the Summary of Diabetes Self-Care Activities Scale.

ANOVAs conducted on the sub-scale scores revealed that gender had a significant effect on the RAS question concerning how well the partner met one's needs ($F_{(1,46)} = 15.411$, $p<.001$) and on the self-care activity of smoking behaviour ($F_{(1,46)} = 6.074$, $p<.05$). For duration of relationship, there was a significant effect on the RAS questions of how well the partner met one's needs ($F_{(1,45)} = 11.799$, $p<.001$) and number of reported problems in the relationship ($F_{(1,45)} = 8.515$, $p<.01$), for the DFBC sub scales of support for diet adherence ($F_{(1,45)} = 6.738$, $p<.05$) and insulin injecting ($F_{(1,45)} = 5.812$, $p<.05$), and for the self-care tasks of diet ($F_{(1,46)} = 4.225$, $p<.05$) and foot care ($F_{(1,46)} = 9.200$, $p<.01$).

Table 9.24. Descriptives for participants sub-scale scores.

		Relationship duration	Mean	SD	N
RAS Q1	Male	Short term	5.000	.000	8
		Long term	4.730	.000	15
	Female	Short term	4.670	.485	18
		Long term	4.000	.000	5
RAS Q7	Male	Short term	2.500	.534	8
		Long term	2.267	.457	15
	Female	Short term	2.667	.485	18
		Long term	2.000	.000	5
DFBC diet	Male	Short term	2.500	1.603	8
		Long term	2.933	1.831	15
	Female	Short term	1.333	.485	18
		Long term	3.200	1.095	5
DFBC insulin	Male	Short term	4.000	1.069	8
		Long term	2.933	1.279	15
	Female	Short term	3.667	2.567	18
		Long term	1.200	3.834	5
Self Care diet	Male	Short term	6.500	.534	8
		Long term	3.667	.748	15
	Female	Short term	3.694	2.067	18
		Long term	4.600	.136	5
Self Care foot care	Male	Short term	1.500	1.603	8
		Long term	1.600	1.021	15
	Female	Short term	.500	.841	18
		Long term	2.900	2.191	5
Self Care smoking	Male	Short term	.000	.000	8
		Long term	.000	.000	15
	Female	Short term	1.111	2.139	18
		Long term	1.200	1.095	5

Interaction effects were found for DFBC sub scale support for blood glucose testing ($F_{(1,45)} = 11.571$, $p<.001$) and exercise behaviour ($F_{(1,45)} = 4.380$, $p<.05$), and for the self-care tasks of diet ($F_{(1,45)} = 15.893$, $p<.001$), foot care ($F_{(1,45)} = 7.787$, $p<.01$) and total adherence to the diabetes self-care regime ($F_{(1,45)} = 16.480$, $p<.001$).

Therefore, those participants engaged in a relationship shorter than 6 years reported more problems in the relationship but that the relationship met their needs and reported overall a better quality relationship. The participants in shorter relationships reported less family support for diet although more support for insulin injecting and reported better self-care in terms of diet but worse self-care in terms of foot care. Interaction effects demonstrated that for the males, *long* term relationships were associated with better support for blood glucose testing and exercise, but worse adherence to the self-care activities of diet, foot care and overall adherence. For the females, this effect was present for those reporting *short* term relationships.

9.5.9 Analysis of results by duration of diabetes and participant gender

The group of participants with diabetes were split into 2 groups, those with a shorter (ST) diagnosis of diabetes (less than and equal to the median diagnosis of 10 years) and those with a longer (LT) diagnosis of diabetes (longer than the median diagnosis of 10 years). 2 x 2 ANOVAs were conducted on all sub-scale and full scale scores.

Table 9.25. Descriptives for participants full scale scores.

		Duration of diabetes	*Mean*	*SD*	*N*
RAS	Male	Short term	4.395	.132	13
		Long term	4.257	.112	10
	Female	Short term	4.225	.309	19
		Long term	4.714	.000	4
DFBC	Male	Short term	13.692	1.797	13
		Long term	12.000	1.885	10
	Female	Short term	11.579	4.811	19
		Long term	10.000	.000	4
Adherence (SDSCA)	Male	Short term	3.865	.406	13
		Long term	3.717	.485	10
	Female	Short term	3.882	.698	19
		Long term	3.208	.000	4
Life threat due to diabetes	Male	Short term	1.384	.506	13
		Long term	1.600	.516	10
	Female	Short term	1.158	1.014	19
		Long term	.000	.000	4

ANOVAs revealed that there was no significant effect of gender on participants' Relationship Assessment Scale scores although there was for duration of relationship. Participants with a long term diagnosis of diabetes reported better quality relationships than those in long term relationship ($F_{(1,46)} = 5.237$, $p<.05$). There was no significant effect of gender for total scores on the Diabetes Family Behaviour Checklist (DFBC) or the Summary of Diabetes Self-Care Activities Scale, but there was a significant effect of duration of diabetes on total adherence to the diabetes self-care regime ($F_{(1,45)} = 4.588$, $p<.05$).

Table 9.26. Descriptives for participants sub-scale scores.

		Duration of diabetes	*Mean*	*SD*	*N*
RAS Q2	Male	Short term	4.310	.480	13
		Long term	4.400	.516	10
	Female	Short term	4.000	.667	19
		Long term	5.000	.000	4
RAS Q5	Male	Short term	4.620	.506	13
		Long term	3.600	.516	10
	Female	Short term	4.370	.496	19
		Long term	5.000	.000	4
RAS Q7	Male	Short term	2.154	.375	13
		Long term	2.600	.516	10
	Female	Short term	2.421	.507	19
		Long term	3.000	.000	4
DFBC diet	Male	Short term	3.538	1.126	13
		Long term	1.800	1.932	10
	Female	Short term	1.895	1.048	19
		Long term	1.000	.000	4
DFBC glucose	Male	Short term	-.846	.375	13
		Long term	-1.600	1.264	10
	Female	Short term	-1.053	1.129	19
		Long term	-3.000	.000	4
DFBC insulin injecting	Male	Short term	2.923	1.497	13
		Long term	3.800	.789	10
	Female	Short term	2.736	3.142	19
		Long term	5.000	.000	4
DFBC exercise	Male	Short term	2.231	1.301	13
		Long term	2.600	2.065	10
	Female	Short term	2.421	.837	19
		Long term	5.000	.000	4
DFBC general	Male	Short term	5.846	1.675	13
		Long term	5.400	.516	10
	Female	Short term	5.579	1.709	19
		Long term	2.000	.000	4
Self Care diet	Male	Short term	4.769	1.569	13
		Long term	4.500	1.554	10
	Female	Short term	4.342	1.728	19
		Long term	1.750	.000	4

ANOVAs conducted on the sub-scale scores revealed that gender had a significant effect on the RAS question concerning how well the relationship met one's expectations ($F_{(1,46)} = 11.764$, $p<.001$) and how many reported problems there were in the relationship ($F_{(1,46)} = 4.469$, $p<.05$). Gender also had a significant effect on DFBC sub-scale score of support for diet ($F_{(1,46)} = 7.622$, $p<.01$), blood glucose testing ($F_{(1,46)} = 5.790$, $p<.05$), exercise ($F_{(1,46)} = 8.237$, $p<.01$) and general support ($F_{(1,46)} = 13.275$,

$p<.001$). Finally, gender had a significant effect on adherence to the self-care task of diet ($F_{(1,46)} = 8.413$, $p<.01$).

For duration of diagnosis of diabetes, there was a significant effect on the RAS questions of how satisfied one is with the relationship ($F_{(1,45)} = 7.935$, $p<.01$) and number of reported problems in the relationship ($F_{(1,45)} = 10.550$, $p<.01$), for the DFBC sub scales of support for diet adherence ($F_{(1,45)} = 8.850$, $p<.01$), insulin injecting ($F_{(1,45)} = 4.108$, $p<.05$), exercise behaviour ($F_{(1,45)} = 10.671$, $p<.01$) and general adherence ($F_{(1,45)} = 15.993$, $p<.001$). There was also a significant effect for the self-care task of diet ($F_{(1,46)} = 6.824$, $p<.05$).

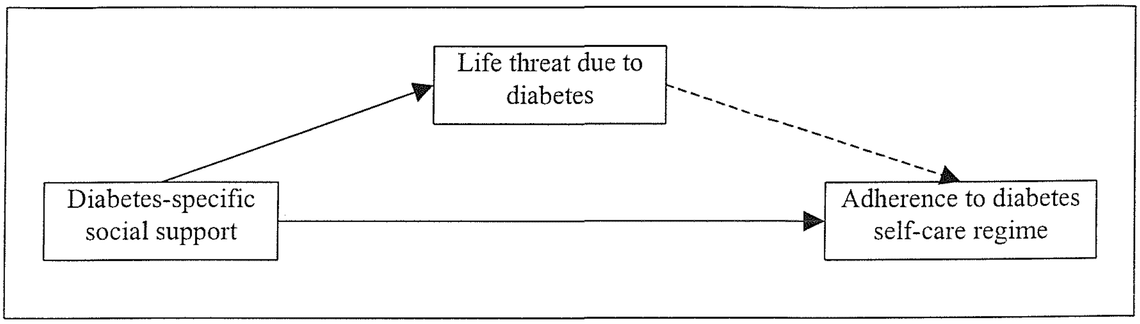
Interaction effects were found for the RAS question of how well one's partner met one's needs ($F_{(1,45)} = 11.937$, $p<.001$), total RAS score (($F_{(1,45)} = 16.790$, $p<.001$) and for the self-care task of exercise ($F_{(1,45)} = 5.743$, $p<.05$).

Therefore, male participants reported more support for diet and general diabetes behaviours and reported less support for blood-glucose testing and exercise behaviour than the female participants. Those reporting a long term diagnosis of diabetes reported greater satisfaction with their partner but also more problems in the relationship, reported more support for blood-glucose testing and insulin injecting but less support for diet, exercise and general diabetes activities, and less engagement in the self-care task of diet. Interaction effects demonstrated that for the males, a *shorter* diagnosis of diabetes was associated with higher scores on the RAS question of how well one's partner met one's needs, how well the relationship met their expectations and a higher overall score on the RAS, but a shorter diagnosis was associated with poorer adherence to the self-care task of exercise. For the female participants, a *longer* diagnosis of diabetes was associated with these factors.

9.5.10 Path Analysis

Analysis of the data collected in studies 1 and 3 indicated that diabetes-specific social support was the main predictor of the young person's adherence to their diabetes self-care regime. The Extended Health Belief Model (Aalto & Uutela, 1987), based on the original Health Belief Model (Rosenstock, 1966; Becker & Maiman, 1975), proposed that this path was mediated by the young person's reported life threat due to their diabetes. This finding was not supported by the data. This section of the model is presented in figure 10 below.

Figure 10. A path diagram showing the relationship between participant scores on the DFBC, life threat due to diabetes and the SDSCA scales (dotted arrow shows path suggested by Aalto & Uutela (1987) based on the original Health Belief Model (Rosenstock, 1966; Becker & Maiman, 1975).



The model presented above was used as a structure for analysing the data collected in this study. All path values presented are statistically significant. First the participant with diabetes' data set was analysed. Path analysis demonstrated that only diabetes-specific social support predicted adherence (path value $\beta = .363$). Social support did not predict the participants reported life threat due to diabetes which in turn did not predict adherence to the diabetes self-care regime. When participant scores on the Relationship Assessment Scale were substituted for the diabetes-specific social support measure, the relationship measure predicted participant life threat (path value $\beta = .287$), however neither life threat nor quality of relationship predicted adherence to the diabetes self-care regime. Thus for the participants with diabetes, reported high levels of diabetes-specific social support predicted good adherence to the self-care regime and a good quality of relationship predicted high life threat suggesting that perhaps the life risk of diabetes seems greater when the participant is engaged in a good quality relationship and has more to lose in death.

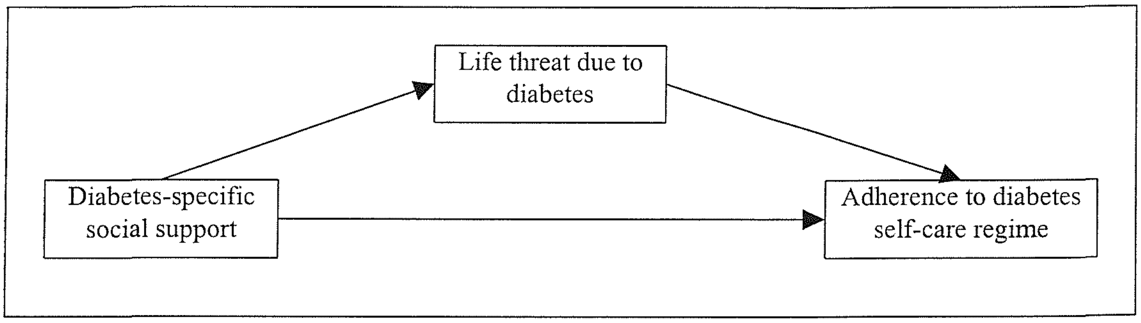
When the spouse/partner data was analysed using the above model, it was demonstrated that high reported diabetes-specific social support predicted high levels of adherence to the diabetes self-care regime (path value $\beta = .714$) but that high reported life threat due to the diabetes predicted high levels of adherence to the diabetes self-care regime (path value $\beta = -.380$). When the diabetes-specific social support measure was substituted with the relationship measure, there were no significant paths. This suggests that the spouse/partner reports of high diabetes-specific social support available to the participant with diabetes and low reports of participant life threat due to diabetes predicted good participant adherence to the diabetes self-care regime.

For the female participants with diabetes, high levels of diabetes-specific social support predicted high adherence to the diabetes self-care regime (path value $\beta = .464$). Scores on the relationship measure did not predict either life threat due to diabetes or adherence to the diabetes self-care regime. For the male participants with diabetes, reports of a good quality relationship predicted good adherence to the diabetes self-care regime (path value $\beta = .714$). Diabetes-specific social support did not predict either life threat due to diabetes or adherence to the diabetes self-care regime. Therefore, high levels of diabetes-specific social support predicts adherence for females but not for males and a good quality relationship predicts adherence for males but not for females. For neither group was life threat due to diabetes predicted by either diabetes-specific social support or quality of relationship.

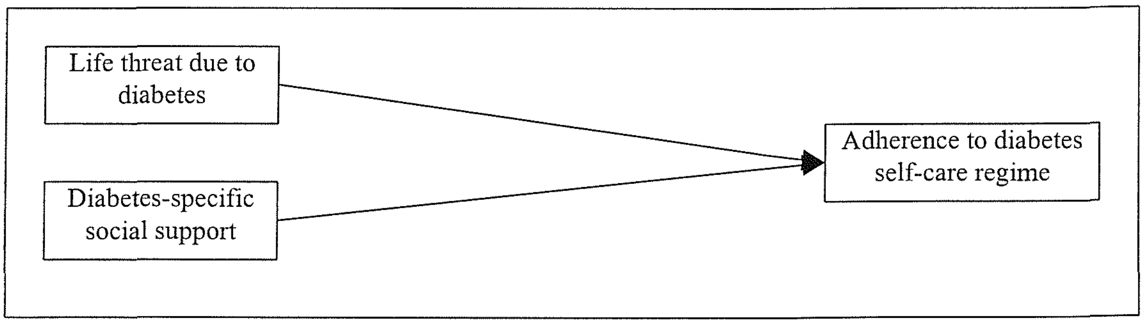
For both the female and male spouse/partners of the participants with diabetes, high reports of available diabetes-specific social support predicted reports of participant adherence to the diabetes self-care regime (females: path value $\beta = .659$; males: path value $\beta = .665$). Spouse/partner reports of quality of relationship did not predict either life threat due to diabetes or adherence to the diabetes self-care regime. Therefore, high levels of diabetes-specific social support predicts better adherence in the spouse/partners of the participants with diabetes irrespective of gender but only for the female participants with diabetes. Better male participant with diabetes' adherence to the diabetes self-care regime was predicted by better reported quality of relationship.

Therefore, the path analysis conducted thus far indicates that for both the participants with diabetes and their spouse/partners, diabetes-specific social support predicted adherence to the diabetes self-care regime. For the participants with diabetes, high reported relationship quality predicted high life threat due to diabetes. For the spouse/partners, high reported life threat due to diabetes predicted poor adherence to the diabetes self-care regime. When the analysis was conducted by gender of participants with diabetes and gender of spouse/partner, high levels of diabetes-specific social support predicted good adherence to the diabetes self-care regime for all but the male participants with diabetes. For them, the reported quality of relationship predicted adherence to the diabetes self-care regime.

