

PSYCHOSOCIAL FACTORS AND DIABETES.

Thesis submitted for PhD

Catherine Elizabeth Lloyd

University College, London

1991.

ProQuest Number: 10797657

All rights reserved

INFORMATION TO ALL USERS

The quality of this reproduction is dependent upon the quality of the copy submitted.

In the unlikely event that the author did not send a complete manuscript and there are missing pages, these will be noted. Also, if material had to be removed, a note will indicate the deletion.



ProQuest 10797657

Published by ProQuest LLC (2018). Copyright of the Dissertation is held by the Author.

All rights reserved.

This work is protected against unauthorized copying under Title 17, United States Code
Microform Edition © ProQuest LLC.

ProQuest LLC.
789 East Eisenhower Parkway
P.O. Box 1346
Ann Arbor, MI 48106 – 1346

ABSTRACT OF THE THESIS.

Chronic illnesses have a significant impact on psychosocial status and on quality of life, and may have important consequences on the life-chances of young adults. In order to evaluate these effects, two groups of young people, aged 16 - 25 years, were interviewed by the author in-depth, using semi-structured psychosocial questionnaires, including the Self Evaluation and Social Support Questionnaire (SESS). A group of 40 young adults with insulin-dependent diabetes mellitus, registered with two North London hospital diabetic clinics, were matched with 40 randomly recruited healthy controls from a local general practice. State of health during the previous year was assessed for both groups by analysing their hospital out-patient and general practice case-notes respectively.

Results showed that young adults with diabetes were significantly more likely to have low self-esteem, compared with their matched controls. In a matched pairs analysis, 12 subjects with diabetes had low self-esteem when their matched controls did not, compared with 3 healthy controls who had low self-esteem when their matched diabetic subjects did not ($p < 0.05$). Those with low self-esteem were somewhat less likely to have obtained higher educational qualifications (1 vs 9; $p = 0.08$). More than half (61%) of the subjects with diabetes reported experiencing difficulties at school, and this was also related to self-esteem. Although there was no difference in the unemployment rate between the two groups, one-third of those with diabetes did report problems in their search for employment.

Chronic illnesses have a significant impact on psychosocial status and on quality of life, and may have important consequences on the life-chances of young adults. In order to evaluate these effects, two groups of young people, aged 16 - 25 years, were interviewed in-depth, using semi-structured psychosocial questionnaires, including the Self Evaluation and Social Support Questionnaire (SESS). Young adults with insulin-dependent diabetes mellitus, registered with two North London hospital diabetic clinics, were matched with randomly recruited healthy controls from a local general practice. State of health during the previous year was assessed for both groups by analysing their hospital out-patient and general practice case-notes respectively.

Results showed that young adults with diabetes were significantly more likely to have low self-esteem, compared with their matched controls. Those with low self-esteem were less likely to have obtained higher educational qualifications. Many of the subjects with diabetes reported experiencing difficulties at school, and this was also related to self-esteem. Although there was no difference in the unemployment rate between the two groups, some of those with diabetes did report problems in their search for employment.

Information on family and social relationships was collected, which demonstrated that subjects with diabetes were more likely to feel socially isolated compared with their matched controls (48% vs 25%; $p<0.05$). At the same time, a matched pairs analysis demonstrated that 14 diabetic subjects exhibited strong feelings against having close relationships when their matched controls did not, compared with 3 controls who reported these feelings when their matched diabetic subjects did not ($p<0.01$). Although both subjects with diabetes and healthy controls were equally committed to marriage and parenthood, subjects with diabetes were somewhat less likely to be married (2% vs 10%; $p=0.06$), and were significantly less likely to have children (2% vs 27%; $p<0.01$) compared with their matched controls. The methods used in this study did not permit the direct observation of the nature of family and peer interactions.

Differences in state of health, both in terms of metabolic control and the presence of diabetic complications, were investigated within the diabetic group, and showed some trends in relation to these psychosocial variables.

There are limitations with regard to the interpretation of these findings due to the small sample size, which had not been estimated prior to the commencement of the study. In particular, the diabetic subjects were a clinic-based sample so it is not possible to generalise these findings to the wider population. Having taken this into account, this study suggests that there may be important effects of chronic disease in many areas of the lives of young adults. Confirmation of these findings should be carried out in a larger, more representative sample, using a prospective design.

Table of Contents.

	<u>Page Numbers</u>
- Abstract of the thesis	2 - 3
- Table of contents	4 - 6
- List of tables and figures	7 - 8
- List of abbreviations used in the text	9
- Acknowledgements	10
- Chapter One: Background and aims of the study	
1.1 - Introduction	11 - 16
1.2 - Aims of the study	17 - 19
- Chapter Two: A review of the literature	
2.1 - The impact of insulin-dependent diabetes mellitus	20 - 29
2.2 - Psychosocial factors and metabolic control	30 - 35
2.3 - The measurement of self-esteem	36 - 45
2.4 - The relationship between self-esteem and diabetes	46 - 53
2.5 - Education and diabetes	54 - 59
2.6 - Diabetes and employment	60 - 70
2.7 - The family	71 - 77
2.8 - Supports outside the family	78 - 83
2.9 - Conclusions from the review of the literature	84 - 85

- Chapter Three: Methods of investigation	
3.1 - Research design	86 - 90
3.2 - Selection of subjects	90 - 93
3.3 - The interview	93 - 97
3.4 - Qualitative and quantitative analysis	98
3.5 - Validation of the SESS	99
3.6 - Case-notes analysis	100 - 101
3.7 - Quantitative data analysis	101 - 102
 - Chapter Four: Results of the study	
4.1 - Response rate	103 - 107
4.2 - Demographic information	107 - 115
4.3 - Negative evaluation of self (NES)	116 - 133
4.4 - Educational achievement	134 - 152
4.5 - Employment experiences	153 - 167
4.6 - Social and family relationships	168 - 193
4.7 - Marriage and parenthood	194 - 200
 - Chapter Five: Discussion	201 - 241
 - Chapter Six: Conclusions and implications	242 - 247
 - References	248 - 278

- Appendices:

I - Letter to diabetic subjects, explaining the study	279
II - Second letter to diabetic subjects asking if they would like to participate	280
III - Letter to the healthy controls, explaining the study	281
IV - Second letter to healthy controls asking if they would like to participate	282
V - Consent form for all subjects	283
VI - The Self Evaluation and Social Support (SESS) Questionnaire	284 - 323
VII - Further questions for subjects with diabetes	324
VIII - The SESS rating sheets	325 - 349
IX - Case-note analysis form - diabetic subjects	350 - 352
X - Case-note analysis form - healthy controls	353 - 355

Table 1: Response rate of subjects with diabetes compared with matched healthy controls	104
Table 2: Sample characteristics	109
Figure 1: Current educational and employment status	111
Table 4: Frequency of diabetic complications	114
Table 5: McNemar's test to evaluate the level of agreement between each pair of subjects for the presence of NES	116
Table 6: McNemar's test to evaluate the level of agreement between diabetic subjects and controls for the presence of high vs low self-acceptance	119
Table 7: McNemar's test comparing matched pairs in terms of the presence of high vs low negative self-definition - attributes	123
Table 8: McNemar's test to evaluate the level of agreement between pairs for the presence of high vs low self-definition - general self-definition	125
Table 9: Health status of subjects with diabetes and Negative Evaluation of Self (NES)	132

Table 10: McNemar's test comparing those with (YES) and those without (NO) one or more GCE O'levels	137
Table 11: McNemar's test comparing those with (YES) and those without (NO) one or more A'levels	137
Table 12: McNemar's test comparing those with (YES) and those without (NO) ONC/equivalent qualifications	137
Table 13: McNemar's test comparing those with (YES) and those without (NO) HND/equivalent qualifications	138
Table 14: Qualifications and self-esteem (NES) in subjects with diabetes	140
Table 15: Glycaemic control and qualifications	150
Figure 2: Occupational status of the sample	154
Table 17: Unemployment and health status of diabetic subjects who have left school	162
Table 18: Social factors and health	169
Table 19: Young adults' relationships with their parents	185
Table 20: State of health and relations with parents	192

List of abbreviations used in the text.

BDA	-	British Diabetic Association
CL	-	Catherine Lloyd
Ghb	-	Glycated Haemoglobin
G.P.	-	General Practitioner
IDDM	-	Insulin-dependent-diabetes mellitus
NES	-	Negative Evaluation of Self
RHBNC	-	Royal Holloway and Bedford New College
SESS	-	The Self Evaluation and Social Support Questionnaire
U.K.	-	United Kingdom
U.S.	-	United States
VCO	-	Very Close Other
WHO	-	World Health Organisation

Acknowledgements.

I owe a great deal to my two supervisors - this is one part they don't have to read! Both Nicola Robinson and Mary Ann Elston have given their unending support and advice, and my warmest thanks go to them. Secondly, I would like to thank John Fuller, who suggested that I do my PhD in the first place - thanks a lot John!! The help and advice of Marion Forkin, Richard Lloyd, Lynda Stevens, Karen Dickinson, Jeanne Blackmore and Sue Collins are gratefully acknowledged. My thanks also go to Dr McHardy Young, Dr Jepson, Dr Sellina Gellert, and Sister Jenny Wootten for access to their patients. I also owe a great deal to the young people who took part in this study, who gave up their time, and allowed me into their personal lives.

Lastly, special thanks go to Andy Simmons; without his unfailing support and culinary skills, this would most definitely have not been written.

1.1 Introduction

Insulin-dependent diabetes mellitus (IDDM) is a chronic and irreversible disease affecting more than one in every thousand children in the U.K. (Stewart-Brown 1983). The estimated incidence of the disease in different parts of this country, has varied from between 6.8 and 18.7 children in every 100,000 (Metcalfe and Baum 1990), and evidence suggests that this may be steadily increasing (Stewart-Brown 1983, Bingley and Gale 1990). There may also be seasonal variation in its onset, with peaks in the autumn and winter months (Gray et al 1979). There is also wide variation in the incidence of diabetes between countries, which suggests that there may be both environmental and genetic factors involved in the aetiology of IDDM (Rewers et al 1988).

IDDM is characterised by the failure of the pancreas to produce the hormone insulin, which plays a crucial part in the metabolic process through which glucose is converted into energy. The presenting symptoms of IDDM include extreme thirst and the frequent passing of urine, often accompanied by a loss of weight and tiredness. In order to stabilise the body's supply of energy, injections of insulin are required for the rest of the patient's life. A daily routine of blood or urine testing to measure glucose level, in addition to a balanced diet and regular exercise are all recommended for the optimal 'control' of diabetes.

IDDM is usually diagnosed in childhood or adolescence, although there are two peak ages of onset at 5 and 12 years (Patterson et al 1983), and so this type of diabetes has previously been called 'juvenile onset diabetes'. A non-significant male excess in the incidence of IDDM has been noted (Bingley and Gale 1990), but this has been shown to be the case only in high incidence populations (Laing and Williams 1989). It is more common for the females to have a higher incidence rate in populations with a low overall incidence, although the reason for this is unknown (Laing and Williams 1989).

The prevalence of IDDM in different ethnic groups is uncertain, although it has been suggested that this type of diabetes affects mainly Caucasians (Cruickshank 1990). Recent evidence has shown however, that Asian children are also affected, although they may be diagnosed at an older age (Samanta 1986, Simmons 1990). Little information is available on the prevalence of IDDM in Afro-Caribbean children in the U.K. However it has been suggested that a certain proportion of this group may in fact have a different form of diabetes altogether (Winter 1987). The limited available data does suggest that IDDM in children of Afro-Caribbean descent is less frequent compared to Caucasians (Cruickshank 1990).

The traditional method of treatment for the patient with IDDM recommends that food intake is divided into regular meals of known carbohydrate content, in addition to the self-administering of two insulin injections each day. (Shillitoe 1988). However, during the 1980's, alternative regimens have been devised.

It is now more common for the number of daily injections to be increased, in order to more closely approximate the body's normal pattern of insulin release. These multiple injections are administered via a less obtrusive and more portable device, which is similar in appearance to a fountain pen. A further advance in technology has been the development of the insulin infusion pump, which follows the body's own delivery of insulin even more closely. The pump is worn constantly, with a needle delivering a continuous supply of insulin permanently inserted into the skin. This therapy is referred to as 'continuous subcutaneous insulin infusion'. Infusion pumps may not be acceptable in the long-term, due to their somewhat restricting nature, but they have been found to be extremely useful in the short-term for stabilising diabetes in patients whose control has proved difficult, and in groups such as pregnant women (Shillitoe 1988).

The complications of diabetes, although usually occurring later on in life, are wide-ranging, often severely debilitating, and may be related to the degree of metabolic control achieved by the patient (Leslie and Sperling 1986, Tchobroutsky 1978). The costs of renal, cardiovascular and other chronic complications of diabetes to both the individual and society are extremely high. More than one in four people with diabetes diagnosed in youth will enter end-stage renal failure or die from vascular disease before they reach the age of 40 (Ireland et al 1982). Approximately half of all those with IDDM will be seriously affected by either one or both of these complications during their life-time (Viberti 1982).

Damage to the retina of the eye (retinopathy) is an important and common complication, and in some study populations it has been found to affect almost all those who have had IDDM for more than twenty years (Orchard et al 1990). Damage to the nerves (neuropathy) is a further debilitating complication.

Although people with diabetes (both insulin-dependent and non-insulin dependent) make up approximately one percent of the population in Britain, they consume between four and five percent of the available health-care resources (Laing and Williams 1989). The highest proportion of these costs come from hospital admissions, although this is not only a direct consequence of diabetes and its complications. Often the diabetic patient will stay in hospital longer than a non-diabetic patient for treatment which is unrelated to their diabetes (Laing and Williams 1989). There is some evidence to suggest a decline in admissions for diabetes itself, although it is unclear whether this is related to improved metabolic control or a move away from in-patient care towards out-patient treatment. Hospital admissions for the complications of diabetes however, may be increasing, especially with the improvements in access to renal replacement therapy (Laing and Williams 1989).

The clinical course of IDDM, in terms of both the degree of metabolic stability, and the development of complications, may be influenced by both physiological and psychosocial factors (Viberti 1982, Johnson 1988). For example, one cause of brittle (extremely unstable) diabetes is thought to be emotional disturbance or reactions to a disturbed environment (Gale and Tattersall 1979).

Young adulthood is the time-period during which many major changes occur and important decisions concerning career, further education and social relationships have to be made. Young adults are faced with difficult choices in a constantly changing environment, when peer pressures are often at their greatest. A chronic disease such as IDDM may exacerbate any difficulties encountered, as it is the patient who is expected to take responsibility for both the treatment and monitoring of their disease, making decisions that affect health in both the short and the long-term.

Studies in older, more heterogeneous groups of patients have indicated that certain sections of the diabetic population encounter psychological problems such as depression and anxiety, and also have a poorer quality of life (Robinson et al 1988, Lloyd et al 1991). The relationship between diabetes and educational achievement is controversial and still needs to be clarified (Ardron et al 1987). With rising unemployment, the attainment of qualifications has become more important. Studies of the employment experiences of insulin-dependent diabetic patients have also been inconclusive, although there is some evidence of difficulties encountered in obtaining employment (Songer et al 1989, Robinson et al 1990). If problems do exist in any of these fields, this could lead to, or reinforce patients' negative perceptions of themselves, which may act as a further barrier to improving health status.

The impact of diabetes has been investigated in more detail for children and adolescents, and the specific experiences of young adults with this disease have not been adequately assessed, either in terms of psychosocial functioning, or in terms of educational and employment opportunities. Moreover, most research that has been carried out takes the perspective of the health professionals rather than that of the patient (Meldman 1987). It is the aim of this research to attempt to redress the balance, by focussing on the experiences of young adults with diabetes.

1.2 AIMS OF THE STUDY.

The main aim of this study was to explore the relationship between state of health and various psychosocial factors in a group of young adults with insulin-dependent diabetes mellitus, in comparison with a matched sample of healthy controls.

More specifically, this investigation has explored the impact of diabetes on self-esteem, social support and family relations, and has investigated the possible differences in educational achievement and employment experiences in young adults with and without chronic disease.

The main hypotheses of this study were firstly, that IDDM may influence the life-chances of young adults, particularly their academic achievement and employment experiences; and secondly, that the relationship between IDDM and various aspects of life may be mediated by level of self-esteem. A third hypothesis was that there may be differences within the diabetic population, in terms of glycaemic control, or the presence of diabetic complications, that might be explained by these various psychosocial factors.

The available evidence with regard to the impact of IDDM on academic achievement has been inconclusive and focuses almost entirely on young children. The employment experiences of young adults have rarely been investigated and most evidence is based on samples in the U.S. or in older people.

Self-esteem has been measured in many different ways, however few studies have assessed the impact of chronic illness on the self-esteem of young adults. Furthermore, there is little in-depth information with regard to whether the experience of problems within the education system, or in obtaining employment, may lead to a reduced level of self-esteem. The relationship between diabetes, education and employment may be influenced by other important factors such as social class, sex and ethnic origin, and these must all be considered in any explanation of the experiences of young adults.

Success in educational terms could also reflect success in achieving good metabolic control, which may in turn prevent or delay the development of diabetic complications. Those who experience unemployment, or difficulties in obtaining work may be more likely to have poor metabolic control or may have already developed these complications. An important aim of this study was to establish whether degree of glycaemic control or the presence of complications was associated with the experiences of young adults in these areas.

The biography of young adults with diabetes has been neglected, and the aim of this study was to identify particular difficulties of young adults in the age group 16-25 years. The social relationships of young people may be different to those of both younger and older age groups, as the transition from the school environment to employment takes place.

The relative importance of, and the quality of interaction with family and peer supports may be affected by the presence of IDDM. Chronic disease may impact on self-esteem, and this in turn may have an important role to play in the development of close relationships. This study aimed to investigate the impact of diabetes on the family with particular reference to the needs of young adults, and to assess the importance of these relationships in influencing metabolic control. By using an in-depth method of inquiry, all these important factors may be investigated in order to document the experiences of young adults with IDDM.

Having outlined the importance of IDDM as a chronic disease in young people, both in terms of its demanding regimen, and in terms of the potentially serious complications that may develop as a result of diabetes, this second chapter will explore the literature which has described the impact of IDDM on the lives of particular groups of patients. Further sections of this chapter will outline previous work in the fields of self-esteem, education and employment, and social and family relationships, with special reference to IDDM.

2.1 The impact of insulin-dependent diabetes mellitus.

It has been recognised in recent years that there are important effects of chronic disease which will influence the individual's quality of life (Strauss 1975, Kelleher 1988, Davis et al 1987, Capelli 1989, Anderson and Bury 1988). Chronic illness is the kind of experience that may disrupt the structure of everyday life (Bury 1982). Not only are taken-for-granted assumptions and behaviours disrupted, but there may be more profound disruptions involving the re-thinking of the individual's biography and self-concept. The response to this disruption, when facing the altered situation, involves the mobilisation of resources. The availability of social supports may be central, although the maintenance of normal relationships may be difficult (Bury 1982).

Different diseases may have different implications for both the present and the long-term outlook for the individual in physical and social terms. A useful classification of disease and impairment is that adopted by the World Health Organisation (WHO) in 1980. The International Classification of Impairments, Disabilities and Handicaps is based on the consequences of disease, disorder or injury, and is important because it allows the consideration of both physical or medical outcomes, and the social outcome of disease.

This classification can be illustrated by describing how, due to illness or injury, an individual may develop a skeletal or aural impairment, which may lead to a disability in locomotion or communication (Lonsdale 1990). The person may then be handicapped on a number of dimensions such as physical independence, social integration or economic self-sufficiency. According to the WHO (1980) definition, people with IDDM have an impairment which may or may not lead to a disability, depending on the development of complications such as blindness, or the level of metabolic stability (although this may only be a temporary disability). They may suffer from handicaps such as employment discrimination, or they may experience difficulties in education or in social relationships which are a direct result of their diabetes.

Diabetes does not just affect the physical aspects of life, but it may disrupt day-to-day living and future plans (Shillitoe 1988). There may be conflict between various aspects of life, such as social relationships and the constant demands of the treatment for diabetes.

This treatment regimen may impinge on important everyday activities, a constant reminder to the individual of their condition and of being different from other people (Kelleher 1988).

Studies investigating the impact of diabetes have focussed on young children or adolescents, and few have differentiated between age groups. The impact of diabetes on the school and work experiences of young adults has been neglected; little research has reported the effects of chronic disease on the choices and decisions that have to be made at this life-stage.

At the onset of diabetes, there may be varied reactions to diagnosis, although Kovacs and colleagues (1986) have suggested that this is minimal for children and any emotional upheaval may be resolved in a short time-period. In this American study of school-aged children and their families, Kovacs found that her subjects viewed themselves as self-confident and emotionally comfortable in spite of their recent diagnosis, and after the first 6 months, both the children with diabetes and their families came to terms quite readily with the disease, even though they mentioned some difficulties with diet, injections and urine tests. No comparison group was used in this study however, and although two different methods of data collection were used (ie. psychiatric interviews and self-report questionnaires) these did not correlate with each other, throwing some doubt on these findings.

In contrast to the above study, Mason (1985) has demonstrated in the U.K., that even 12 months after diagnosis, adult patients had worries and uncertainties about their disease and their adjustment to it. In this study, the subjects were adults aged over twenty years, and included both non-insulin-dependent or insulin-dependent diabetic patients. Tape-recordings were made of the consultations between the doctor and the dietician and the patient, and home interviews, knowledge and anxiety tests were also performed. At the initial consultation, when confirmation of their diagnosis was given, nearly half of the patients did not understand the information given to them. This uncertainty was mirrored in the results of the diabetes knowledge tests. At the first interview, half of the subjects described themselves as very worried, and one year later this proportion had increased to 75%. Worries were related to the fear of complications, disability, financial difficulties and death.

Whether or not psychological or emotional difficulties occur more frequently in young people with diabetes compared to those who do not have this disease, is still open to debate. In a follow-up study of 4 - 17 year olds, Annsjo et al (1981) found no difference in mental state, as assessed by psychiatrists, between subjects newly diagnosed with diabetes and matched healthy controls, although those with diabetes were more likely to show an increase in symptoms of aggression. These researchers did not find any differences in the degree of social problems or in intellectual capacity between the two groups.

The study did not mention differences according to age, except that girls below the age of 12 showed a greater tendency towards a low utilisation of intellectual and emotional capacities at the onset of their diabetes. It may be important not to overlook the possibility of differences within diabetic populations in relation to age, particularly as in many studies a wide range of ages has been investigated which may obscure these differences.

In an early study of mental health in a group of school-children, Sterky (1963), found that there were no differences in either mental status or in the level of achievement at school between subjects with diabetes and their controls. The mothers of the children with diabetes were however, more likely to be mentally disturbed, and this was in turn related to symptoms of mental health and poorer diabetic control in these children. In another investigation of school children, Gath and colleagues (1980) also reported that those with diabetes did not show any more signs of behavioural or emotional problems in comparison with healthy controls. Partridge (1972) concluded that teenagers with diabetes viewed themselves in the same light as non-diabetic teenagers in terms of their personal freedom and responsibility for their daily lives.

A scale developed by Sullivan (1979), has measured life adjustment in adolescent girls with IDDM, in terms of peer and family relations, body image, dependence-independence conflicts, school adjustment and attitudes towards diabetes. Sullivan argued it may be important to identify adjustment problems during adolescence if we are to intervene in order to prevent 'pathological adjustment' persisting in later life.

Sullivan's questionnaire aimed to elucidate the subjects' thoughts and feelings about their diabetes, using questions that were thought to reflect how diabetes influenced lifestyle. Sullivan found that overall, these girls were 'relatively well adjusted' to life. In a further report (1979a), poor adjustment was found to be significantly associated with self-esteem and depression, and Sullivan concluded that this adjustment scale could be a useful screening device to detect poor self-esteem and depression in adolescent girls.

Zeltzer et al (1980) have studied the perceived impact of illness in different groups of both chronically ill and healthy adolescents, including subjects with diabetes (IDDM), cystic fibrosis, cancer and cardiac and rheumatologic diseases. As was expected, those with chronic illness reported more current illness than those without chronic disease, however one-third of the so-called 'healthy' group reported one or more current illnesses, such as allergies, colds and headaches. The authors concluded that the overall impact of illness did not differ between those with and without chronic disease. Areas that were most frequently reported as being disrupted were freedom and popularity, together with family relations. However, compared to all the other chronic illness groups investigated, those with diabetes reported the least impact of illness. In the same study, subjects with diabetes also reported less illness-related peer disruption compared with healthy adolescents.

In all the chronically ill groups, including the subjects with diabetes, there was a significant correlation between the perceived impact of illness and level of self-esteem. These findings are difficult to interpret however, because it is not clear whether the measurement of the perceived impact of illness referred specifically to the experience of illness at the time of the interview, or whether it incorporated previous illness. This is especially important as only one-third of the 'healthy' group reported current illnesses. Zeltzer et al (1980) noted a de-emphasis or denial of their condition for many of those with a chronic disease, which they related to the notion of 'psychologic inoculation' - the theory that successful coping with mild stress strengthens an individual's ability to cope with subsequent greater stresses. Zeltzer (1980) suggested that those who were constantly exposed to minor stresses such as insulin injections may build up a tolerance to illness-induced stress, and this would explain why patients with diabetes reported less impact of illness in some areas than did healthy adolescents, whereas rheumatic and oncologic patients reported more. They suggested that the stress associated with treatment for these two latter groups of patients may be so great, that the "coping system is overloaded, leading to a perception of more disruption of activities".

In a more recent investigation of adults with diabetes aged between 16 and 60 years, Surridge (1984) has shown that, although clinical depression was rare, other symptoms such as fatigue and energy loss were common, and lead to the disruption of spare time activities.

In the same study Surridge has shown that the younger the patients were at the time of diagnosis, and especially before the age of 19 years, the more likely they were to have a delayed psychosexual development. It is unclear however, how this was measured, except through indications of a delay in the development of interest in the opposite sex in comparison with siblings and peers. This had been picked up during the interviews although no formal measurement procedure was used.

Whether or not the diagnosis of a chronic condition necessarily leads to a negative outlook, in terms of the adaptation and full adjustment of the patient, is a controversial question. Some studies have demonstrated that teenagers with diabetes do have certain concerns and worries about their disease and their outlook for the future, both in terms of physical health and in terms of career and other opportunities. For example, in a study of teenagers, both the subjects with diabetes and cystic fibrosis demonstrated a concern with the reactions of other family members and worries about their future health - for those with diabetes this was related to fears about the development of diabetic complications (Capelli, 1989).

At the same time however, these subjects perceived that they had adequate social supports, were socially competent, and felt in control of their lives. The author has suggested that these rather discrepant results may be related to the use of two different methods of investigation, that is, both interviews were carried out and questionnaires were completed.

Although the questionnaires were all standardised instruments, the semi-structured questionnaire was developed specifically for their study. It was not made clear in the report whether any validation of the new questionnaire had taken place, and this may also account for some of the differences.

The concerns of people with diabetes have been investigated in children aged between 8 and 17 years (Allen et al 1984). Using a semi-structured interview, the participants were categorised in terms of whether or not they had an advanced concept of their disease, that is they were able to understand their disease. Adjusting for age, those with the more advanced disease concepts were more likely to report that diabetes would alter their adult life-styles, especially in terms of career opportunities and participation in social and athletic activities, and would also affect their relationships with their peers. This group were also more likely to express concerns over their future medical condition. The authors suggested that being more aware of the problems associated with diabetes could lead to better self-management skills but that it could also lead to greater anxiety.

A chronic disease such as diabetes may make a significant impact on the life of the individual, although this may depend on various factors such as knowledge of diabetes, emotional stability and the presence of social supports. Some of those with IDDM may feel that they have adapted well and do not view themselves differently from their peers, while others may perceive their lives as disrupted and may find it difficult to adjust.

Although some disagreement within the literature may exist with regard to the overall impact of IDDM, there is some degree of consensus in terms of the initial impact of the disease, and its influence upon both the individual with newly diagnosed diabetes, and those around them. Whether or not the person with diabetes returns to a life-style similiar to that of their peers after diagnosis, or whether the future is constantly affected, has not yet been established, and may be determined by many different physiological and psychosocial factors.

2.2 Psychosocial factors and metabolic control.

The long-term effects of diabetes are severe, and may include blindness, heart disease and renal failure (Kannel and McGee 1979, Jarrett et al 1982). Good diabetic control may be beneficial in terms of delaying or preventing these diabetic complications (Unger 1982). In the United States, the effects of maintaining strict metabolic control are currently being assessed by the Diabetic Control and Complications Trial Group (DCCT Research Group 1990).

Knowles, in his review of 85 articles and various writings in this field in 1964, discussed how the majority of these expressed the view that control decreased the progress of vascular disease. In a recent review of six prospective, controlled clinical trials, Johansen (1988), concluded that these trials suggested that near-normalisation of blood glucose levels is able to retard or arrest the progression of these complications.

In order to achieve good diabetic control, it is necessary to identify those factors which influence this metabolic balance, and this includes the consideration of psychosocial variables. Some of the research in this area has linked stress with raised blood glucose levels but it has often been criticised on conceptual and methodological grounds (Bradley 1988, Kemmer 1986, Wing et al 1985). There has also been variability of findings with regard to the direction of the blood glucose change associated with different stressors, which casts doubt on the design of some of the studies (Bradley 1988).

Laboratory-based research has shown how stress can lower blood glucose levels (Vandenburgh 1966). However Wing et al (1985) have demonstrated that stress can delay the blood glucose response in subjects who do not have diabetes. Individual reactions to stress may have been ignored in this research, in favour of identifying overall group differences in stress-response (Bradley 1988). It is also unclear as to whether a direct link between stress and glycaemic control exists, or whether this relationship is mediated through changes in self-care or management of diabetes in times of stress (Hanson et al 1987a). Other research has suggested that personality may effect the response to stress, for example the presence of Type A behaviour patterns, which include characteristics such as competitive drive, impatience and aggression (Stabler et al 1986, 1987).

Emotions may play an important role in elevating blood glucose levels (Greydanus and Hofmann 1979, Citrin et al 1981, Orr et al 1983, Cox et al 1984). Dunn and colleagues (1986) showed an improvement in control with greater emotional adjustment. In a study of diabetic subjects aged 23 - 59 years, Sanders (1975) observed a correlation between emotional instability and the presence of complications. In addition, when the sub-group without complications were studied separately, those who had experienced severe hypoglycaemia were more likely to have fears about the possibility of future complications. Sanders emphasised the importance of this fear for both the patients and their relatives, and suggested that this was a crucial consideration for those who care for patients with IDDM.

The relationship between diabetic control and adjustment, for example in terms of social and family relationships, attitudes towards school, and adaptation to disease, has been examined by various investigators (Peyrot and McMurray 1985, Welin et al 1985, Grey et al 1980, Davis et al 1987). Adjustment may affect metabolic control through both behavioural and psychophysiological mechanisms. For example, there may be indirect effects on control through deterioration in self-care caused by lack of adjustment to the illness, or there may be more direct effects such as through anxiety (Peyrot and McMurray 1985). Although there have been many studies carried out in relation to adjustment and diabetes, this term has had a wide range of meanings, and needs to be clarified if useful comparisons between findings are to be made.

Difficulties with diabetes management may be more severe in patients with insulin-dependent diabetes compared with patients with non-insulin dependent diabetes, and this may be related to the more complex regimen imposed on patients requiring insulin. Davis et al (1987) reported that insulin-dependent patients suffered a greater number of control problems, social problems, and greater difficulties in adhering to their treatment regimen compared with non-insulin dependent patients. The insulin-dependent subjects were also more aware of the risk of developing diabetic complications. The authors concluded that these psychosocial factors should not be ignored as they may be more amenable to change than many of the other factors influencing metabolic control.

Some writers have suggested that psychiatric status is associated with the degree of metabolic control achieved (Krosnick 1970, Swift et al 1967). This has been confirmed more recently, although subjects were not clinically diagnosed with psychiatric disorder (Mazze et al 1984). Others have identified a relationship between certain personality characteristics, such as impulsiveness, and glycaemic control (Ohwovoriole and Omololu 1986, Lane et al 1988).

Other researchers have disagreed with the view that psychiatric status influences metabolic control (Simonds 1977, Rihmer and Arato 1982). In one study, diabetic subjects in good metabolic control showed fewer signs of psychiatric problems compared to both diabetic subjects in poor control, and matched healthy controls (Simonds 1977). The 'good-control' diabetic group also reported fewer interpersonal conflicts with peers and family compared with the healthy controls. Simonds suggested that the reason for their better mental health was associated with the challenge of having diabetes. If this challenge was dealt with successfully this could lead to the whole family gaining confidence in their ability to manage diabetes. At the same time, if the families were better organised they would have better diabetes management and would also be less prone to conflicts. It remains unclear however, as to why families without a diabetic member would have more family conflicts and more psychiatric problems compared to families with a diabetic member, when other studies have shown that diabetes may have a profound impact on family life (Hauenstein et al 1989).

If the family is involved in the management of diabetes this may be a positive step towards better metabolic control (Bruhn 1977, Cerreto and Travis 1984). Anderson (1981) has demonstrated the effects of the family environment on metabolic control, and has argued that there may be a complex interplay between the diabetic adolescent's psychological and physical functioning, better metabolic control, and more cohesion and less conflict among family members. Intervention strategies, designed to improve metabolic control, which use a family-centred approach may be particularly appropriate for children with diabetes (Grey et al 1980).

Ludvigsson (1977) has demonstrated the importance of knowledge of the disease alongside positive attitudes, in order to ensure optimal management. Jacobson (1990) reported how adult patients (aged 21 - 40 years) with poor metabolic control had a higher threshold for the physical symptoms of hyperglycaemia and reported feeling physically better at higher blood glucose levels. It was not possible to determine however, whether subjects' reports were accurate perceptions of their state or whether they were post hoc justifications of poor metabolic control. However, the authors did suggest that their findings highlighted the problems that need to be addressed in order to change or improve patterns of self-care.

Many psychosocial variables would seem to be important in the study of metabolic control, particularly family factors and emotional adjustment. Successful adaptation to a life with a chronic disease such as IDDM may also require the presence of a co-operative attitude towards the disease (Challen 1988). Other factors have not been considered in this review such as the increasing literature on 'locus of control', that is the degree to which the subject feels that events are a consequence of their own or others' actions (Chazan et al 1982, Edelstein and Linn 1986, Burns et al 1986). If the individual possesses an internal locus of control, they may feel that the management of their diabetes is in their own hands, rather than in those of the medical profession.

Life-stage and the social circumstances of the individual may also influence adjustment to diabetes, however there has been little agreement in the literature so far on the relative importance of all these psychosocial variables. Diabetes may disrupt the lives of individuals in many ways but the mechanism through which metabolic control is affected has not yet been clearly defined. In order to improve quality of life and perhaps delay the onset of diabetic complications the ways in which this occurs should be specified.

2.3 The Measurement of Self-esteem.

One of the central factors in my investigation was self-esteem, both in terms of the role it may play as a mediating variable between chronic disease and education and employment experiences, and also as an important end-point in itself. Whether or not the presence of diabetes influences the ways in which individuals see themselves has not been established, and may depend on a variety of individual characteristics such as age, sex and social class. This section of the literature review explores the ways in which self-esteem has been defined and measured in previous research. This will be followed with a section outlining some of the findings of these studies in relation to diabetes.

The measurement of self-esteem has been the subject of many research investigations, and has been defined in various ways. Coopersmith (1981), one of the most famous proponents of self-esteem research, has defined self-esteem as follows: "By self-esteem we refer to the evaluation which the individual makes and customarily maintains with regard to himself; it expresses an attitude of approval or disapproval, and indicates the extent to which the individual believes himself to be capable, significant, successful and worthy. In short, self-esteem is a personal judgement of worthiness that is expressed in the attitudes the individual holds toward himself."

The measurement of self-esteem has its theoretical basis in the sociological tradition of symbolic interactionism, developed by theorists such as Herbert Blumer, Charles H Cooley, and George Herbert Mead. Symbolic interactionism rests on three basic assumptions. Firstly, that social reality, as it is sensed and understood by individuals, is a social production, and individuals produce their own definition of situations. Secondly, symbolic interactionism assumes that humans are capable of shaping their own behaviour and that of others, and thirdly that, in taking their own standpoint and fitting that standpoint to the actions of others, humans interact with one another. This interaction is negotiated, and can be unpredictable, and it is symbolic because it involves the manipulation of words, meanings and symbols (Denzin 1989).

Symbolic interactionism has, as one of its central concepts, the notion of the 'self'; in the idea that we develop our self-concept, or how we see ourselves, in relation to others around us, through our interaction with other people. George Herbert Mead (1934) described two conceptually separate parts of the self; the 'I' and the 'me'. He suggested that the 'I' is the part that functions and acts spontaneously; and the 'me' reflects and evaluates these actions. In order to evaluate our actions, we need to look through the eyes of others around us. The individual does not learn about himself or experience himself directly, but rather, sees himself as others see him, and evaluates himself accordingly.

Charles Cooley (1922) used the metaphor 'looking-glass self' and listed three elements to describe this process: firstly, the imagination of our appearance to others, secondly, the imagination of these others' judgements of that appearance and finally, some sort of self-feeling such as pride or mortification. Cooley suggested that "we always imagine and in imagining, share the judgements of the other mind" (Hewitt, 1976).

From an early age the individual develops his self-concept through interaction with others around him - both specific, for example parents, friends, colleagues, children, and more generalised others, such as organisations, political parties and society as a whole. At the same time during which the self-concept is developed, the individual also acquires his self-esteem, which is the evaluative aspect of self-concept. There are, suggests Hewitt (1976), two types of self-esteem; firstly, there is situational self-esteem, by which is meant the individual's feelings about his imagined appearance to a specific other in a given situation. Secondly, there is cumulative self-esteem, which is built out of the individual's experiences with situational self-esteem. Self-esteem is not only a product of interaction, but is brought to each new situation of social interaction and will influence actual conduct, for example to secure a particular kind of appraisal from others, or to support already held self-conceptions, the individual will conduct himself in a particular way.

The development and maintenance of self-esteem is not a one-way process but is a two-way interaction. Rosenberg (1986) suggested that the maintenance of self-esteem is a major human motive. The imagined conceptions of others and one's own conception of self will affect the individual's disposition (eg. anxiety, depression, happiness, pride) which will then affect their conduct. In order to fit the desired images of themselves, people will act in certain ways. Conceptions of the self are linked to ideals of what the person ought to be like. These ideals may be structural, eg. religious, class and other social differentiations; or they may be more allied to the expectations of others around them in specific situations.

It has been suggested that the many different meanings of the term 'self-esteem' are dependent upon the standpoint of the writer (Robson 1988) and it is often assumed that there are 'common-sense' definitions of the word, which may be misleading. Some researchers view self-esteem as stable, whereas others see it as more susceptible to manipulation. Robson (1988) suggested that self-esteem may stabilise as an individual progresses into adolescence. Many investigators have argued that there are different dimensions of self-esteem that should be both defined and measured separately. Coopersmith (1981) suggested that "self-esteem may vary across different areas of experience and according to sex, age, and other role-defining conditions". He argued that all areas should be weighted according to their subjective importance, enabling a general level of self-esteem to be established.

Both Brissett (1972), and Franks and Morolla (1976) have suggested that there are two main aspects of self-esteem to be considered. Brissett (1972) called these the 'process of self-evaluation' and the 'process of self-worth'. Self evaluation is the "process of making a conscious judgement regarding the social importance or significance of ones's self". The individual appraises himself in terms of certain criteria or standards; these are certain goals, achievement standards, norms or rules, and moral precepts. "In the process of bringing such criteria to bear on himself, an individual assesses his relative value" (Brisset 1972). Brisset called the second dimension of self-esteem, the process of self-worth, which he explained, referred to feelings of self, and involved a sense of 'competence', such that the self is seen as causally important, and effective in the world.

Brissett (1972) argued that self-evaluation and self-worth often parallel each other, for example in situations in which the individual evaluates himself highly and at the same time experiences a sense of mastery. Franks and Marolla (1976) have described what they called the 'outer' and the 'inner' self-esteem. The 'outer' self-esteem referred to feedback from other people such as social approval which gave rise to feelings of self-worth. The 'inner' self-esteem was described as 'the individuals feelings of efficacy and competence derived from his own perceptions of the effect he has on his environment' - this gives rise to feelings of power and competence. They suggested that both the active and reflective components of self-esteem should be considered in any approach to its study.

The multitude of definitions of self-esteem is paralleled by a great number of instruments measuring self-esteem. Wylie (1979) in her extensive review of self-esteem, concluded that there was little consensus on either the definition of, or the measurement of the concept. Most instruments are self-complete checklists. Some, such as Rosenberg's scale (1965), which is one of the most widely used, are global measures, and involve a relatively small number of items. Others such as Coopersmith (1959) and Piers-Harris (1984) are longer instruments compared to Rosenberg's scale, and identify specific aspects of self-esteem as well as providing an overall measure.

Rosenberg has suggested that there are two different connotations to the term 'high self-esteem'; one being that the person thinks he is 'very good', the other being that he is 'good enough'. It is, therefore, possible for a person to consider himself superior to others, but to feel inadequate in terms of certain standards he has set for himself. Rosenberg suggested that we might consider using the term 'self-acceptance', since this term implies that the individual knows what he is, is aware of his virtues and deficiencies, and accepts what he sees without regret. Rosenberg added to this a measure of respect; suggesting that subjects with high self-esteem do not simply accept themselves, they respect the self they observe, note the deficiencies and aim to overcome these. Low self-esteem, on the other hand, implies self-rejection, self-dissatisfaction and self-contempt, and the individual lacks respect for the self he observes (Rosenberg 1965).

It may be crucial to investigate self-esteem in terms of the different component parts, for example in terms of peer relations, the family, and occupational roles. A study of adolescence by Norris and Kunes-Connell (1985) demonstrated how self-esteem in young adults was influenced by perceived levels of success in relation to different spheres of life such as employment, interpersonal relations and parenting roles.

Rosenberg (1965) suggested that adolescence is a time of life when the individual is constantly aware of his/her self-image, because the "self-image at this time is so vitally implicated in such important life decisions...". Rosenberg's famous study (1965), carried out in over 5000 adolescents aged between 15 and 18 years, started with the assumption that the self-image is central to the subjective life of the individual, largely determining his or her thoughts, feelings and behaviour. He argued that the individual's 'self-picture' is a more or less clear portrait, based upon the information provided by their social experience.

Low self-esteem may be the result of devaluing experiences occurring in the social groups to which a person belongs (Brown 1990 ii). There may be many other factors which influence level of self-esteem, and the development of the self-concept. Some of the factors most frequently investigated are social class, sex and ethnicity. Rosenberg (1965, 1986) has argued that the self-concept is influenced, not only by those people directly surrounding the individual, but also by the broader social structure, and especially the system of social class stratification.

The impact of social class on the individual's self-concept may also be dependent upon the age of that individual; social class in the adult has been achieved (at least in principle), whereas for the child it is ascribed. Rosenberg suggested that the available evidence indicated that social class affected the self-esteem of the adult, but that there were little or no effects for the adolescent or the child. However, he also concluded that, although a relationship may exist between social class and self-esteem, this was probably influenced by other variables such as sex or parent-child relationships. In her review of self-esteem research, Wylie (1979) concluded that there is little evidence for a direct relationship between social class and self-esteem.

The self-concept may be determined partly by specific situations (Wylie 1979). Wylie suggested that the self-concepts of the sexes may differ according to these different situations, so that women feel more self-confident in certain situations and men in others. However this has yet to be addressed in any systematic way. In general, the theoretical rationale behind the assertion most often stated, that females have a poorer self-concept than males, is related to womens' devalued and derogatory position in society compared to men, including notions of their economic and social dependency (Wylie 1979).

However, Wylie (1979) concluded in her review that there was little strong evidence to suggest a relationship between sex and self-esteem, for either children or adolescents. This may have been related to the fact that there has often been a failure to establish that the sex groups are comparable on other possibly relevant variables. At the same time, Wylie suggested that certain personal qualities may be more important to females than to males, and vice versa, but these differences may be hidden because global measures of self-esteem, using total scores for comparison, are usually employed.

The effect of social class on self-esteem levels has been mentioned in this review. However ethnic group must also be considered. The influence of ethnic origin on self-esteem may be related to parental values and child-rearing practices, or upon the child's personal experience of what goes on outside the home. At the same time, any suggested link between ethnic group and self-concept may be mediated by whether or not the person has a sense of ethnic identity (Wylie 1979).

Until recently it was widely assumed that blacks had lower self-esteem compared to whites (Rosenberg 1986). If a group such as Afro-Caribbeans experience prejudice on the basis of their colour, and if the members of that group are treated badly, then it may be expected that this group would have low self-esteem. However, in his original investigation, Rosenberg (1965) demonstrated that black Americans did not have particularly low levels of self-esteem, in spite of their experience of prejudice and discrimination.

The development of a poor self-concept may be mediated by important factors such as relationships with family members and others close to them, and many authors have suggested that the parents of black children are highly valued 'significant others' who are capable of building strong self-regard in black children in the early years (Porter and Washington 1982). Later on in life, membership of a distinctive subculture which provides alternative and achievable criteria of success could also lead to a more positive self-concept (Yancey et al 1972).

The measurement of self-esteem has received much attention, however the factors that may influence its positive development have not been conclusively defined. The use of short checklist measures has been common, with most studies assessing overall or global self-esteem, rather than identifying specific components. For the purposes of the present study, it is necessary to move on to a discussion of the literature on the influence of diabetes on self-esteem, and it is to this subject that I now turn.

2.4 The Relationship between self-esteem and diabetes.

As reported above, factors such as sex, social class and ethnic origin may possibly influence level of self-esteem, however the evidence is far from conclusive. The effects of chronic disease on level of self-esteem has also been a controversial area of research. Many studies have investigated the effects of illness on children, in whom the development of self-concept may be occurring at a crucial time. However, few investigations have considered the relationship between chronic illness and self-esteem in young adults, and there has been little agreement on useful methods or in the findings.

Studies which have focussed on adolescents have described this stage in life as one of the most problematic periods of change and uncertainty an individual may face, which is further complicated by the presence of a chronic disease. Children with chronic illness may have greater psychological problems than children who do not suffer with disease, and some descriptive studies of psychiatric problems, have suggested that there may be a delay in psychosexual maturation, for example in the adolescents' interest in the opposite sex (Cernelc et al 1977, Surridge et al 1984). The child with diabetes may have a distorted self-image, and Krosnick (1970) has suggested that this may be accompanied by a sense of inadequacy, which is conventionally expressed in terms of physical development, athletic skills and performance, marriage and child-bearing.

A significant loss of self-esteem may only occur when activity is restricted and is accompanied by visible evidence of the disease (Walsh 1989). This may apply to those young adults with IDDM, who may have to excuse themselves from certain activities with their peers because of the requirements of their diabetes, for example, eating at regular times, injecting at the correct time.

Patients who are chronically ill may have a lower level of ego development and less complexity of self-image (Hauser et al 1979). In this latter study however, subjects with diabetes had slightly higher levels of self-esteem compared with healthy controls, although the authors also noted that self-esteem was related to the duration of the disease. General self-esteem was significantly related to ego development and at lower levels of ego development the authors found diminished self-esteem. In a further study at the same paediatric clinic, children with recent onset of diabetes (IDDM) were compared with a group of children with a recent acute medical problem (Jacobson et al 1986). Using a self-report instrument which measured adjustment approximately five months after either diagnosis of diabetes, or after treatment for a medical problem, no differences were observed with regard to their levels of self-esteem. There were strong correlations however, between level of adjustment to diabetes and personality and behavioural problems, and social functioning. These findings may be problematic however, as the comparison group consisted of children who had had an acute illness but who were medically completely recovered and although were assessed on average five months post-diagnosis, only 18% were seen within the first three months.

This control group would seem to be inappropriate as this study design ignores the long-term implications for the subjects with diabetes. Furthermore, although those with diabetes were interviewed on average five months after diagnosis, nearly half were seen within the first three months. Other researchers have found this time-scale too early to make any accurate assessment of adjustment (Kovacs et al 1986), and also have shown that self-esteem is related to adjustment (Sullivan 1979a).

Several investigations into illnesses other than diabetes, such as cystic fibrosis and cancer, have shown that the presence of chronic disease may not necessarily lead to lower self-esteem (Pearson et al 1985, Simmons et al 1985, Jamison et al 1986, Capelli et al 1989), although any decrease in self-acceptance may also be related to the duration of the disease (Stanowska et al 1990).

In her review of the available evidence, Johnson (1980) concluded that youngsters with diabetes have consistently demonstrated 'adequate' self-perceptions. However, in the same review, she described other studies in which those with diabetes were found to be less well-adjusted and to have more depression than those without diabetes. Other research has also shown that chronic illness does not influence self-esteem level (Collier 1969, Zeltzer et al 1980), and in a study of 80 chronically ill children and 40 healthy children, diabetic subjects were found to have levels of self-esteem which were comparable to levels in both asthmatic children and children who were free from disease (Nelms 1989).

Delbridge (1975) found in his study of 37 diabetic children and their parents, that the children, as a whole, did not feel personally inferior to their peers, although they were more likely to show signs of social maladjustment. Delbridge argued that this was to be expected in view of the restrictions placed on diet, social activities and the timing of activities by having diabetes. Kellerman and colleagues (1980) have compared measures of anxiety, self-esteem and health locus of control in healthy adolescents and young people with various chronic diseases. No differences in terms of these measures were found, however there were socio-economic, age, and race differences between the groups, which may have influenced these results.

There is therefore, some evidence that may lead us to question any assumption that there is a relationship between chronic illness and level of self-esteem. Other research however, supports this hypothesis, such as the study of older insulin-dependent diabetic patients (32-52 yrs) in which Jensen (1986), has argued that a common reaction to diabetes may be a reduction in bodily self-esteem, although it is unclear how this was measured. Others have demonstrated a link between level of self-esteem and age at onset of diabetes (Ryan and Morrow 1986). More specifically, girls with early onset (ie before the age of five), had lower self-concept scores compared to the early onset boys. This was specifically related to physical appearance; all girls with either early or later onset had consistently poorer body-images than boys.

The authors of this report suggested that the occurrence of diabetes early on in life may interfere with the development of even a rudimentary body-image. Adolescent girls were more likely to have a poorer body-image if they had a chronic illness as they were more likely to be affected by changes in physical appearance than boys.

Level of self-esteem may influence management of the disease (Grossman et al 1987). Using a 'self-efficacy for diabetes scale', Grossman et al studied two groups of diabetic campers, aged between 12 and 16 years. The scale measured the subjects' perceived ability in managing their diabetes. The authors also implemented the Coopersmith self-esteem questionnaire (Coopersmith 1959) and found a clear link between strong diabetes self-efficacy beliefs and greater self-esteem. Diabetes self-efficacy was also associated with metabolic control for the girls, however this was not the case for the boys. The authors suggested that it was possible that boys were less tied to feedback from others for their self-evaluation and approval. Other research has also demonstrated a link between a negative self-concept and poorly controlled diabetes (Bruhn 1977), although a study by Close and colleagues (1986) suggested that tight metabolic control may also have other detrimental effects. In their study of 69 eighteen year-olds with diabetes, those with better diabetic control had poorer self-esteem and were more likely to report emotional or behavioural difficulties. However, other evidence has contradicted this, suggesting that tight metabolic control during childhood does not necessarily lead to social, emotional or work-related problems later on in life (Pless 1988).

Although much of the work on self-esteem and chronic illness has concentrated on school-age children (Swift et al 1967, Kovacs et al 1986), there is a growing interest in the study of children attending summer-camps for diabetics. Research has incorporated both the investigation of differences in levels of self-esteem and also the design of intervention programmes in an attempt to raise low levels of self-esteem and to improve knowledge of the disease.

The number of diabetic camps held has increased, especially in America, since early studies demonstrated the beneficial effects of this experience for young people with diabetes (McCraw and Travis 1973, Hoffman et al 1982). Zimmerman et al (1987), in a study of children aged 8 - 14 years attending an integrated camp, showed that the self-concept scores of children with diabetes were correlated with knowledge of the disease. Both the group of children with diabetes and those who did not have diabetes showed increases in knowledge and self-concept scores after one-week's camping experience, thus demonstrating the positive effects of this experience.

Self-esteem has also been associated with the degree of family cohesion (Hanson et al 1987a) and to family functioning (Anderson et al 1981). Well-controlled young people with diabetes exhibited less anxiety, a more positive self-concept and reported more cohesion and less family conflict. At the same time these subjects were in better diabetic control, and the families reported a less negative impact of the illness on the other members of the family (Anderson et al 1981).

The complex interplay of family factors with the self-esteem of those with diabetes and their metabolic control, needs to be investigated further in order to delineate which specific factors influence family functioning and how family functioning affects the metabolic control of the individual with diabetes.

The evidence for and against the influence of diabetes on level of self-esteem is inconclusive. If there is an impact however, this will have implications for health-care providers (Gendron 1984). Mason (1985) has suggested that the imposition of the diagnostic label leads to the structuring of a new identity, that of 'diabetic'. There is a world of difference between 'you have diabetes' and 'you are a diabetic'. Information provided in medical encounters then becomes crucial for self-definition and how each individual copes with the disease.

The role of mediating variables such as social class, sex or ethnic group, and the age of the individual should also be considered. In larger studies there has been little evidence of an association between chronic illness per se and self-esteem, but in smaller studies of particular illnesses there have been indications of an effect of disease on self-esteem (McAnarney 1985).

The studies reported here have provided evidence both for and against the hypothesis that the presence of diabetes influences level of self-esteem. However, most available evidence has been related to young children and adolescents, because these are the ages at which basic self-concepts develop.

Studies in older populations have shown that chronic illness impacts on life-style in many ways, but self-esteem had been barely alluded to, let alone explicitly investigated. If, as some of the literature suggests, specific situations and experiences influence self-esteem, then we need to explore these in young adults with IDDM, in order to be able to identify how their level of self-esteem is established or changed.

The question of whether or not the presence of chronic disease influences educational performance is controversial. The effect of a chronic illness such as diabetes on further educational attainment has only been partly researched and most studies have investigated the experiences of students below the age of 18 years. It is possible that young adults with diabetes may be faced with difficulties in the later stages of their education, even though they may have been successful in obtaining the qualifications required in order to attend university or college. If there are negative side-effects of diabetes on young people at any age during their school career, this will have serious implications for their future employment prospects and career plans.

The impact of chronic disease on the academic experiences of children has been reported in studies of various disorders such as diabetes, cancer, asthma, and haemophilia (Schlieper 1985, Gortmaker et al 1990). In a study of school absence and achievement, children with chronic diseases experienced more absenteeism and had lower academic achievement scores compared to healthy children (Fowler et al 1985). However, children with diabetes were not amongst those at greatest risk of low academic achievement; those who did perform badly at school were those with epilepsy, spina bifida and sickle cell disease. School absence was unrelated to achievement, but was associated with the number of clinic visits, the degree of activity limitation, sex and specific health conditions. Schlieper (1985) also concluded that frequency of school days missed was not associated with poorer achievement within patient groups.

The school performance of children with diabetes may be as good as that of their non-diabetic siblings (Weil and Ack 1964, Sterky 1963). However an earlier study by Ack et al (1961), demonstrated that level of intelligence, as measured by the Stanford-Binet Intelligence Scale, was significantly related to age of onset of diabetes in children aged 3 - 18 years. Two more recent studies have demonstrated the comparable achievements of young patients with IDDM and local school leavers (Mok et al 1984, Ardron et al 1987). The latter study had its limitations however, as those who did well academically were significantly more likely to have come from the higher social classes, and this may have had an important influence on these findings. Those who were diagnosed at a younger age were more likely to have obtained qualifications, compared to those who were diagnosed after the age of 13 years. The authors suggested that one reason for this finding may have been that those who were diagnosed during adolescence may be thrown into emotional turmoil during their studies for examinations, with poor performance being the result.

Although the majority of children who have chronic illnesses may be of 'normal' intelligence, there is some evidence to suggest that some children do under-achieve academically compared with their healthy peers (Weitzman 1984). Pless and Roghmann (1971), in their analysis of data from the National Survey of Health and Development, demonstrated that average aggregate scores on tests of achievement obtained by chronically ill children were significantly below those of healthy children.

Fallstrom (1974) found more than half her sample had difficulties at school, and Gath et al (1980) found that children with diabetes were more backward in reading, although the study groups were not matched for intelligence. Laron (1972) has suggested that performance in the higher grades of school may be lower than in the earlier grades.

The evidence is inconclusive with regard to whether poor school performance could be the result of poor adjustment, frequency of school absences or lower intelligence. There may also be an important social class influence, as children from families lower down the social scale tend to fare less well academically compared to those higher up the social scale. For those with diabetes, an alternative hypothesis has been proposed, suggesting that episodes of hypoglycaemia when young may effect early brain development, resulting in reduced intellectual ability (Weil and Ack 1964, Ryan et al 1985). Koski (1969) demonstrated that below-average performance was common in children who had unstable diabetes.