This finding was followed up by investigating whether the quality of relationship acted as either a moderator or as a mediator in the path between diabetes-specific social support and adherence to the diabetes self-care regime. The path analysis equations were written to test relationship quality as a mediator:



And relationship quality as a moderator:



When the participants with diabetes' data was analysed, relationship quality acted as neither a moderator nor a mediator in this path. For the spouse/partner data, again, relationship quality acted as neither a moderator nor a mediator. However, relationship quality was only a predictor of adherence to the diabetes self-care regime for the male participants with diabetes. When the data was analysed by gender for both participants with diabetes and their spouse/partner, for male participants with

9.6. Discussion

9.6.1 Summary of Findings

The participants with diabetes reported higher scores on the Relationship Assessment Scale, the Diabetes Family Behaviour Checklist and of life threat due to diabetes and lower scores on the Summary of Adherence to Diabetes Self-Care Activities than their partner/spouse. Therefore, the participants with diabetes reported a better quality relationship, more diabetes-specific social support, more life threat due to the diabetes and worse adherence to the diabetes self-care regime than did their partner/spouse. There were high correlations between participant with diabetes and their partner/spouse on all measures indicating that the couples were generally in agreement with each other on the experience of the relationship and of diabetes. In particular, partner/spouse reported levels of participant adherence to the self-care regime correlated with both their own and their partner with diabetes' report of diabetes-specific social support.

A better quality relationship (indicated by higher scores on the Relationship Assessment Scale) and reporting fewer problems in the relationship correlated with participant with diabetes' greater reported life threat due to diabetes and high reported levels of diabetes-specific social support which in turn was correlated highly with reported adherence to the diabetes self-care regime for both the participant with diabetes and for the partner/spouse. The quality of relationship reported by the participants with diabetes correlated positively with the level of diabetes-specific social support but negatively with the adherence to the diabetes self-care regime both as reported by their partner/spouse. However, the quality of relationship reported by the partner/spouse is positively correlated with both diabetes-specific social support and adherence to the diabetes self-care regime as reported by the participant with diabetes. This suggests that a better quality relationship reported by the participant with diabetes corresponds to a better perception of social support by the partner/spouse but also to a lower adherence to self-care. Yet when the partner/spouse reports a better quality relationship, the participant with diabetes reports better social support and better adherence to self-care. This provides support for the hypothesis that participants with diabetes and their partner/spouse reporting a better quality of relationship also report higher levels of diabetes-related social support. However the participant with diabetes only reports better adherence to the diabetes self-care regime when the partner/spouse reports a better quality of relationship and in fact the participants with diabetes report better adherence when they report lower quality relationships. That the participants with diabetes report greater life threat due to diabetes when both they and their spouse/partner report a better quality relationship suggests that the implications for developing diabetes-related complications and ultimately early mortality are more significant to those engaged in a better quality relationship.

The findings of the analysis by participant gender revealed that those participants engaged in a relationship shorter than 6 years reported more problems in the relationship but that the relationship met their needs and reported overall a better quality relationship. The participants in shorter relationships reported less family support for diet although more support for insulin injecting and reported better self-care in terms of diet but worse self-care in terms of foot care. Interaction effects demonstrated that for the males, *long* term relationships were associated with better support for blood glucose testing and exercise, but worse adherence to the self-care activities of diet, foot care and overall adherence. For the females, this effect was present for those reporting *short* term relationships. When the data was investigated by duration of diabetes, male participants reported more support for diet and general diabetes behaviours and reported less support for blood-glucose testing and exercise behaviour than the female participants. Those reporting a long term diagnosis of diabetes reported greater satisfaction with their partner but also more problems in the relationship, reported more support for blood-glucose testing and insulin injecting but less support for diet, exercise and general diabetes activities, and less engagement in the self-care task of diet. Interaction effects demonstrated that for the males, a *shorter* diagnosis of diabetes was associated with higher scores on the RAS question of how well one's partner met one's needs, how well the relationship met their expectations and a higher overall score on the RAS, but a shorter diagnosis was associated with poorer adherence to the self-care task of exercise. For the female participants, a *longer* diagnosis of diabetes was associated with these factors.

The analysis shows that the females in longer term relationships are reporting a similar experience with their diabetes as the males in shorter term relationships. The median value for relationship length for the female participants with diabetes was 4 years, but for the male participants with diabetes, the median value for relationship length was 8 years. Thus, the effects reported may be due more to relationship length than to gender. To investigate this the data set was split into 3 groups, those reporting shorter term relationships up to the female group median of 4 years (ST group), those reporting medium term relationships between 4 and the male group median of 8 years (MT group) and a third of those reporting longer term relationships over 8 years in length (LT group). Initially analysis on duration of relationship was based on 2 groups divided on the group median of 6 years. This revealed only that the participants in longer term relationships (over 6 years) reported worse quality of relationships but no effect on diabetes-specific social support or adherence to the diabetes self-care tasks. By splitting the participants into 3 groups, it is proposed that the longer the relationship the more social support and adherence to the diabetes self-care tasks will be reported.

The mean scores for the shorter term, medium term and longer term groups for each sub-scale and total scale are presented in table 9.45. ANOVAs were calculated and post-hoc tests (Tukey's test) conducted on significant results. Analysis indicated that there was a significant difference between the three groups in reporting quality of relationship ($F_{(2,47)} = 3.163$, p=.05), diabetes-specific support for diet ($F_{(2,47)} = 3.324$, p=.05), total diabetes-specific support ($F_{(2,47)} = 3.117$, p=.05) and adherence to the self-care tasks of blood glucose testing ($F_{(2,47)} = 3.647$, p=.05) and foot care ($F_{(2,47)}$ =8.668, p=.001). Post-hoc analysis revealed that for reporting quality of relationship and total diabetes-specific social support, the participants in the MT group (reporting duration of relationship as between 4-8 years) were significantly different to the participants in the ST or LT group. The MT group also reported higher scores for quality of relationship, diabetes-specific support for diet, total diabetes-specific support, and adherence to the self-care tasks blood glucose testing and foot care.

Table 9.27 Participants full-scales and sub-scales on all measures by shorter term, medium term and longer term relationship.

		Shorter Term Relationship (N=18)	*Medium Term Relationship (N= 21)*	*Longer Term Relationship (N=11)*	*F*	*df*	*p*
RAS	Mean	4.30	4.42	4.21	3.163	2,47	.051
	SD	.35	.16	.07			
DFBC	Mean	12.67	15.24	10.73	3.117	2,47	.054
	SD	4.20	6.13	3.82			
Adherence	Mean	3.76	4.07	3.62	2.515	2,47	.092
(SDSCA)	SD	.66	.61	.39			
Life threat	Mean	1.11	1.29	1.27	.230	2,43	.795
	SD	.90	.85	.75			
DFBC diet	Mean	2.00	3.43	2.18	3.324	2,47	.045
	SD	1.19	2.25	1.89			
DFBC blood	Mean	-1.22	-1.05	-1.73	1.518	2,47	.230
glucose	SD	1.06	1.07	1.01			
DFBC insulin	Mean	3.22	3.81	2.36	1.630	2,47	.207
	SD	2.46	1.47	2.69			
DFBC	Mean	2.33	3.81	2.81	2.851	2,47	.068
exercise	SD	.84	2.58	1.88			
DFBC	Mean	6.33	5.24	5.09	2.079	2,47	.136
general	SD	1.75	2.32	1.13			
SDSCA diet	Mean	4.64	4.50	3.95	.546	2,47	.583
	SD	1.92	1.93	.92			
SDSCA	Mean	3.44	3.31	3.13	.061	2,47	.941
exercise	SD	2.51	1.99	2.55			
SDSCA blood	Mean	5.67	7.00	6.63	3.647	2,47	.034
glucose	SD	2.56	.00	.50			
SDSCA	Mean	7.00	7.00	7.00	-	-	-
insulin	SD	.00	.00	.00			
SDSCA foot	Mean	.72	2.35	1.00	8.668	2,47	.001
care	SD	1.26	1.45	.97			
SDSCA	Mean	1.11	.28	.00	2.780	2,47	.072
smoking	SD	2.14	.72	.00			

This finding suggests that increasing duration of relationship does not predict increasing quality of relationship, increasing availability of diabetes-specific social support or adherence to the diabetes self-care regime. However, those participants reporting relationships between 4 and 8 years in length did report better quality relationships, better available total diabetes-specific support and better adherence to some self-care activities than those in shorter term relationships and those in longer term relationships (over 8 years in length). Thus rather than the length of relationship, quality of relationship could predict better available diabetes-specific social support and better adherence to the diabetes self-care regime. The correlations conducted between quality of relationship and all the other sub-scale and total scale scores indicated that participants with diabetes reporting a better quality of relationship also reported higher levels of diabetes-related social support. However the participant with diabetes report better adherence when they report lower quality relationships. To test this finding further, the data set was split into 2 groups, those reporting good quality relationships (participants with scores above the median score of relationship quality of 4.29) and those reporting poorer quality relationships (participants with scores equal to and below the median score of 4.29).

Table 9.28 Participants with diabetes' full-scales and sub-scales on all measures by reported better and poorer quality relationship.

		Poorer quality relationship (N=12)	*Better quality Relationship (N= 20)*	*t*	*df*	*p*
DFBC	Mean	10.33	12.00	-1.199	30	.240
	SD	5.54	2.25			
Adherence (SDSCA)	Mean	3.92	3.76	.716	30	.479
	SD	.22	.74			
Life threat	Mean	.33	.49	-4.068	30	.000
	SD	1.40	.82			
DFBC diet	Mean	1.33	1.60	-.637	30	.529
	SD	.98	1.23			
DFBC blood glucose	Mean	-1.67	-1.40	-.581	30	.556
	SD	.98	1.39			
DFBC insulin	Mean	1.67	4.20	-3.024	30	.005
	SD	3.55	1.00			
DFBC exercise	Mean	3.67	2.40	2.551	30	.016
	SD	.98	1.53			
DFBC general	Mean	5.33	5.20	.178	30	.860
	SD	2.14	1.99			
SDSCA diet	Mean	4.33	4.75	-.577	30	.568
	SD	.61	2.44			
SDSCA exercise	Mean	5.33	3.00	3.135	30	.004
	SD	.49	2.53			
SDSCA blood glucose	Mean	6.67	5.80	1.197	30	.241
	SD	.49	2.46			
SDSCA insulin	Mean	7.00	7.00	-	-	-
	SD	.00	.00			
SDSCA foot care	Mean	.17	.25	-2.187	30	.037
	SD	1.00	1.29			
SDSCA smoking	Mean	.00	1.00	-1.677	30	.104
	SD	.00	2.05			

Table 9.29 Participants with diabetes' spouse/partners' full-scales and sub-scales on all measures by reported better and poorer quality relationship.

		Poorer quality relationship (N=12)	*Better quality Relationship (N= 20)*	*t*	*df*	*p*
DFBC	Mean	11.00	9.60	.403	30	.690
	SD	5.22	11.26			
Adherence (SDSCA)	Mean	3.94	4.85	-.827	30	.415
	SD	.36	3.82			
Life threat	Mean	1.08	1.00	.287	30	.776
	SD	.51	.92			
DFBC diet	Mean	.83	.80	.028	30	.978
	SD	.39	4.12			
DFBC blood glucose	Mean	-.67	-1.00	.514	30	.611
	SD	1.43	1.95			
DFBC insulin	Mean	3.33	3.20	.194	30	.847
	SD	1.43	2.09			
DFBC exercise	Mean	4.00	3.60	.703	30	.487
	SD	1.04	1.78			
DFBC general	Mean	3.50	3.00	.502	30	.619
	SD	1.88	3.11			
SDSCA diet	Mean	4.54	4.55	-.019	30	.985
	SD	.69	1.44			
SDSCA exercise	Mean	3.08	2.40	.820	30	.419
	SD	2.72	1.98			
SDSCA blood glucose	Mean	7.00	3.50	4.100	30	.000
	SD	.00	2.94			
SDSCA insulin	Mean	6.67	5.60	1.251	30	.220
	SD	.78	2.87			
SDSCA foot care	Mean	2.33	1.50	1.508	30	.142
	SD	1.77	1.33			
SDSCA smoking	Mean	.00	11.60	-2.292	30	.029
	SD	.00	17.42			

Analysis revealed that those participants in better quality relationships reported greater life threat, more family support for insulin injecting and less family support for exercise. Participants also reported worse adherence to the self-care task of exercise and better adherence to the self care task of foot care. The spouse/partners reporting better quality relationships reported their partner with diabetes adhering less to the self-care task of blood glucose testing and more smoking behaviour.

Path analysis indicated that diabetes-specific social support predicts adherence to the diabetes self-care regime for all but the male participants with diabetes. For the participants with diabetes, high reported relationship quality predicted high life threat due to diabetes. For the spouse/partners, high reported life threat due to diabetes predicted poor adherence to the diabetes self-care regime. For the male participants with diabetes, the reported quality of relationship predicted adherence to the diabetes self-care regime. Further analysis demonstrated that for male participants with diabetes, relationship quality acts as a mediator between reported diabetes-specific social support and adherence to the diabetes self-care regime.

9.6.2 Comparison of Findings to Previous Studies

The participants with diabetes of this study were older, had longer diagnoses of diabetes and were reporting lower HbA_{1C} values indicating better metabolic control than the participants in studies 1 and 3. Therefore, the comparisons that can be made between these groups are limited. On the Diabetes Family Behaviour Checklist, the participants with diabetes of this study reported greater support for diet (Cohen's d = 1.02), insulin injecting, exercise behaviour and for general diabetes care (Cohen's d = 1.91) but less support for blood glucose testing (Cohens' d = .91) than the participants in studies 1 and 3. On the Summary of Adherence to Diabetes Self-Care Activities Scale, participants with diabetes of this study reported greater adherence to diet, blood glucose testing (Cohen's d = 1.18) and insulin injecting but worse adherence to exercise, foot care and less smoking behaviour (Cohen's d = .72) than the participants in studies 1 and 3. Life threat due to diabetes reported by the participants with diabetes of this study was greater than participants in studies 1 and 3 (Cohen's d = .83) as was total diabetes-specific family support (Cohen's d = 1.48) but not total adherence to the diabetes self-care activities (Cohen's d = .02).

9.6.3 Comparison of Findings to Other Published Studies

The participants of this study reported higher total scores on the Relationship Assessment Scale compared with similar sample published scores (Hendrick, Dicke & Hendrick, 1998). The participants with diabetes of this study felt their partner met their needs (Cohen's d = .71), their relationship was better compared to most (Cohen's d = .87), and had met their original expectations (Cohen's d = .51) more than a matched published sample (Hendrick, 1988) but also wished they had not got into the relationship more than the published sample (Cohen's d = 1.05). The participants with diabetes of this study reported more total diabetes-specific social support than a published sample (Schafer, McCaul & Glasgow, 1986) (Cohen's d =

1.49). The participants with diabetes of this study reported slightly more adherence (Cohen's $d = .13$) to all the diabetes self-care tasks on the Summary of Diabetes Self-Care Activities scale than the published findings (Toobert & Glasgow, 1994). In particular, participants with diabetes of this study reported greater adherence to blood glucose testing (Cohen's $d = .79$), insulin injecting (Cohen's $d = .65$) and foot care (Cohen's $d = 1.22$). The participants with diabetes of this study also reported greater life threat due to diabetes (Cohen's $d = .58$) compared with a similar published sample (Aalto & Uutela, 1997).

9.6.4 Use of the internet as a data collection tool

The internet proved an effective tool for collecting data however, the participants of this study did not match those of previous studies for age, duration of diabetes and HbA_{1C}. The participants in this study were older, had diabetes for longer and reported better metabolic control than the participants in the previous studies and the comparisons that could be drawn on the diabetes-specific family support, life threat due to diabetes and adherence to diabetes self-care regime measures for the participants in this study and those in the previous studies were thus limited. The reasons for attracting a different group of participants could be due to the way the study was advertised on diabetes groups' message boards. The previous participants were drawn from hospital patient lists which had accurate date of birth recorded and thus a precise participant pool could be contacted and data collected. With the use of the internet, the participants who respond to an advertisement only have the advertisement to judge their suitability for the study and filtering of unsuitable participants can only happen after the data has been collected. The advertisement for any study must therefore be very specific in describing its target audience in order for the researchers to receive data from their proposed target population. That said however, previous research has indicated that internet and/or e-mail or other electronic surveys have similar response rates to mailed paper-based surveys (Kerlinger, 1986) and the respondents to electronic format surveys appear to be representative of the population as a whole (Cook, Heath & Thompson, 2000). Certainly, by advertising on diabetes groups' message boards on the web, message boards that were mostly moderated by a member of each group, the advertisement was shown to a target audience of adults with diabetes and the data is unlikely to be collected from 'hoax' or 'prank' participants. No problems were reported in terms of user interface or other issues of usability by the respondents to the advertisement and no comments were made as to the length of the survey indicating that the participants in the study found the electronic version of the survey acceptable to use. Therefore, the use of electronic surveys with a targeted population is considered acceptable but the advertisement used for the research must be very precise in defining its target audience and the participants must be reassured of their suitability to contribute to the study.