In order to test this hypothesis, a comparison of children with diabetes aged 6-13 years, and matched sibling controls was carried out, with childrens' abilities measured by the Wechsler Intelligence Scale for verbal meaning and visual-motor integration (Rovet et al 1987). The diabetic subjects, when classified into early and late onset patients, were more likely to be at a greater risk of neuro-cognitive impairment if diagnosed prior to the age of 4 years. Those with early onset scored significantly lower on tests of visuo-spatial ability, and were more likely to require special education or had failed a grade in the past.

In the same study, subjects with an early onset of diabetes had more hypoglycaemic convulsions than those with a later onset, and both these factors (ie. convulsions and age at onset) were associated with poorer performance in tests of cognitive functioning.

Ryan and his colleagues (1984, 1985) have carried out several investigations into the possibility of cognitive deficits in youngsters with diabetes. In one study, using a battery of intelligence and ability tests, Ryan et al (1984) compared a group of teenagers with diabetes who were diagnosed after the age of five years with healthy controls who were demographically similar. The authors found that although diabetic subjects performed within normal limits on all tests, the diabetic group obtained lower scores on measures of verbal intelligence, and on a series of visuomotor tasks. The authors stated that they were not entirely convinced that the poorer performance of those with diabetes was related to some form of brain damage induced by diabetes. They suggested that were that the case, they would have found a greater range of deficits in testing. There was a tendency for the subjects with diabetes to reach correct solutions for tasks at a slower rate than those without diabetes, and Ryan et al (1984) argued that this may reflect a response style, whereby those with diabetes were more cautious, and attended more to detail compared with those without the disease, which may be due to the demands of their disease. Lower scores in academic achievement reported in a further study (Ryan 1985) were explained by frequent school absences, rather than by degree of metabolic control or duration of diabetes.

However, more recently Ryan (1990) has investigated the effects of mild hypoglycaemia on cognitive functioning in a group of eleven patients with diabetes aged 11 to 18 years. A series of cognitive tests were performed before and after plasma glucose concentrations were artificially dropped. Ryan demonstrated that induced hypoglycaemia was associated with a marked reduction of mental efficiency in both children and adolescents with diabetes. The authors also reported that there may be a time lag between the attainment of normal levels of glycaemic control and when usual mental efficiency is resumed. These findings may have important implications for those with diabetes who are at school, especially if prone to episodes of hypoglycaemia, for example fluctuations in blood glucose may affect performance during examinations.

In contrast to the available evidence which has suggested that there might be certain problems for young people with chronic disease in educational terms, several authors have described the optimism of young adults with diabetes, in terms of their career plans. In a study of 16 to 22 year olds with diabetes who were temporarily working at a diabetic summer camp, responses to a questionnaire indicated that more than half of the respondents expected to finish college and a third expected to attend graduate school (Khurana and White 1971). Although this was not a representative sample of young people with diabetes, other studies have also demonstrated that youngsters with diabetes may have developed occupational goals or career plans (Davis et al 1965, Fallstrom 1974).

Literature that has been concerned with the relationship between diabetes and educational achievement remains inconclusive. It may be important to focus on certain aspects of the individual's school career, such as the attainment of qualifications, especially as these are becoming more important in the face of increasing unemployment. This may have particular implications for young adults with diabetes, as it may be even more important for those with a chronic disease to obtain qualifications, especially if reservations about the employability of diabetic workers exists on the part of prospective employers. Decisions that have to be made at sixteen and eighteen in terms of moving on to further or higher education (and also to what type of education), or applying for jobs, may be affected by both examinations already taken and the presence of a long-term illness. However, the specific difficulties of young adults with diabetes within the education system have not been previously identified.

At the same time, except for some anecdotal evidence, little is known about the day-to-day experiences of this age-group, such as how the attitudes of teachers and classmates may impact on self-esteem. Although the measurement of formal qualifications is important in assessing academic achievement, this could be complemented by research documenting the thoughts and feelings of the young adults themselves, with regard to how they felt they did at school. It was to this end that the present study was to be partly directed.

2.6 Diabetes and employment

Most young adults at some time face the future with some trepidation, especially when having to make crucial career decisions. Young adults with a chronic disease such as diabetes have an additional element to take into consideration. There are some occupations which are recommended as unsuitable for people who have diabetes (British Diabetic Association 1984). There may also be some types of work that they themselves feel are inappropriate, solely because of their illness, or they may face discrimination from employers because of the same reason. As a result, some young people with diabetes may withhold information about their illness, which could be potentially dangerous both to the person with diabetes, and to their co-workers. Conditions at work may be problematic, for example, eating at certain times, availability of medical facilities, and whether patients are given time off for clinic appointments are all issues of concern. Few studies have been carried out in recent years, and most of the investigations relate to the situation in the U.S.; the prospects of young people in the U.K. may be quite different.

Although some studies have suggested that people with diabetes do suffer from discrimination by potential employers (Mastbaum 1974, Zagoria 1982), others have indicated otherwise (Tetrick and Colwell 1971, Hutchison et al 1983). In the latter study however, those with insulin-dependent diabetes were more likely to have been refused work at some time or made redundant because of their disease, compared with those with non-insulin-dependent diabetes.

The authors of this report (Hutchison et al 1983) argued that these results may be related to the greater cumulative experience of this group because of the longer duration of their diabetes, compared with those with non-insulin dependent diabetes.

In one study, the reasons most frequently advanced by employers against the employment of people with diabetes were absenteeism, job-interruption, accidents at work due to insulin reactions, and higher contributions for insurance cover owing to the occurrence of diabetic complications (Petrides 1980). Problems may also occur when diabetes is diagnosed during employment. If the working environment is no longer suitable for the newly diagnosed diabetic worker, then 'vocational rehabilitation' may be necessary. Of course, as Petrides pointed out (1980), it is not a simple task to learn a new profession and find a new job, especially in times of high unemployment. When newly diagnosed, the individual may suffer from having to give up their career or a job in which they were interested and take up employment in a field that they perhaps have little or no interest in, or where they will receive a lower salary.

On the basis of surveys made in industry, Brandaleone (1959) argued that all the reasons listed by employers for rejecting an applicant with diabetes for employment could be challenged, and that education of employers, doctors and management could remove most of the objections to the employment of people with diabetes. An understanding of the problems of those with diabetes would, he claimed, further reduce any existing objections to employing people who had diabetes.

Brandaleone (1959) concluded that if the worker with diabetes was well-controlled and co-operative and presented himself for periodic examinations with his physician, he could be a useful employee. Mastbaum (1974) noted the "unwarranted discrimination" that those with diabetes have long suffered when seeking employment, and in a further article he argued that "any diabetic whose disease is well controlled is employable" (Mastbaum et al 1980).

There is legislation to help protect people against discrimination in employment. A law exists which states that in companies which employ more than 20 workers, 3% of the workforce should be registered disabled workers. A report from the World Health Organisation has also stated that those with diabetes should not be discriminated against at their places of work (WHO report 1980). However, as shown above, these recommendations are clearly not always put into practice. Those with diabetes may perform as well as, if not better than, their healthy colleagues in a variety of settings (Laron 1984), however some physicians have still argued that those with diabetes must not work in certain occupations (Lister 1983). These arguments have been strongly disputed (Sonksen 1982).

The British Diabetic Association (BDA) has also made recommendations on the suitability of various occupations for those with diabetes (BDA 1984). They have suggested that people who require insulin should not work in situations where sudden attacks of hypoglycaemia could endanger themselves or others.

For this reason, they explained, this group of diabetic patients could not hold heavy goods vehicle or public service vehicle licences. They are also not able to become pilots, drive trains, or join the armed forces. The BDA recommendations state that people requiring insulin therapy are able to carry out shift work, may be allowed to become taxi drivers (depending upon the decision of individual local authorities) and can drive a car, or small van in the course of their work. It may be up to the doctors advising employers, other health-care providers and careers advisors to clarify the needs of people with diabetes, and at the same time dispel previously held notions about their unemployability.

The Committee on Employment 1955-56 for the American Diabetes Association carried out a survey of the employment of people with diabetes in some of the major industries. They stated that at that time, there existed a more enlightened attitude towards the employment of adults with diabetes in America's leading business and industrial concerns. However, the findings were not entirely favourable and it was noted that some companies, including larger ones where more adequate medical facilities were available, did not employ people with known diabetes and most companies did not make any concessions as to the rotation of shifts. It must be remembered however, that this study was carried out during a time of low unemployment, and there may be more serious implications of these findings in the 1990's, as employment rises.

The employment experiences of those with diabetes have been observed in early studies (Wade 1959, Kantrow 1961). Approximately 20,000 workers (mainly white males) were studied by Wade (1959), and a prevalence of diabetes of 1.3% was found, with one-quarter requiring insulin therapy. Only in a few instances was the diagnosis of diabetes a cause for job reassignment, although it was found that if a promotion or reassignment were necessary for managerial reasons, limitations might have to be imposed by the medical department. In the same study, although there were fears regarding diabetic workers' ability to function effectively due to the possibility of insulin reactions, workers continued satisfactorily in both sedentary jobs and heavy physical work. Wade concluded that diabetes did not preclude productive employment, although physicians should advise their patients on their choice of careers.

Kantrow (1961) observed the employment experiences of young adults with diabetes aged 18 - 34 years who were attending a summer camp, and found the full range of occupations from professional careers to unskilled labour. Educational experiences were comparable with the general population. However, in his analysis he found that over half of the respondents had been refused employment because of their condition, and 14% had indicated some problem in their work experience. All except one of the subjects with diabetes related their problem to symptoms of hypoglycaemia. Many of those who had been rejected for employment had decided to conceal their diabetes when applying for work in the future, and some of those who had never been rejected for employment had always concealed their diabetes.

These findings cannot be generalised to other people with diabetes however, as only 30% of the 400 young people contacted responded to the questionnaire. At the same time, the original sample base was biased as the study was carried out only in diabetic subjects who were attending a summer camp.

Other studies have also indicated that those with a chronic illness may have a lower chance of being employed, with employers stating their reasons for this discrimination as the costs of insurance and sickness absenteeism (Weinstock and Haft 1974). A case-control comparison has demonstrated that the prevalence of unemployment among people with diabetes was significantly higher than among those who did not have diabetes (Friis and Nanjundappa 1986). Others have confirmed these findings; in a larger UK study both males and females with diabetes were more likely to be unemployed when compared to matched controls (Robinson et al 1989).

Conversely, other writers have suggested however, that those with diabetes do not necessarily have a greater risk of unemployment. McGregor (1977) followed up a small group of subjects with diabetes in order to see how they had fared in various areas of their lives. He reported that more than half of those he had surveyed were employed, the other half consisted of housewives, those still at school and the unemployed. No comparisons with healthy subjects were made however, so that no conclusions can be made from this study.

Johanssen et al (1979) has shown that the proportions of young people with diabetes entering further education or a trade were comparable to the proportions found in local school leavers in the same year. This report only considered employment at the time of the study however, and did not investigate subjects' experiences prior to this.

Greater absenteeism has often been cited as a reason for not employing people with diabetes. However, several studies have challenged this assumption. Moore and Buschbom (1974) have demonstrated that workers with diabetes compare favourably with those who do not have the disease, in terms of work absenteeism, thus also challenging the often firmly entrenched view that those with diabetes make unreliable workers.

In an earlier study, Brandaleone (1953) sent a questionnaire to the medical directors of nearly 350 representative companies in the United States and Canada. Although only 70 replies were received, he concluded from this limited study that there were no differences in the rate of absenteeism for workers with and without diabetes, indeed the rate was lower for time-off for non-medical reasons, and the calibre of work was the same for the two groups. It may be problematic however, to make these conclusions from this study as such a low response rate was achieved, indicating that the replies that were obtained may not be representative.

However, on the basis of these findings, Brandaleone (1953) argued that companies may play an extra role, in terms of early detection, supervision, proper job placement, and in the education of those with diabetes in industry. They could also play an important role in the furthering of knowledge of the disease through the collection of data concerning diabetes in industry.

Although there has been some evidence in the past to suggest that workers with diabetes experience a greater frequency of sickness absenteeism compared with their colleagues (Pell and D'Alonzo 1967), there is other evidence to dispute this (Dublin 1950, Moore and Buschbom 1974, Robinson et al 1990). A recent case-control study has shown that cases with diabetes had a similar frequency of periods of absence compared to controls, although they did have longer episodes of absence (Waclawski 1990). This was especially true for male manual workers under the age of forty, and this may have been related therefore, to the type of diabetes (ie. insulin-dependent diabetes). Other studies have not matched their samples for occupation when comparing different groups and it is for this reason that Waclawski suggested his findings may be a more accurate picture. Although this may be important, other research has been unable to detect any social class difference in sickness absence of people with diabetes (Robinson 1990).

Shiftwork or physically demanding occupations may not be appropriate for all people with IDDM, and this view may be supported by employers. One example of this type of occupation is nursing, where there has been some interesting research carried out with regard to policies on employing those with IDDM as nurses (Bagshaw 1980). In a letter to the British Medical Journal, Bagshaw outlined a piece of research she had carried out amongst all the health authorities in England, in which she had found a wide range of policies on this subject.

Some health authorities had strong reservations about night-duty and the physical demands required of nurses, however others were quite willing to accept people with diabetes provided that their diabetes was well-controlled. In total, 12 nursing schools stated that they would automatically reject all applications from people with diabetes. In 1988, Robinson and colleagues carried out a further survey in all schools of nursing in Great Britain, and demonstrated that this situation had improved somewhat (Robinson 1988a). They concluded that the evidence suggested that all suitably qualified people with stable diabetes were able to train as nurses.

Although there are policies against discrimination in employment in the U.K., young people with diabetes may still face some difficulties in obtaining work. These problems may be exacerbated in times of high unemployment when even physically healthy young adults find it difficult to obtain work, especially if lacking in either qualifications, experience, or both (Olafsson and Svensson 1986).

Those who develop diabetes at an older age have usually had some experience of employment and have therefore had the opportunity to establish themselves prior to the onset of the condition. The younger patient with insulin-dependent diabetes may not have had that chance. Individual counselling may be of assistance, including advice on management of the diabetic regimen and on suitable employment. (Mills et al 1973).

Employers may lack knowledge regarding the needs of workers who have a chronic disease. In one study, nearly one-third of employers did not know whether they employed anyone with diabetes, although only 1% of firms reported that they would not consider hiring a person with diabetes (Robinson 1989a). A second UK study reported that certain companies had a lower than expected number of diabetic workers, and only half of the respondents (occupational physicians) could report on the number of people with diabetes working for their company (Waclawski 1989).

There is little evidence from recent years to indicate whether or not people with diabetes experience greater difficulties in obtaining employment in comparison with their healthy peers. However one such study has found that people with diabetes were as likely to be employed after leaving full-time education compared with non-diabetic adults from the same area (Ardron 1987). Although this was an encouraging finding, the subjects with diabetes who participated in the study were more likely to be in the top social classes, where risk of unemployment would be lower than that for those in the lower social groups.

The effects of unemployment per se have been thoroughly researched, however the specific problems of young adults with diabetes have been neglected. If level of self-esteem is influenced by the presence of disease, this in turn may exacerbate difficulties experienced in employment. Alternatively, it may be important to address the particular problems that young adults with diabetes may encounter in the work-place, as these may also have a significant impact on level of self-esteem.

2.7 The family.

The presence of a chronic disease such as diabetes may have serious consequences for the maintenance of supportive family relationships. The "dramatic impact" of the diagnosis of diabetes upon the entire family, "precipitating a state of shock in all concerned", has been clearly described by Laron (1984). However, there is some evidence to suggest that the siblings of chronically ill children are not at a greater risk of psychosocial impairment compared with siblings of healthy children (Ferrari 1984). There may be much confusion with regard to how parents and others, such as peers, should behave towards the child with diabetes, both in terms of relationships and also concerning medical management (Laron 1984). Mok and co-authors (1984) stated that few other diseases placed as much medical responsibility upon the family, and that the added stresses of management could expose flaws in family life and relationships. Others have noted increased stress levels in families with a diabetic member (Hauenstein 1989). Parents may be more aware of the dangers of the complications of diabetes than their children and this could be a further source of tension within the family (Gil et al 1977).

Skyler (1980) has suggested that the two interrelated factors of parental emotions and family organisation can be identified as influencing patients' outcome with regard to diabetes management. Parental attitudes may also have an important effect on the child's adjustment to diabetes (Pond 1979).

Parents may be guilt-ridden or anxious, they may be over-protective, or may 'over-manage' the illness, to the detriment of the child. Pond (1979) suggested these attitudes could also influence the development of a positive relationship with health-care providers.

Family functioning has been considered to be a major mediating variable in terms of the patient's overall adaptation (Wertleib et al 1986). Family characteristics such as size, structure, functioning and ways of coping with diabetes may influence the impact of this illness upon all family members (Pless 1973). Grey et al (1980) used a 'family functioning index', and have linked this to the psychosocial adjustment of the young person with diabetes. The authors pointed to the importance of parental self-esteem and family communication, closeness and cohesiveness in the adjustment of children to their illness, however numbers in the study were small and no control group was used.

In a study where 63 families who had a pre-adolescent or adolescent child with IDDM were compared with a group of 69 control families who had a child with a recently experienced acute illness, Wertleib (1986) concluded, "any assumption of behaviour pathology as a necessary component of IDDM is unwarranted, at least at the early stage of the illness". In the same study it was shown that, although families who had a child with diabetes showed a high degree of "normalness" compared to the comparison group, the children with diabetes perceived a more intense emphasis on organisation and structure in their families.

Different family structures may be more conducive to the attainment of metabolic stability. Good diabetic control may be achieved by those who belong to families with a rigid organisation, although this type of family structure could also lead to less independence and autonomy on the part of the adolescent, which could lead to serious difficulties later on (Evans et al 1987). Kaye (1976) and Baker et al (1975) have described how different patterns of family organisation can affect the level of diabetic control; for example, in "enmeshed" families there were inadequate boundaries between members, with individuals involved in each other's business, and without resolution of conflicts. Baker called this type of family the "psychosomatic family" and reported good results with family therapy in terms of improvements in level of diabetic control.

Koski and Kumento (1977), in a study of 10 - 21 year olds with diabetes, showed that families defined as "helpless" by the authors were more likely to have had a diabetic member in poorer metabolic control compared with families who were not rated as helpless. Helpless families were those who were unable to recognise the child's need for counselling, and were characterised by omnipotence regarding the care of the child with diabetes. The authors suggested that special care and guidance is required by patients with diabetes whose families are disturbed or seen as helpless.

Disturbance and conflict within families may influence the degree of glycaemic control attained (Anderson et al 1981, Delbridge 1975, Koski 1969). Encouragement from parents to behave independently has also been associated with improved diabetic control (Anderson et al 1981). A study of 5-16 year olds has demonstrated that those with better glycaemic control had more cohesive families, without conflict, with emotional expressiveness and with mothers who were satisfied with their marriage (Marteau 1987). Socio-economic factors such as social class, employment status and income, did not influence level of diabetic control. The author suggested that these family factors may be related to metabolic control via either a behavioural or a physiological pathway. Management of the child's diabetes may be affected, which in turn could influence diabetic control, or alternatively, family functioning could directly affect the physiological status of the child.

The family is not only a source of stress itself, the members may encounter stress outside the family which they may then introduce into that family domain (Pearlin and Turner 1986). The family may also act as the source of resources to deal with stress and can provide an arena for the support and cohesion required by people with diabetes in order to adjust to their disease. In a study of patients aged over 16 years, with either insulin-dependent or non-insulin-dependent diabetes, Jenny (1984) demonstrated that the youngest group of patients (mean age, 20 years) reported the most social supports.

This group described their parents and other relatives as the most supportive people around them. McAnarney (1985) has also concluded that the family is an important support system for the adolescent whilst attempting to achieve independence.

A study of 4-16 year olds with various chronic diseases including diabetes, rheumatoid arthritis and cerebral palsy, has shown that these children were at risk for developing adjustment problems because they reported greater family difficulties compared to those recorded in normative data (Wallander et al 1989a). This study demonstrated that both family and peer support were associated with improved adjustment.

In an investigation which compared a group of 'diabetic families' with families containing a child who had recently had a serious acute illness, Hauser et al (1986) demonstrated how chronic illness influenced interaction patterns within the family. The authors reported that the children with diabetes and their parents expressed more "enabling" (eg, focussing, problem solving, active understanding) speeches than their 'acute' controls. However there were also indications of particular constraining interactions (devaluing) occurring between fathers and diabetic children. Hauser argued that these findings reflected the influence of the child's diabetes on family life, augmenting or amplifying important affective currents within the family.

The diagnosis of a chronic illness in the family may produce both reactions of solidarity and cohesion, and also support for the member who has just been diagnosed. At the same time it may lead to more suppressed feelings of anger, guilt and discomfort. There may be significant effects of family functioning on degree of metabolic control.

Perceived parental support may be associated with adolescents' adherence to their treatment regimen (Hanson et al 1987). In this last study, the younger adolescents received more support than the older adolescents. Adherence was significantly related to metabolic control as might be expected, and it was concluded that parental support was a crucial factor in the adaptation of chronically ill children.

There is much evidence to suggest that the family is an important source of support for the child with diabetes, and this may also apply to older patients. A more holistic approach towards understanding and assisting those with diabetes and their families may be required, taking into account both the physical and emotional impact of diabetes on both the patient and the family (Popkess-Vawter 1983). Certain types of family functioning may be related to adjustment to and control of diabetes, although some instruments designed to measure supportive attitudes within the family may not be appropriate for this age-group (Schafer 1986). The provision of ongoing support and counselling could assist those families with the more severe problems (White et al 1984).

There has been to date, little research which considers the issues most pertinent to young adults (Ahlfield et al 1985). A special emphasis should be placed post-adolescence, in terms of both marital and peer relationships, and decisions on whether or not to have children. Young adults may still be living with their families and their specific concerns may differ in important ways from those of younger age groups.

For those still living at home, family relations may influence glycaemic control, for example in times of stress or conflict. The support of the family may still be important once the young adult has left the family home. The opportunity to discuss their feelings or worries about their diabetes may or may not be available and it may be important to be able to feel that other family members are understanding and supportive. These concerns have yet to be addressed in research and one of the aims of the present investigation was to do so.

2.8 Supports outside the family.

Having considered family relationships in this review, it is also necessary to evaluate the importance of other social supports. These may be many and varied, and previous studies have identified a relationship with both the onset and the clinical course of disease. There has been a diversity of measures of social support and some studies have focussed on the availability of social ties or support in times of crises (Henderson 1984, Sarason et al 1983). It may be important to differentiate between actual social support (in times of crisis) and feelings of attachment and dependency (O'Connor and Brown 1984). A recent study found that the risk of depression was significantly related to the absence of social supports in times of crisis (Brown et al 1986).

There have been two main categories of measurement; those instruments that measure the quantity of support and interaction, and those that measure qualitative aspects such as the functions and adequacy of supports. Studies such as the Alameda County study (Berkman and Syme 1979) used quantitative methods and a prospective design, and demonstrated a relationship between a sparse social network and increased mortality. Qualitative studies such as those by Henderson (1984) and Bell et al (1982) have measured the functional aspects of social support and the perceived availability of supports in times of crisis. Henderson (1984) argued that in his study the crucial factor was not the level of support provided but rather its perceived adequacy in the eyes of the respondent.

More recently there have been several attempts to measure both quantitative and qualitative aspects of social support in the same investigation (Sarason 1983, Funch et al 1986). Both groups of instruments have been reviewed by Orth-Gomer and Unden (1987), who have concluded that the quantitative measures were more easily applicable, the questions more easily understood, and their predictive capacity for chronic illness fairly well established. The qualitative instruments were the most carefully tested for psychometric properties but their capacity to predict the onset of illness was less well examined. Finally, they concluded that they could not identify any instrument which satisfied all desirable requirements. This may however, be dependent upon the needs of the study in question, ie. whether it is necessary to collect in-depth information or whether a simple count of the number of contacts is required. If the nature or quality of social support is found to be important in the study of either the onset or the course of disease, then qualitative instruments will need to be refined so that they are of more use.

Apart from the issue of measurement, there has been a plethora of studies investigating how and why social supports influence the impact of illness. Both a preventive role and a buffering one have been suggested. The degree of social support may mediate the impact of stress on individuals (Kaplan et al 1977, Bruhn and Philips 1983, Cassel 1976). Social supports may act as a buffer against disease in times of psychosocial stress, or could act as the stressor itself (Dean and Lin 1977, Cohen and Wills 1985).

The loss or absence of social supports has been linked to both morbidity and mortality of various conditions, such as heart disease, cancer, and mental health problems, suggesting a possible preventive role for social supports (Pilisuk and Froland 1978, Lin et al 1981, Bruhn and Philips 1983). Migration, mobility, social change and other phenomenon have been shown to have a strong influence on the ability to maintain enduring and effective ties so that people find themselves isolated, and in these situations social supports, or rather the lack of them, are the stressors. The absence of a close, confiding relationship has been shown to be associated with greater risk of depression in the presence of other adverse events (Brown 1975).

Social isolation has been associated with increased mortality (Berkman and Syme 1979, Schoenbach et al 1986, House et al 1982), however most of these studies only have data on Caucasian groups, and few compare men with women (Berkman 1986). Those who are not married, and therefore do not have this most intimate relationship (whether single, separated, widowed or divorced), have been shown to experience higher mortality rates compared to married people (Berkman 1981). There may also be an association between lack of social bonds and the presence of neurotic symptoms (Henderson et al 1978).

Social support has been associated with level of self-esteem. In a study by Brown and colleagues (1986), the authors linked low self-esteem and lack of social supports, especially in times of crises, with a greatly increased risk of subsequent depression once a stressor had occurred.

Physically disabled people with a high level of support may have higher levels of self-esteem compared to those with low levels of support, and this could help them to cope with the everyday problems of being disabled (Patrick et al 1986). Social support may encourage problem-solving and may also reduce the impact of further stresses for those with a pre-existing illness. In Patrick's study (1986), a low level of social contact was associated with a deterioration in emotional functioning, but only in the presence of adverse life-events such as a major illness or financial difficulty. Confiding relationships did not appear to be important for adults who had a pre-existing illness and were not at a significant risk of developing stress-related conditions. The authors suggested that these relationships may be more important for those who have a psychiatric condition.

The relationship between social support and the onset or course of chronic disease is a complex one. Stress may be deflected by the presence of social supports, protecting the individual from illness that might otherwise occur. Alternatively, there may be a reciprocal relationship between stress and social support (McFarlane et al 1983) or chronic illness may influence the ability or desire to maintain social ties. This may be because of the feared stigma of the disease or fears of being 'found out' (Scambler 1988).

Both family and peer supports have been associated with adjustment in children with IDDM aged 6 to 16 years, although peer support was more important in the older subjects (Varni 1989). This age effect was not detected in a study of hypertension in older adolescents aged between 12 and 19 years (Greenberg 1983). It may be that once the difficulties associated with the adolescent period are coming to an end, parental support becomes more welcome.

There may also be important effects of social support on adjustment in older people with diabetes (Carpenter et al 1983). In a study of people over the age of 15 years, Carpenter found that the perception of being positively supported by others, the quality of supports and overall satisfaction with relationships were all related to the process of adjusting to their condition.

There is some evidence to suggest that support from peers and from family should be investigated separately (Lyons 1988). In a study of adults with diabetes compared to a sample of psychiatric patients and a group of college under-graduates, Lyons (1988) measured the level of support received from both family and friends. He found no differences in the perceived level of family support between the college sample and those with diabetes, however those with psychiatric illness did report lower levels of family support. College students appeared to have more peer support than the psychiatric patients, but did not differ this way from the subjects with diabetes. In the same study, the author found that those with diabetes who reported higher perceived support from friends, also reported feeling healthier.

Kelleher (1988a) has described how friendships with peers helped adolescents with diabetes to see themselves as 'normal'. At the same time, he suggested that many teenagers with diabetes experienced in an extreme form, the opposing pressures involved in trying to lead as normal a life as possible with all the associated risks.

Social relationships may be an important source of both practical and emotional help for the young adult with diabetes, but little research has been carried out in this section of the population to evaluate this. Young adults may have different needs compared to younger patients, and there is sparse information to date, on how the disease itself impacts on the development of relationships outside the family. Degree of social isolation, or whether or not young people are able to maintain close relationships, may be associated with degree of metabolic control and ultimately to the serious development of the complications of diabetes. In the vast literature on social support there is little to confirm or dispute these issues.

2.9 Conclusions from the review of the literature.

The literature cited in this chapter leads to many questions, such as whether the presence of diabetes influences educational attainment or the employment experiences of young adults, and if so, are the effects mediated through level of self-esteem. It is also questionable how diabetes in young adults influences family life, and whether having a chronic disease impacts on social relationships outside the family. Large scale studies, incorporating many different diseases, may not identify the effects of specific illnesses on other areas of life. Smaller scale investigations of a single disease may not be representative in terms of their ability to generalise from one set of results to wider populations. However, they are important in view of their ability to identify the particular impact of disease on the lives of individuals, allowing more detailed information to be collected.

The question of the relationship between IDDM, educational attainment and unemployment remains largely unanswered. How chronic illness effects self-esteem may need to be evaluated by looking at specific groups of patients, using more in-depth methods of data collection. Shorter checklist methods of inquiry may not be appropriate at this stage in understanding.

Studies investigating metabolic control have rarely addressed the question of how young people actually feel about their diabetes or their current situation. Many different questionnaires have been employed to measure personality, intelligence or adjustment, but rarely are the thoughts and concerns of the individual studied seriously from their perspective. The balance between family and peer support may change as the transition from school to either further education or the world of work takes place. The experience of illness may lead to the formation of certain attitudes towards the development of close relationships, or it may affect feelings with regard to long-term commitments or marriage and ideas about parenthood.

All these issues have been neglected in the literature on diabetes, and the following chapter of this thesis will outline how the present study was designed with these ideas in mind. The design of the study started from the premise that there may be an important relationship between IDDM, self-esteem, and the education and employment experiences of young adults, which has yet to be evaluated.

3.1 Research design.

In the previous section I have noted the deficiency of research on the experiences of young adults with diabetes, in terms of their education and employment and also with regard to their social and family relationships. One of the hypotheses to be tested in the present study was that the presence of diabetes may in some way influence level of self-esteem in young adults. A further hypothesis was that these two factors (ie. IDDM and self-esteem), either separately or together might affect the life-chances of these young people, in particular their educational and employment experiences.

In order to test this hypothesis, a sample of young adults with IDDM was required. The age-range of 16 to 25 years was decided upon because this would incorporate many of the major changes young people experience, such as examinations, leaving school, employment and developing close relationships. Two local hospital out-patient clinics served by the same diabetic liaison sister, were able to provide a list of all the registered patients with IDDM.

Many of the previous studies reported in the literature have suffered in their design from the absence of a control group and so a local general practice was approached for the purpose of selecting healthy control subjects.

The use of a control group was important to this study, in order to be able to test the hypothesis that it was the presence of chronic disease that influenced education and employment, rather than other factors. To ensure that differences in age and sex did not affect the findings of the proposed study, the control subjects were matched with each diabetic subject on the basis of these two variables. Obviously, other demographic and social factors might play an important role in educational achievement and employment experiences, and these would need to be considered during the analysis of the findings.

Different psychosocial factors such as self-esteem or social support could influence state of health within the two groups of subjects. For example, for those with IDDM glycaemic control could be related to the presence of social or family supports. It was also important to assess the presence of any past or present illness in the healthy control group, as this could influence the findings of the study. This data was available in the form of subjects' case-notes, either from their diabetic out-patient clinic or from their general practice. Information was collected on past medical history, and detailed information was recorded for the year prior to interview.

The methods employed to obtain information from the participants in the present study were chosen for their appropriateness in relation to the nature of the data that was to be collected. Most previous studies in this area of research have used checklist measures, which were not suitable in this case for the eliciting of detailed information about different aspects of self-esteem.

They also did not facilitate the recording of information on subjects' thoughts and feelings about education, employment and social relationships. Earlier childhood experiences may be important for those whose diabetes was diagnosed at an early age, and could influence metabolic control and/or the development of complications. Information on these experiences was unlikely to be obtained satisfactorily by a questionnaire, even if it was extremely lengthy, so a semi-structured interview was deemed to be more appropriate. In order to collect this in-depth information interviews had to be tape-recorded and transcribed later.

The collection of both qualitative and quantitative data was possible in this study; an approach that can be very useful. These two methods are often thought of as entirely separate, however sometimes they are combined, often with one method accorded greater prominence over the other (Bryman 1990). From a quantitative standpoint, qualitative data can be used to illustrate the findings of a study; on other occasions the findings of a predominantly qualitative study may be presented in a quantified form.

In addition, researchers have sometimes used structured interviews in order to simultaneously collect both types of data (Bryman 1990). Silverman (1985) suggested that the use of quantitative data, or 'simple counting procedures', helps to avoid the temptation to use "merely gobbets of information" (ie. qualitative data) in order to support the researchers' interpretation of the findings. The use of quantitative data gives the findings of the whole sample in a summary form and can encourage further qualitative analysis (Silverman 1985).

The specific instrument I proposed to use in my investigation was a semi-structured in-depth interview schedule. Interviews would take several hours and would have to be tape-recorded. This method had both advantages and disadvantages attached to it. The main disadvantage was the lengthy nature of the interviews, and the time-consuming method of transcribing the verbal responses of each subject after the interview had taken place.

However, although this might mean a smaller sample size would have to be used, these disadvantages were compensated for by the amount of detailed information actually obtained. The interview schedule that was used for the study was an appropriate one as it had been recently modified for use with teenagers, and it included sections on self-esteem, education, employment and social relationships. Extra questions specifically related to diabetes would have to be devised separately.

Before I could use this instrument however, I first had to be trained in its application. This entailed listening to interviews which had been tape-recorded by other researchers who were using this method, and learning to record by hand the relevant information for the 'rating' of the data (this method will be described in detail later in this chapter). Personal guidance was available from the originator of this method, and a training manual had also been devised. Once this was successfully completed I was then able to commence my own investigation.

3.2 Selection of subjects

Young adults with insulin-dependent diabetes mellitus (IDDM) and a group of healthy general practice controls matched for sex and age (within one year) were recruited to the study between January 1988 and August 1990. Local ethics committee approval was obtained prior to commencement of the study.

For subjects with diabetes the inclusion criteria were as follows:

- aged between 16 and 25 years
- commenced insulin therapy within 1 year of diagnosis of their diabetes
- on insulin therapy for 9 months or more
- registered as attending diabetic out-patient clinics at either of two hospitals in North West London

Patients with IDDM were approached during their usual diabetic clinic out-patients appointment and the interviewer (CL) discussed the nature of the study with them. Patients failing to attend their clinic appointment received a letter explaining the study (see Appendix I). One week later patients were telephoned and asked if they would like to take part in the study. If the patient did not have a telephone they received a second letter (Appendix II) asking them if they would like to take part. Enclosed with the letter was a reply slip for completion by the patient, and a pre-paid envelope for its return. If no reply was received within two weeks a visit was made to the patient's home, as a final check to see whether they would like to participate. These visits were made in the evening, after normal working hours, to allow time for the patient to have returned home from work.

For those patients who agreed to participate in the study, through either of these recruitment methods, arrangements were made for the interview to take place either in the subject's own home, or at the offices of the Diabetes Epidemiology Unit, Central Middlesex Hospital. Informed written consent was obtained from all subjects (Appendix V).

Criteria for inclusion - neighbourhood controls.

Healthy controls were eligible for selection if the following criteria were met:

- aged between 16 and 25 years
- free from all chronic illnesses (defined as any long continued or permanently established mental or physical illness, whether or not treatment was required)
- registered with one specific general practice unit in North West London

Each diabetic subject was matched for age and sex with a healthy neighbourhood control. Controls were recruited using the computerised list of all patients registered at a local general practice in the same area as the hospitals. Three controls were randomly selected for each subject with diabetes - for example, for a diabetic female born in 1970, all healthy females born in 1970 were listed and, using random number tables, three names randomly selected. G.P. notes were scanned for the presence of any chronic illness.

The first name randomly selected and free from chronic illness received a letter from the general practice doctors (see Appendix III) explaining the nature of the study, and after one week they were telephoned and asked if they would like to take part in the study.

If the subject did not have a telephone they received a second letter asking if they would like to participate (see Appendix IV). As with those subjects with diabetes, a reply slip and pre-paid envelope were enclosed for their response. If no reply was received within two weeks a visit was made to their home during the early evening as a final check. Similarly when subjects agreed to take part, either via the telephone or letter/visit, arrangements were made to carry out the interview either in their own home or at the offices of the Diabetes Epidemiology Unit.

3.3 The Interview.

Interviews took place either in subjects' homes or at the offices of the unit and lasted between 90 minutes and 3 hours. Subjects were interviewed using the Self Evaluation and Social Support Questionnaire, known as the 'SESS' (O'Connor and Brown 1984) (see Appendix VI). The SESS was developed at the Royal Holloway and Bedford New College, University of London, and consisted of a semi-structured tape-recorded interview. The original version was developed over a period of four years in a random sample of women living in North London and took more than 6 hours to administer.

In this study however, the shortened version for teenagers was used. The validation of the SESS will be described later in this chapter. The SESS contained questions on basic demographic details such as date of birth, occupation, marital status and family history, length of residence in the area and number of relatives living close-by etc (see Appendix VI).

Ethnic group was determined by recording both the place of birth for the subject and also the place of birth for their parents. Questions on the presence of any other illness, smoking history, and for those with diabetes, the date of diagnosis were also included. Social class was defined by their own occupation, or, if not working their father's occupation, using the Registrar General's Classification of Occupations (O.P.C.S. 1980). This consisted of the following categories: I - professional, II - managerial, IIINM - skilled non-manual, IIIM - skilled manual, IV - semi-skilled, and V - unskilled.

The demographic section also included questions on the number and type of qualifications obtained and a full employment history. Unemployment was recorded from subjects' reports of any unemployment they had experienced since they had left school. This did not include the six week period immediately after leaving school (ie. the official school summer break) as it was common for many young people not to start work during this period, and many subjects commenced further education courses or started apprenticeships in the September after leaving school.

For those subjects with diabetes, more detailed information in relation to education and employment was also collected; for example whether subjects had experienced any difficulties with regard to their diabetes in these areas in terms of physical, practical or attitudinal problems (see Appendix VII). These questions were devised after considerable review of the literature and were piloted on the first six subjects with diabetes, with any amendments to the questions made at this time.

The SESS method incorporated the recording of qualitative information, but at the same time quantitative data is obtained via the 'rating' of this descriptive information, and this method will be described below. The SESS questionnaire consisted of seven broad areas. The first of these, the 'Self Section', considered the subject's level of self-esteem and the extent to which subjects accepted themselves the way they were both in terms of specific attributes (eg, easy going, attractive, shy) and in terms of the various roles the subject may hold (eg, mother, worker, student).

In this section (self section), separate ratings were made for degree of self-acceptance, positive and negative self-definition for attributed self, and both positive and negative self-evaluation for general self-definition (see Appendix VIII). This section was focussed on the respondents' own evaluation of their more or less enduring characteristics (O'Connor and Brown 1984). Emphasis was placed on those attributes to which the subjects themselves gave the most importance.

The other six sections of the SESS covered the different areas of the subjects' lives and not all sections applied to all subjects (see Appendix VIII). These sections covered education, employment, childhood and parents, marriage, parenthood, and social contacts. In all these sections, the interviewer investigated the subjects' level of 'felt competency' in each area of life, that is, how the subjects perceived themselves in terms of each role, for example, a hard worker, a good husband, a caring mother. Both positive and negative aspects of these were considered and rated separately. The SESS questionnaire also measured the level of commitment the subject had to each of these areas of life, for example their commitment to work or to education. Commitment could be both emotional and personal, and reflected how the person wanted to be, that is, it reflected the ideal self.

The childhood and parents section included questions on lack of approval in childhood and presence of antipathy between the subject and parents. The social contact section included information on the subject's social isolation, their involvement in their peer group, and also several ratings which measured subjects' attitudinal constraints towards close relationships. Separate rating sheets were completed for each person (up to 5) that the subject reported they felt 'very close to'. A 'very close other' or VCO, was defined as someone named in response to the question, "Can you think of anyone you feel very close to?".

A VCO could not be a spouse/partner or boy/girlfriend, but could be other friends or relatives. The ratings on the VCO sheets included information on the degree of emotional and practical support given to the subject, the existence of negative interaction between them, and the level of confiding in those persons. A confidant was defined as someone who was named in response to the question, "If you had a problem of some sort, who would be the first person you would want to discuss it with?" This could include a spouse, partner or boyfriend, as well as other friends or relatives.

In all these six sections of the SESS there were both 'subjective' ratings, based upon the subjects' reported feelings (for example commitment, felt competence) and more 'objective' ratings (such as negative interaction and level of support) which, although relying on the subjects' reports were based on evidence of actual behaviour and examples of relevant incidents. These 'objective' scales were rated contextually, that is, the ratings reflected what the interviewer judged most subjects would have felt in similar circumstances, taking account of the particular biographical situation. All the scales used in this study are described in more detail in the results section.

3.4 Qualitative and quantitative analysis.

On the basis of the qualitative data collected during the interviews a rating procedure was carried out by the investigator. All sections of the SESS were rated on a 4-point scale, ranging from 1 - marked, 2 - moderate, 3 - some, to 4 - little or none.

The tape-recordings of the interviews were played-back by the interviewer at a later date, and each subjects' comments were recorded by hand on the relevant rating sheets. The interviewer must extract the relevant information, which may be scattered throughout the interview, and collate it, in order to make these ratings. Responses to standard questions and also spontaneous comments, made at any time during the interview, were both taken into account when making the ratings. This process was extremely time-consuming as there were between 90 and 200 different ratings to be made, depending on the individual subject (for example, there were extra ratings if the subject was married, or had children). This procedure took approximately eight hours to complete, but in some cases in this study took much longer depending on the length of the interview in question.

Anchoring examples for some of these ratings were compiled at Royal Holloway and Bedford New College (RHBNC) in the form of a dictionary for easy reference. This had been carried out using the results of the initial studies at RHBNC, but was supplemented in the early stages of the research with standardised examples from this study, so that reference could be made to subjects with and without diabetes.

3.5 Validation of the SESS

The SESS has been used previously in a longitudinal study of depression in women in an inner-city district of London (Brown et al 1986). Formal tests of reliability were carried out by comparing the independent ratings of interviewers and observers. This showed satisfactory correlation coefficients ranging from .7 to .9 (O'Connor and Brown 1984). More recently it has been employed in a study of the daughters of the original participants and also in a study of stress in male civil servants. The self-esteem ratings of the SESS have been validated against the Rosenberg Questionnaire (Rosenberg 1965). A correlation of .43 ($p < 0.05$) was found between the overall ratings of self-esteem and scores on the Rosenberg questionnaire for the RHBNC study of daughters (Andrews 1991, personal communication).

After the first 10 interviews had been completed in the present study, a comparison was made between all the interviewer's (CL) ratings on each section of the SESS, and those made on the same interviews by the project leader of the RHBNC study of daughters (Andrews). Ratings were made blind to those already recorded by myself, and an extremely high rate of agreement was obtained (94%).

3.6 CASE-NOTE ANALYSES

A retrospective analysis of subjects' case-notes was carried out for the study participants using the hospital clinic-notes for those with diabetes (Appendix IX) and the general practice notes for the healthy controls (Appendix X). In both cases, the analysis covered the twelve months prior to interview. For both groups of subjects medical notes were also analysed for those who refused to take part in the study. All the case-notes of those with diabetes whom it was impossible to contact were analysed, and a 20% random sample of those from the general practice. Although it would have been possible to carry out case-note analysis in a greater proportion of refusals from the healthy control group this number was seen as adequate, especially in view of the large number of people in this group who could not be contacted (see response rate in results section).

For subjects with diabetes, the number of attendances during the 12 months prior to interview were recorded, as were the presence of any diabetic complications, the most recent blood sugar and urine results, the most recent blood pressure reading, and a record of retinopathy and peripheral neuropathy. Proteinuria was defined by the recording of albusix positive in the patients' notes. Visual acuity was defined as impaired if readings were 6/12 or above.

Glycated Haemoglobin (Ghb) measurements were obtained from the case-notes. This measurement is a method of assessing the level of glucose in the blood during the previous 6 -8 weeks, thus giving a more accurate picture of metabolic control. Ghb has been shown to be a useful measurement in the care of those with diabetes (Goldstein 1984). In the present study Ghb was measured by the affinity chromatography method (Gould 1982), at the laboratory attached to one of the hospitals where the patients with diabetes attended clinic.

For neighbourhood controls, a full medical history was recorded, as was the number of attendances during the 12 months prior to interview. Reasons for any consultations in the previous year and any current treatment being received were also noted.

3.7 Quantitative data analysis.

Quantitative data was entered on a personal computer using D-Base software, and subsequently transferred to the University of London Computer Centre for analysis. Statistical analyses, using the Statistical Package for the Social Sciences (Hie 1983), were carried out using both matched pairs and unmatched tests where appropriate (Fleiss 1973, Bland 1987).

When comparisons were made between the two matched groups (ie. subjects with diabetes and matched controls) and when the variables were dichotomous, McNemar's matched pairs test was employed. In the same situation, but where data was continuous, matched t-tests were used. Elsewhere, Chi-square, student's t-test, and analysis of variance were used in order to test for significant associations between the variables.

CHAPTER FOUR: RESULTS OF THE STUDY.

Having outlined both the aims and the methods of this investigation, it is the purpose of this next chapter to report the findings of the study. The first two sections, parts 4.1 and 4.2, describe the response rate and demographic details of the participants, and are followed by further sections on self-esteem, education and employment. Finally parts 4.6 and 4.7 report the findings on family and social support, and marriage and parenthood.

4.1: Response rate.

A list of 56 young adults with insulin-dependent diabetes (IDDM) was obtained from the two hospital out-patient clinics. Of these, 11 (20%) patients had either moved away and could not be contacted, or did not reply to the letters that were sent out, and did not respond to a personal visit to their home. A total of 45 young adults with diabetes were therefore approached for this investigation. Of these, 40 young adults agreed to participate, giving a response rate of 89% (see Table 1).

A total of 130 healthy neighbourhood controls were written to and asked whether they would like to participate in the study. Half of these were unable to be contacted, either because they had moved away or because they did not respond to two letters and a personal visit to the address. For those who did not respond, it was difficult to ascertain whether or not these people still lived at the address in question.

For the former group however, information was obtained from neighbours or present residents that the person in question had definitely moved away and so were unable to be contacted. In total 64 healthy adults were approached, 40 of whom agreed to participate, giving a response rate of 63%.

Table 1: Response rate of subjects with diabetes compared with matched healthy controls.

	<u>Diabetic Subjects</u>	<u>Controls</u>
	n (%)	n (%)
<u>Total number of subjects contacted</u>	45	64
Agreed/Interviewed	40 (89%)	40 (63%)
Refused	5 (11%)	24 (37%)
<u>Total number of subjects not contacted</u>	11	66
Moved	5 (45%)	36 (55%)
No reply	6 (55%)	30 (45%)

Of the subjects with diabetes, responders and refusals did not differ significantly in terms of age, mean Glycated Haemoglobin (Ghb), number of visits to out-patients or admissions to hospital in the previous year, or in terms of the presence of diabetic complications as recorded in their case-notes. Proportions of males and females and each ethnic group did not differ between those with diabetes who refused to take part and those who agreed to participate.

As Table 1 shows, a large number of healthy young adults whose names were on the computerised register at the general practice had moved from the address given in their medical notes and were unable to be contacted. It was also possible that some of those who did not respond had also moved. There are difficulties in using an age/sex register such as this, especially in relation to this age group, when many young people are likely to be leaving the parental home or changing their address more frequently than older adults. Local population statistics for 1989 (O.P.C.S. 1989) showed that in Brent and Harrow health authority the highest rate of mobility, both in and out of the area was in the 15 - 29 year age group. A study in West London has reported that the highest rates of mobility in that area were in the 16 - 24 year age range (Hanson and Wilks 1984).

In addition, this age group are the least likely to attend their doctor, except for reasons of birth control, as they are probably at the most healthy time of their lives.

Thus, changes of address are less likely to be recorded or may be recorded later after the actual move, in comparison with other sections of the population. It was probably for a combination of these reasons that control subjects were extremely difficult to track down. Once young adults were actually contacted the majority were happy to take part in this study, as the response rate indicates.

Case-note analysis was completed for all the healthy controls who participated in the study, for all those who refused to take part, and for a proportion (20%) of both those who either did not reply, or for whom it was assumed they had moved house. Detailed case-note analysis was carried out at the end of the study, and by this time some of the group who had moved had also changed their general practice, their case-notes had been transferred, and so were not available for review. For those healthy controls whose notes were available, a comparison of various factors was made between the respondents and those who refused, did not reply or who had moved. This analysis demonstrated that there were no differences between respondents and these different groups in terms of the number of attendances at the surgery during the last year or presence of any reported illnesses during this time, including consultations regarding allergy or skin problems, high blood pressure, stomach complaints, difficulties sleeping or headaches, or gynaecological problems.

Healthy adults who refused to participate or who could not be contacted, did not differ significantly from those who took part in terms of sex or mean age. It was not possible to determine the ethnic origin of the non-responders in the healthy control group.

4.2 Demographic Information.

Profile of the study area.

This study took place in the outer London Borough of Brent, which is in the north west of the capital. Brent is characterised by a high proportion of ethnic minority residents, and also by a high proportion of young people aged 15 -29 years. According to the last census in 1981, 33.5% of the population of Brent were either from or descended from the New Commonwealth and Pakistan (as defined by the birth place of the head of household). A further 11.3% were Irish, and 9% originated from other countries around the world, leaving a total of 46.2% born in the UK, or descended from parents born in the UK.

In 1988, the age distribution of Brent showed a peak between the ages of 15 and 29 years, which was more marked than the national picture (Brent Health Authority Report 1988). Brent also had a high level of social disadvantage, as indicated by the Jarman Index (Jarman 1983), which includes factors such as the proportion of unemployed, ethnic minorities, under 5's, one parent families and unskilled workers.

The social class distribution in Brent as recorded for the 1981 census, showed the greatest proportion of residents to be in social class III (48%), with twice the number of manual to non-manual workers in this group (OPCS 1981 Census). Approximately one-third of those living in Brent at this time were in the top two social classes, and 22% were in social classes IV and V.

Demographic details of the study participants.

The demographic details of the sample are shown in Table 2. Proportions of male and female participants in the study were similar. More than half of the subjects (both those with diabetes and controls) were Caucasian. Approximately one third of the diabetic group were of Asian origin, with over 70% born outside the U.K., although more than half of these subjects moved to the U.K. early on in life, at least before school-age. Although only 4 healthy controls were of Asian origin, this did not reflect a higher rate of refusal by these young people, but was due to the comparatively small number of Asians registered at the particular general practice used for the study.

Just over one third of the control group were comprised of Afro-Caribbean subjects, who were mainly born in the U.K. The mean age ($\pm$ SD) of the subjects was 21 ($\pm$ 3) years. Over 80% of both the diabetic subjects and their controls were single and were currently living at home with one or more parent at the time of the interview.

Table 2: Sample characteristics.

		<u>Diabetic Subjects</u>	<u>Controls</u>	<u>Total</u>
		n (%)	n (%)	n (%)
<u>Sex</u>	Males	19 (48)	19 (48)	38 (48)
	Females	21 (52)	21 (52)	42 (52)
<u>Ethnic</u>	Caucasians	22 (55)	21 (52)	43 (54)
<u>Group</u>	Afro/Caribbeans	6 (15) *	15 (38)	21 (26)
	Asians	12 (30) *	4 (10)	16 (20)
<u>Social</u>	I, II	8 (20)	11 (28)	19 (24)
<u>Class</u>	IIINM	29 (73)	20 (50)	49 (61)
	IIIM, IV	3 (7)	9 (22)	11 (14)
<u>Marital</u>	Single	33 (83)	35 (88)	68 (85)
<u>Status</u>	Married	1 (2)	4 (10)	5 (6)
	Cohabiting	6 (15)	1 (2)	7 (9)
<u>Housing</u>	Owner Occs.	24 (60)	16 (40)	40 (50)
<u>Tenure</u>	Private rent.	9 (23)	5 (12)	14 (18)
	Council Rent.	7 (17) *	19 (48)	26 (32)

* p<0.05 compared with controls

in the group with diabetes, Caucasians were significantly less likely to be living at home compared with Afro-Caribbeans and Asians (41% vs 83% vs 83% ; $p < 0.05$). There was no such difference in the healthy control group. For the total sample, subjects who had left home at the time of interview were significantly older than those who were still living at home (23.0 ± 1.8 yrs vs 20.5 ± 3.0 yrs ; $p < 0.001$). A similar observation was made when the group with diabetes and the healthy controls were analysed separately.

Social class, as measured by subjects' or parents' occupation, did not differ between subjects with diabetes and controls. Over half of those with diabetes (60%) lived in housing that was owner occupied, usually by their parents. Of the remainder, approximately half lived in local authority (council) housing and half in privately rented homes. Fewer controls (40%) lived in owner occupied homes, while the remainder were more likely to rent accommodation from their local authority compared to subjects with diabetes ($p < 0.05$). Only a small proportion of control subjects (12%) rented their homes privately. Housing tenure was not influenced by ethnic group in this study.

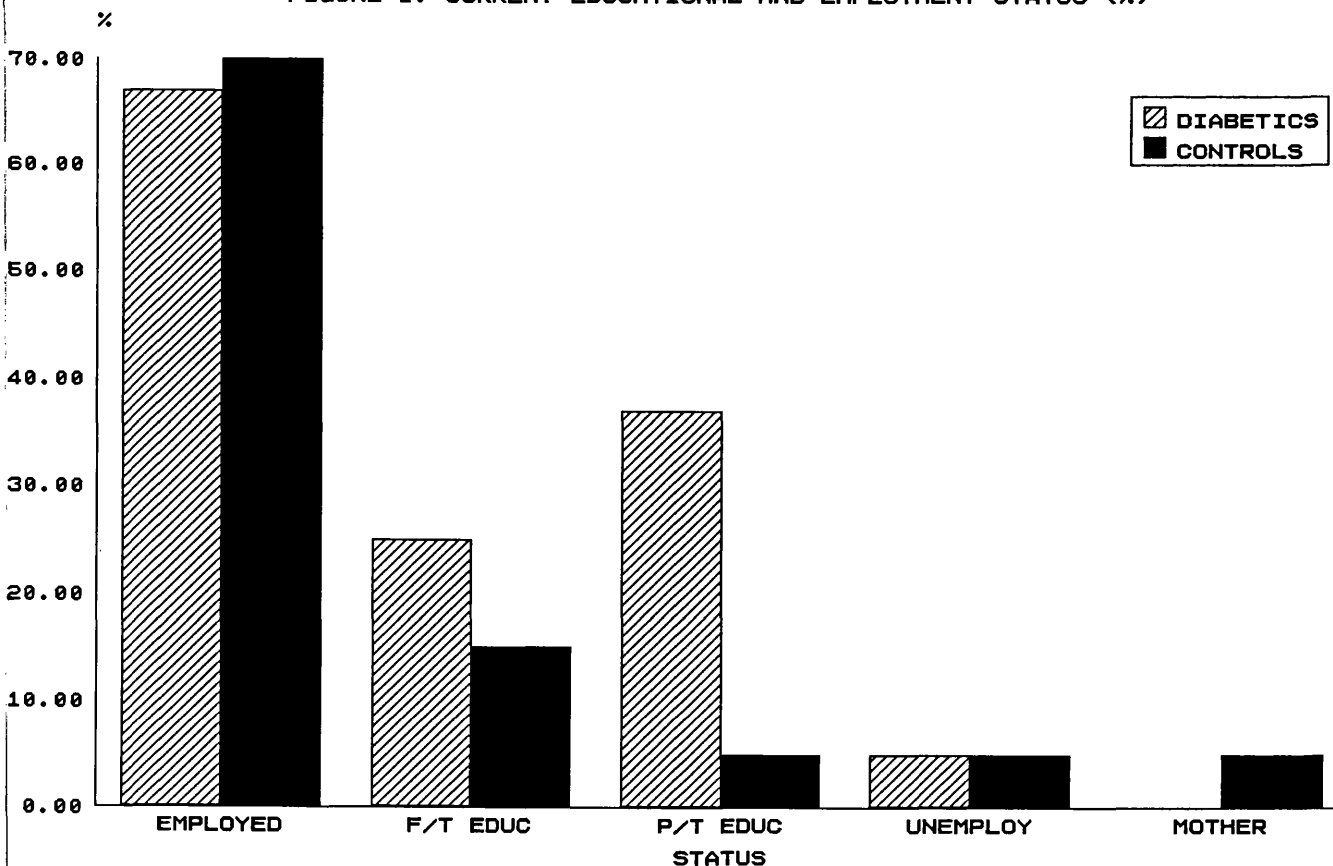
Ethnic group was not significantly associated with subjects' social class as defined by either their own (if employed) or their parent's occupation. However, when parents' occupation alone was taken as the indicator of subjects' social class position, a greater proportion of Asian subjects were in social classes I, and II (77%), compared with both Afro-Caribbean subjects (12%) and Caucasians (23%). This difference remained significant when the controls were analysed separately and a non-significant trend was evident for the diabetic subjects.