9.6.5 Limitations

The use of the internet as a data-collection tool has been discussed and is considered a useful medium for the collection of data but the limitations of the technique became clear when the completed surveys were returned. The target population had not been made explicit enough (young adults aged 16-25 years) in the advertisement and so a number of participants returned their surveys who were between 20 and 30 years of age. Although this may not necessarily present a problem, it was expected that the data collected over the internet could be used comparatively with the data collected in the previous studies, but this was not the case. Future use of the internet as a data-collection tool would be enhanced by being very specific regarding the target audience of the research and confirming the participants' appropriateness for the study at the beginning of the survey. The participants in this study were a little older than the previous participants had been, and although the scores on each of the measures were on occasion different to published scores for similar populations, on the whole they were similar and it can be argued that the participants for this study were representative of young adults with diabetes as a whole population. One of the difficulties in approaching participants over the internet and not from a precise patient list is that it would be difficult to prove whether the participants of this study actually had diabetes. As discussed in the results section 9.5.2, the similarities between the participants with diabetes scores and their spouse/partner scores lend support to the assumption that the participants did indeed have diabetes, the significant differences found between the participants of this study's scores and the participants of the previous studies may reflect contamination of the data set by people without diabetes or may reflect the difference in experience of diabetes between those young people aged 16-25 years of studies 1 and 3, and those young people aged 20-30 years in this study who report currently being in a partner relationship.

9.7 Conclusions

The aims of this study were to investigate further the effect of social support on adherence to the diabetes self-care regime by investigating the contribution the young person's partner has as provider of social support and to obtain information on this from both the young person with diabetes and from their partner. It was predicted that those participants reporting a better quality relationship (indicated by higher scores on the Relationship Assessment Scale (Hendrick, 1988) would report more available social support and greater adherence to the diabetes self-care regime. Participant scores were predicted to correlate highly with partner scores on all measures. The previous studies indicated that women report more diabetes-specific social support and it was therefore predicted that women will report more diabetes-specific social support in this study.

The findings of this study demonstrate that participants' reports of a better quality relationship do predict some better available diabetes-specific social support and some greater adherence to the diabetes self-care regime. The scores of participants with diabetes and their spouse/partner did correlate highly and the female participants did report greater available diabetes-specific social support than the male participants. The female participants with diabetes also reported greater adherence to the diabetes self-care regime and rated their relationship quality as better than the male participants with diabetes. The female participants with diabetes also reported lower life threat due to diabetes than did the male participants with diabetes, thus supporting the aims of the study.

The Relationship Assessment Scale proved a useful brief measure of relationship quality that could be tested statistically. Using median values on this measure to create two groups reporting low quality relationship and reporting high quality relationship found that those reporting better quality relationships reported greater life threat, more family support for insulin injecting and less family support for exercise. Participants also reported worse adherence to the self-care task of exercise and better adherence to the self care task of foot care. The spouse/partners reporting better quality relationships reported their partner with diabetes adhering less to the self-care task of blood glucose testing and more smoking behaviour.

That the participants with diabetes report greater life threat due to diabetes when both they and their spouse/partner report a better quality relationship suggests that the implications for developing diabetes-related complications and ultimately early mortality are more significant to those engaged in a better quality relationship. Interestingly, path analysis did not demonstrate that relationship quality was a mediator of adherence for any of the participants with diabetes. Research by Argyle & Furnham (1987) however has suggested that in terms of providers of social support for diabetes self-care tasks, men tend to see their spouse/partner as the greater provider of social support whereas women tend to see their family and friends as the main providers of that social support. This lends support to the finding of this study that for the female participants with diabetes, diabetes-specific social support from friends and family was the main predictor of adherence to the self-care regime whereas for the male participants with diabetes, this source of social support was important but the relationship quality with their spouse/partner was a strong, influencing, mediating factor in adherence to the diabetes self-care regime.

Chapter 10: Discussion

10.1 Aims of the thesis

This thesis aimed to consider the psychological issues in diabetes and specifically investigated these in young people aged 16 to 25 years of age. People this age are experiencing a lot of change in their lifestyles (leaving home, starting new jobs or going to University, starting families of their own), the demands of the diabetes regime are still present and it can be difficult to balance the demands of a changing lifestyle with the demands of caring for themselves with a view to the long-term (and preventing diabetes-related complications of health). By understanding what young people believe about their health and diabetes, the issues related to metabolic control and adhering to the diabetes self-care regime in young people can be explored more thoroughly.

Health issues are relevant and important to the young person with diabetes. Peer influences and parental support help the young person to balance the demands of living with diabetes with the demands of being a social young adult. The increasing effectiveness of the treatments available for diabetes combined with the increasing ease of use of blood glucose testing and insulin injecting equipment should help with the practical issues of adherence, whilst an increased understanding of the complex psychological issues surrounding diabetes should improve the ability of the researcher to gauge the impact diabetes has on the young person.

When the Health Belief Model is augmented to include specific measures of social support, self-efficacy, locus of control and quality of life (Aalto & Uutela, 1997), the Extended Health Belief Model pulls together the models and theories of health behaviour into one larger model and incorporates all the factors considered important in influencing health threat appraisal and coping processes. With a specific view to diabetes management, the Extended Health Belief Model provides a structure for and seeks to understand what factors affect the person's adherence to the diabetes self-care regime and how these factors interact to provide a model of the person's experience of diabetes. It is this model which was tested in the empirical work of this thesis.

10.1.1 Aims and summary of findings of study 1

Study 1 aimed to investigate the experience of diabetes in young people aged 16 to 25 years within the Extended Health Belief Model framework. On the basis of previously published work, it was anticipated that participant reports of high internal locus of control, high diabetes-related empowerment, coping with hypoglycaemia and diabetes-specific social support would indicate good patient adherence to the self-care regime.

The study found that participant adherence to their diabetes self-care regime was predicted by high diabetes-specific social support scores. Those participants exhibiting poor metabolic control reported lower levels of diabetes-specific social support, higher levels of life threat due to diabetes, reported being in worse metabolic control and reported less worry about hypoglycaemia and engaged in fewer hypoglycaemia preventive behaviours. It was suggested that the model explained the experience of those young adults with diabetes reporting good metabolic control better than it did the young adults reporting poor metabolic control.

10.1.2 Aims and summary of findings of study 2

It was important to investigate these issues by semi-structured interviews with the young people. The findings of study 1 indicated that the Extended Health Belief Model appeared to explain the experience of those young people in good metabolic control more than it did young people in poor metabolic control. To investigate further why this was the case, interviews were arranged with patients in poor metabolic control (HbA_{1C} > 10.0%) and patients in good metabolic control (HbA_{1C} 5-8%).

Participant numbers in study 2 were low, however some differences could be seen between the two groups. Those participants in good metabolic control were more accepting of their diabetes, had both a daily routine for managing it and felt able to respond to their insulin requirements if necessary. The family were more likely to offer them support both in practical terms and emotional needs. Participants in good metabolic control were more likely to discuss their diabetes with their work colleagues and love partners and found them accepting and actively supportive.

10.1.3 Aims and summary of findings of study 3

As this was the first time the EHBM has been specifically tested with young people aged 16-25 years with Type 1 diabetes, study 3 replicated study 1 using the same measures in the same format but with different participants.

Study 3 did replicate the findings of study 1, the data fit to the proposed final Extended Health Belief Model was excellent and explained 29.4% of variance in adherence to the diabetes self-care regime for the participants of study 3. Again, participant high levels of adherence to the diabetes self-care regime was predicted by high levels of diabetes-specific social support.

When combined to form a single group the data fit to the proposed final Extended Health Belief Model was good for the combined data set and explained 11.5% of the variance in behaviour for the participants of this research and social support was still indicated as a strong predictor in the young person's adherence to the diabetes self-care regime. Again, the revised version of the Extended Health Belief Model appeared to explain the experience of young people with diabetes exhibiting good metabolic control better that it did the experience of young people with diabetes in poor metabolic control.

The studies demonstrated the suitability of the Extended Health Belief Model (EHBM) as a model for explaining the experience of young adults with diabetes and in particular, demonstrated the validity of the model in explaining some of the processes involved in the young adult choosing to adhere to their diabetes self-care regime.

Further analysis of the data showed that females reported greater levels of diabetes-related support than males and in particular, reported a greater level of support for insulin injecting. High levels of support for insulin injecting are extremely important as support for insulin injecting was highly correlated with support for general diabetes care and total diabetes-related support. Support for the diabetes self-care tasks was highly correlated with adherence to the diabetes self-care regime for those young people reporting good metabolic control.

10.1.4 Aims and summary of findings of study 4

The aims of this study were to investigate further the effect of social support on adherence to the diabetes self-care regime by investigating the contribution the young person's partner has as provider of social support and to obtain information on this from both the young person with diabetes and from their partner.

It was predicted that those participants reporting a better quality relationship as indicated by higher scores on the Relationship Assessment Scale (Hendrick, 1988), would report more available social support and greater adherence to the diabetes self-care regime. Participant scores were predicted to correlate highly with partner scores on all measures. The previous studies indicated that women report more diabetes-specific social support and it was therefore predicted that women would report more diabetes-specific social support in this study.

The findings of study 4 demonstrated that the Relationship Assessment Scale proved a useful brief measure of relationship quality that could be tested statistically. Participants' reports of a better quality relationship predicted some better available diabetes-specific social support and some greater adherence to the diabetes self-care regime. The scores of participants with diabetes and their spouse/partner correlated highly and the female participants did report greater available diabetes-specific social support than the male participants.

10.2 Comparison of findings to other published studies

A definition of health presented at the beginning of the thesis suggested that health encompasses the biological and social roles we perform and includes psychological issues such as attitudes and perceptions (Gochman, 1988). The use of the Extended Health Belief Model to test the experience of diabetes in young people has permitted the use of measures to test all these aspects related to health behaviour in a structured way that has allowed the use of path analysis techniques to reveal the connective paths existing between these variables. The measures used have been both rigid in their pursuit of factual data but also flexible enough to embrace a variety of prescribed self-care regimes. The DCCT (1996) reported that no difference was found in quality of life from those participating in intensive or regular treatment regimes and in particular, the use of the Summary of Diabetes Self-Care Activities Scale and the Audit of Diabetes-Dependent Quality of Life measure have provided the flexibility needed to embrace both intensive treatment regimes and regular treatment regimes.

It has been suggested that the family influences the development of health beliefs and the execution of health behaviour until critical periods occur in the young persons life when his/her friends/peers assume greater influence (Lau, Quadrel & Hartman 1990). This series of studies has revealed this to be true. The spouse/partners provided a great source of social support to the participants with diabetes. Females more than males, younger people more than older people and low risk-takers more than high risk-takers also appear to perceive a greater risk outcome of unhealthy activities (Small, Silverberg & Kerns, 1993). Life threat due to diabetes in these studies however revealed that the male participants reported greater life threat, life threat increased with age and was not related to adherence to the diabetes self-care regime. The reason for this difference could be that simply by having diabetes, the young people already have a greater sense of life threat than young people without diabetes and the gender difference can simply be explained by the fact that the male participants were older than the female participants thus confounding the gender/age results. That life threat did not correlate or predict adherence to the self-care regime is not surprising. Aalto & Uutela (1997) did not find that life threat due to diabetes predicted adherence. Taylor (1978) reported that 34% people engaged in good health behaviour (taking antihypertensive treatment) still exhibited poor health outcome and similar findings were reported for a group of young people with diabetes whereby 18% of the young people engaged in good adherence but still exhibited poor health outcome (Bennett Johnson, 1994). The adoption of health behaviour is controlled by the young person themselves, but within the constraints imposed by family (Schucksmith & Hendry, 1998), thus without the support of the family the young person is unlikely to be able to adhere to a diabetes self-care regime within reasonable boundaries if these are not put into place by their family members or spouse/partner.

The emotions related to their diabetes described by the participants in study 2 were similar to those described by other authors. The participants reporting poor metabolic control described themselves as having few friends and feeling lonely (supported by research published by Kovacs, 1997), feeling distress and frustration at others' perception of the diabetes and feeling depressed on occasion (supported by research published by Rubin & Peyrot, 1992). However, the participants reporting good metabolic control tended to describe the ameliorating effect of supportive friends, partner and/or family. This replicates published findings indicating the importance of social support in the young person's adherence to the diabetes self-care regime and better metabolic control (Hanson, Henggeler & Burghen, 1987b; La Greca et al., 1995; Wallander & Varni, 1989).

In alignment with published research, the women with diabetes in this series of studies reported worse adherence to the diabetes self-care regime (supporting research published by Hanna & Guthrie, 1999) and as reported by La Greca et al., (1995) for all participants, receiving more diabetes-specific social support was related to younger age, shorter duration of diabetes but also greater adherence to the diabetes self-care regime. That social support is more readily available in the early stages following diagnosis is an important finding as the availability of social support in the immediate years following diagnosis has been found to be critical of good adaptation to the diagnosis (Burroughs, Harris, Pontious & Santiago, 1997) and subsequent good adherence to the self-care regime (Wysocki, Hugh, Ward & Green, 1992).

The paths indicated in the final version of the Extended Health Belief Model were all supported by published research findings. The lack of a link found between adherence to the diabetes self-care regime and metabolic control can be explained by the data received. The participants completed the Summary of Diabetes Self-Care Activities scale by reporting on their adherence to the self-care tasks over the previous seven days. Thus, the participant scores of adherence to the diabetes self-care regime were based on very recent behaviour. However, metabolic control data (reported as HbA_{1C} values) were often values calculated up to 2 years previous to the participant completing their questionnaires and as such were not current. Therefore, it would be extremely unlikely for the two scores to correlate or predict each other in any way. Research supporting a link between adherence to the diabetes self-care regime and participants' metabolic control is based on current values for both measures and not on historical values for either. Recently published research has highlighted the importance of diabetes-specific self-efficacy in the young persons' adherence to the diabetes self-care regime (Rose, Fleige, Hildebrandt, Schirop & Klapp, 2002).

Perceiving the diabetes self-care regime to be effective in managing their diabetes predicted the young persons' adherence to the self-care task of diet which in turn was related to better metabolic control (Skinner & Hampson, 2001). Indeed, adherence to the diabetes self-care regime is indicated as an important mediator in the relationship between self-efficacy and ultimate HbA_{1C} values (Johnston-Brooks, Lewis & Garg, 2002). However, again, it has been reported that good adherence to the diabetes self-care regime does not always predict good metabolic control (Toljamo & Hentinen, 2001). The amount of variance explained by the final version of the Extended Health Belief Model compares well for this age group – 9-25% (Bond, Aiken & Somerville, 1992), 41-52% (Brownlee-Duffeck et al., 1987) and 14% for adherence to diet and 21% for adherence to blood glucose testing (Aalto & Uutela, 1997).

The participants of study 4 differed significantly from those of study 1 and study 3. They were older and had been diagnosed with diabetes for longer. The participants with diabetes' scores on the Relationship Assessment Scale indicated that they reported a better quality relationship than a published matched (but no diabetes) sample, however, their spouse/partner scores on the Relationship Assessment Scale did not differ significantly from the published matched sample indicating that the presence of a chronic illness, in this case diabetes, has a significant positive effect on reported relationship quality for the chronically ill person but also, importantly, the presence of chronic illness does not affect the perceived relationship quality for the healthy spouse/partner. That the relationship quality did not appear to mediate the link between diabetes-specific social support and adherence to the diabetes self-care regime for the participants was disappointing but the research of Hafstrom and Schram (1984), demonstrated that for both the spouse and the chronically ill partner, coping efficacy and illness impact appear to be an important factor in the spouse's psychological adjustment to the illness (Manne & Zautra, 1990; Bigatti & Cronan (2002). What is apparent however, is that better reported quality of relationship has a protective effect on the perceived negative impact of having diabetes and better quality of life and although the effect was not significant, Trief, Himes, Orendorff & Weinstock (2001) reported that a better quality of relationship corresponds to better metabolic control.

10.3 Why does the Extended Health Belief Model not explain the experience of the young people exhibiting poor metabolic control?

The studies indicate that the EHBM explained the experience of young people in good metabolic control better than it did those in poor metabolic control. Analysis of the data revealed that those reporting poor metabolic control were more likely to live in high environment support conditions, yet there was no correlation between levels of diabetes-related support received and actual adherence to the diabetes self-care tasks for the young people in poor metabolic control. However, those young people living in high environment support conditions and reporting high levels of diabetes-related support also reported worse adherence to the diabetes self-care tasks which may suggest that the presence of family members or partner/spouse actually inhibits adherence to the diabetes self-care tasks. Perhaps the young people are not taking responsibility for their diabetes and are relying on their family members to remind them to do tasks and take care of themselves. Living in a highly supportive environment may actually be a hindrance for this age group as the family members have to adopt the young person's diabetes care as part of their responsibilities for the young person which in turn prevents the young person from learning to fully take care of themselves and being independent and responsible for their diabetes management. Those young people exhibiting good metabolic control living in a low support environment, reporting lower levels of diabetes-related support considered themselves at greater risk from their diabetes than those living with their parents or with spouse/partner and reporting higher levels of diabetes-related support. Perhaps this consideration of the risks of poor diabetes management acts as a motivational aspect to good adherence to the diabetes self-care regime in the young person who lives independently, which is missing when the young person lives in a family situation.