A greater proportion of subjects with diabetes were still in full time education compared to the control group (25% vs 15% n/s), as shown in Figure 1 below. At the time of interview, there were no significant differences in employment status between those with diabetes and healthy controls. Of those subjects who had left school, 40% of people with diabetes had experienced some unemployment, compared with 53% of controls (n/s).

Key: F/T EDUC = Full-time education

P/T EDUC = Part-time education

FIGURE 1: CURRENT EDUCATIONAL AND EMPLOYMENT STATUS (%)



All subjects with diabetes who participated in the study were insulin-dependent. To fulfill the accepted criteria for insulin-dependent diabetes, a patient had to have been diagnosed prior to the age of 31 years (which included all potential subjects anyway) and must have commenced insulin therapy within one year of diagnosis (Head and Fuller 1991).

Age at the time of diagnosis of diabetes ranged from 3.8 to 23.3 years, with a mean duration of the disease at the time of interview for the whole group of 7.5 ($\pm$ 5.2) years (range: 9mths to 19yrs). Half of these subjects were diagnosed before the age of 13, with a further 25% diagnosed between 13 and 16 years of age and the remaining 25% being diagnosed over the age of 16. Age at time of diagnosis was not associated with either ethnic origin or sex.

Ghb measurements, taken from subjects' case-notes, gave a mean value of 12.2%. The lowest Ghb recorded was 5.4% and the highest was 31.3% (normal range: 3.5 - 8.0). The average number of increases in insulin dosage ('doses-up') recorded for those who attended out-patients was less than one during the year prior to interview, as was the average number of hospital admissions. Those who had had 'doses-up' were significantly younger compared to those who had not had increases in insulin dose (19.6 ± 3.1 yrs vs 21.8 ± 2.6 yrs; $p < 0.05$) and had a somewhat shorter duration of diabetes (8.6 ± 5.0 yrs vs 5.5 ± 5.4 yrs; $p = 0.09$). Mean systolic blood pressure for all subjects with diabetes was 125.7 ($\pm$ 13.0) mm/Hg and mean diastolic blood pressure was 76.3 ($\pm$ 10.5) mm/Hg.

Case-note analysis revealed that 15 (38%) had already developed one or more diabetic complications by the time of interview (see Table 4). There were no differences in the prevalence of diabetic complications in terms of sex or ethnic group. The most common complications recorded were the presence of proteinuria and the development of retinopathy. Ghb, although higher in the group who had complications, was not significantly different in comparison with those who did not have complications (14.2% vs 12.3% ; n/s). The mean number of Ghb measurements taken during the previous year was 1.4 ($\pm$ 1.5), and the mean number of blood glucose measurements taken at clinic appointments was 2.1 ($\pm$ 2.4). The average number of months between last recorded Ghb and interview was 3.3 ($\pm$ 4.1) months, and for blood glucose it was 1.3 ($\pm$ 3.9) months.

Mean systolic and diastolic blood pressures, number of 'doses-ups' and hospital admissions did not differ between those diabetic patients who had complications and those who did not. Patients with complications were somewhat more likely to have had their diabetes diagnosed at a younger age compared with patients who did not have complications, but this was not statistically significant (12.9 $\pm$ 4.9 yrs vs 14.1 $\pm$ 4.4 yrs).

Table 4: Frequency of diabetic complications. #

<u>Type of Complication</u>	n
Retinopathy	6
Impaired visual acuity	4
Proteinuria	6
Autonomic neuropathy	1
Peripheral neuropathy	1
Total number of subjects with complications	15

Subjects may have more than one complication

The average number of clinic attendances during the 12 months prior to interview was three, however four of the participants in this study did not attend clinic and obtained their insulin supplies from their G.P. These subjects reported dissatisfaction with the diabetic out-patient system, complaining of long waiting times, seeing a different doctor every time, and general feelings of just 'being a number' or being 'herded about like cattle':

D027: "At the clinic everyone's older than you which I don't mind but they look at you, pitying you. And you are there for two to three hours, and then you go in and see a doctor whom you've never seen in your life before, and you're trying to have a conversation with him and he's trying to find out about you and in five, ten minutes you're gone. And you get a ticking off for not controlling your sugar or he'll bring something up about pregnancy or something, and you think 'what the hell', and then you're gone and he says 'please look after yourself', and you say 'yes doctor', and you know you're going to see someone else next time"

It may be difficult to come to any firm conclusions about the type of patient who is a regular attender at out-patients. Those who do attend may be more likely to be in poor metabolic control, although information on Ghb for the non-attenders was not available in the present study. Alternatively, those who attend out-patients could be more motivated in terms of self-care, although it may be unwise to generalise about the behaviour of this group of patients. In the present study those who did not attend were no more likely to be male than female, and did not differ from those who did attend hospital out-patients in terms of their ethnic origin or social class. Although numbers were small, those who did not attend were no more likely to have complications compared with those who did attend the clinic.

Subjects with diabetes were significantly more likely to have Negative Evaluation of Self (NES) compared to healthy controls (see Table 5). Negative Evaluation of Self, or NES, was defined by a composite score for which subjects had to score high or moderate on one (or more) of three separate scales which measured a) degree of self-acceptance, b) degree of negative evaluation of attributed self-definition and c) degree of negative evaluation of general self-definition. These different scales are described in more detail below.

In a matched pairs analysis, 12 subjects with diabetes had NES when their matched controls did not, compared with 3 healthy controls who had NES when their matched diabetic subjects did not ($p < 0.05$). (see Table 5).

Table 5: McNemar's test to evaluate the level of agreement between each pair of subjects for the presence of NES.

		<u>DIABETIC SUBJECTS</u>	
		<u>NES</u>	<u>NO NES</u>
<u>CONTROLS</u>	<u>NO NES</u>	12	24
	<u>NES</u>	1	3

*

* $p < 0.05$

The presence of NES was not related to the sex of the subject, when the diabetic subjects and healthy controls were considered together. However if these two groups of subjects were analysed separately, females with diabetes were significantly more likely to have NES than males with diabetes (48% vs 16%; $p < 0.05$). This sex difference was not observed for the healthy controls, although only 4 subjects in this group had NES, which would have made possible differences difficult to detect. The presence of NES was not associated with any particular ethnic group or social class.

In all the following sections, where subjects' responses are reported in full, the notation 'I' indicates the interviewer's questions, the letter 'C' identifies the control subjects' responses and the letter 'D' indicates the replies of the subjects with diabetes.

Self-acceptance.

The component parts of the overall NES rating were also analysed separately. The first aspect, the degree of self-acceptance shown by subjects, took into account the extent to which the subjects accepted themselves and/or felt unhappy with the kind of person they were. This rating also incorporated comments that subjects may make regarding things that they would like to change about themselves, and whether they would like to change places with anyone because of either the type of person others were, or the kind of person they themselves were.

Respondents were also asked whether they felt that anyone might like to change places with them and for what reason. The self-acceptance rating took account of responses to the other aspects of the self-esteem questions such as the subjects' satisfaction with their performance in certain roles, or their acceptance of their various attributes. Ratings were made on a four-point scale, ranging from marked, to little/none, but for the purposes of analysis were dichotomized into high (the top two points on the scale) and low (the lower two points on the scale). Some subjects showed a low degree of self-acceptance, for example a young girl with diabetes responded to questioning as follows:

I: "How happy are you with yourself, and the way you are?"
D003: "Not very happy."
I: "Is there anyone you would like to change places with..?)"
D003: "Everyone, no not really, I don't think so, no."
I: "Do you think anyone might like to change places with you?"
D003 "Oh God no, they don't know what its like to be me. I mean, no-one's commented recently how lucky I am, people at school, friends I used to know, I mean they wouldn't want to change places with me."

Other respondents portrayed a marked degree of self-acceptance, as this 25 year old female healthy control demonstrated:

I: "How happy are you with yourself, and the way you are?"
C0301 "I'd rather be me than anybody else, I like me the way I am."
I: "Is there anyone you would like to change places with?"
C0301 "No, I'm not going to say I'd change places with anyone."
I: "Do you think anyone might like to change places with you?"
C0301 "They might do sometimes."

Subjects with diabetes were somewhat more likely to exhibit a low degree of self-acceptance compared with their matched controls (see Table 6). A matched pairs analysis indicated that six diabetic subjects had low self-acceptance when their controls did not, compared with only one healthy control who had low self-acceptance when their matched diabetic subject did not (n/s).

Table 6: McNemar's test to evaluate the level of agreement between diabetic subjects and controls for the presence of high vs low self-acceptance.

		<u>DIABETIC SUBJECTS</u>	
		<u>HIGH</u>	<u>LOW</u>
<u>CONTROLS</u>	<u>LOW</u>	1	1
	<u>HIGH</u>	32	6

In total, 7 subjects with diabetes had low self-acceptance compared with only 2 of the controls. Self-acceptance was not associated with social class, ethnic group or sex of the subjects.

Almost half (43%) of those with diabetes exhibited a low degree of acceptance of their disease and said that they would rather not have diabetes. Not all those who showed a lack of acceptance of their disease had a low level of self-esteem (ie. NES), but for some there was a connection:

- I: "Do you think anyone might like to change places with you?"
- D005 "No, I mean, how many injections do I take a day?, four, oh, mouths gape open, so, no, no way."
- I: "Is there anyone you know that you'd like to change places with?"
- D001 "I wouldn't like to be a diabetic, but I don't think I'd like to change places with anyone. I hate being a diabetic, because my sisters were married at this time, by the time they were my age..."

Both of the young diabetic females quoted above were of Asian origin, however the former subject was much younger (16 years old compared to 23 years of age for D001) and did not have as low a level of self-esteem as the latter. This subject (D001) remarked that she felt that the reason why she had not yet been married was because she was not a 'good catch' for any man. D001 came from a very traditional Asian family and was to have an arranged marriage. However this was proving difficult to organise, and both the subject and her mother blamed her diabetes for this state of affairs.

Other respondents also demonstrated a low degree of acceptance of their disease, mentioning quite early on during their interview, their feelings about their illness:

D006: "I think I would like it if I wasn't diabetic."

D013: "I really wish I wasn't diabetic."

D029: "Well, I wish I wasn't diabetic. At certain times you think, oh shit, you gotta plan this and you gotta plan that, you know."

Other subjects were less concerned about having diabetes, and demonstrated that for them, their illness was not so important to their level of self-esteem. These subjects seemed to accept their condition more readily as a part of their lives, and instead asserted that there was nothing about themselves that they would like to change:

D007: "Health-wise, there's no great problem really, maybe if it was a bit more serious, or if there were problems involved then maybe I would think, 'oh God', but no, not really."

D025: "Well I've learnt to live with it. If I could change it obviously I would, but it's something that can't happen, so you've got to live with it."

D008: "I'm alright, apart from the diabetes and doing the injections, apart from that I'm alright."

D009: "No, not really, to me it doesn't seem a very big barrier."

Similar proportions of male and female diabetic subjects accepted their diabetes. Acceptance of their condition was also unrelated to ethnic origin, social class, chronological age or age at diagnosis of diabetes.

Attributed Self.

The second component part of the NES rating incorporated an evaluation of the attributed self, that is, the degree of negative evaluation of the self in terms of the subject's attributes. This rating was more specific compared to the first, in that it took into account statements about the kind of person they were, such as comments about physical attractiveness, or emotional and intellectual attributes. Evaluation of these attributes by the subject, both in terms of their own personal standards and in terms of comparisons the subjects might make between their own attributes and those of others, were also recorded. The ratings were again made on a four-point scale and divided into high and low negative evaluation for the purposes of analysis.

A matched pairs analysis demonstrated that subjects with diabetes were somewhat more likely to have a high negative evaluation of their attributes compared to healthy controls. A total of eight of those with diabetes had high negative evaluation when their controls did not, compared to two controls who had high negative evaluation when their matched diabetic subjects did not (n/s) (see Table 7).

Table 7: McNemar's test comparing matched pairs in terms of the presence of high vs low negative self-definition - attributes.

		<u>DIABETIC SUBJECTS</u>	
		<u>HIGH</u>	<u>LOW</u>
<u>CONTROLS</u>	<u>LOW</u>	8	29
	<u>HIGH</u>	1	2

In total, only 3 controls had high negative evaluation of attributes, compared to 9 subjects with diabetes. This aspect of NES was not influenced by subjects' social class or ethnic group. However, diabetic females were significantly more likely to have negative evaluation of attributes compared with diabetic males (9 vs 0 ; $p < 0.01$). This sex difference was not found for the healthy controls. Respondents often described themselves in both positive and negative terms, and these would be rated on two separate scales:

D004: "I'm a bit shy. I'm not really intelligent, I'm not backward though, I'm somewhere in between. I give way to other people. I like to get on with people, I don't like to be enemies with people. I'm a friendly person."

C0011 "I can be fun, I can be moody. If I don't feel well I can be irritable. I've never been a very confident person, I don't mix very easily. I'm quite efficient. I'm not of the highest intelligence, but I'm not stupid."

Other respondents reported mainly negative attributes such as the following two subjects:

D003: "A bit shy, stubborn, I don't think I'm worse than other people, I'm average. There are some things about me that people hate."

C0031: "I'd like my weight to go down a bit more and I want my stammering to stop forever, but I can't see that happening whatever happens. No, I think I'm bloody ugly, that's how I feel about myself inside, that I'm not nice."

General Self - Definition.

The third aspect of NES is the degree (either high or moderate) of negative self-evaluation in terms of the subject's general self-definition. This rating took into account both negative evaluation of attributes as in the previous rating, but also incorporated negative evaluation in terms of the subject's positions or roles in life, for example as a parent, or spouse, or as a student or employee. When making this rating it was necessary to look for evaluative statements regarding attributes and also comments relating to the subject's performance in roles that were relevant for that particular individual. Indicators for this rating also included the subject's comparison of their performance in these roles with that of others, as well as in terms of their own personal standards.

To assist in this rating, the scores given on the felt competence/incompetence scales in the marriage, motherhood, education and work sections were also taken into account. As with the previous ratings, the four-point scale was dichotomized for analysis into high and low scores.

A matched pairs analysis demonstrated that four subjects with diabetes had high negative general self-definition when their matched controls did not, compared with only one healthy control who had high negative general self-definition when their matched diabetic subject did not (n/s) (see Table 8).

Table 8: McNemar's test to evaluate the level of agreement between pairs for the presence of high vs low negative self-definition - general-definition.

		<u>DIABETIC SUBJECTS</u>	
		<u>HIGH</u>	<u>LOW</u>
<u>CONTROLS</u>	<u>LOW</u>	4	34
	<u>HIGH</u>	0	1

The first subject recorded below exhibited high negative general self-definition. She was studying for her A' levels through a correspondence course. A good education was of paramount importance to her, as it was a means not only to becoming educated (an important goal in itself in her eyes), but it was also a door to the outside world; a way to leave home through attending college or University. This subject lived with her parents who had been on the verge of separation for many years and her earliest memories were of her "parents arguing and then dad walking out".

Her older sister shared a bed with her, which made it difficult for her to sleep, and she often tried to snatch a few hours sleep during the day. She received little, if any, sympathy or support from her family in relation to her diabetes, and had decided that the most important aim in her life was to leave home and 'better herself'. However, although her commitment to education was high, this subject's felt competence in educational terms was not, and her self-esteem was low:

I: "What do you think matters most to you?"

D003: "Getting my A'levels, getting healthier. Most women feel they're going to finish their secondary school and go and get married and that, but to me, I'm not thinking of getting married, I'm thinking of how to better myself."

I: "Have you done well at school?"

D003: "No, I don't think so. If its common sense yes, but when it comes to studying I'm slow".

"I always seem to be late for school."

"No-one can tell me what to do, I've always been like that." (feels this is detrimental to her studies)

The following young female with diabetes reported that she felt that she had been good at sports until she was diagnosed as having diabetes at the age of 12. Her parents had worked abroad, although this had not led to frequent changes of environment or school for her. By the age of 16, this subject had completely lost the sight in one eye, and had had an operation on the other:

D035: "I was quite a good runner before I became diabetic. I was 12, before that I won all these cups, all these medals. I had long legs then. I used to win all the medals. When my diabetes hit me, you sort of lose all confidence. You think, 'if I run too fast I'm going to have a hypo'. At my last school I wasn't that good anymore, there were people better than me."

It is important when measuring self-esteem to take into account other social roles that are significant in young adults' lives. This may be central to the development of self-esteem for certain individuals, for example being a parent or a wife or having a specific level of felt competence in social roles, as a 'social animal', as the following example illustrates:

C0011: "I've never been a very confident person, I don't mix very easily. I find it hard if I'm in a crowd of people and I don't know everyone. Unless someone talks to me or makes the effort I'm inclined to just sit there and not ..., but then I've always been like that. Now I'm going out more again I do try and talk to people."

This last respondent had been fairly isolated as a single mother caring for her young child. At the time of interview she exhibited a high commitment to a social life, having decided that it was time to get out more, and had been taking up offers of child-minding from her close family. Thus when rating this subject it was important to take account of how she felt with regard to her sociability.

Positive ratings on the SESS.

Two other aspects of self evaluation were recorded during the interview, although they did not make up part of the NES rating; firstly, that of positive self-definition in terms of attributes, and secondly, a rating of the level of positive general self-definition.

The first, positive self-definition of attributes, took into account similar aspects as the rating for negative self-definition of attributes, but, as the title suggests, took the positive aspects rather than the negative ones. As before, the ratings were divided into high and low scores.

Subjects with diabetes were significantly more likely to have a low positive self-definition in terms of attributes, compared with the control group. In a matched pairs test, 10 subjects with diabetes had low positive self-definition when their healthy controls did not. None of the healthy controls had a low positive self-definition ($p < 0.01$). Positive self-definition was not influenced by subjects' sex, social class or ethnic origin.

The following two respondents, the first a female with diabetes and the second a diabetic male, exhibited a low degree of positive self-definition:

I: "Do you feel you are an intelligent person, or not really?"

D013: "I wouldn't say I'm brilliant at anything, but I don't think I'm stupid."

I: "Do you feel you are an attractive person or not really?"

D013: "Not particularly. Other people might think I am, but I'm not too sure."

I: "Do you think you are better or worse than other people?"

D017: "Not either actually. I think I'm pretty average myself. I don't think I'm very special. But certainly I think I have my own views and I think I view situations in a different way to other people. I believe I'm distinct in those terms."

The final aspect of self-evaluation measured in this study, level of positive general self-definition, took into account the subjects' descriptions of themselves in terms of both attributes and their performance in roles. Again, as with the previous rating, the indicators used were the positive aspects of the same scale that had been used for rating negative general self-definition.

A matched pairs analysis demonstrated that eleven subjects with diabetes had low general self-definition when their matched controls did not, in comparison with none of the controls having a low general self-definition when their matched controls did not ($p < 0.001$).

The following respondent, a 22 year old female with diabetes, was not diagnosed with diabetes until after her 19th birthday, and had spent some of her teenage years away from the area where she grew up, when her parents decided to move away from London. She left home shortly after being diagnosed, and lived with her boyfriend and his flat-mates. This subject had passed a two-year pre-nursing course and had initially been accepted to train as a nurse. However, after a medical, she was told they were unable able to accept her as they found her diabetes to be unstable. Her present occupation was as a clerical worker. She had only a few friends whom she saw 'once in a blue moon', and did not have anyone she felt very close to. She showed a low level of positive self-definition:

D016: "I'm OK at my job.

I: "Do you feel you are a sociable sort of person, or not really?"

D016: "No, not really. I think people find it hard to get on with me. I'm an easy person to live with. I wouldn't say I'm very popular, no I'm not popular, just average really. I wouldn't put over my opinion, I'm a listener really, you never know, you could say the wrong thing, so I'm more of a listener."

The following diabetic subject was one of the youngest to participate in this study, and was still at school studying for his 5th year exams:

I: "Do you feel you are a sociable person or not really"

D023: "Sometimes. Not that popular, no."

I: "What kind of student are you?"

D023: "Average" (S doesn't know whether he is doing well in his studies).

Whilst in this sample the majority of subjects were single, did not have children, and were either in full-time education or employment, some had other important roles. The following healthy subject was a full-time mother, highly committed to the idea of motherhood, and described her son as her "whole world":

C0011: "I think I'm a better person really. When you see girls of my age and their kids, and they're all dolled-up and the kids look bad, I think to myself, oh how can they be like that, I couldn't you know, C comes first - if he needs something I can go without. I can walk around in old clothes but not my son. He always looks as nice as I can make him. I think I'm a better mum for that. But I don't think I'm better in general than anyone, but no-one's better than me."

Negative Evaluation of Self (NES) and the state of health of subjects with diabetes.

A comparison of the state of health of the diabetic subjects who did and did not have NES is shown in Table 9. The presence of diabetic complications was not significantly related to NES, although a slightly greater proportion of those with NES had complications (46% vs 33%; n/s). Diabetic subjects who had NES tended to have had their diabetes diagnosed at a slightly younger age compared to those with diabetes who did not have NES (12.9 ± 5.2 yrs vs 14.0 ± 4.3 yrs n/s), but this was not significantly different. Duration of diabetes did not differ between these 2 groups (8.5 ± 5.4 yrs vs 7.0 ± 5.1 yrs n/s).

Negative Evaluation of Self (NES).

	<u>NES</u>	<u>NO NES</u>
	(n=13)	(n=27)
	n (%)	n (%)
With complications	6 (46)	9 (33)
With increase in insulin dose in last year	7 (54)	7 (26) *
	<u>NES</u>	<u>NO NES</u>
	MEAN (SD)	MEAN (SD)
Ghb (%)	13.8 (3.4)	12.8 (5.1)
Blood Glucose (mmol/l)	11.7 (5.7)	10.4 (6.3)
Systolic Blood Pressure (mmHg)	123.0 (14.9)	127.1 (12.2)
Diastolic Blood Pressure (mmHg)	73.5 (12.0)	77.8 (9.7)
Mean number of visits in last year (n)	3.2 (2.2)	2.7 (1.8)
Duration of diabetes (yrs)	8.5 (5.4)	7.0 (5.1)
Age at diagnosis (yrs)	12.9 (5.2)	14.0 (4.3)

* p<0.05 compared to diabetic subjects with NES

Mean Gnb did not differ significantly between the two groups. However those with NES were significantly more likely to have required an increase in insulin dose in the 12 months prior to interview, compared with the diabetic subjects without NES (54% vs 26% ; ($p < 0.05$). There was no difference in blood pressure level between those with and those without NES.

This section of the results has shown that the presence of IDDM was significantly related to low self-esteem, or NES, thus supporting one of this study's hypotheses. Although the presence of NES was not related to social class or ethnic origin, more females than males had NES. A second hypothesis was that the presence of low self-esteem may be associated with differences in state of health, in terms of poorer metabolic control, or the presence of diabetic complications. This hypothesis was not supported by the findings of this study. Almost half of the diabetic respondents demonstrated a low acceptance of their disease, and for some of these subjects this was related to their level of self-esteem. Low self-esteem may be associated with poorer educational performance or with negative employment experiences, and it is the aim of the following chapters to address these questions.

This section of the results evaluates whether subjects with diabetes fare less well in terms of their educational achievement compared with their matched controls, and also whether low self-esteem plays a significant role in this relationship. The experiences of those who had diabetes whilst at school will also be described.

Age at which subjects left school.

At the time of interview, 25% of subjects with diabetes and 15% of controls were in full-time education. Of the remaining people, no difference was detected in the mean age at which those with diabetes and their matched controls had left school (diabetic subjects: 17.7 ± 1.7 yrs vs controls: 17.4 ± 1.2 yrs; n/s). For the total sample, those in the lowest social classes were significantly less likely to have left school after the age of 17 years, compared with those in the other social classes (18% vs 61% vs 77% ; $p < 0.001$, for social classes IIIM,IV, IIINM, and I,II respectively). This social class difference in school leaving age was also apparent when the subjects with diabetes were analysed separately, but was not evident for the healthy controls. The age at which subjects left school was unrelated to either sex or ethnic origin.

Both groups were committed to the idea of obtaining a good education. A matched pairs test demonstrated that there was no difference in level of commitment between diabetic subjects and controls, with 21 pairs (53%) being highly committed to education. A total of 70% of the controls and 62% of those with diabetes were highly committed to education; either because this meant that they would be able to obtain a better job if they had a good education, or for education's sake, as an end in its own right:

I: "How important is it to have a good education?"
D001: "I think its really important. It's been important to me"
I: "Do you think if people haven't been well educated they are at a disadvantage in life?"
D001: "To earn their living, from that point of view, yes."

I: "How important is it to have a good education?"
C0081: "Very important. I had a very good education, I was lucky. I won't be able to afford the same type of education for my son which worries me a bit. When I see the schools around here, I really don't think much of them. Its very, very important."

Two Asian subjects with diabetes, explained how important it was in the context of their ethnic background to have a good education:

D008: "Very important, especially in an Indian family, you have to come up to their standards."

D006: "It's pretty important because in our religion if you have a higher education then you are more likely to get a nicer husband, or that's how they see it, so its good to do better in your education..."

For the total sample, subjects who were highly committed to education were also more likely to feel moderately or highly competent in education, compared to those who were not highly committed (81% vs 53% ; $p<0.05$). They were also more likely to have taken some sort of further education, compared to those who were not so highly committed (80% vs 20%; $p<0.05$). Commitment to education was not influenced by either the subject's or the parent's social class position, or by sex. Diabetic Caucasians were significantly less committed to education compared with Afro-Caribbean or Asian diabetics (46% vs 100% vs 75% ; $p<0.05$). Conversely, there were no ethnic group differences in commitment for the healthy controls.

Academic qualifications

There were no differences in the level, type or number of qualifications obtained by subjects with diabetes in comparison with the healthy control group. Those with diabetes appeared to do as well as their matched controls in academic qualifications, such as CSE or GCE O'level examinations (see Table 10), and in higher or further qualifications, such as A'levels, ONC level or HND level (see Tables 11, 12, and 13).

There was no difference in the proportion of those with diabetes and their healthy controls who had failed further educational qualifications. Females and males achieved comparable qualifications, except for CSE's, where females obtained fewer qualifications.

Table 10: McNemar's test comparing those with (YES) and those without (NO) one or more GCE O'levels.

		<u>DIABETIC SUBJECTS</u>	
		<u>YES</u>	<u>NO</u>
<u>CONTROLS</u>	<u>NO</u>	10	7
	<u>YES</u>	16	7

Table 11: McNemar's test comparing those with (YES) and those without (NO) one or more A'levels.

		<u>DIABETIC SUBJECTS</u>	
		<u>YES</u>	<u>NO</u>
<u>CONTROLS</u>	<u>NO</u>	3	31
	<u>YES</u>	2	4

Table 12: McNemar's test comparing those with (YES) and those without (NO) ONC or equivalent qualifications.

		<u>DIABETIC SUBJECTS</u>	
		<u>YES</u>	<u>NO</u>
<u>CONTROLS</u>	<u>NO</u>	6	23
	<u>YES</u>	5	6

Table 13: McNemar's test comparing those with (YES) and those without (NO) HND or equivalent qualifications.

<u>DIABETIC SUBJECTS</u>		
	<u>YES</u>	<u>NO</u>
<u>NO</u>	5	29
<u>CONTROLS</u>		
<u>YES</u>	2	4

For the total sample, subjects in the highest 2 social classes were more likely to have obtained both GCE O'levels and A'levels, compared with those in the other social classes (GCE O's: 84% vs 65% vs 44% ; $p < 0.05$. for social classes I,II, IIINM and IIIM,IV respectively. A'levels: 37% vs 12% vs 3% ; $p < 0.01$, for social classes I,II, IIINM and IIIM,IV respectively.) No other social class differences in qualifications were evident for the whole sample.

When subjects with diabetes and the controls were analysed separately, controls in social classes I and II were more likely to have passed A'levels (45%) compared to controls in social class IIINM (10%) and social classes IIIM, IV (0%) ($p < 0.01$). This difference was not present in the subjects with diabetes, however in this group those in social classes I and II were more likely to have passed GCE O'levels (100%) compared with those in social class IIINM (69%) and social classes IIIM, IV (44%) ($p < 0.05$).

When only those subjects who had left school were investigated, in the same way as above, similar findings with regard to social class and qualifications were observed. Ethnic origin was not significantly associated with whether or not subjects had obtained GCE O'levels, A'levels, HND or equivalent, or a Degree, and did not influence whether or not subjects had failed any further educational qualifications. However, Afro-Caribbean subjects were significantly more likely to have obtained ONC qualifications when considering the total sample, and the diabetic subjects and controls separately. For the total sample, 48% of Afro-Caribbean subjects, 28% of Caucasians, and none of the Asians had obtained ONC qualifications ($p < 0.01$).

Again for the total sample, Afro-Caribbean subjects were also somewhat more likely to have obtained CSE qualifications; 71% of this group had obtained CSE's, compared with 47% of Caucasians, and 38% of Asians ($p = 0.08$). There was a similar non-significant trend for both subjects with diabetes and controls when analysed separately. These findings were not related to the age of subjects.

Educational achievement and self-esteem in subjects with diabetes.

Further comparisons were made within the diabetic group, in order to investigate whether the presence of NES was related to actual academic achievement, and whether any sex differences predominated. Whether or not subjects with diabetes had passed one or more ordinary level qualifications was unrelated to NES (Table 14).

with diabetes.

	<u>NES</u>	<u>NO NES</u>
	(n=13)	(n=27)
	n (%)	n (%)
<u>Qualifications</u>		
One or more CSE's	8 (62)	11 (41)
One or more GCE O' levels	9 (69)	17 (63)
ONC or equivalent	4 (31)	7 (26)
One or more A' levels	0 (0)	5 (19)
HND or equivalent	1 (8)	6 (22)
Degree	0 (0)	2 (7)

However, the number of GCE O'levels passed was related to the presence of NES in this group; those who did not have NES passed significantly more O'levels than the diabetic subjects who did have NES (6 vs 4 $p < 0.05$). Although numbers were small, diabetic subjects without NES were more likely to have obtained higher educational qualifications (either A' levels, HND or Degree), compared to those with NES (9 vs 1 ; $p = 0.08$). Similar non-significant results were observed when all those who had NES (ie. both subjects with diabetes and healthy controls) were compared to all those who did not have NES.

If the specific type of qualification passed is considered, diabetic subjects without NES were more likely to have obtained one or more A' levels compared to diabetic subjects with NES ($p = 0.09$), and were somewhat more likely to have obtained HND qualifications or a degree (see Table 14). They were also less likely to have failed further educational qualifications, although these findings did not reach significance.

These trends suggesting possible differences between diabetic subjects with and without NES and their academic achievement, were also observed when the sexes were analysed separately.

When each social class grouping was considered separately, a non-significant trend existed, such that those with NES were less likely to have obtained qualifications compared with those who did not have NES, however the numbers were small.

Subjective competence in school.

Although it has been demonstrated that academic achievement may possibly be related to the presence of NES, a more specific measure of self-esteem was also used, that of the level of 'felt competence' in educational terms. The overall NES rating encompasses the level of felt competence in education, but also includes other aspects of self-esteem. Level of felt competence in education was indicated by the extent to which subjects evaluated their ability at school positively or negatively, both in terms of their own standards and in comparison with their peers. Although this more specific rating incorporated non-academic as well as academic areas of educational experience, subjects tended to focus on their academic achievements. There was a significant correlation between felt competence in education and NES; all subjects, both cases and controls, who felt low in competence were more likely to have NES, compared with subjects reporting high felt competence in education (45% vs 12%; $p < 0.01$).

Those who were still in full-time education were questioned with regard to their felt competence at school, and responses were measured on a 4-point scale ranging from high/marked to little/none. These scores were dichotomized into high and low felt competence. Those who had completed their full-time education were asked similar questions but were referred back in time to the last 2 years of their education.

Some respondents showed a high degree of commitment to education and also felt moderately or highly competent. The diabetic female quoted below was highly committed to education and aimed to continue into higher education:

D002: "I like the non-science subjects. I'm OK (behaviour-wise). I'm good at sociology. I'm not good at chemistry, I might not be entered for that one. I'm doing alright at the moment."

This second example, a male healthy control, had left school with good examination results, both at O'level and A'level:

C0081: "I did OK, I did better than most. Luckily I'm the kind of person who doesn't have to revise so... I didn't really excel at anything, I'm more of an all-rounder."

Those with diabetes were significantly less likely to feel highly competent in terms of their performance within the education system compared to their healthy controls. A matched pairs analysis demonstrated that 13 controls felt highly competent when their matched subjects with diabetes did not, compared to only 2 diabetic subjects who felt highly competent when their matched controls did not ($p < 0.01$). When the sexes were analysed separately, male controls were significantly more likely to feel highly competent in education compared to diabetic males (83% vs 53%; $p < 0.05$). Female controls were also more likely to rate themselves as competent in comparison with diabetic females, but this was not significant (91% vs 70%; $p = 0.09$).

Those in the lower social classes were less likely to feel competent in education compared with those in the higher social classes (58% vs 80% vs 95% ; $p<0.01$). This social class difference was also found for the controls when analysed separately, however there were no social class differences in felt competence within the group with diabetes. Ethnic group did not influence felt competence in education for the total sample, or for the controls, however, diabetic Caucasians were somewhat less likely to feel competent compared to diabetic Afro-Caribbeans or Asians (45% vs 80% vs 83% ; $p=0.06$).

Subjective competence and qualifications.

For the total sample, those who felt highly competent in education were significantly more likely to have obtained A'levels compared with those who felt less competent (11 (19%) vs 0 (0%) ; $p<0.05$). A similar but non-significant trend was found for HND qualifications and GCE O'levels. Similar results were observed for those with and without diabetes, when these two groups were analysed separately. For all subjects, those who felt high in competence were more likely to exhibit a high commitment to education compared to those who felt low in competence (83% vs 55% ; $p<0.05$).

The majority (83%) of the diabetic subjects who participated in this study were diagnosed as having diabetes while at school, and of these 20 (61%) reported that they had experienced problems while at school. This was not confined only to those still at school at the time of the interview. Subjects who had already left school also reported having had difficulties whilst they were there. There were no sex, ethnic group or social class differences in terms of who reported these problems, which ranged from physical education to peoples' attitudes. Difficulties often started before diagnosis:

D028: "Just when I first became a diabetic. I missed lots of school cos of being in hospital. Before I was diagnosed I had a lot of problems because I kept needing to get a drink of water or go to the toilet, and I became very grumpy with people. I wasn't listening in class, I was asleep most of the time. Luckily I was caught, it was only a few months before I was found out"

D031: "I only had problems at first when it was diagnosed. When it was under control there were no problems."

Once diabetes was diagnosed there was the fear that the people around them might change their attitude towards them. The first respondent quoted below reported his feelings when attending an interview in order to be accepted at the local grammar school:

D034: "I remember thinking maybe they won't take me now cos I'm diabetic."

The following subject was also diagnosed while still at school, and was also concerned about the way he might be treated:

D037: "At first when they first heard about it they did (treat me differently), but after a while they were just normal."

A small proportion (15%) reported that they either did not tell anyone about their diabetes or refused to talk about it at school. This was a relatively easy task if they did not have any hypoglycaemic attacks whilst at school:

D031: "I didn't tell anyone. I used to take sandwiches. I didn't have any hypos."

D014: "I don't talk about it. If someone offers me something to eat I say I've already eaten or that I don't eat in the day time." (He denies its because of diabetes if asked).

About one quarter of the respondents who reported any problems in relation to their diabetes and their education, described those difficulties in terms of the change in other people's attitudes. Some subjects reported positive changes which were sometimes welcomed, such as being more understanding or showing a more caring attitude:

D029: "They treated me better , took more care, more understanding, the teachers as well."

D012: "They looked after me kind of. I knew who my friends were, they were the ones who came to see me in hospital."

However other subjects reported changes for the worse, describing a lack of understanding and a misinterpretation of the symptoms of the disease. The following case, a young Asian school-boy was a good example:

D023: "What they actually think is that I've just eaten too many sweets and chocolates and that's why I'm diabetic, which I don't like, but I just ignore them, they don't understand."
"The teachers treat you differently, if you're running around they worry."

Another female respondent described how she had frequently been absent during the first few years after diagnosis, and how she perceived the teachers' sympathy for her, which she had tried to ignore. At the same time the other children told her she was lucky being able "to get away with time off". A young male with diabetes described his friend's reaction when he was first diagnosed at the age of 14:

D038: "There was one lad who found my insulin and asked what it was for. I said it was for an injection, and the lad said 'ugh', like I had the lurgy, stuff like that."

This last respondent said he did not bother explaining to his friend, in the hope that he would eventually forget about it.

Approximately 20% of subjects with diabetes reported difficulties with physical education, with some respondents replying that they had had to be "extra careful" or take extra glucose:

D025: "A couple of times I threw a wobbler, I didn't know what I was doing, that's when I got hurt." (S fell off climbing bars in the school gymnasium).

Others reported how they had lost interest in sports or felt that they were now limited in what they could do sports-wise since being diagnosed as having diabetes. In this study more than half of the young adults with diabetes had extensive problems at school for a variety of reasons. Some difficulties may have been easier to overcome than others, for example some subjects reported a positive change in attitude or popularity as more fellow-students befriended them due to their ability to leave the school at will to buy food or sweets:

D029: "I used to be able to go to the shop anytime I wanted to. My friends all used to come up to me and say, 'here J get us this, get us that'."

Difficulties within the education system may have a detrimental effect on self-esteem levels and in this study, of those who had had diabetes at school, diabetic subjects who had NES were more likely to report problems compared with diabetic subjects who did not have NES, although this finding was not significant (45% vs 10% ; $p=0.09$). At the same time, those who reported problems also fared less well in terms of academic achievement.

Subjects with diabetes who had been diagnosed prior to the age of 17 (n=30) were less likely to have obtained educational qualifications, particularly at A' level or degree level, compared with the ten diabetic subjects who were diagnosed after this age (A' level: 2 (7%) vs 3 (30%) ; $p=0.05$, Degree level: 0 (0%) vs 2 (20%) ; $p=0.01$). Although numbers were small, for all subjects with diabetes, those who had passed qualifications had a somewhat lower mean Ghb level, compared with those who had failed to gain any qualifications (see Table 15). This was a non-significant trend however, and for many subjects a significant time-period existed between obtaining qualifications and the recording of their Ghb. The blood glucose measurements, taken at the subjects' last out-patient appointment prior to interview, did however show some significant differences (see Table 15). These findings must be interpreted with caution as these measurements do not inform the observer of the level of metabolic control over a period of time any longer than 6 - 8 weeks in the case of Ghb, and in the case of blood glucose measurements, refer only to the glucose level at the time it was measured. For some, therefore, these measurements do not pertain to the same time period during which these subjects were attending school. An analysis of Ghb levels for those who were still at school demonstrated that, although numbers were small, those who had taken CSE's, GCE O'levels or A'levels had a higher mean Ghb level, compared with those who were still at school but had not obtained these qualifications (n/s).

Table 15: Glycaemic control and qualifications.

	<u>NO CSE'S</u>	<u>1+ CSE'S</u>	
	MEAN (SD)	MEAN (SD)	
Mean Ghb (%)	14.1 (5.0)	12.0 (3.9)	
Mean Blood Glucose (mmol/l)	12.4 (6.6)	9.0 (5.0)	*
	<u>NO GCE'S</u>	<u>1+ GCE'S</u>	
	MEAN (SD)	MEAN (SD)	
Mean Ghb (%)	13.7 (6.1)	12.9 (3.6)	
Mean Blood Glucose (mmol/l)	14.4 (7.1)	8.8 (4.4)	*
	<u>NO A'LEVELS</u>	<u>1+ A'LEVELS</u>	
	MEAN (SD)	MEAN (SD)	
Mean Ghb (%)	13.3 (4.7)	12.2 (3.9)	
Mean Blood Glucose (mmol/l)	11.1 (6.3)	9.1 (4.2)	
	<u>NO ONC</u>	<u>ONC</u>	
	MEAN (SD)	MEAN (SD)	
Mean Ghb (%)	13.5 (5.0)	12.1 (2.9)	
Mean Blood Glucose (mmol/l)	10.6 (6.3)	11.5 (5.9)	
	<u>NO HND</u>	<u>HND</u>	
	MEAN (SD)	MEAN (SD)	
Mean Ghb (%)	13.3 (4.7)	12.8 (4.4)	
Mean Blood Glucose (mmol/l)	11.7 (6.2)	6.8 (3.6)	*

* p<0.05 compared with those without qualifications

Diabetic subjects who had had an increase in insulin dose recommended to them at clinic during the previous year were less likely to have higher educational qualifications, although these findings were only significant for A'levels (A'levels: 5 vs 0 ; $p<0.05$. Degree: 2 vs 0 ; n/s. HND: 5 vs 2 ; n/s). At the same time however, those who had had increased doses were also more likely to be younger at time of interview, and were therefore less likely to have obtained higher qualifications due to their age.

Those who had developed diabetic complications were less likely to have obtained A' level qualifications (0 vs 5 ; $p=0.06$) and were less likely to have obtained ONC or HND qualifications although not significantly so. Diabetic subjects who had failed any further educational qualifications (ONC, HND, A' levels, degree), had a significantly longer duration of their diabetes, compared to those who had not failed any qualifications ($11.4 \text{ yrs} \pm 6.0$ vs $6.6 \text{ yrs} \pm 4.6$; $p<0.05$).

This section of the results has demonstrated that subjects with diabetes and their matched healthy controls obtained comparable academic qualifications, both at ordinary and higher levels of attainment. Both of these groups of subjects were highly committed to the idea of education, and this was related both to level of felt competence in education, and also to whether or not subjects had attempted some type of further studies.

Level of felt competence in education was significantly related to NES, and diabetic subjects who had low self-esteem were less likely to have obtained higher qualifications and had passed fewer O'levels.

Although there were some social class differences in educational attainment, when this factor was accounted for in the analysis there was still the same relationship between self-esteem and qualifications. More than half of the subjects with diabetes in this study reported experiencing problems at school, including the reactions and attitudes of both the teachers and their fellow-students, and this may be related to low self-esteem. All those with diabetes who had high commitment but who also felt low in terms of competence had failed to obtain any higher qualifications, and 63% of this group reported difficulties at school.

Of those who stated that they had had difficulties at school with their diabetes, only one had obtained any further or higher qualifications, and two had failed their further education examinations. None of those who had complications at the time of interview had obtained A' levels. Subjects who had passed their A'levels or who had obtained a degree were more likely to have been diagnosed after the age of 16, and the mean age at diagnosis for those who reported problems was 12.7 years compared to 14.7 years for those who did not report difficulties at school. This further evidence also suggests that those who were diagnosed at an earlier age may have experienced difficulties at school which led to a lower level of academic achievement, which in turn is likely to affect employment opportunities.

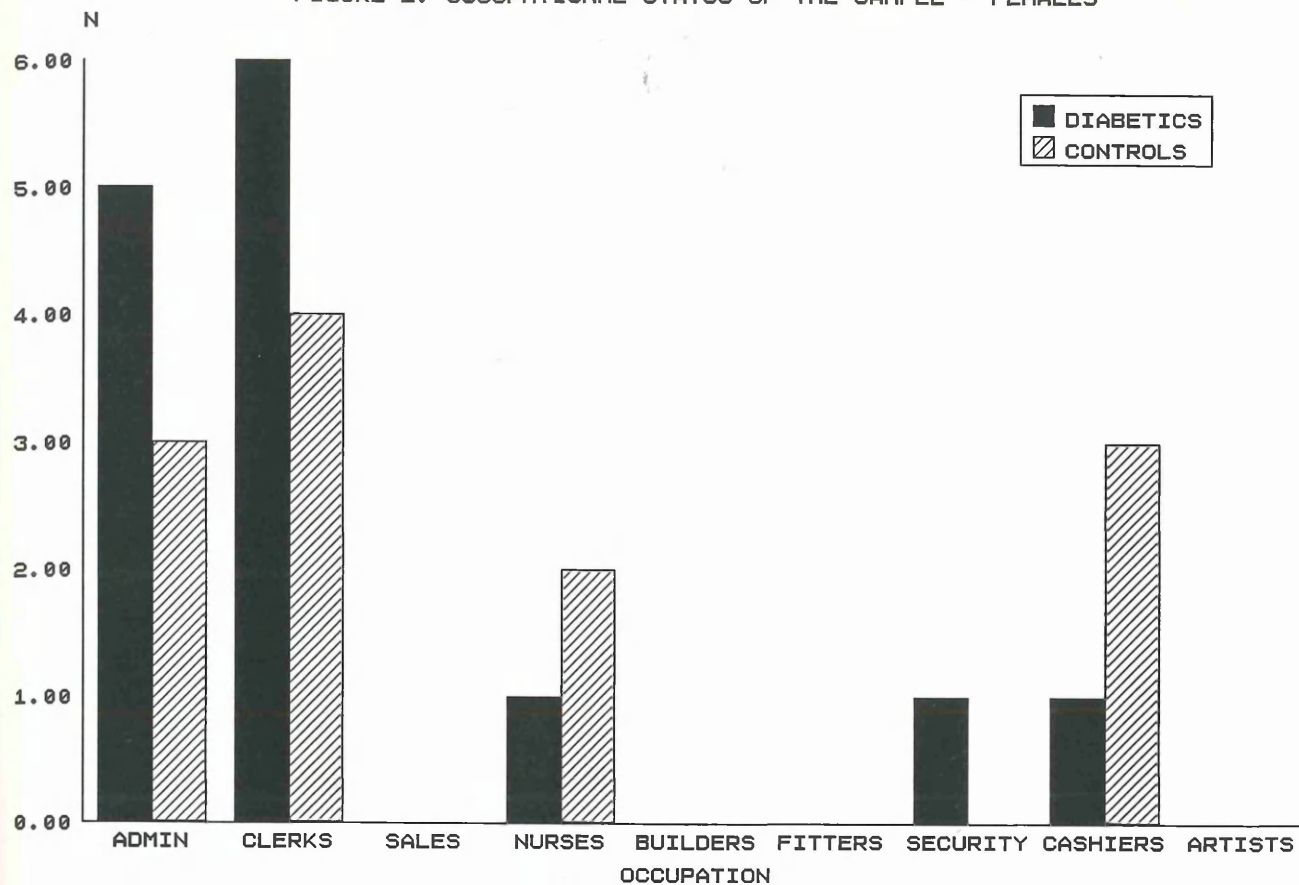
4.5. Employment experiences.

At the time of interview, 67% of young adults with diabetes and 63% of healthy controls were in full-time employment. Only 8% of controls and none of those with diabetes were in part-time employment, and 2 (5%) of each group were unemployed at this time. Social class, as measured by either the subject's occupation, or, if unemployed, by either parents' or spouses' occupation, was classified according to the Registrar General's Classification of Occupations (OPCS 1980). As reported earlier, the social class distribution of the subjects with diabetes and healthy controls was similar (see Table 2). Figure 2 shows the type of occupation in which subjects were employed. Each category shown on the figure also includes similar occupations to the titles shown. Type of occupation differed between males and females, as females were more likely to be employed in sedentary jobs and classified into social class IIInm (46% vs 18%; $p<0.05$), whereas males were more often found to be working in manual jobs (46% vs 18%; $p<0.05$).

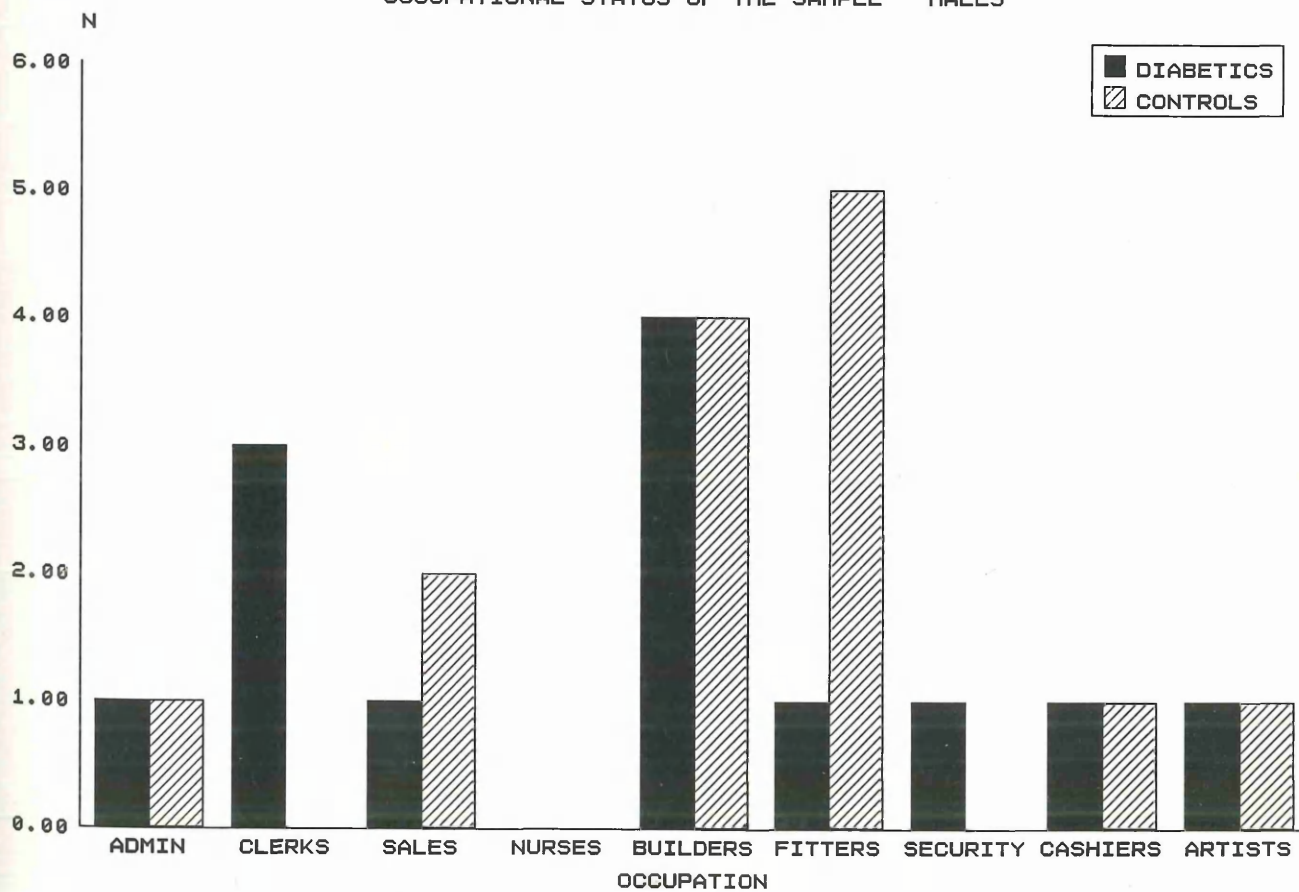
Commitment to employment.

Level of commitment to employment did not differ between subjects with diabetes and healthy controls. In a matched pairs analysis, 36 (90%) pairs showed agreement in terms of a high commitment to the world of work. The first subject quoted below was a female with diabetes, who had had difficulties in obtaining employment, until her father suggested that she should register disabled.

FIGURE 2: OCCUPATIONAL STATUS OF THE SAMPLE - FEMALES



OCCUPATIONAL STATUS OF THE SAMPLE - MALES



Prior to this, she had taken a computer course because she thought it would help her in her search for employment. She described her feelings when looking for work:

D004: "It's as though they didn't want someone who had to keep going to the hospital all the time. I blame myself for saying it (ie. telling prospective employers she had diabetes), but I suppose they have to know some time."

By law, 3% of all employees must be registered disabled, if the company has 20 or more workers. It was because of this law that this respondent finally obtained employment, working as an invoice clerk. This subject had a high commitment to working, both in financial terms and for work as an end in itself:

D004; "With what I'm doing, I get to learn more about it, makes you more independent, you get your own money. When I was at home, I used to stay at home, and feel bored. It's better to have something to do than sit around doing nothing."

The following subject was still in full-time education, however work was important to him, both in the present in the form of a Saturday job, and for the future:

D007: "I think it would be quite important, mainly for the money. I've got a Saturday job now - it's very useful for the money. I don't have to ask my parents for money, I've got money of my own, I've got more independence. For the future it's pretty important, for the standard of living, otherwise you really will fall behind."

Control subjects were equally committed to employment, both those still at school, as the first control below demonstrated, and those working at the time of interview, such as the second subject quoted below:

C0031: "Very important I think. I want to work 'cos after putting in all these years of studying, what's the use of studying all that time if you don't work? So you have to."

C0081: "I love it. I'd hate to sit about all day doing nothing. I like a week off, but nothing more. I couldn't stand not working, even if I was a mega millionaire I'd work. It's boring to sit at home. If you go to work you feel you've done something. (If unemployed) I'd be suicidal I imagine."

Females, regardless of health status, were significantly more likely to be highly committed to employment compared to males - 100% of the females in this study were highly committed, compared to 89% of the males ($p < 0.05$). This sex difference remained significant for healthy controls but was not evident for the diabetic subjects when the groups were analysed separately. Level of commitment was not influenced by social class or by ethnic origin, and was not associated with either the experience of unemployment, or with level of subjective competence in the work place.

Felt competence at work.

Both subjects with diabetes and their matched controls reported feeling highly competent about their performance at work, although those with diabetes were somewhat less likely to describe these feelings (90% and 100% ; $p=0.09$). Competence at work was indicated by statements made by subjects with regard to how they evaluated their performance at work, both in general terms and also the frequency with which they had 'bad days', and their ability to keep up with the work each day.

The first respondent quoted below was a full-time student who was employed at the weekends. However, he described his work as important to him and said that in the future he would "like to make it big in the world". He wanted to study chemical engineering and business studies at university in order to fulfil his ambitions:

D014: "I'm usually given a lot of responsibility (at work); you need to be efficient to handle it."
"I'm hoping to be a freelance chemical engineer and run a business at the same time."

The following young female with diabetes, had been promoted the week prior to interview from an office position to sales executive. This meant that she would be out travelling to meet clients each day, and her job would include taking customers out to lunch.

She was worried that this would affect her diabetic control and said that she would have to be extra careful from now on. She had been unemployed in the past, during which time she said she had felt demoralised. This subject was highly committed to working, and reported feeling highly competent about her performance at work:

D039: "I feel a lot of people respect me because I'm good at my job, I know what I'm doing, and I can answer more or less any question that someone will ask me. Nine out of ten people will come up to me to ask a question or advice about something rather than go to anyone else, and I like that."

The subject below was on sick leave at the time of his interview, since having a car accident several months before in which his legs had been badly injured. However, this male healthy control reported feeling highly competent regarding his performance as an electrician, working on building sites, particularly as he had qualified earlier than other electricians of his age:

C0111: "Oh yes, I think I'm fairly efficient in that sense, yes. Good enough, considering my age and that."

A young female control, who had been recently transferred to a new work place also described feeling very competent in her employment:

C0301: "I think I'm very good at my job."

There was no difference in the level of felt competency between males and females. In this sample, level of felt competency at work was not significantly related to the presence of NES, although a non-significant trend existed such that a greater proportion of those with high felt competence did not have NES.

Unemployment.

There was no significant difference in the proportion of subjects with diabetes and their healthy controls who had experienced any unemployment since leaving school. As described in the methods section, unemployment during the first six weeks after leaving school was not included in the analysis. There was no difference in the length of unemployment experienced; on average subjects with diabetes (who had left school) had had 5.8 months of unemployment ($\pm$ SD 6.5) compared to 6.4 months ($\pm$ SD 4.6) for the healthy controls. Experience and length of any unemployment were not significantly related to negative self-esteem.

There were no sex or ethnic group differences in the proportion who had experienced any unemployment or any differences in the length of unemployment. For the total sample, those in the lowest social classes (IIIM, IV) were more likely to have experienced some unemployment (64%) compared to those in social class IINM, where 26% had experienced some unemployment ($p < 0.05$). A surprising 46% of social classes I and II had experienced some unemployment.

There were no social class differences in unemployment for the group with diabetes when they were analysed separately. In the healthy control group, 75% of the lowest social classes (IIIM and IV) had been unemployed compared with 33% of social class IIINM, and 38% of classes I and II ($p=0.09$).

Unemployment was not related to the number of ordinary level qualifications that had been obtained either by subjects with diabetes or by controls. However, for the total sample, those who had experienced any unemployment were less likely to have obtained higher educational qualifications (A' levels, HND/equivalent or Degree) compared to those who had not experienced any unemployment (7% vs 35% ; $p<0.01$). This finding was independent of the effects of social class, and remained significant for the controls when analysed separately (0 (0%) vs 6 (38%) ; $p<0.01$). However, diabetic subjects with and without unemployment experience did not differ significantly in terms of gaining higher educational qualifications (2 (17%) vs 6 (33%) ; n/s).