Research into the effect of motivation in young people with diabetes suggests that the link between motivation and metabolic control is weak. Trigwell, Grant & House (1997) researched the effect of motivation on metabolic control with a study grounded in Prochaska & DiClemente's model of health behaviour, the Stage of Change model (described earlier on in the thesis). Prochaska & DiClemente argued that one undergoes a series of contemplative stages in health behaviour – from precontemplation (where the person is not considering changing their behaviour), to contemplation, determination, action and then maintenance (where changes in health behaviour are sustained without recurrence of the previous problem behaviour). Trigwell, Grant & House predicted that as people with diabetes progressed through the stages (and hence increased their motivation to adopt better adherence to the diabetes self-care regime), so their HbA_{1C} readings would fall, indicating better metabolic control. The authors gave 361 adults with diabetes a modified version of the Stages of Change, Readiness and Treatment Eagerness Scale to assess their position in the motivation-based Stage of Change model and asked for recent HbA_{1C} readings.

The results indicated that metabolic control was better (HbA_{1C} of 7.4%) when the adults were engaged in the precontemplation stage of the model, then rose for the contemplation stage (HbA_{1C} of 8.5%) and steadily decreased over the interim stages to a low at the maintenance stage (HbA_{1C} of 7.5%). There was no significant association between HbA_{1C} and age, gender or type of diabetes, thus the effect on metabolic control could be directly related to motivation. However, the correlations were extremely low (ranging from -.22 to .22) and if motivation is an indicator of metabolic control, then the authors considered it weak. Perhaps the link between motivation and engagement in actual behaviour change is vulnerable to the vagaries of engaging in good health behaviour for diabetes which is complex and takes into account diet, exercise, insulin injecting, blood glucose testing, foot care and not smoking.

Thus if motivation is not a strong indicator of metabolic control in adults with diabetes, perhaps the difference lies in personality differences between those who manage to maintain good metabolic control and those who exhibit poor metabolic control. The findings of studies 1 and 3 indicate that poor metabolic control correlated highly with low social support, high life threat due to diabetes and low worry about hypoglycaemia and low engagement in preventive behaviours to avoid hypoglycemia. The findings of study 2 revealed that those in poor metabolic control were low in acceptance of their diabetes, had no daily routine for dealing with their diabetes, were not able to respond to unique events creating unusual demands for their diabetes care and reported poor family support. All of these factors are important variables in the structure of the Extended Health Belief Model and it could be for this reason, that the EHBM does not predict the situation of the young adult in poor metabolic control.

A review of current research conducted with young people with poor metabolic control reveals that there are certain characteristics associated with hyperglycaemia. Richardson, Adner & Nordstrom (2001) found that adults exhibiting poor metabolic control were characterised by low acceptance of diabetes and a poor sense of coherence. Surgenor, Horn, Hudson, Lunt & Tennent (2000) found that poor metabolic control was associated with self-report of the experience of loss of psychological control, feelings of inadequacy, reduced control in interpersonal relationships and reduced control of bodily function. Poor metabolic control has also been linked to reports of poor quality of life (Wikblad, Leksell & Wibell, 1996) and disordered eating behaviour (Rydall, Rodin, Olmstead, Devenyi & Daneman, 1997). Poor metabolic control has been associated with poor adherence to diabetes self-care regime, less cohesive family structure and more family conflict (Hanson, DeGuire, Schinkel & Kosterman, 1995). Poor metabolic control is also more common in women and is associated with high levels of depression and anxiety (LaGreca, Swales, Klemp et al., 1995) and with a poorer physical self-image (Boeger & Seiffgekrenke, 1994; Ryden et al., 1994).

The notion of a personality type being at risk for poor health behaviours is not a new one, and has been researched in the field of diabetes. Orlandini et al., (1995) investigated personality traits using the Personality Diagnostic Questionnaire – Revised (PDQ-R: Hyler, Skodol, Kellman, Oldham & Rosnick, 1990) an 152 item self-report measure in 77 adults (mean age = 27.82, SD = 7.05, mean duration of diabetes = 3.25 years, SD = 2.51) with Type 1 diabetes. The PDQ-R investigates personality traits including Paranoid, Schizoid, Antisocial, Histrionic, Narcissistic, Obsessive (as described by the DSM-IIIR). Principle components analysis revealed three personality types displayed by the adults with diabetes. Personality type 1 was described as 'withdrawn-suspicious' and was indicated by paranoid, schizoid, schizotypal, obsessive-compulsive and passive-aggressive traits. Personality type 2 was described as 'dramatic-dependent' and was indicated by borderline, histrionic, narcissistic and dependent personality traits. Personality type 3 was described as 'aggressive-irresponsible' and was indicated primarily by antisocial and sadistic personality traits. Of the three personality types, personality type 2 'dramatic-dependent' predicted poor metabolic control (b = .467 (SE = .173), t = 2.703, p = .009, β = .288, partial correlation - .299). Personality type 2 was characterised by instability in mood and self-image, interpersonal relationships characterised by the need for counselling and soothing, and poor impulse control – the person was quick to turn to drugs, alcohol or self-destructive behaviours with relatively little inhibition. The authors suggest that the adults displaying personality type 2 were in poor metabolic control because they either had difficulty in functioning autonomously and the participant felt they could survive only if with the significant other they depend on. Alternatively, that the non-compliance to diabetes self-care regime is a self-destructive behaviour due to the low impulse control and high rage towards themselves. Or it could be that presenting with poor metabolic control could be an attempt (either conscious or unconscious) to request healing by others and in order to guarantee the intense, dependent relationship the adult needs, the participant tries to induce others to take care of them through non-compliant behaviour. The authors argue that personality is a developmental issue and that by age 18 years, personality traits appear during adolescence and persist into adulthood. By conducting the study on an adult onset population (diagnosed with diabetes after the age of 18 years) with developed, persistent personality traits, the study may indicate a causal relationship between personality traits and poor metabolic control. The authors indicate that the best way to deal with persons exhibiting this personality type is to increase contact with the care team to satisfy their dependency needs and to investigate the major events in the person's relational, professional and social life which diminish compliance in view of the person's emotional and interpersonal instability.

This study (Orlandini et al., 1995) and the others cited above reflect the complex issues surrounding the young person in poor metabolic control. Issues of personality type, high levels of depression and anxiety, and poor adjustment to the demands of the diabetes self-care regime are prominent alongside issues of family cohesiveness and adaptation and indicate areas worthy of investigation in the high risk group of people with poor metabolic control. None of the studies cited investigate all of these issues concurrently in the same population and none looked specifically at the experience in young adults aged 16-25 years. If these issues of personality type, depression and anxiety, and adjustment to the demands of diabetes are so important in older adults in poor metabolic control, it would be interesting to see if they apply in younger adults in poor metabolic control. A better understanding of the psychological issues surrounding poor metabolic control in young adults would enable the diabetes team to address the needs of the young adult more specifically. The implications of which would be to address the issues of contention of these young people in poor metabolic control and by working towards resolving those, improve the empowerment and motivation of these young people to take more responsibility for their diabetes care and to ultimately reduce their HbA_{1C} readings and maintain better metabolic control.

10.4 Methodological limitations of the work

The main methodological limitation apparent at the completion of this work remains in the participants' use of the Summary of Diabetes Self-Care Activities Scale. All participants were aware of the need for insulin injecting and blood glucose testing, but some wrote on their surveys that they were not aware of their prescribed self-care regime for diet and exercise adherence and foot care. Many requested further information and leaflets purporting to describe the appropriate care regime for these aspects, but participant self-report adherence to these areas was understandably low. This highlights an area for attention in the clinic setting for these young people. Certainly, young people would appear to benefit from the provision of more information at clinic from their Consultant Diabetologist or Diabetes Specialist Nurse, but also in paper and electronic form to take or to access from home. A related limitation of these studies was the use of the measure of metabolic control (HbA_{1C} reading) which was, for many participants, not a recent reading. That there was no relationship found between adherence to self-care regime and actual metabolic control is not surprising when the measure for adherence was based on a 7-day recall of events and, for some, the latest reading available for metabolic control dated anything up to two years previous to the study.

A secondary methodological limitation apparent in this series of studies is in the use of the internet as a data-collection tool. With the target population not explicit enough (young adults aged 16-25 years) in the advertisement, a number of participants returned their surveys who were between 20 and 60 years of age. Although this may not necessarily have presented a problem, it was expected that the data collected over the internet could be used comparatively with the data collected in the previous studies, but this was not the case. Future use of the internet as a data-collection tool would be enhanced by being very specific regarding the target audience of the research and confirming the participants' appropriateness for the study at the beginning of the survey. However, although the participants in this study were a little older than the previous participants had been, the scores on each of the measures were not significantly different in the main to published scores for similar populations and it can be argued that the participants for this study were representative of young adults with diabetes as a whole population.

10.5 Conclusions

The Diabetes Control and Complications Trial (1996) concluded that whether or not a person adhered to an intensive diabetes care regime compared to a regular or conventional diabetes care regime, the young person's reported quality of life was not detrimentally affected. As the series of studies presented in this thesis have shown, participant quality of life is an important part of the Extended Health Belief Model and is certainly an important component of a model predicting adherence to the diabetes self-care regime. Thus it may be assumed that prescribing an intensive care regime over a more conventional regime will have no detrimental impact on the young person's adherence overall.

The importance of social support had been discussed in the introductory chapters, in particular that high levels of family and friends' support was related to greater adherence to the diabetes self-care regime (Hanson, Henggeler & Burghen, 1987b; Wallander & Varni, 1989; La Greca et al., 1995) and for this series of studies to provide further validation of this lends support to this notion extending from late adolescence to early adulthood. It is worthwhile to note that even though many of the young people who took part in this study were living independently or with partners away from the family home, still their family members were important providers of social support. Particularly as it had been suggested that in fact as the young people got older and had been diagnosed with diabetes for longer, that their perception of social support from the family reduced (La Greca et al., 1995), a finding that was consistent in this thesis. However, by incorporating research investigating the role of the romantic partner as provider of social support allowed this thesis to investigate the findings of Lau, Quadrel & Haufman (1990) that although the family was the main provider of social support in young people, during critical periods (in this study, moving away from the family home and becoming autonomous), friends and romantic partners become the main source of health beliefs. Indeed, the findings of this thesis indicated that the romantic partners were very much the main source of health beliefs for the young people with diabetes.

This series of studies have provided evidence for the acceptability of use of the Extended Health Belief Model to structure research into the experience of diabetes in young people. The measures used throughout were effective tools for use with young adults aged 16-30 years of age and the use of both paper-based surveys and electronic surveys with this age group proved an economical method both in terms of time and expense. That the Extended Health Belief Model proved a more accurate describer of the experience of young people in good metabolic control was an interesting finding and worthy of further investigation. The use of spouse/partner data in the final study offered a new dimension to research into the psychological experience of diabetes in young people and provided a different viewpoint into a situation commonly investigated in the person with diabetes alone or in their immediate family. By researching the spouse/partner viewpoint, it was possible to begin to reveal their very personal experience of diabetes and to gain some idea of the social support these people provide daily. Future research into this field of psychology would benefit from a greater understanding of the role of the spouse/partner in the young peoples' lives and the management of the diabetes – both as providers of practical support and as providers of emotional support as it is these people that young adults are in daily contact with who as peers provide perhaps a different point of view from the one projected from the immediate family. Unfortunately, this series of studies did not reveal identifying characteristics in the experience of diabetes in the young person exhibiting poor metabolic control, however, the studies did indicate that perhaps these young people need to develop independence from the family structure and not rely on their family members to act as prompts for their diabetes care if they are to develop any responsibility for their diabetes management and the skills necessary to achieve good metabolic control both on a daily basis and for unique events where the young person needs to be more responsive to their diabetes-related needs. All these studies have contributed immensely to our understanding of the psychological experience of all young people with diabetes and in particular have revealed the important role as provider of social support the spouse/partner plays in the young person's adherence to the diabetes self-care regime.

APPENDIX A

Figure 1: Health Belief Model Becker & Maiman (1975)

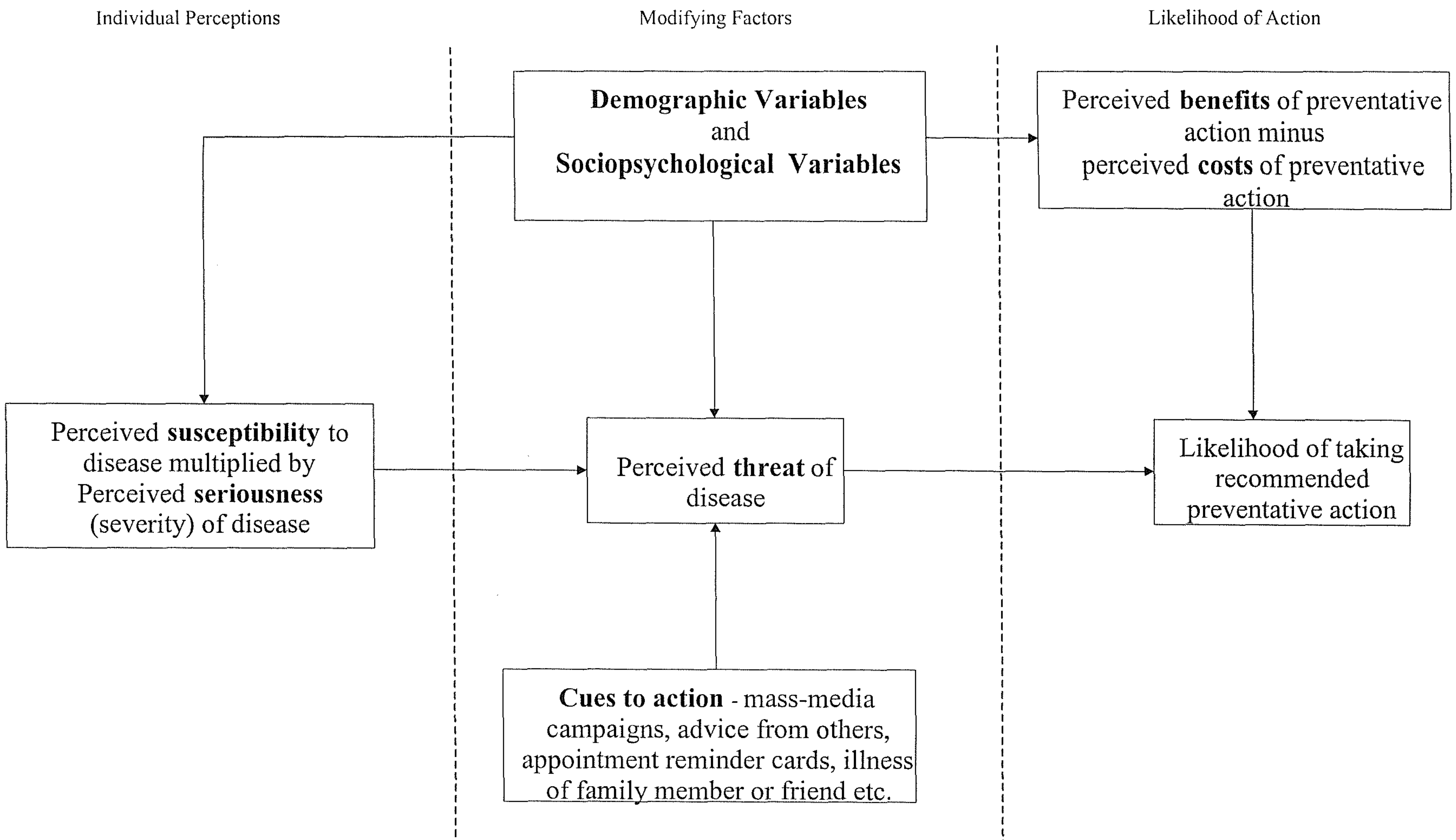


Figure 2: Protection Motivation Theory - Rogers (1985)