For the total sample, those who had been unemployed were somewhat more likely to have left school prior to the age of 18 years when compared with those who had not been unemployed (67% vs 44% ; $p=0.07$). When the two groups were analysed separately this finding was also apparent, although not significantly so, for the controls (78% vs 50% ; $p=0.09$), but was not evident for the group with diabetes.

with diabetes.

Those subjects with diabetes who had experienced unemployment had a higher mean Ghb and a higher mean blood glucose level, compared to the diabetic subjects who had not experienced any unemployment (see Table 17). Mean Ghb for the group who had been unemployed was almost 2% higher than for the group who had not been unemployed, but this was not significant (14% vs 12.1%; n/s). Blood glucose (the most recent measurement recorded in subjects' hospital case-notes) was significantly higher for those who had been unemployed (15.1 vs 8.6; $p<0.01$).

Actual experience of unemployment was not significantly related to either age at diagnosis or to duration of diabetes. However, although not statistically significant, those who reported difficulties in obtaining employment were younger at diagnosis and had a longer duration of diabetes compared with those who did not report difficulties (mean age at diagnosis; 11.4 ± 4.4 yrs vs 15.0 ± 4.7 yrs; $p=0.06$. Mean duration; 10.1 ± 4.9 yrs vs 7.5 ± 5.6 yrs; n/s). Half of those who had experienced unemployment also had diabetic complications compared with only 25% of those who had never been unemployed, however this difference was also not statistically significant (Table 17).

Table 17: Unemployment and health status of diabetic subjects

who have left school.

	<u>Never Unemployed</u>	<u>Unemployed</u>
	n=28	n=12
	n (%)	n (%)
Diabetic subjects with NES	7 (25)	4 (33)
Diabetic subjects with complications	7 (25)	6 (50)
	MEAN (SD)	MEAN (SD)
Ghb (%)	12.1 (3.3)	14.0 (6.4)
Blood glucose (mmol/l)	8.6 (4.7)	15.1 (6.5) **

** p<0.01 compared to diabetic subjects who had never been unemployed

One-third of diabetic subjects agreed that having diabetes had altered their views on employment and the type of job they were able to carry out. One-third of young adults with diabetes also reported that there were jobs that they would like to do but could not, specifically because of their diabetes. People with diabetes have been advised not to take on certain occupations, such as those involving public transportation and becoming pilots, (BDA memorandum 1984) and these were some of those most often mentioned by the respondents:

D037: "I wanted to be a pilot, but I couldn't get into the army or airforce because of that. I wanted to go into the army to be an officer, but I couldn't get in because of that. That's what I've always wanted to do, but I just can't, because of my diabetes."

D025: "I wanted to be a policeman, I was told no chance. I also wanted to join the army."

Although disappointed about not being able to join the police, this last male subject had a high commitment to employment, and enjoyed his present job as a carpenter, saying there was a 'great atmosphere'.

The subject quoted below, was an 18 year old male whose diabetes had been diagnosed 2 years before, just after he had come to live in the U.K. He was still in full-time education, and was doing well, having passed 9 O'levels, and was currently taking 3 A'levels:

D014: "I wanted to be a pilot before, so everything changed."

Although this respondent states his previous desire to be a pilot, he had also stated during the interview that he wanted to become a chemical engineer and run his own business. Although therefore, a change of direction had been necessary, he nevertheless still set his sights high when it came to his future employment.

Subjects sometimes gave the reason for refusal in personal terms such as their lack of qualifications or experience or other personal attributes, rather than as the presence of a chronic illness:

D037: "I probably wouldn't have got into the airforce anyway, because my qualifications weren't good enough."

D012: "I wanted to be a pilot but I'm not big enough anyway."

One young adult with diabetes had not suffered unduly herself when it came to her employment, but had heard about the potential difficulties from other people. As regards her own employment, she was a nurse who had not experienced any difficulties with obtaining her job, completing her training, or with shift work and received sick pay and time off for clinic appointments.

She was however, well aware of the potential problems that could occur and had concluded that it was probably best to obtain the best qualifications possible in order to overcome this:

D010: "I don't know if it's being diabetic or not, but I've met a lot of diabetics who have had problems getting jobs. I don't know if you should conclude that you must get your A' levels, but it does help."

Only 9 of those who were either currently employed or who had been employed or actively seeking work in the past (n=30) reported experiencing some problems in obtaining employment which were related to their disease. This did not necessarily lead to them withholding this information when next applying for employment, although in some cases subjects felt that this was the appropriate action to take until at least they were settled into their new job. One subject reported how he avoided applying for jobs for which a medical examination was required, although he had not so far experienced any discrimination when applying for employment.

Those who reported problems in obtaining employment were those subjects who were employed in occupations classified in social class IIINM or lower, but they had not experienced a greater amount of actual unemployment. There was no ethnic group difference with regard to who reported employment difficulties.

A large proportion (87%) of those who had either worked in the past or were working at the time of interview said that their employer knew that they had diabetes. Almost the same proportion had also informed their colleagues. Fear of discrimination in employment seemed to be minimal in these subjects with diabetes, only four had not told their employers that they had diabetes. Of these, one replied that she would rather wait until she had been in the job for a while before declaring her illness. She had been sacked from her last job because she had been late for work after being delayed at her clinic appointment.

Two young males with diabetes suggested that if their employers knew they had diabetes they would not be allowed to carry on in their jobs, as they explained:

D033: "There are things you have to be careful with, things that I'm doing (ie. working in the building industry), that I don't tell anybody that I'm diabetic. (If S did tell prospective employer) it would probably stop you getting work. I never tell anyone, so there's no trouble (getting work)."

This second subject, reported below, had told his present employers that he had diabetes, because he had already been in the job for some time when he was diagnosed, and had not had any problems with his diabetes whilst there. If he changed jobs in the future however, he said he would not tell his new employers that he had diabetes:

D040: "You see on building sites it's very dangerous work. I'm up ladders most of the day. Say if I changed my job now I'd be up ladders and scaffolds most of the time, so like the firm's bosses won't really like that, 'cos if I had a turn I could just fall off or whatever. So I probably wouldn't tell them."

The majority of those reporting difficulties with employment however, were female, 78% of this group were women ($p=0.08$). At the same time, those who had employment problems were more likely to have NES, compared with those who did not have employment problems (56% vs 24% ; $p=0.09$). This finding would be expected, due to the greater proportion of women who had NES. Just under half (44%) of those who reported problems in obtaining employment already had diabetic complications, and a further 2 subjects had other health difficulties, one of which was diabetes related, which prohibited them from easily obtaining a job.

These results have demonstrated that young adults with diabetes experienced comparable levels of employment and unemployment as their healthy controls. Unemployment in the diabetic subjects was not explained by either social class or educational qualifications, and was somewhat related to both glycaemic control and the presence of complications, although not significantly so. Although one-third reported having to change their views on employment specifically because of their diabetes, only 26% reported actual problems in obtaining employment. For some, this could lead to the concealment of their condition until firmly established in their employment.

Diabetic females, who were more likely than diabetic males to have a high commitment to employment, were at the same time more likely to have experienced work difficulties in the past, and to have NES. This suggests that past negative employment experiences may have been associated with level of self-esteem.

The previous two sections have described the relationship between diabetes and educational achievement and employment experiences. Overall young people with diabetes appear to fare as well as their healthy peers, however, for a sub-group of those with diabetes certain difficulties have been described, especially for those who have low self-esteem (NES). In this section, another important area in young adults' lives will be discussed, that of their social and familial relationships.

Living arrangements and household size.

As described earlier, young adults with diabetes were more likely to be living in privately rented or owner occupied accommodation compared to their healthy controls, who were significantly more likely to be living in rented local authority housing. Young adults with diabetes were less likely to have been living in the area of the study for one year or more compared with their matched controls (see Table 18). This finding was not influenced by ethnic group but may have been related to the selection of the controls, that is this sample would be likely to consist of some of the more stable young adults (in terms of living in the area for a longer period of time). Others would have been less likely to be in the sample, precisely because they had moved.

Table 18: Social factors and health.

	<u>Diabetic Subjects</u>	<u>Controls</u>	
	n=40	n=40	
	n (%)	n (%)	
Living in area for less than 1 year	8 (20)	0 (0)	**
Living with parents	24 (60)	27 (68)	
Has children	1 (2)	11 (27)	**
Some isolation	19 (48)	10 (25)	*
Has VCO	19 (48)	28 (70)	*
Has Confidant	37 (92)	38 (95)	
	MEAN (SD)	MEAN (SD)	
Number of relatives in area of study	3.4 (1.9)	4.6 (2.4)	*
Number of relatives in same country	3.8 (1.7)	5.0 (2.4)	*

* p<0.05 compared with diabetic subjects

** p<0.01 compared with diabetic subjects

All those who had been living in the area for less than one year (these were all subjects with diabetes) lived in their own home (ie. without their parents), with 5 living in privately rented accommodation and 3 living in a home which they had purchased. Diabetic subjects who had lived in the area for longer than one year were more likely to be living with their parents in owner-occupied accommodation than living in their own homes. There were no differences in the household size of those with diabetes and their controls; the average size being three other people for both groups of subjects. Healthy controls had significantly more close relatives living nearby compared to diabetic subjects - this included parents, siblings, and any adoptive close relatives (see Table 18). Healthy controls also reported having significantly more close relatives in the country as a whole compared to subjects with diabetes. These findings were not influenced by social class. When the sexes were analysed separately, these significant differences only remained for diabetic males compared with their controls. Females with and without diabetes had similar numbers of close relatives both within the region of the study and in the country as a whole. For the sample as a whole, ethnic origin was unrelated to the number of relatives living close-by or in the U.K. However for those with diabetes, Caucasians had fewer close relatives living nearby compared to both Afro-Caribbeans and Asians with diabetes. Afro-Caribbeans had more relatives in the U.K. compared to both Caucasians and Asians with diabetes. These ethnic differences were not found in the control group. Control subjects were significantly more likely to have divorced parents, compared to subjects with diabetes (35% vs 7% ; $p < 0.01$).

Approximately equal proportions of both subjects with diabetes and healthy controls were still living with their parents. Reasons for leaving home were varied, however healthy controls were more likely to have left home because of pregnancy (5 vs 0). Subjects with diabetes were more likely to have left home in pursuit of employment (7 vs 2), and were possibly more likely to have left home in order to "get away from home" (4 vs 2 ; $p < 0.05$).

Young adults with diabetes were significantly more likely to experience some social isolation compared to healthy controls (48% vs 25%; $p < 0.05$). The social isolation scale measured the subject's lack of social participation - not in terms of the subject's feelings about the matter, but in terms of concrete evidence that the subject did not have very close friends ('very close others') or confidants, or had a small or non-existent social circle. Social isolation was not associated with social class, ethnic origin or sex. Young diabetic subjects with NES were more likely to experience some social isolation compared with diabetic subjects without NES, but this was not significant (62% vs 41%; n/s).

Commitment to social arenas.

Both subjects with diabetes and their controls exhibited comparable commitment to social arenas outside the home, such as leisure activities or visiting friends. A matched pairs analysis demonstrated that there was no difference in level of commitment between diabetic subjects and controls, with 22 pairs being highly committed to social arenas. Level of commitment did not differ between males and females. For the total sample, Caucasian subjects were more likely to have a high commitment to social arenas compared with Afro-Caribbean and Asian subjects. When the two groups were analysed separately this ethnic difference remained apparent for controls. However, for the respondents with diabetes, ethnic origin did not influence level of commitment.

Subjects with diabetes who had a low commitment to social arenas outside the home, were more likely to be socially isolated compared with diabetic subjects with high commitment (75% vs 36% ; $p < 0.05$). A similar association was found for the healthy control group (56% vs 13% ; $p < 0.01$).

Commitment was indicated by statements made by subjects which related to the importance of activities that existed other than school or work. Behavioural indicators were also taken into account, such as whether or not subjects had concrete plans to retain or develop other social outlets. Nearly one-third (30%) of young adults with diabetes in this study demonstrated a low degree of commitment to having a social life.

The following respondent has already been described in some detail with regard to her difficulties at home with her parents. She also reported a lack of friends:

D003: "I don't go out on a Friday night like most teenagers. I had a group of friends at school, it was childish, I grew out of that. I prefer to be away from people."

The male with diabetes reported below, was diagnosed two and a half years prior to interview, and had lived in the U.K. for less than three years. He had been voted head of the sixth form committee at school, however this popularity did not seem to extend out of school hours:

D014: "No, I don't go out in the evening. I wouldn't say they're the sort of friends I'd go to for a talk."

Close relationships.

Young adults with diabetes were significantly less likely to name someone they felt very close to (VCO) compared to healthy subjects (48% vs 70%; $p < 0.05$). A VCO could not include either a spouse or a partner. Presence/absence of one or more VCO's was unrelated to the presence of NES. A greater proportion of single subjects (both people with diabetes and controls) had one or more VCO; 65% of single respondents had a VCO compared with only 20% of those who were married and 29% of those who were cohabiting ($p < 0.05$).

There were no differences in the proportion of those with diabetes and controls who named someone they could confide in; in both groups this proportion was very high indeed; 95% for controls and 92% for the diabetic subjects. Only 5 single subjects did not name anyone in whom they could confide; all married and cohabiting subjects were able to name a confidant, and this was usually their partner. Whether or not subjects could name either a VCO or a confidant was unrelated to length of residence in the area, or to the age or sex of the subject, and was unrelated to ethnic group or social class position.

The presence of 'true VCO's' was also assessed; this differed from the previous measurement of VCO's in that it included concrete evidence of both confiding behaviour and frequency of contact, rather than relying entirely on subjects' reports of who they felt very close to. A true VCO was someone named as very close, but who was also highly or markedly confided in, and who was seen at least once a month. A 'low confiding VCO' was defined as someone who was named as very close, and who was seen at least once a month, but who was only confided in at a low level.

Subjects with diabetes were somewhat less likely to have one or more true VCO's compared to healthy controls, although this finding was not statistically significant (35% vs 52% n/s). Those with diabetes were significantly less likely to have low confiding VCO's compared to controls (20% vs 40% ; $p < 0.01$). These findings were unrelated to negative self-esteem.

Females were more likely to report having a true VCO compared to males (55% vs 32% ; $p<0.05$). This sex difference was also found for the group with diabetes when they were analysed separately, although not significant (48% vs 21%; $p=0.08$). There was no sex difference in the presence of true VCO's for the healthy controls group (62% vs 42% n/s). Presence of a true VCO or a low confiding VCO was not associated with social class for the total sample, or for the healthy controls. However, for the diabetic subjects, those in social classes I or II were significantly more likely to have a true VCO (75%) compared with those in social class IIINM (19%) and social classes IIIM, IV (31%) ($p<0.05$).

Marital status was somewhat related to the presence of a true VCO for healthy controls, but not for the group with diabetes; 57% of single controls had a true VCO, compared with none of the married controls ($p=0.06$). The presence of a true VCO was unrelated to length of residence in the area, however those who reported a close but low confiding relationship had lived in the area for a greater number of years (6.1 ± 2.0 yrs vs 4.4 ± 2.8 yrs ; $p<0.01$). Subjects' age was unrelated to the presence of true VCO's or low confiding relationships, and there were no ethnic group differences in terms of the presence/absence of true VCO's. Finally, for the single subjects, there was no difference as to whether or not subjects had a boy/girlfriend (this did not include cohabitees); those with diabetes were equally as likely to have a relationship of this kind as the healthy controls.

Attitudinal constraints to close, confiding relationships.

Although there was only a small difference in the proportion of diabetic subjects and controls who reported having a true VCO, those with diabetes were significantly more likely to indicate that they had marked or moderate attitudinal constraints towards having close, confiding relationships. These attitudinal constraints were indicated by statements made by the subjects during their interviews which demonstrated how they felt about having very close relationships, and about whether or not they should get emotionally involved with other people. Statements in which subjects portrayed feelings against talking to people about personal matters were also taken into account.

A matched pairs test showed that 14 diabetic subjects exhibited attitudinal constraints when their matched controls did not, compared with 3 controls who exhibited these feelings when their matched diabetic subjects did not ($p < 0.01$).

The subject below, a young female with diabetes, had spent the first ten years of her life living abroad with an aunt, after which time she was sent for by her parents who had started a new life for the family in the U.K. Although she was not very close to either of her parents, she could name one friend as 'very close'. At the same time, this subject exhibited high attitudinal constraints towards close, confiding relationships, and only confided in her VCO "...sometimes, not all the time", particularly when it came to her diabetes:

D004: "I think it's best to be close to your family, but friend-wise, I don't think its too wise. I wouldn't say not to be too close to them, but you never know what they might say or do. Family and close relatives is OK, but not friends."

The young Asian male with diabetes below, also showed attitudinal constraints, especially in terms of people outside the family:

D007: "Family-wise its nice, the whole family should understand what you're saying. You should understand their feelings. With school friends, you can have the odd close companion, but home life should be separate."

Finally, the third subject in this section has already been quoted when she described her commitment to having a social life, which was low. She also portrayed high attitudinal constraints towards having close relationships:

D003: "I prefer to be away from people, because if someone is close to you and knows everything there is to know about you, they could use it against you, I'm not saying they will, but they might."

There was no difference in the proportions of diabetic subjects and controls who demonstrated attitudinal constraints as regards eliciting care or comforting responses from other people. These responses included practical responses, such as support with child care, or financial support. It could be quite possible for the individual to show high attitudinal constraints as regards eliciting care but at the same time to show low attitudinal constraints towards close relationships:

- C008: "No, I don't like to ask for help. I don't like to admit that I need help, that's it basically. It's very difficult for me to ask for anything."
- C008: "I see no harm at all (in having people close). I think you need very close friends...."
- D039: "If I can I would rather try and do it on my own, achieve it on my own. But in a way I'm too proud to ask for help, but it depends who I'm asking."
- D039: "I think it can be very dangerous depending on someone, but then again it's nice to be close. Being close and being dependent are two different things."

Subjects with diabetes were also significantly more likely to demonstrate a fear of intimacy compared to their matched controls. In a matched pairs analysis, 14 subjects with diabetes demonstrated a fear of intimacy when their controls did not, compared with 3 controls who exhibited this fear when their matched diabetic subjects did not ($p < 0.05$). This scale is more specific than the previous two, in that it measures the extent to which respondents report an actual fear of closeness, such as feeling uncomfortable or anxious when others attempt to get close to them, or try to confide in them. Feelings of fear or discomfort if the subject confides in others is also rated, along with the extent to which this fear is generalised to all or only certain other people, for example, non-family members, or all males, etc. Finally this scale takes into account the extent to which past adverse experiences add to the fear of getting close to people.

The following Asian female with diabetes worried about socialising because she had a nervous stammer. Although she did not feel she had ever been very unpopular, a close friendship had broken up in the past and she felt that this sometimes stopped her from getting close to people:

D006: "I broke up with my friend and I did feel rejected. I sometimes think it does (stop her being close), but I try to put it out of my mind."

Although there is some evidence in what the above subject said to suggest that there may have been previous experiences which lead to her fear of intimacy, the young male reported below demonstrated much more clearly the reasons for his fear of intimacy:

D008: "Yes, a long time ago at school when I was going out with this girl. I learnt since then not to be that close to anyone. I don't get too close to anyone. It's habit, I don't want to get hurt, I have a fear of that. I'm quite happy (with people confiding in him) - it means that I don't have to confide in them. If I got into that situation (where he was too close to someone) I would drop it."

There were no sex, social class or ethnic group differences in the presence of attitudinal constraints for either the total sample, or those with diabetes and controls separately. Diabetic subjects with NES were more likely to demonstrate attitudinal constraints compared to diabetic subjects without NES.

More specifically, diabetic subjects with NES indicated significantly more attitudinal constraints towards care eliciting compared with diabetic subjects who did not have NES (54% vs 22%; $p < 0.05$). Level of confiding in their VCO's, and emotional support received by the same, did not differ between people with diabetes and controls; a high degree of both was reported by the two groups.

Social contacts and diabetes.

The vast majority (93%) of subjects with diabetes had told their friends about their disease. However, 6 did not like to discuss their diabetes with their friends, and 13 reported feeling that their friends did not understand their condition. Some subjects described how their friends made jokes about diabetes. In the first example reported below, jokes were made when this subject was out with his friends or at work. However he described how he dispelled any notions his friends may have had as regards him being any different from them:

D040: "They take the mick..... they just take the mick about taking insulin... 'Cos usually I drink them all under the table anyway..."

At the same time, his friends kept a watchful eye on him:

D040: "There's the odd time when I may be over the limit and they probably will say to me 'take it easy', and I just say OK, yes, and that's it."

The following young female with diabetes described how she felt that her friends were embarrassed and frightened about her diabetes, and saw this as the reason for their jokes:

D016: "They called me 'junkie ' but that was just a little joke, which soon fizzled out. I think they're frightened by it."

A male respondent reported that he did not mind his friends calling him names, although if they started giving him advice about his diabetes he would be quite annoyed:

D025: "....saying 'here comes dartboard - full of holes', or saying 'popeye' and 'only eating spinach or cabbage'."

A small proportion (7) described their friends as 'shocked' when they first found out that they had diabetes, and only one-third (14) of all these subjects with diabetes reported that they felt that their friends were supportive and interested.

State of health and social relationships.

Although the presence of diabetes per se seems to be related to whether or not subjects had any type of VCO or confidant, or were socially isolated or not, the existence of these relationships was not significantly related to state of health in terms of glycaemic control.

However, subjects who had diabetic complications were more likely to be living away from home as described earlier, and were significantly more likely to be experiencing some social isolation at the time of interview compared to those who did not have complications (73% vs 32% ; $p < 0.05$). There was a non-significant trend for those with complications to be less likely to report the presence of any type of VCO.

This section has shown that subjects with diabetes and their matched controls exhibited comparable levels of commitment to social arenas, but at the same time those with diabetes reported greater attitudinal constraints toward having close relationships. Diabetic subjects were also more likely to be socially isolated. Although for different reasons, similar numbers of those with diabetes and controls had already left home. Diabetic subjects who had complications were more likely to be living away from home, and this was not explained by age. Whether or not subjects lacked close relationships was not influenced by the length of time they had lived in that area, nor was it associated with low self-esteem. For those with diabetes, these social differences were not manifested in terms of degree of glycaemic control, but those who were socially isolated were more likely to have diabetic complications.

In the literature review, I reported that several studies had demonstrated how important family relationships were, for example for the adjustment of the individual with diabetes, or in terms of the attainment of good metabolic control. This next section evaluates the relationship between young adults and their parents in order to assess whether differences exist between young adults with diabetes and healthy controls. Both childhood experiences and current relationships will be examined, and also the possibility of differences related to state of health in the group with diabetes.

In this study, information on relationships between parents and young adults was collected in two ways; firstly in terms of childhood experiences up to the age of 17 years (so for some subjects this included their current relationship with their parents), and secondly through the information collected from all subjects regarding current relationships with their parents.

Only two of the subjects with diabetes regarded their parents as VCO's, compared with eight of the controls ($p < 0.05$). At the same time, only one of the diabetic subjects reported that they confided in either of their parents, compared with six of the controls ($p < 0.05$). These findings were unrelated to age, and did not depend upon whether subjects were living with their parents at the time.

For the total sample, there was a relationship between the absence of a parent as a VCO and the presence of NES; none of the subjects who had NES reported having a parent as a VCO, whereas 10 of the subjects who did not have NES had this relationship with one or other of their parents. This finding was similar for both diabetic subjects and controls when analysed separately, although numbers were too small to detect any statistically significant differences. Similarly, none of those who had NES reported having either parent as a confidant, whereas seven of those who did not have NES did have this relationship.

Parental approval.

Subjects were asked whether they felt that their parents had approved of them, and healthy controls were more likely to answer in the positive compared to subjects with diabetes. Parental approval was divided into that given by the mother and that given by the father, and related to the time period up until age 17. It included approval shown with regard to any aspect of the subjects' life, such as educational achievement, or friendships. A greater proportion of controls felt that they had had their mothers' approval during childhood compared with diabetic subjects (81% vs 48%; $p < 0.05$) (see Table 19). There was no difference for fatherly approval.

Table 19: Young adults' relationships with their parents.

	<u>Diabetic Subjects</u>	<u>Controls</u>	
	(n=40)	(n=40)	
	n (%)	n (%)	
<u>With mother's approval</u>			
All subjects	22 (55)	31 (76)	*
Females	10 (48)	17 (81)	*
Males	12 (63)	14 (74)	
<u>With father's approval</u>			
All subjects	22 (55)	24 (60)	
Females	12 (57)	13 (62)	
Males	10 (53)	11 (58)	
<u>Negative interaction</u> <u>with parent(s)</u>			
All subjects	9 (23)	3 (8)	
Females	5 (24)	2 (10)	
Males	4 (21)	1 (5)	

* p<0.05 compared with diabetic subjects

All subjects who had NES, both those with diabetes and controls, were less likely to report that their mothers had approved of them compared to subjects who did not have NES, although this was not statistically significant (53% vs 70%; n/s). When subjects with diabetes were considered separately, those who had NES were also less likely to report their mothers approval compared to diabetic subjects who did not have NES, but this finding was also not significant (39% vs 63%; n/s).

Some of the comments made by subjects are reported below. The first of these was made by a 16 year old Asian girl who described her current relationship with her parents. She also mentioned that she felt that her brother was favoured more because he was a boy, although at the same time she believed her parents were interested in her, for instance in how she did at school and her friendships.

D002: "They don't praise me or go on about me. I think they're proud of me, they're very hard to please, especially my mum, with housework, things like that. Now that I'm growing older they expect more from me than before and I find that very hard at times."

The second female Asian reported that she had never felt close to her parents. Her father had died when she was 14 years old, and from then on her older brothers behaved more like surrogate fathers towards her. She felt that her brothers were interested in how she did at school, but that her mother did not listen to her, saying she was 'very domineering':

D001: "I can't remember her praising me. I've always felt a burden on her."

The subject quoted below lived at home with her parents, although she spent most of her time at home in her own bedroom:

D013: "No, never praise, they don't really say anything. They are disapproving over quite a few things."

Parental approval was not significantly associated with social class or ethnic origin. Diabetic females were significantly less likely to report their mother's approval compared with female controls (10 vs 17 ; $p < 0.05$). This difference did not exist for the males. There were other sex differences in approval for the group with diabetes; for females, age at diagnosis was significantly related to presence of father's approval. Females who had had their father's approval during childhood were diagnosed at a younger age compared with those who had not had their father's approval (10.9 ± 4.2 yrs vs 15.3 ± 4.3 yrs ; $p < 0.05$). There was no significant difference in age at diagnosis for diabetic males with and without parental approval.

Chronological age was unrelated to father's approval for those with diabetes. Similarly, this was also true for both parents' approval for the healthy controls. However, diabetic subjects who reported having their mothers' approval were significantly younger at the time of interview, than those who did not report mothers' approval (20.3 ± 2.9 yrs vs 22.1 ± 2.6 yrs ; $p < 0.05$).

Young adults with diabetes reported somewhat more current negative interaction at time of interview with their parents compared to healthy controls (24% vs 8% ; $p=0.06$). Negative interaction was not associated with whether subjects were living at home at the time of the study. Those who reported negative interaction with their parents were no more likely to have NES however, nor were they of a particular sex, ethnic group, or social class.

Parental relationships and state of health.

Negative interaction with parents was unrelated to state of health, either in terms of glycaemic control or presence of complications, and did not differ according to whether subjects lived at home with their parents or not. In just over half of all diabetic cases, support from parents in terms of help with injections, diet and tests appeared to have been forthcoming, either in the past when younger, or at the time of interview. The diabetic female reported below was living away from home at the time of interview, and described her mother's behaviour when she was younger:

D035: "She'd get the scales out, she used to weigh everything for me. She used to inject me."

The next respondent quoted was living with her parents and had a fairly volatile relationship with them both, although she felt they were interested in her diabetes, especially since her mother also had diabetes (non-insulin dependent):

D027: "Yes, when I was younger she used to do my injections for me sometimes. She always makes me anything I want (to eat), and tries out different herbal remedies. Its not that she doesn't care, she does, she's just fed up 'cos she feels that I don't try with my diabetes. She worries for the both of us."

Of those who reported that they had their parents support, 15 (71%) also described their parents as interested in their condition. Whether or not parents were interested in their diabetes was not associated with level of self-esteem. However, the presence of parental support was somewhat related to NES; diabetic subjects who had NES were less likely to have parental support compared to those who did not have NES, although this just failed to reach significance (4 (31%) vs 17 (63%) ; $p=0.06$).