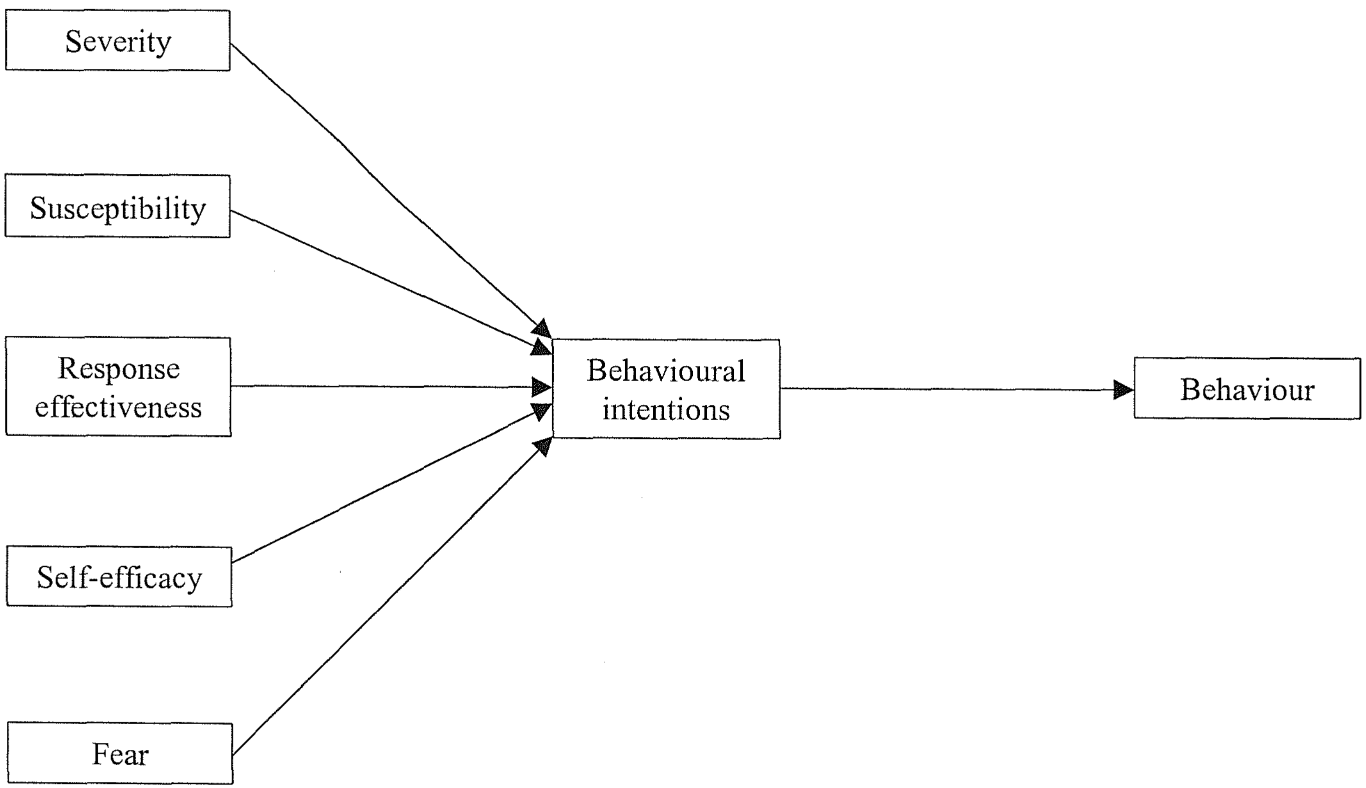


Figure 3 : Leventhal's Self-Regulatory Model of Illness Behaviour - Leventhal & Cameron (1987)

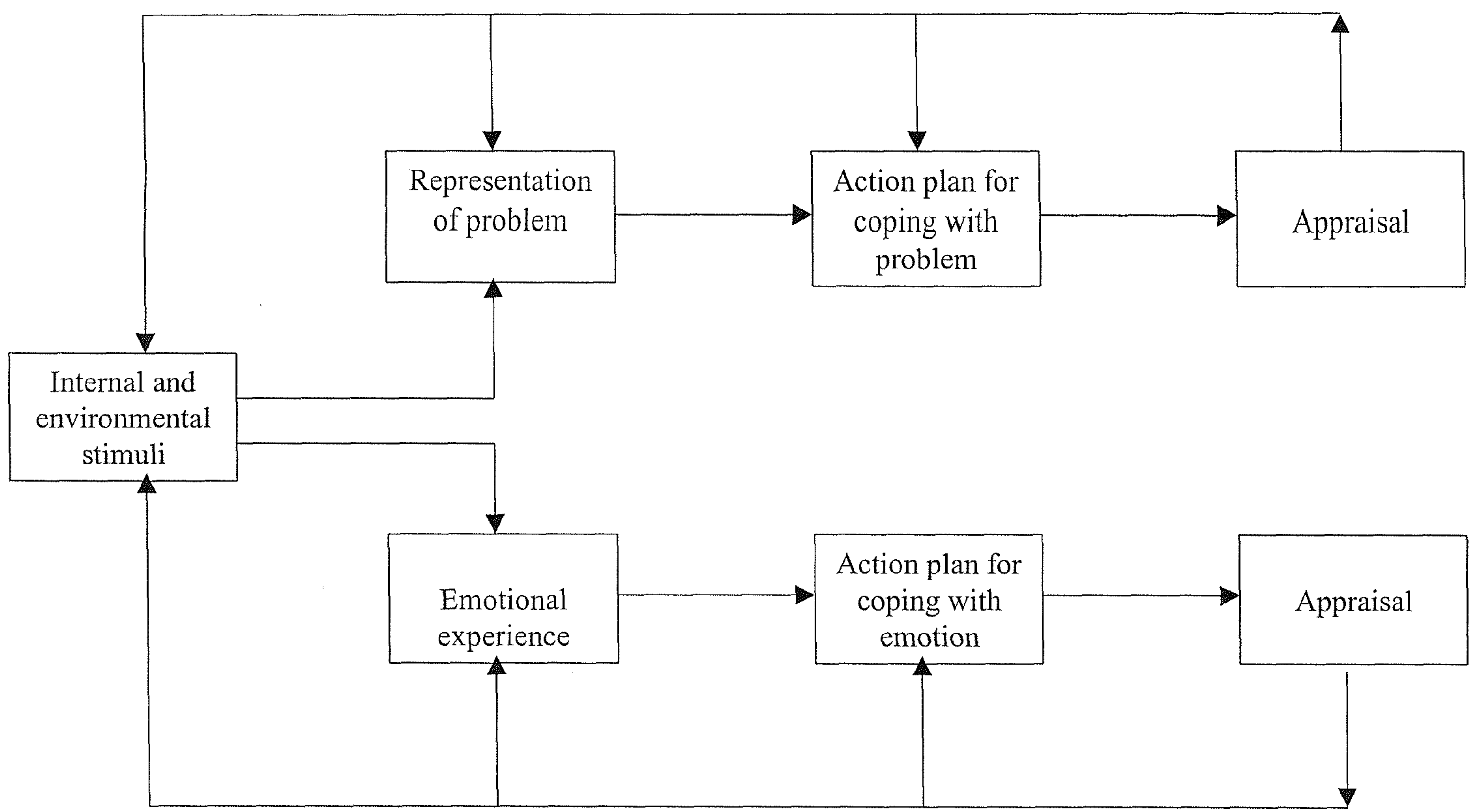


Figure 4: Theory of Reasoned Action - Fishbein & Ajzen (1975)

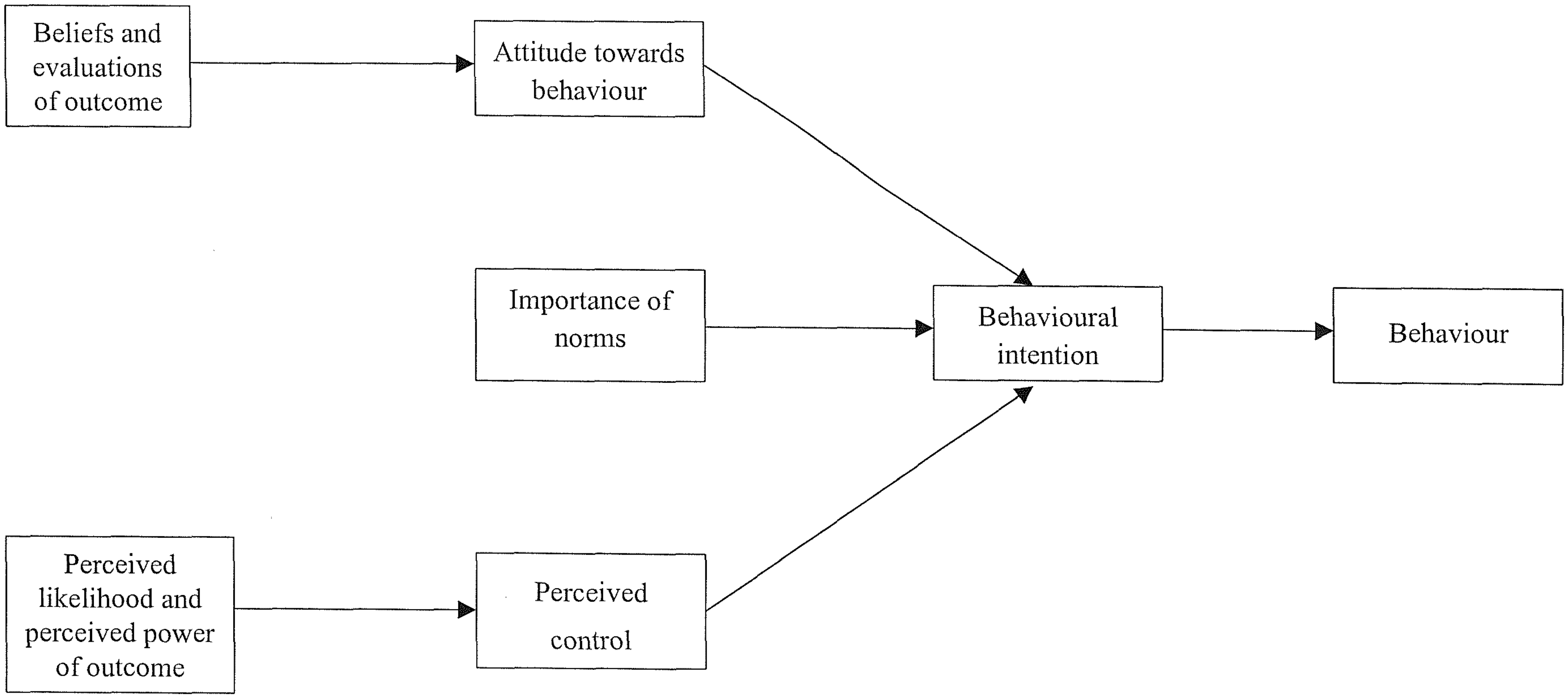


Figure5 : Theory of Planned Behaviour - Ajzen (1985)

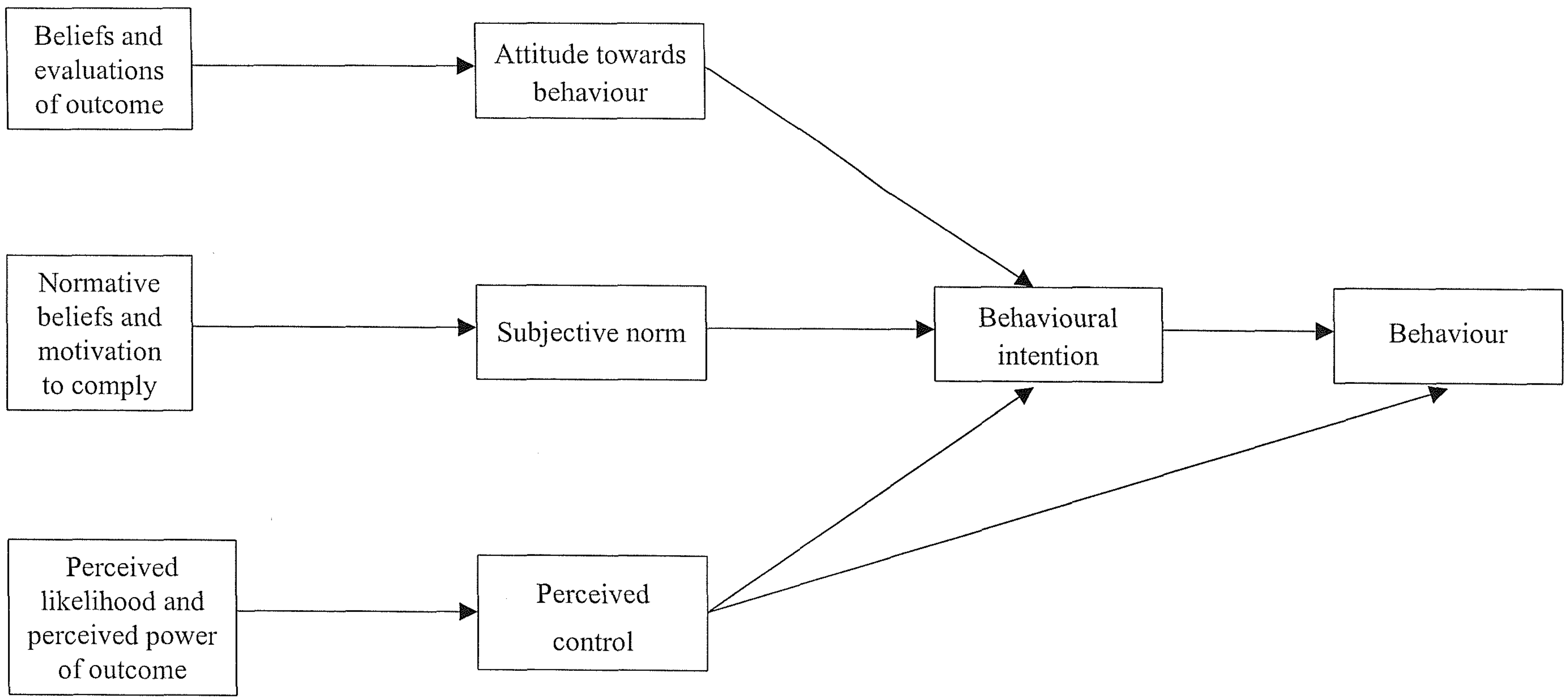


Figure 6: Extended Health Belief Model as Proposed by Aalto & Uutela, 1997 - simplified diagrammatically

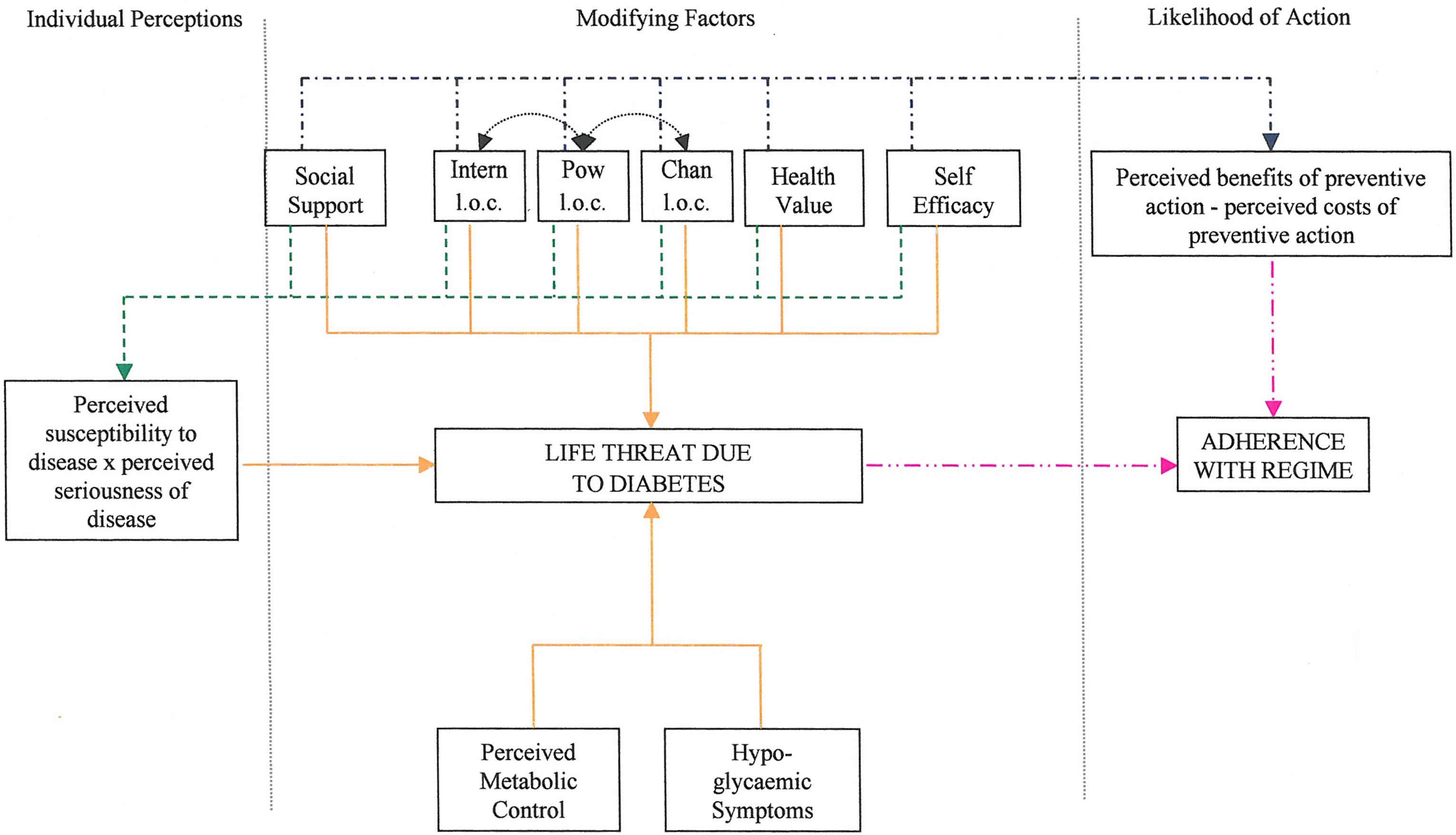


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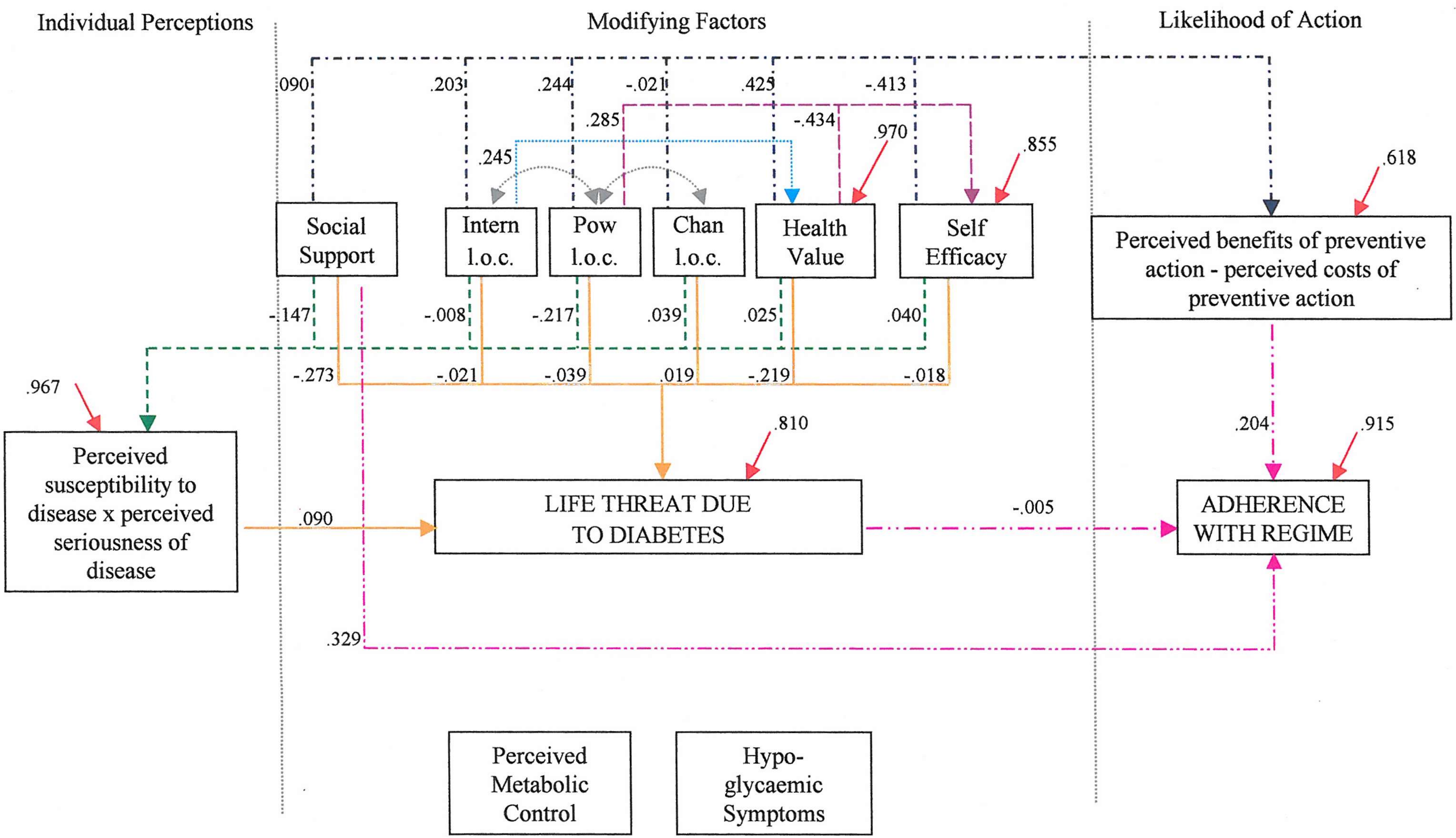
Figure 7: Final Model - total adherence to diabetes self-care activities with path values indicated to the left



5

Figure 8: Final Model - adherence to diet with path values indicated to the left

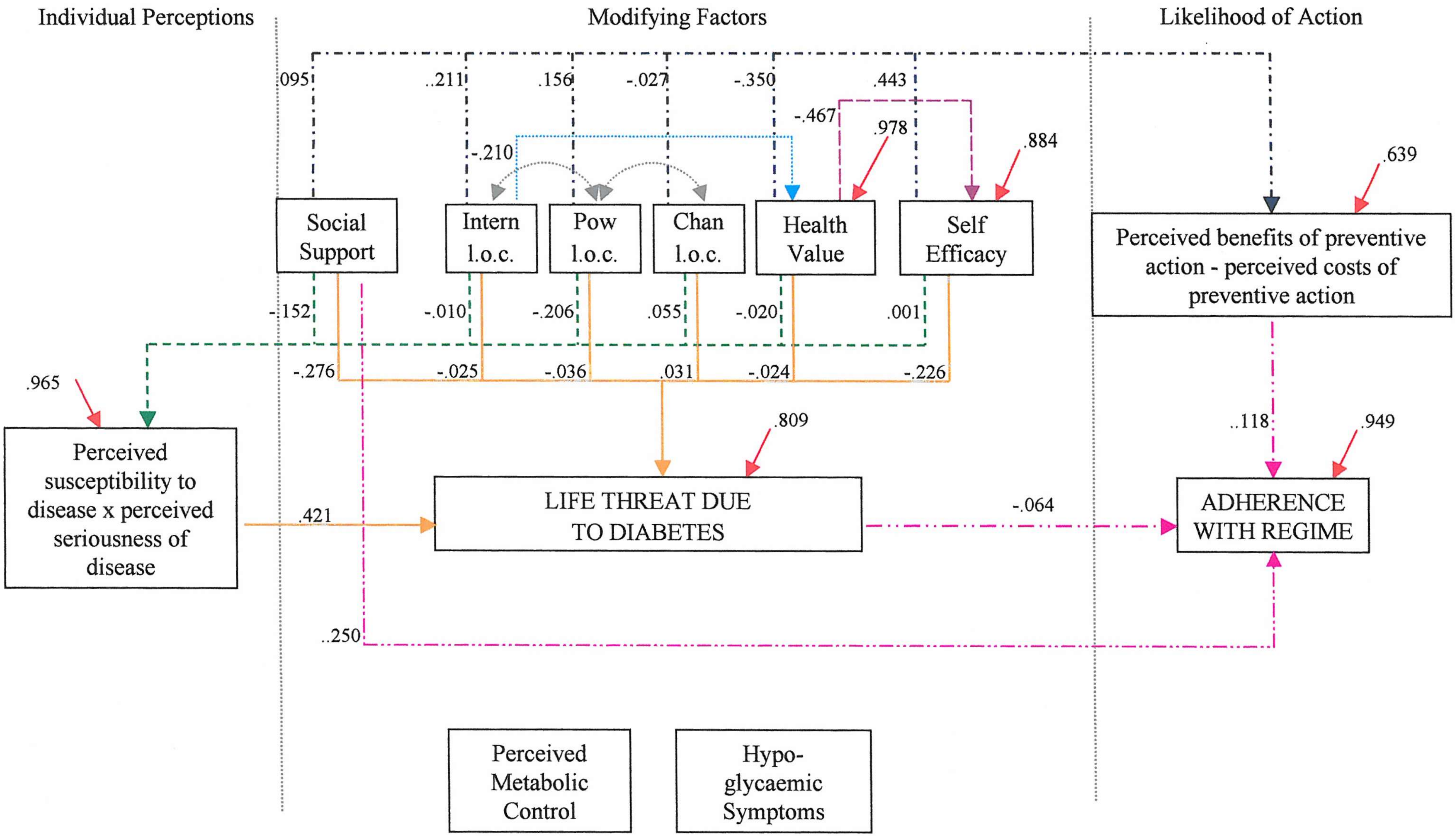


Figure 9: Final Model - adherence to blood glucose testing with path values indicated to the left

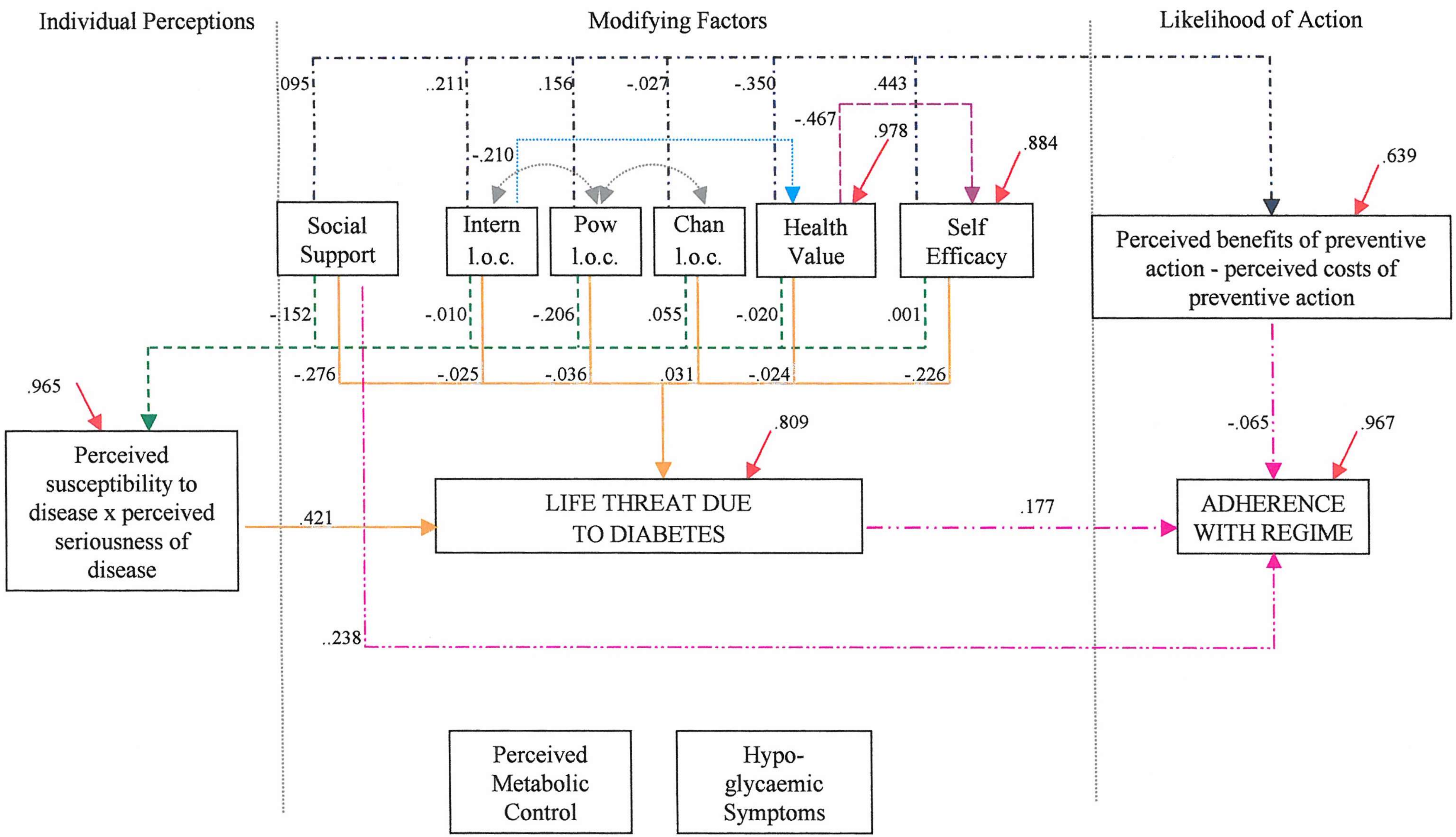
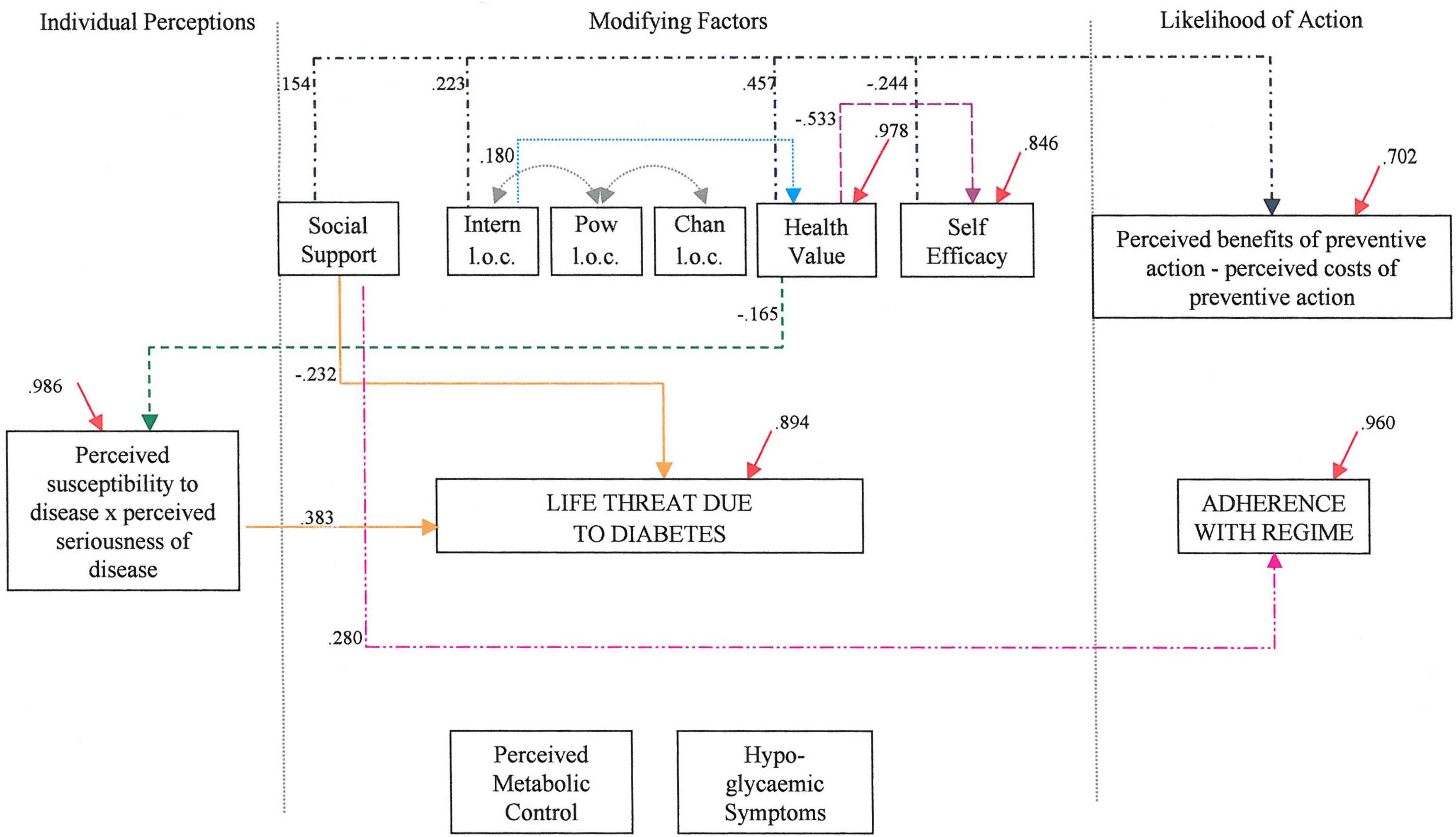


Figure 10: Final Model – total adherence to diabetes self-care activities, significant paths, with path values indicated to the left



APPENDIX B

PLEASE READ THIS CAREFULLY AND SIGN AT THE BOTTOM

Young People's Experience of Diabetes
Consent Form for Research Participants

Information Sheet

I am Rachel Gillibrand, a PhD Student at the department of psychology and I am requesting your participation in a study into your experience of having diabetes. This will involve completing a series of questionnaires designed to help us understand how you feel about your diabetes. Your opinion is extremely important and the more we can find out about your experience, the more we can do to help. Personal information will not be released to or viewed by anyone other than researchers involved in this project. Results of this study will not include your name or any other identifying characteristics.

Your participation is voluntary and you may withdraw your participation at any time.

If you have any questions please contact me on (023) 80 594 586 and/or on email at <Rachel.Gillibrand@soton.ac.uk>.

Sincerely,

Rachel Gillibrand

A

Statement of Consent

I ____________________________have read the above informed consent form.
[participant's name]

I understand that I may withdraw my consent and discontinue participation at any time without penalty or loss of benefit to myself. I understand that data collected as part of this research project will be treated confidentially, and that published results of this research project will maintain my confidentially. In signing this consent letter, I am not waiving my legal claims, rights, or remedies. A copy of this consent letter will be offered to me.

(Circle Yes or No)

I give consent to participate in the above study. Yes No

Signature .... Date.............................

Name ....

I understand that if I have questions about my rights as a participant in this research, or if I feel that I have been placed at risk, I can contact the Chair of the Ethics Committee, Department of Psychology, University of Southampton, Southampton, SO17 1BJ. Phone: (023) 8059 2612

B

Before you start, I would like to know a few details about you:

Name: ....

1. **How long have you been diagnosed with diabetes? ....**

2. **What are your living arrangements ? (please tick)**

Live with parents		Live with other members of family	
Live in shared (student / friends) house		Live with partner / spouse	
Live alone		Other (please state)	

3. **How well do you think you are managing to control your diabetes?**

1	2	3	4	5
Not very well		OK		Very well

4. **How healthy do you think you are?**

1	2	3	4	5
Not very healthy		OK		Very healthy

5. **How much shorter do you think your life expectancy is due to diabetes compared to that of a non-diabetic person?**

1	2	3
not at all	somewhat shorter	considerably shorter

Thank you for completing these questions. Now turn to the next page.

Please remember that if you feel uncomfortable answering any of the questions then you may feel free to leave the answer blank.

Please circle one of the numbers on each of the scales to indicate **how strongly you agree or disagree** with each of the following statements.

On these scales 6 would indicate that you strongly agree
5 = moderately agree
4 = mildly agree
3 = neither agree nor disagree
2 = mildly disagree
1 = moderately disagree
0 = strongly disagree

	strongly **disagree**						strongly **agree**
1. Regular, controlled exercise helps in the management of my diabetes	0	1	2	3	4	5	6
2. Controlling my diabetes well imposes restrictions on my whole lifestyle	0	1	2	3	4	5	6
3. Controlling my diabetes well interferes with my work (school, household or paid work)	0	1	2	3	4	5	6
4. The risk of insulin reactions (hypos) is reduced if I eat meals at regular intervals	0	1	2	3	4	5	6
5. It is not just possible to control my diabetes properly and live in a way that is acceptable to me	0	1	2	3	4	5	6
6. Controlling my diabetes well interferes with my leisure activities	0	1	2	3	4	5	6
7. It is important for me to visit the diabetic clinic regularly even in the absence of symptoms	0	1	2	3	4	5	6
8. High blood sugars can be prevented if I plan ahead	0	1	2	3	4	5	6
9. Sticking to my diet makes eating out difficult	0	1	2	3	4	5	6
10. Insulin reactions (hypos) can be prevented if I plan ahead	0	1	2	3	4	5	6
11. Controlling my diabetes when I am away from home often causes me embarrassment	0	1	2	3	4	5	6
12. By careful planning of diet, exercise and insulin, I can control my diabetes at least as well as most other people with diabetes	0	1	2	3	4	5	6

Please circle one of the numbers on each of the scales to indicate **how serious you think the following problems would be if you were to develop them.**

On these scales 5 would indicate that the problem is extremely serious
4 = very serious
3 = moderately serious
2 = mildly serious
1 = not serious enough to be worrying
0 = not serious at all

	not at all serious					extremely serious
1. Stomach ulcer	0	1	2	3	4	5
2. High blood pressure	0	1	2	3	4	5
3. Bronchitis	0	1	2	3	4	5
4. Problems with hearing	0	1	2	3	4	5
5. Deteriorating eyesight	0	1	2	3	4	5
6. Aching legs	0	1	2	3	4	5
7. Ingrown toenail	0	1	2	3	4	5
8. Heart trouble	0	1	2	3	4	5
9. Numbness in the feet	0	1	2	3	4	5
10. Loss of bladder control	0	1	2	3	4	5
11. Diabetic coma (high sugar coma)	0	1	2	3	4	5
12. Flu	0	1	2	3	4	5
13. Blurred vision for more than one day	0	1	2	3	4	5
14. Your diabetes now	0	1	2	3	4	5
15. Your diabetes in 20 years time	0	1	2	3	4	5
16. Hypoglycaemic coma (low sugar coma)	0	1	2	3	4	5
17. Piles (haemorrhoids)	0	1	2	3	4	5
18. Arthritis	0	1	2	3	4	5
19. Insulin reaction (hypo)	0	1	2	3	4	5
20. Very high sugar levels for more than one day (blood sugars 17mmol/L or more or urine sugars 3% or more)	0	1	2	3	4	5
21. Shortness of breath	0	1	2	3	4	5
22. Depression requiring treatment	0	1	2	3	4	5
23. Circulatory problems in the feet	0	1	2	3	4	5
24. Loss of appetite for more than one day	0	1	2	3	4	5
25. Cancer	0	1	2	3	4	5
26. Broken arm	0	1	2	3	4	5
27. Kidney problems	0	1	2	3	4	5
28. Excessive weight gain	0	1	2	3	4	5
29. Constipation	0	1	2	3	4	5
30. Gall stones	0	1	2	3	4	5
31. Complications arising from diabetes	0	1	2	3	4	5

Please circle one of the numbers on each of the scales to indicate **how <u>likely</u> you feel you are to develop the following problems.**

On these scales 5 would indicate that you are very likely to develop the problem
4 = quite likely
3 = probably
2 = probably not
1 = quite unlikely
0 = very unlikely

	very unlikely					very likely
	0	1	2	3	4	5
1. Gall stones	0	1	2	3	4	5
2. Arthritis	0	1	2	3	4	5
3. Deteriorating eyesight	0	1	2	3	4	5
4. Kidney problems	0	1	2	3	4	5
5. Diabetic coma (high sugar coma)	0	1	2	3	4	5
6. Stomach ulcer	0	1	2	3	4	5
7. Broken arm	0	1	2	3	4	5
8. Circulatory problems (of the feet)	0	1	2	3	4	5
9. High blood pressure	0	1	2	3	4	5
10. Numbness in the feet	0	1	2	3	4	5
11. Aching legs	0	1	2	3	4	5
12. Piles (haemorrhoids)	0	1	2	3	4	5
13. Blurred vision for more than one day	0	1	2	3	4	5
14. Bronchitis	0	1	2	3	4	5
15. Excessive weight gain	0	1	2	3	4	5
16. Insulin reaction (hypo)	0	1	2	3	4	5
17. Heart trouble	0	1	2	3	4	5
18. Problems with hearing	0	1	2	3	4	5
19. Complications arising from diabetes	0	1	2	3	4	5
20. Ingrown toenail	0	1	2	3	4	5
21. Hypoglycaemic coma (low sugar coma)	0	1	2	3	4	5
22. Depression requiring treatment	0	1	2	3	4	5
23. Cancer	0	1	2	3	4	5
24. Loss of bladder control	0	1	2	3	4	5
25. Flu	0	1	2	3	4	5
26. Very high sugar levels for more than one day (blood sugars 17mmol/L or more or urine sugars 3% or more)	0	1	2	3	4	5
27. Constipation	0	1	2	3	4	5
28. Shortness of breath	0	1	2	3	4	5
29. Loss of appetite for more than one day	0	1	2	3	4	5

Please circle one of the numbers on each of the scales to indicate **how strongly you agree or disagree** with each of the following statements.

On these scales 5 would indicate that you strongly disagree
4 = disagree
3 = neutral
2 = agree
1 = strongly agree

In general, I believe that I:	**strongly agree**				**strongly disagree**
1. ...know what part(s) of taking care of my diabetes that I am satisfied with	1	2	3	4	5
2. ...know what part(s) of taking care of my diabetes that I am dissatisfied with.	1	2	3	4	5
3. ...know what part(s) of taking care of my diabetes that I am ready to change	1	2	3	4	5
4. ...know what part(s) of taking care of my diabetes that I am not ready to change.	1	2	3	4	5
5. ...can choose realistic diabetes goals.	1	2	3	4	5
6. ...know which of my diabetes goals are most important to me.	1	2	3	4	5
7. ...know the things about myself that either help or prevent me from reaching my diabetes goals.	1	2	3	4	5
8. ...can come up with good ideas to help me reach my goals.	1	2	3	4	5
9. ...am able to turn my diabetes goals into a workable plan.	1	2	3	4	5
10. ...can reach my diabetes goals once I make up my mind.	1	2	3	4	5
11. ...know which barriers make reaching my diabetes goals more difficult.	1	2	3	4	5
12. ...can think of different ways to overcome barriers to my diabetes goals	1	2	3	4	5
13. ...can try out different ways of overcoming barriers to my diabetes goals.	1	2	3	4	5
14. ...am able to decide which way of overcoming barriers to my diabetes goals works best for me.	1	2	3	4	5
15. ...can tell how I'm feeling about having diabetes.	1	2	3	4	5
16. ...can tell how I'm feeling about caring for my diabetes	1	2	3	4	5
17. ...know the ways that having diabetes causes stress in my life.	1	2	3	4	5
18. ...know the positive ways I cope with diabetes-related stress.	1	2	3	4	5
19. ...know the negative ways I cope with diabetes-related stress.	1	2	3	4	5
20. ...can cope well with diabetes- related stress.	1	2	3	4	5
21. ...know where I can get support for having and caring for my diabetes.	1	2	3	4	5
22. ...can ask for support for having and caring for my diabetes when I need it.	1	2	3	4	5
23. ...can support myself in dealing with my diabetes	1	2	3	4	5

G

Continued from previous page ...

On these scales 5 would indicate that you strongly disagree
4 = disagree
3 = neutral
2 = agree
1 = strongly agree

In general, I believe that I:	**strongly agree**				**strongly disagree**
24. ...know what helps me stay motivated to care for my diabetes.	1	2	3	4	5
25. ..can motivate myself to care for my diabetes.	1	2	3	4	5
26. ...know enough about diabetes to make self-care choices that are right for me.	1	2	3	4	5
27. ...know enough about myself as a person to make diabetes care choices that are right for me.	1	2	3	4	5
28. ...am able to figure out if it is worth my while to change how I take care of my diabetes.	1	2	3	4	5

Below is a list of things people with diabetes do in order to avoid low blood sugar. Read each item carefully. Circle one of the numbers to the right that best describes what you do during your daily routine to AVOID low blood sugar.

On these scales 4 would indicate that you always do this
3 = often
2 = sometimes
1 = rarely
0 = never

	never				**always**
1. Eat large snacks at bedtime	0	1	2	3	4
2. Avoid being alone when my sugar is likely to be low	0	1	2	3	4
3. If test blood glucose, run a little high to be on the safe side	0	1	2	3	4
4. Keep my sugar high when I will be alone for a while	0	1	2	3	4
5. Eat something as soon as I feel the first sign of low blood sugar	0	1	2	3	4
6. Reduce my insulin when I think my sugar is low	0	1	2	3	4
7. Keep my sugar high when I plan to be in a long meeting or at a party	0	1	2	3	4
8. Carry fast-acting sugar with me	0	1	2	3	4
9. Avoid exercise when I think my sugar is low	0	1	2	3	4
10. Check my sugar often when I plan to be in a long meeting or out to a party	0	1	2	3	4

H

Below is a list of concerns people with diabetes sometimes have. Please read each item carefully (do not skip any). Circle one of the numbers to the right that best describes how often you WORRY about each item because of low blood sugar.

I worry about:

	never				always
11. Not recognising / realising when I have low blood sugar	0	1	2	3	4
12. Not having food, fruit or juice with me	0	1	2	3	4
13. Passing out in public	0	1	2	3	4
14. Embarrassing myself or my friends in a social situation	0	1	2	3	4
15. Having a reaction while alone	0	1	2	3	4
16. Appearing stupid or drunk	0	1	2	3	4
17. Losing control	0	1	2	3	4
18. No one being around to help me during a reaction	0	1	2	3	4
19. Having a reaction while driving	0	1	2	3	4
20. Making a mistake or having an accident	0	1	2	3	4
21. Getting a bad evaluation or being criticised	0	1	2	3	4
22. Difficulty thinking clearly when responsible for others	0	1	2	3	4
23. Feeling light-headed or dizzy	0	1	2	3	4

We want to know how often family members do each of the following things. Just put down what usually happens at home - there are no right or wrong answers. Circle one of the numbers to the right that best describes how often that person does the following things.

On these scales
5 would indicate that they do this at least once a day
4 = several times a week
3 = once a week
2 = twice a month
1 = never

	never				every day
1. Praise you for following your diet	1	2	3	4	5
2. Nag you about testing your glucose level	1	2	3	4	5
3. Suggest things that might help you take insulin on time	1	2	3	4	5
4. Criticise you for not exercising regularly	1	2	3	4	5
5. Help you decide if changes should be made based on glucose testing results	1	2	3	4	5
6. Nag you about following your diet	1	2	3	4	5
7. Argue with you about your diabetes self-care activities	1	2	3	4	5
8. Encourage you to participate in sports activities	1	2	3	4	5
9. Plan family activities so that they will fit in with your diabetes self-care schedule	1	2	3	4	5
10. Congratulate you for sticking to your diabetes self-care activities	1	2	3	4	5
11. Criticise you for not recording the results of glucose tests	1	2	3	4	5
12. Eat at the same time that you do	1	2	3	4	5
13. Exercise with you	1	2	3	4	5
14. Let you sleep late rather than getting up to take your insulin	1	2	3	4	5
15. Buy you thinks containing sugar to carry with you in case of an insulin reaction	1	2	3	4	5
16. Eat foods that are not part of your diabetic diet	1	2	3	4	5

The questions below ask you about your diabetes self-care activities during the past 7 days. If you were sick during the past 7 days, please think back to the last 7 days that you were not sick.

Circle the number that applies to the **number of days** that you carried out the activity.

1.	On how may of the last SEVEN DAYS have you followed a healthy eating plan?	0	1	2	3	4	5	6	7
2.	On average, over the past month, how many DAYS PER WEEK have you followed your eating plan?	0	1	2	3	4	5	6	7
3.	On how many of the last SEVEN DAYS did you eat five or more servings of fruit and vegetables?	0	1	2	3	4	5	6	7
4.	On how many of the last SEVEN DAYS did you eat high fat foods such as red meat or full-fat dairy products?	0	1	2	3	4	5	6	7
5.	On how may of the last SEVEN DAYS did you participate in at least 30 minutes of physical activity? (continuous activity, including walking)	0	1	2	3	4	5	6	7
6.	On how many of the last SEVEN DAYS did you participate in a specific exercise session (such as swimming, walking, biking) other than what you do around the house or as part of your work?	0	1	2	3	4	5	6	7
7.	On how many of the last SEVEN DAYS did you test your blood sugar?	0	1	2	3	4	5	6	7
8.	On how many of the last SEVEN DAYS did you test your blood sugar the number of times recommended by your health care provider?	0	1	2	3	4	5	6	7
9.	On how many of the last SEVEN DAYS did you take your recommended insulin injections?	0	1	2	3	4	5	6	7
10.	On how many of the last SEVEN DAYS did you check your feet?	0	1	2	3	4	5	6	7
11.	On how many of the last SEVEN DAYS did you inspect the inside of your shoes?	0	1	2	3	4	5	6	7
12.	Have you smoked a cigarette - even one puff - during the past SEVEN DAYS?	0 = No. 1 = Yes - please answer the next question							
	If yes, how many cigarettes did you smoke on an average day?	No. of cigarettes =							

These statements refer to how you feel about your control of diabetes. Circle a number to the right of each item to reflect how much you **agree** or **disagree** with each statement.

On these scales 6 would indicate that you strongly agree with the statement
5 = moderately agree
4 = agree slightly
3 = disagree slightly
2 = moderately disagree
1 = strongly disagree

1.	If I take the right actions, I can keep my diabetes in control	1	2	3	4	5	6
2.	If I avoid diabetic complications, it's because of my efforts.	1	2	3	4	5	6
3.	No matter what I do, my diabetes is likely to go out of control	1	2	3	4	5	6
4.	No matter what I do, I'll probably develop diabetic complications	1	2	3	4	5	6
5.	When my diabetes goes out of control, it's usually by accident	1	2	3	4	5	6
6.	The main thing which affects whether I will develop diabetic complications is what I do for myself	1	2	3	4	5	6
7.	If I take care of myself, I can minimise diabetic complications	1	2	3	4	5	6
8.	If I'm able to avoid diabetic complications, it's because other people (for example, doctors, nurses, family, friends) have been taking good care of me.	1	2	3	4	5	6
9.	My family has a lot to do with whether or not I will develop diabetic complications	1	2	3	4	5	6
10.	Having regular contact with other people who have diabetes is the best way for me to avoid developing diabetic complications	1	2	3	4	5	6
11.	Having regular contact with my doctor is the best way for me to keep my diabetes in control.	1	2	3	4	5	6
12.	The main thing which affects my diabetic control is what I do for myself	1	2	3	4	5	6
13.	If my diabetes goes out of control, it is my own behaviour which determines how soon I get back in control again.	1	2	3	4	5	6
14.	Most things that affect my diabetes happen by accident	1	2	3	4	5	6
15.	When I'm able to keep my diabetes in control, it's because other people (for example, doctors, nurses, family, friends) have been taking good care of me.	1	2	3	4	5	6
16.	My family has a lot to do with my diabetes being in control or out of control	1	2	3	4	5	6
17.	If it's meant to be, my diabetes will stay in control	1	2	3	4	5	6
18.	Avoiding diabetic complications is largely a matter of good fortune	1	2	3	4	5	6

K

ADDQoL

ıis questionnaire asks about your quality of life and the effects of your diabetes on your quality of ɘ. Your quality of life is how good or bad you feel your life to be.

ease shade the circle which best indicates your response on each scale.

ıere are no right or wrong answers; we just want to know how you feel about your life now.

In general, my present quality of life is:

O	O	O	O	O	O	O
excellent	very good	good	neither good nor bad	bad	very bad	extremely bad

ɔr the next statement please consider the effects of your diabetes, its management and any ɔmplications you may have.

I) **If I did not have diabetes, my quality of life would be:**

O	O	O	O	O	O	O
very much better	much better	a little better	the same	a little worse	much worse	very much worse

lease respond to the 18 more specific statements on the pages that follow.

or each statement, please consider the effects of your diabetes, its management and any omplications you may have on the aspect of life described by the statement.

In each of the following boxes:

a) shade a circle to show how diabetes affects this aspect of your life;

b) shade a circle to show how important this aspect of your life is to your quality of life.

Some statements have a "not applicable" option. Please shade this "not applicable" circle if that aspect of life does not apply to you.

) **If I did not have diabetes, my working life and work-related opportunities would be:**

O	O	O	O	O	O	O
very much better	much better	a little better	the same	a little worse	much worse	very much worse

) **This aspect of my life is:**

O	O	O	O
very important	important	somewhat important	not at all important

O not applicable

If I did not have diabetes, my family life would be:

O	O	O	O	O	O	O
very much better	much better	a little better	the same	a little worse	much worse	very much worse

This aspect of my life is:

O	O	O	O
very important	important	somewhat important	not at all important

O not applicable

If I did not have diabetes, my friendships and social life would be:

O	O	O	O	O	O	O
very much better	much better	a little better	the same	a little worse	much worse	very much worse

This aspect of my life is:

O	O	O	O
very important	important	somewhat important	not at all important

4a) If I did not have diabetes, my sex life would be:							
O very much better	O much better	O a little better	O the same	O a little worse	O much worse	O very much worse	O not applicable
4b) This aspect of my life is:							
	O very important	O important	O somewhat important	O not at all important			

5a) If I did not have diabetes, my physical appearance would be:						
O very much better	O much better	O a little better	O the same	O a little worse	O much worse	O very much worse
5b) This aspect of my life is:						
	O very important	O important	O somewhat important	O not at all important		

6a) If I did not have diabetes, the things I could do physically would be:						
O very much increased	O much increased	O a little increased	O the same	O a little decreased	O much decreased	O very much decreased
6b) This aspect of my life is:						
	O very important	O important	O somewhat important	O not at all important		

If I did not have diabetes, my holidays or leisure activities would be:

O	O	O	O	O	O	O
very much better	much better	a little better	the same	a little worse	much worse	very much worse

This aspect of my life is:

O	O	O	O
very important	important	somewhat important	not at all important

If I did not have diabetes, ease of travelling (local or long distance) would be:

O	O	O	O	O	O	O
very much better	much better	a little better	the same	a little worse	much worse	very much worse

This aspect of my life is:

O	O	O	O
very important	important	somewhat important	not at all important

If I did not have diabetes, my confidence in my ability to do things would be:

O	O	O	O	O	O	O
very much increased	much increased	a little increased	the same	a little decreased	much decreased	very much decreased

This aspect of my life is:

O	O	O	O
very important	important	somewhat important	not at all important

0a) If I did not have diabetes, my motivation to achieve things would be:						
O	O	O	O	O	O	O
very much increased	much increased	a little increased	the same	a little decreased	much decreased	very much decreased

10b) This aspect of my life is:

O	O	O	O
very important	important	somewhat important	not at all important

11a) If I did not have diabetes, the way society at large reacts to me would be:

O	O	O	O	O	O	O
very much better	much better	a little better	the same	a little worse	much worse	very much worse

11b) This aspect of my life is:

O	O	O	O
very important	important	somewhat important	not at all important

12a) If I did not have diabetes, my worries about the future would be:

O	O	O	O	O	O	O
very much decreased	much decreased	a little decreased	the same	a little increased	much increased	very much increased

12b) This aspect of my life is:

O	O	O	O
very important	important	somewhat important	not at all important

) **If I did not have diabetes, my finances would be:**

O	O	O	O	O	O	O
very much better	much better	a little better	the same	a little worse	much worse	very much worse

ı) **This aspect of my life is:**

O	O	O	O
very important	important	somewhat important	not at all important

ı) **If I did not have diabetes, my need to depend on others for things I would like to do for myself would be:**

O	O	O	O	O	O	O
very much decreased	much decreased	a little decreased	the same	a little increased	much increased	very much increased

ɔ) **This aspect of my life is:**

O	O	O	O
very important	important	somewhat important	not at all important

a) **If I did not have diabetes, my living conditions would be:**

O	O	O	O	O	O	O
very much better	much better	a little better	the same	a little worse	much worse	very much worse

b) **This aspect of my life is:**

O	O	O	O
very important	important	somewhat important	not at all important

16a) If I did not have diabetes, my freedom to eat as I wish would be:

O	O	O	O	O	O	O
very much increased	much increased	a little increased	the same	a little decreased	much decreased	very much decreased

16b) This aspect of my life is:

O	O	O	O
very important	important	somewhat important	not at all important

17a) If I did not have diabetes, my enjoyment of food would be:

O	O	O	O	O	O	O
very much increased	much increased	a little increased	the same	a little decreased	much decreased	very much decreased

17b) This aspect of my life is:

O	O	O	O
very important	important	somewhat important	not at all important

18a) If I did not have diabetes, my freedom to drink as I wish (e.g. sweetened hot and cold drinks, fruit juice, alcohol) would be:

O	O	O	O	O	O	O
very much increased	much increased	a little increased	the same	a little decreased	much decreased	very much decreased

18b) This aspect of my life is:

O	O	O	O
very important	important	somewhat important	not at all important

If there are any other ways in which diabetes, its management and any complications affect your quality of life, please say what they are overleaf.

Thank you for taking the time to complete the questionnaires, your opinion is really important to us.

Don't forget to return your completed questionnaire by the 2nd November!

APPENDIX C

(Person with diabetes)

Please fill in the following questions. These will not be used to identify you. This information will be used to work out the characteristics of the people filling in our questionnaire

Gender: male female

How long have you known your current partner/spouse?

What are your living arrangements?

Living with parents
Living with other members of family
Live in shared (student/friends) house
Live with partner / spouse
Live alone
Other

Marital Status:

Single Married Co-habiting Widowed Separated Divorced Engaged

Age:

Ethnicity:

White/Caucasian Black Asian Far East Asian South Mixed Other

Employment:

Unemployed Employed full time Employed part time Full time student

Latest HbA_{1C} result: (approximate if you do not remember the exact figure)
This information is not compulsory but would be beneficial to the study. All information is treated with confidence and all data collected is anonymous.

1. **How long have you been diagnosed with diabetes? ....**

3. **How well do you think you are managing to control your diabetes?**

1	2	3	4	5
Not very well		OK		Very well

4. **How healthy do you think you are?**

1	2	3	4	5
Not very healthy		OK		Very healthy

5. **How much shorter do you think your life expectancy is due to diabetes compared to that of a non-diabetic person?**

1	2	3
not at all	somewhat shorter	considerably shorter

A

Please circle one of the numbers on each of the scales to indicate your relationship with your partner / spouse.

How well does your partner meet your needs?

1 not at all well	2	3 OK	4	5 very well

In general, how satisfied are you with your relationship?

1 not at all satisfied	2	3 OK	4	5 very satisfied

How good is your relationship compared to most?

1 not very good	2	3 OK	4	5 very good

How often do you wish you hadn't got into this relationship?

1 never	2	3 sometimes	4	5 always

To what extent has your relationship met your original expectations?

1 not at all	2	3 some	4	5 totally

How much do you love your partner?

1 not at all	2	3 some	4	5 totally

How many problems are there in your relationship?

1 many	2	3 some	4	5 none

B

We want to know how often family members do each of the following things. Just put down what usually happens at home - there are no right or wrong answers. Circle one of the numbers to the right that best describes how often that person does the following things.

On these scales 5 would indicate that they do this at least once a day
4 = several times a week
3 = once a week
2 = twice a month
1 = never

	never				every day
1. Praise you for following your diet	1	2	3	4	5
2. Nag you about testing your glucose level	1	2	3	4	5
3. Suggest things that might help you take insulin on time	1	2	3	4	5
4. Criticise you for not exercising regularly	1	2	3	4	5
5. Help you decide if changes should be made based on glucose testing results	1	2	3	4	5
6. Nag you about following your diet	1	2	3	4	5
7. Argue with you about your diabetes self-care activities	1	2	3	4	5
8. Encourage you to participate in sports activities	1	2	3	4	5
9. Plan family activities so that they will fit in with your diabetes self-care schedule	1	2	3	4	5
10. Congratulate you for sticking to your diabetes self-care activities	1	2	3	4	5
11. Criticise you for not recording the results of glucose tests	1	2	3	4	5
12. Eat at the same time that you do	1	2	3	4	5
13. Exercise with you	1	2	3	4	5
14. Let you sleep late rather than getting up to take your insulin	1	2	3	4	5
15. Buy you thinks containing sugar to carry with you in case of an insulin reaction	1	2	3	4	5
16. Eat foods that are not part of your diabetic diet	1	2	3	4	5

c

Summary of Diabetes Self-Care Activities Scale

The questions below ask you about your diabetes self-care activities during the past 7 days. If you were sick during the past 7 days, please think back to the last 7 days that you were not sick.

Circle the number that applies to the number of days that you carried out the activity.

1. On how may of the last SEVEN DAYS have you followed a healthy eating plan?	0	1	2	3	4	5	6	7
2. On average, over the past month, how many DAYS PER WEEK have you followed your eating plan?	0	1	2	3	4	5	6	7
3. On how many of the last SEVEN DAYS did you eat five or more servings of fruit and vegetables?	0	1	2	3	4	5	6	7
4. On how many of the last SEVEN DAYS did you eat high fat foods such as red meat or full-fat dairy products?	0	1	2	3	4	5	6	7
5. On how may of the last SEVEN DAYS did you participate in at least 30 minutes of physical activity? (continuous activity, including walking)	0	1	2	3	4	5	6	7
6. On how many of the last SEVEN DAYS did you participate in a specific exercise session (such as swimming, walking, biking) other than what you do around the house or as part of your work?	0	1	2	3	4	5	6	7
7. On how many of the last SEVEN DAYS did you test your blood sugar?	0	1	2	3	4	5	6	7
8. On how many of the last SEVEN DAYS did you test your blood sugar the number of times recommended by your health care provider?	0	1	2	3	4	5	6	7
9. On how many of the last SEVEN DAYS did you take your recommended insulin injections?	0	1	2	3	4	5	6	7
10. On how many of the last SEVEN DAYS did you check your feet?	0	1	2	3	4	5	6	7
11. On how many of the last SEVEN DAYS did you inspect the inside of your shoes?	0	1	2	3	4	5	6	7
12. Have you smoked a cigarette - even one puff - during the past SEVEN DAYS?	0 = No. 1 = Yes - please answer the next question							
If yes, how many cigarettes did you smoke on an average day?	No. of cigarettes =							

Person without diabetes

Please fill in the following questions. These will not be used to identify you. This information will be used to work out the characteristics of the people filling in our questionnaire

Gender: **male** **female**

How long have you known your current partner/spouse?

What are your living arrangements?

Living with parents	Living with other members of family	Live in shared (student/friends) house
Live with partner / spouse	Live alone	Other

Marital Status:

Single Married Co-habiting Widowed Separated Divorced Engaged

Age:

Ethnicity:

White/Caucasian Black Asian Far East Asian South Mixed Other

How much shorter do you think your spouse/partner's life expectancy is due to diabetes compared to that of a non-diabetic person?

1	**2**	**3**
not at all	somewhat shorter	considerably shorter

Please circle one of the numbers on each of the scales to indicate your relationship with your partner / spouse.

How well does your partner meet your needs?

1	2	3	4	5
not at all well		OK		very well

In general, how satisfied are you with your relationship?

1	2	3	4	5
not at all satisfied		OK		very satisfied

How good is your relationship compared to most?

1	2	3	4	5
not very good		OK		very good

How often do you wish you hadn't got into this relationship?

1	2	3	4	5
never		sometimes		always

To what extent has your relationship met your original expectations?

1	2	3	4	5
not at all		some		totally

How much do you love your partner?

1	2	3	4	5
not at all		some		totally

How many problems are there in your relationship?

1	2	3	4	5
many		some		none

F

We want to know how often family members do each of the following things. Just put down what usually happens at home - there are no right or wrong answers. Circle one of the numbers to the right that best describes how often you do the following things for your spouse/partner with diabetes.

On these scales 5 would indicate that you do this at least once a day
4 = several times a week
3 = once a week
2 = twice a month
1 = never

	never				every day
1. Praise them for following their diet	1	2	3	4	5
2. Nag them about testing their glucose level	1	2	3	4	5
3. Suggest things that might help them take insulin on time	1	2	3	4	5
4. Criticise them for not exercising regularly	1	2	3	4	5
5. Help them decide if changes should be made based on glucose testing results	1	2	3	4	5
6. Nag them about following their diet	1	2	3	4	5
7. Argue with them about their diabetes self-care activities	1	2	3	4	5
8. Encourage them to participate in sports activities	1	2	3	4	5
9. Plan family activities so that they will fit in with their diabetes self-care schedule	1	2	3	4	5
10. Congratulate them for sticking to their diabetes self-care activities	1	2	3	4	5
11. Criticise them for not recording the results of glucose tests	1	2	3	4	5
12. Eat at the same time that they do	1	2	3	4	5
13. Exercise with them	1	2	3	4	5
14. Let them sleep late rather than getting up to take their insulin	1	2	3	4	5
15. Buy them things containing sugar to carry with them in case of an insulin reaction	1	2	3	4	5
16. Eat foods that are not part of their diabetic diet	1	2	3	4	5

Summary of Diabetes Self-Care Activities Scale

The questions below ask you about your spouse/partner's diabetes self-care activities during the past 7 days. If your spouse/partner was sick during the past 7 days, please think back to the last 7 days that they were not sick.

Circle the number that applies to the number of days that your partner carried out the activity. If you do not know, tick the 'don't know' box.

1.	On how may of the last SEVEN DAYS did your spouse/partner follow a healthy eating plan?	0	1	2	3	4	5	6	7
2.	On average, over the past month, how many DAYS PER WEEK did your spouse/partner follow their eating plan?	0	1	2	3	4	5	6	7
3.	On how many of the last SEVEN DAYS did your spouse/partner eat five or more servings of fruit and vegetables?	0	1	2	3	4	5	6	7
4.	On how many of the last SEVEN DAYS did your spouse/partner eat high fat foods such as red meat or full-fat dairy products?	0	1	2	3	4	5	6	7
5.	On how may of the last SEVEN DAYS did your spouse/partner participate in at least 30 minutes of physical activity? (continuous activity, including walking)	0	1	2	3	4	5	6	7
6.	On how many of the last SEVEN DAYS did your spouse/partner participate in a specific exercise session (such as swimming, walking, biking) other than what they do around the house or as part of their work?	0	1	2	3	4	5	6	7
7.	On how many of the last SEVEN DAYS did your spouse/partner test their blood sugar?	0	1	2	3	4	5	6	7
8.	On how many of the last SEVEN DAYS did your spouse/partner test their blood sugar the number of times recommended by their health care provider?	0	1	2	3	4	5	6	7
9.	On how many of the last SEVEN DAYS did your spouse/partner take their recommended insulin injections?	0	1	2	3	4	5	6	7
10.	On how many of the last SEVEN DAYS did your spouse/partner check their feet?	0	1	2	3	4	5	6	7
11.	On how many of the last SEVEN DAYS did your spouse/partner inspect the inside of their shoes?	0	1	2	3	4	5	6	7
12.	Has your spouse/partner smoked a cigarette - even one puff - during the past SEVEN DAYS?	0 = No. 1 = Yes - please answer the next question							
13.	If yes, how many cigarettes did your spouse/partner smoke on an average day?	No. of cigarettes =							

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