Only 50% of all diabetics said that one or more of their parents had attended out-patients with them at some point, usually while the subject was still in their early teenage years:

D037: "Yes, she did, she helped me with my food. She used to go (to out-patients) with me when I was younger."

Parental interest was not entirely welcomed by all respondents, and feelings of being over-protected were sometimes reported:

D009: "She's telling me what to eat and it gets on my nerves a bit, cos I know what I'm supposed to do with diabetes. It's this constant building up and emphasising the point of my diabetes, and that really gets on my nerves."

Another 17 year old subject reported how she was not allowed out in the evening because her injection would be due. At the same time however, she also felt that they had been more restrictive because she was studying for her A'levels. These qualifications were seen as extremely important both for the subject and for the whole family, because it increased her chances of making a good marriage. She saw her father as especially hard to please, and she described her feelings about the situation:

D006: "Since I've been doing my A'levels I've wanted to go out more, and I see them as being more restrictive. I think they're concerned about me passing my exams more than anything. If I want to go out, they always want to know where and with whom. Sometimes they expect more than I can give them and I get really down about that."

Less than half (43%) of the respondents with diabetes reported that they discussed their condition with their parents, and this was possibly related to level of self-esteem; 77% of those who had NES did not discuss their diabetes with their parents, compared with only 48% of those who did not have NES ($p=0.08$).

All those who had had increases in insulin dosage in the previous year, and all those who had complications, reported the absence of either parent as a VCO or a confidant. Although numbers were small, subjects who did not have either parent as a VCO had somewhat higher Ghb compared with subjects who did have this relationship ($13.4\% \pm 4.5$ vs $10.2\% \pm 6.7$;n/s).

Parental support was not significantly related to the presence of complications or with level of glycaemic control. Whether or not subjects discussed their diabetes with one or other parent was unrelated to level of glycaemic control or the development of complications. Mean Ghb did not differ significantly between those who had had their mother's approval and those who had not (see Table 20). However, mean Ghb was significantly lower for those who had had their father's approval compared with those who had not had father's approval (11.8% vs 15.0% ; $p<0.05$). This was only significant for those diabetic subjects who were living away from the parental home (11.3 ± 2.0 vs 14.5 ± 2.1 ; $p<0.05$).

Table 20: State of health and relations with parents.

	<u>Mean Ghb (%)</u>	<u>N(%) with complications</u> (n=15)	<u>N(%) without complications</u> (n=25)
	<u>MEAN $\pm$ SD</u>	<u>n (%)</u>	<u>n (%)</u>
No approval from mother	13.3 (2.9)	10 (67)	8 (32)
Approval from mother	13.1 (5.8)	5 (33)	17 (68) *b
No approval from father	15.0 (5.3)	11 (73)	7 (28)
Approval from father	11.8 (3.6) * a	4 (27)	18 (72) **

* a $p < 0.05$ compared to diabetic subjects without father's approval

* b $p < 0.05$ compared to diabetic subjects with complications

** $p < 0.01$ compared to diabetic subjects with complications

subjects who had received parental approval were also less likely to have developed complications. Both mother's and father's approval was significantly related to the absence of complications for the males only. In this group, 10 of the males without complications had their mother's approval compared with only 2 of the males with diabetic complications ($p < 0.01$). At the same time, 9 males who did not have complications had their father's approval, whereas only 1 of the males with complications had their father's approval ($p < 0.01$). Approval from either parent was unrelated to duration of diabetes.

Relationships between young adults and their parents are complex, and in this study subjects with diabetes were shown to be experiencing greater problems than their healthy matched controls. Diabetic subjects were less likely to regard either parent as very close to them or as a confidant. They received less approval from their mothers during their childhood, irrespective of age at diagnosis, and reported more current negative interaction.

Parental support concerning their diabetes was reported by only half of the diabetic subjects in this study, and less than half discussed their condition with their parents. This study has shown that parental support and whether or not parents were VCO's or confidants may be associated with the presence of low self-esteem, and this could possibly be related to different levels of metabolic control.

4.7: Marriage and parenthood.

In previous sections of this thesis, it has been demonstrated that young adults with diabetes and their matched controls were equally committed to education, employment and to social arenas. At the same time, a sub-group of the sample have not fared as well or have experienced certain difficulties in these areas, and this may be related to self-esteem. In the final part of the results section, marriage and parenthood will be considered, both in terms of subjects' experiences and in terms of their attitudes towards these roles in society.

As described earlier and shown in Table 2, equal proportions of subjects with and without diabetes were of single status, however a greater number of subjects with diabetes were cohabiting and more controls were married ($p=0.06$). For both groups less than one quarter (24% and 20%) had a marked commitment to marriage. Commitment to marriage was influenced by whether or not subjects wanted to have children in the future and marriage was seen as an important state for this purpose:

I: "Compared with married people, do you think that single people miss out on anything important?"
D002: "Yes, a family."

The following diabetic female had recently broken off a long-term relationship in order to commence a new one with a man she reported feeling very close to. Even though they had only been together for one month this man had already proposed to her, and she was unsure what her response to this would be:

D039: "I don't know, you don't have to be married these days do you. I don't think you have to be married to be happy, just live with someone. But if you have children it's only right that you are married really."

Other respondents were highly committed to the idea of marriage, the position of being a husband or wife being an important one for them:

C0081: "Miss out? Absolutely, I love to come home at the end of the day and there's somebody there waiting for me. Even if you've had a row you know that they're there. When you come home there's somebody there you can talk to."

The following subject, a single woman with diabetes, was currently cohabiting. Although considering marriage as a possible part of her future, she had only a low commitment to the idea at the time of interview. She did not see herself as married, and described her feelings towards the idea of marriage:

D016: "Sometimes I think I'd like to live on my own, just to see what it's like. I suppose single women can do what they want, they've got no-one telling them, no-one to think of. I often say that (I would like to be single again) but I don't know, I don't know what it would be like, being single again. I think about marriage, but for the distant future, I'd like to have a go at it. It might not work out, it's a gamble, but I'd like to have a go at it."

I: "Do you see yourself as married?"

D016: "No way."

A 24 year old Asian diabetic male, diagnosed 9 months prior to interview, did not see his illness as in any way affecting his marriage prospects. He had firm ideas about when he should get married, although he had no particular person in mind at the time:

D017: "I get the feeling that I should start thinking about it at this stage, but put it off for at least 2 years. But it's always there in the back of my mind that that's what I want to do. There's a certain security in marriage. In the long term I would like to be settled down, married and have a place of my own."

Commitment to marriage was not influenced by the age or sex of subjects. Healthy controls in the lowest social classes were possibly less likely to have a high commitment to marriage compared to the other social classes (0 vs 3 vs 4 ; $p=0.06$). There were no social class differences for the subjects with diabetes, however in this group subjects were somewhat more likely to be highly committed to the idea of marriage if they were diabetic Caucasians (8) compared with Afro-Caribbeans (1) and Asians (0) ($p=0.07$). There were no ethnic group differences in level of commitment for the healthy control group.

Parenthood

Only one subject with diabetes had children, a young diabetic male who had only recently become a father, whereas 11 (27%) of healthy controls had children ($p < 0.01$). Commitment to parenthood was however, comparable for the two groups; 33% of controls and 26% of diabetics indicated a marked commitment to parenthood, even though a large proportion of these subjects did not have children.

The following female with diabetes was engaged to be married during the forthcoming year, and said that she would feel 'awful' if she was unable to have children:

- I: "In your ideal world, how many children would you like to have?"
D030: "At the most, four I would say."
I: "How would you feel if you were unable to have children?"
D030: "I would feel a bit left out - you'd see other people with their own children. Alright you can foster them, but I'd prefer to have my own."

This next male subject was married with one child, and would like to have more, although at the time of interview they were living with his wife's family and felt that it was not possible until they had acquired a place of their own:

- D0081: "We discussed it before we got married and we decided that we would have 3. I love kids, I've always wanted kids. I suppose first and foremost I'm a father. Everything I do is centred around him. I tell everybody I'm a dad."

Commitment to parenthood varied according to the sex of the subjects. For both subjects with diabetes and controls together, females were significantly more likely to be highly committed to parenthood compared with males (20 vs 3 ; $p<0.001$). In the healthy control group, Asians were less likely to report high commitment to parenthood (0) compared with Caucasians (5) and Afro-Caribbean controls (8) ($p=0.08$). There was no ethnic group difference in commitment for the group with diabetes, and no social class effects for either group. For the healthy controls, those with high commitment to parenthood were significantly older compared to those with low commitment (mean age: 23.1 ± 2.3 yrs vs 21.2 ± 2.9 yrs ; $p<0.05$). There was no age difference in commitment to parenthood for the diabetic group.

State of health, marital status and parenthood.

A greater proportion of those who had complications were single at the time of interview, although this was not significant; 67% of those who had complications were single compared to 34% cohabiting or being married (n/s). Commitment to marriage and parenthood was not influenced significantly by the presence of complications.

Only 30% said that having diabetes had altered their views on marriage, and an even smaller proportion, 13% agreed that their condition would lead to changes in their plans, either at the time of interview or in the future.

Most of these changes were related to having children rather than the actual state of getting married, although the two were highly linked:

D003: "Yes, in terms of when you get married - you have babies, and I'm worried about having babies."

D014: "Yes, in terms of complications - impotence."

D030: "I'll just have to be more careful, more strict before becoming pregnant. It's worrying, sometimes I don't have much self-control."

A further 23% envisaged that their diabetes would cause them problems in the future, either because of the prospect of long-term complications, or in terms of having a family, where a prominent worry was whether or not their children would also have diabetes:

D035: "I think it might affect me when I get pregnant, unless I really look after myself. I know all the bad bits about that, I still feel worried about it."

D020: "No, apart from the fact that they could have it. That's the only thing - I wouldn't like that."

This last female with diabetes still lived at home, but at the age of 17, she already had diabetic neuropathy.

The following young male with diabetes was concerned about passing on his condition. However he was philosophical about it, especially since his mother also had diabetes:

D034: "Well I did think at one time I wouldn't like to have kids in case they had it, but if my mum had been like that, I wouldn't be here now would I?"

The results of this section demonstrate that subjects with diabetes and their matched healthy controls had comparable levels of commitment to both marriage and to parenthood. At the same time however, diabetic subjects were significantly less likely to be married and were less likely to have children. These factors may be related to the concerns reported by the young adults with diabetes in this study, with regard to their condition when at this stage in their lives. These findings, and those of previous sections will be discussed further in the following chapter.

This study has examined the relationship between the experience of chronic disease and self-esteem, education, employment and social relationships. A group of young adults with insulin dependent diabetes have been focussed on, who, once diagnosed, have had to take full responsibility for their disease in terms of their insulin therapy, diet and achieving metabolic control. This ongoing management of diabetes must be done at the same time as coping with the usual concerns of young adults, which may take precedence. This group of young people with diabetes were matched for age and sex with healthy control subjects. Although these two groups were also comparable in terms of social class, there were ethnic differences which could have influenced the findings of this study, and for this reason separate analyses were carried out.

Self-esteem.

One of the central factors of the present study was self-esteem, the measurement of which has received much attention in the past, as has been outlined in the literature review. However little in-depth information has been available on the relationship between self-esteem and other facets of life such as education, employment and social relationships in young adults.

The use of an in-depth semi-structured instrument for this investigation had both disadvantages and advantages. The main disadvantage was the lengthy nature of the interviews, and the time-consuming method of recording each subject's verbal responses onto the appropriate rating sheet prior to the actual rating procedure. However, a major advantage was the in-depth nature of the information collected. In addition, using such a semi-structured method elicited spontaneous verbal information which would not have been recorded if the interviews had been more structured. This spontaneous information is important in the light of one critical point, namely that low self-esteem (NES) could influence reporting behaviour. The SESS method entails the recording of respondents' replies to standard questions, in which they may seek to rationalise their experiences at school, work etc. However, other comments made in the context of other sections of the interview are also picked up, and this may be some sort of control for the influence of NES on reporting.

Self-esteem has been extensively investigated in the past, although it is more usual for self-completed questionnaires to be used in its assessment. These earlier measures have included some which identify the importance of a 'global' self-esteem, such as Rosenberg's scale (1965), and others which include sub-scales measuring subjects' self-evaluation in relation to different aspects of their lives, such as school and peer relations (Coopersmith 1959).

The SESS identifies both a more 'global' indicator of level of self-esteem, that is negative evaluation of self (NES) and also measures level of felt competence in relation to the individual's various roles in life, such as an employee, parent or student. Although comparisons between the present study and previous research may be problematic, because alternative methods for assessing self-esteem have been employed, it is important to consider whether the findings of this study differ in any important respects from other research investigations.

One of the main aims of this study was to assess whether the presence of a chronic illness, ie. diabetes, led to lower levels of self-esteem. The present study has demonstrated that young adults with IDDM were significantly more likely to have negative evaluation of self (NES), compared with their matched healthy controls. Neither social class nor ethnic origin influenced this finding, but diabetic females were more likely to have NES than diabetic males. In particular, females with diabetes were also more likely to have a high negative evaluation of their attributes, compared with their male counterparts. This sex difference was not found for the healthy control group. Subjects' negative evaluation of their attributes included various comments about intelligence, personality, and comments about their physical appearance.

It has been reported in other studies of both healthy and diabetic subjects that females have lower levels of self-esteem compared with males (Rosenberg and Simmons 1982, Antonucci and Jackson 1983, Ryan and Morrow 1986). Apart from differences in self-esteem between the sexes, there may also be a difference in self-consciousness (Rosenberg and Simmons 1982). These latter authors have shown that females cared more about 'being liked', were more concerned with what other people thought about them, and were more 'people oriented' than males.

This is supported in the present study, in which diabetic females were more concerned with what others thought of them in general terms, compared with both healthy females and diabetic males. Kelleher (1988) noted that women were more likely to be concerned about their diabetes, and suggested that this was in line with other work in this area, which has also reported the greater propensity of women to worry about their health and seek treatment. He argued that those who constantly worry about their health find that it interferes with their other roles, and their diabetes takes up a dominant position in their identity.

The relationship between chronic disease and self-esteem has been a controversial issue, although differences in other research findings may be partly attributed to the wide variety of measures used. A previous study by Antonucci and Jackson (1983) of over 2,000 adults aged over 21 years, demonstrated that those who reported health problems of any type had significantly lower self-esteem scores on the Rosenberg (1965) self-esteem scale compared with those who did not report health problems.

Severity and type of reported illness were also related to lower levels of self-esteem, with those reporting the worst physical disabilities having the lowest levels of self-esteem; this was independent of socio-demographic factors such as education, employment and income. Antonucci's study (1983) demonstrated the importance of considering different types and severity of illness separately.

The conclusion has often been reached that children with diabetes have self-esteem levels comparable with those of healthy subjects (Johnson 1980), or with levels found in children with recent acute illness (Jacobson 1986). However, there may be important differences between the self-concept of children and that of young adults, who are at a stage in their lives where their self-concept is likely to be less stable than when they were younger (Rosenberg 1965). Whether or not self-esteem changes or remains stable is controversial. One view suggests that self-esteem is a relatively enduring, stable characteristic, and another argues that self-esteem may be regulated by environmental events (O'Malley and Bachman 1983). This issue has yet to be resolved.

The presence of NES was unrelated to the level of glycaemic control or to the presence of diabetic complications, but this may have been due to the small sample size. Previous research has suggested that there may be a relationship between psychological factors and glycaemic control (Sullivan 1979, Citrin et al 1981, Anderson et al 1981, Bruhn 1977).

At the same time, metabolic control may be indirectly affected via non-adherence to the diabetic regimen. In a study of 9 to 15 year olds, Jacobson et al (1986) found that poor self-esteem was related to non-compliance with treatment. The issue of adherence to treatment was not addressed in the present study.

Although more than one-third of the diabetic subjects in the present study had already developed complications, many of these were minimal, such as diminished visual acuity (which may not necessarily be directly related to their diabetes) and these would not have had the same effect on self-esteem as would more severe complications which could lead to diminished social participation or greater difficulties in obtaining employment.

While no direct relationship was detected between self-esteem and Ghb or diabetic complications, those who had NES were significantly more likely to have had one or more increases in their insulin dose during the previous year. This may be an alternative indicator of the health status of these young adults, reflecting the level of self-care which could indirectly influence metabolic control. In the present study, the prevalence of NES in diabetic subjects was unrelated to either the duration of diabetes, or to age at diagnosis. This conflicts with the findings of Ryan and Morrow (1986) who associated low self-esteem with early diagnosis in childhood.

Although other specific indicators of health status, ie. Ghb, were unrelated to self-esteem in this study, it has been demonstrated that low self-esteem was significantly associated with the presence of the condition itself. This is an important finding and shows that some of these young adults have a poorer quality of life in these terms, compared to their healthy peers.

When the three component parts of the overall NES rating were considered separately, no single factor emerged as the most important in determining self-esteem (although there was a sex difference in negative evaluation of attributes). This is supported in the work carried out by the originator of the SESS (Brown et al 1990i) it was more the overall number and range of negative comments that distinguished those with low self-esteem, rather than any specific factor.

There may be a direct relationship between presence of disease and low self-esteem, especially in a society which places a high value on health and on the full participation of its members, and emphasises the negative or deviant connotations attached to chronic disease. At the same time, low self-esteem may also result from the 'side-effects' of illness, such as the loss of function, or reduced levels of participation in areas which are important to the individual.

Education.

One of the main aims of this study was to test the hypothesis that chronic disease, ie. IDDM, leads to poorer educational attainment. The present investigation has shown that subjects with diabetes achieved comparable academic qualifications as their healthy matched controls.

Previous research studies investigating the effects of diabetes on formal educational attainment have been inconclusive. Some studies have demonstrated that students with chronic disease compare favourably with their healthy peers (Weil and Ack 1964, Sterky 1963) while others have demonstrated poorer achievement (Gath 1980, Pless and Roughmann 1971). The findings of a longitudinal study (Wadsworth 1986) reported that both males and females who had had any serious illness in childhood were less likely to have gained qualifications, especially if they had been ill during the pre-school years, or for a long time.

However, in a comparison of those with diabetes and a group of matched controls, the same author demonstrated comparable academic achievement between these two groups (Wadsworth 1986). A comparison of the examination results of my study with those of the School Examination Survey 1988-89 (Department of Education and Science 1991), showed that both those with diabetes and healthy controls achieved slightly better results at Ordinary level compared with England as a whole. However, both groups were slightly less likely to have obtained A'levels, compared with the overall standard for England.

Although most investigations have been limited to the school achievements of young children, one study has investigated the academic experiences of young diabetic patients aged between 13 and 25 years (Ardron et al 1987). This study observed that the educational achievements of more than 100 people with diabetes were similar to those of the local non-diabetic population. Ardron's study (1987) confirmed the findings of an earlier study in 1984 by Mok and colleagues, who have also demonstrated comparable educational achievements in diabetic school leavers and the local population.

These results are supported by the present study, however, Ardron went on to show that those who were diagnosed at a younger age were more likely to have obtained qualifications compared to those diagnosed after the age of 13 years. This is in contrast to the present study, where no differences were found in level of academic achievement between those diagnosed before and after the age of 13. Instead a difference was found only between those who were diagnosed before and after the age of 17 years. In the present study, diabetic subjects who were diagnosed prior to the age of 17 years were less likely to have obtained qualifications, particularly at the higher levels, and this may be an important reflection of the disruptive effects of the diagnosis of chronic disease whilst at school.

Some diabetic subjects had spoken of the need to take time off school, and of the unwelcome change in attitude of both teachers and peers. These alterations in academic life may have influenced their later attainment.

People with diabetes were also more likely to have left school prior to the age of 17 years if they had been diagnosed in childhood, therefore allowing fewer chances for attempting further educational qualifications.

Ardron (1987) has also shown that those with diabetes who were diagnosed in childhood were more likely to be of social classes I or II, compared to those diagnosed later in life, and this may go some way to explaining the findings of his study. Social class differences in the prevalence of diabetes have been noted in the past, and have indicated an over-representation of people with diabetes from social class I (Tarn et al 1983, Debono et al 1983).

In the present study however, no differences were found between social class and age at diagnosis, and diabetic subjects were no more likely to be in the top two social classes than were healthy controls.

This study also examined the relationship between state of health in those with diabetes and their academic achievement. Although those who had passed educational qualifications had lower Ghb levels during the year prior to interview, this can only be suggestive of a relationship between success at school and success in achieving good metabolic control. Furthermore, even the glycaemic levels achieved by those who had obtained qualifications were still outside the recommended levels for good diabetic control.

Interpreting these results is made problematic because of the time-gap which existed for some subjects between obtaining qualifications and the measurement of Ghb taken for this study. If metabolic control has been stable throughout the individual's diabetic history, then one could surmise that the motivation to do well at school could be associated with the motivation to control blood glucose levels. However, it is not possible to firmly draw this conclusion from this study.

A further aim of this investigation was to assess the relationship between diabetes, academic achievement and self-esteem. When measuring self-esteem it is important to take into account both individual aspirations and general societal attitudes; for example, it is generally held to be important in western society to be successful in employment, and to obtain a good education. Rosenberg (1965) suggested that these goals may also differ according to the smaller social groups (for example social class or ethnic group) one belongs to: "Every society or group has its standards of excellence, and it is within the framework of these particular standards that self-evaluation occurs".

Commitment to education in this study was not influenced by social class. However ethnic group was associated with commitment for the subjects with diabetes. In this group, Caucasians were less committed to education compared to both Afro-Caribbean and Asian subjects with diabetes.

Although this may seem surprising, many Caucasians with diabetes commented on the low standard of education they felt that they had received in Brent, and this may have influenced their feelings about the importance of a good education. An unpublished study in Brent carried out in 1986, reported that Afro-Caribbean parents were highly committed to education, especially for their children (Troyna 1990). In other studies, Afro-Caribbean females have been shown to have a higher commitment to education compared to Afro-Caribbean males (Mac An Ghaill 1988).

Asian families have also been shown to possess the 'positive attitudes necessary for educational success' (Tomlinson 1983). Although a high proportion of Asian subjects had been born outside the U.K. more than half had come to live in this country before school age and so had experienced the same education as the indigenous white population in Brent. Indeed, three-quarters of all the Asians who participated in this study, were still in full-time education at the time of interview, ranging from the completion of 16 year exams to being a medical student.

Commitment to education may be related to level of felt competence in education. In the present study, although overall self-esteem was found to be an important measure, I have also demonstrated the usefulness of measuring the level of felt competence in education.

Rosenberg (1965) suggested that if students perceived their academic competence as high, they were more likely to value education, compared with those who had perceptions of low competence. This was also the case in the present study; high felt competence was related to a higher level of commitment to education. More specifically, diabetic Caucasian subjects were less likely to feel competent and were also less likely to feel committed to education, compared with the other two ethnic groups.

Although the measure of educational competence used in this study included non-academic areas, such as positions of responsibility, or membership of clubs or sports teams, respondents focussed on their academic performance. This highlights the importance of educational qualifications for these young people, in terms of their aspirations for the future. A significant proportion of respondents said that qualifications were crucial if one wanted to 'get on in the world'.

The use of a specific measure of academic self-esteem has been advocated by some researchers (eg Wylie 1979, Alsaker 1989). They have suggested that, although there might be a relationship between academic achievement and overall level of self-esteem (such as that indicated by NES), a stronger relationship between these factors may be found when a more specific measure, such as that of perceived academic competence is used.

The present investigation has supported the hypothesis that there is a relationship between overall level of self-esteem (NES) and actual academic achievement. This was especially so with regard to the attainment of higher level qualifications. Diabetic subjects who had low self-esteem (NES) were less likely to have obtained higher educational qualifications compared to those who did not have NES. Furthermore, when the more specific measure of felt competence in education was used, those diabetic subjects who felt less competent were those who obtained fewer qualifications. (Although this was true for all subjects, those with diabetes were less likely to feel competent compared to controls). These subjects were also highly committed to education, and failure to obtain formal qualifications was for them, confirmation that they were not academically competent in this way.

An association between level of self-esteem and academic achievement has also been demonstrated by other researchers (Rosenberg 1965, Coopersmith 1981, Gilberts 1983). In a review by the latter author, it was also suggested that people with a relatively high regard for themselves tended to be better students, and that people who had a strong sense of self-worth appear to be adjusted, happy and competent.

Other factors such as ethnic origin, may also influence educational achievement, and earlier research has documented the underachievement of West Indian children compared to both Caucasians and Asian pupils (Reeves and Chevannes 1988, Tomlinson 1983).

There may also be sex differences within the black population in terms of academic performance (Riley 1988, Savvides 1987). It has also been suggested by the latter authors that differences in achievement may be explained in terms of negative self-esteem. In the present study it was not possible to detect any sex differences within each ethnic group in terms of academic qualifications because of small numbers.

The results of this investigation have shown that Afro-Caribbean subjects were somewhat more likely to have obtained CSE qualifications, and were significantly more likely to have passed ONC or equivalent qualifications. Although this could indicate that Afro-Caribbean students follow a specific path at school, ie. a more practical one through which the 'tools of the trade' are learned, further analysis showed that Afro-Caribbean subjects also performed as well at the higher levels of education. None of the Asians had taken ONC qualifications and many were studying for their A'levels, which may reflect a desire expressed by many of the Asians to go on to university once they had completed their secondary education. This may also have been related to differing social class attitudes towards education, as the Asians were more likely to be in the higher social classes, compared with the other ethnic groups.

There is evidence to suggest that, in general, black children are less likely to do well compared with white children in academic terms. For example there is a disproportionately large number of black pupils in lower streams, and attending ESN schools (Troyna 1984).

However, this evidence has been challenged on the grounds that it reflects teachers' assessments of educational performance rather than the ability of pupils per se (Troyna 1984). Other factors may also influence attainment, such as social class, sex, and possible differences in educational experiences, including teacher expectations and racism (McFie and Thompson 1970, Yule et al 1975, Troyna 1984). In the present study, social class was an important variable associated with educational achievement, and the experiences of those with diabetes may also have influenced their academic attainment.

In the present study, subjects with diabetes appeared to attain comparable qualifications with healthy controls, but at the same time an association was found between self-esteem, academic achievement and the school experiences of subjects with diabetes.

This investigation has outlined some of the important specific effects of diabetes and its associated regimen on the school lives of young adults, and has shown that more than half of those who had diabetes at school age reported that they had experienced problems at school. This was associated with the presence low self-esteem; a high proportion (82%) of those who had NES reported having had difficulties at school and this same group were less likely to have obtained higher qualifications.

It is unclear however, whether failure to do well at school has resulted in lower levels of self-esteem in this group of young adults with diabetes (especially if the individual is highly committed to obtaining a good education), or whether low self-esteem existed prior to any attempts to obtain formal qualifications and somehow influenced individual behaviour. This question can only be resolved through the use of a prospective method of inquiry.

Employment.

A further aim of this study was to evaluate whether or not young adults with diabetes were likely to experience greater problems in obtaining employment or were more likely to have been unemployed, compared with matched healthy control subjects. The type of employment might also be different, especially in relation to possible discrimination on the part of employers, but also because certain occupations have been recommended as unsuitable for people with diabetes (British Diabetic Association 1984).

There were no social class differences, as defined by occupation, between subjects with diabetes and their controls. Type of occupation differed between male and female subjects, but did not differ between those with diabetes and their controls. Differences may not yet be apparent and may be more likely to be observed when these people are older. This may be especially the case if diabetic complications develop, as these may permanently disable individuals, possibly leading to changes in employment down the occupational scale.

Social class was not related to the presence of negative self-esteem in this study. This confirms the findings of Rosenberg's study (1965) of adolescents, in which he concluded that there were no large differences in self-esteem levels between students from different social classes. He argued that any differences that did exist could be explained by other factors such as sex, and to different types of parent-child relationships.

For social class to influence level of self-esteem, it may be necessary for other factors to be present such as the importance of social class position for the individual, and his/her perception of their relative class position in comparison with others around them (Kaplan 1971). Wylie (1979) also suggested in her review, that the tone of most writings on the subject seems to imply that a sense of one's socio-economic identity is at least in part, a mediator of the effects of social appraisal upon self-regard (self-esteem). The present investigation did not address the issue of the saliency of social class for young adults. However, Wylie and Kaplan amongst others may have an important point, particularly in relation to the young, for whom the idea of social class position may not be important at this stage in their lives, particularly for those who are still in full-time education.

Rosenberg (1965) pointed out that the social class position of adolescents is ascribed, not achieved, and this may have an important influence on any association between class and self-esteem: "... in the adolescent world, the reflected glory deriving from the occupational achievement of one's father may be less important." (p61).

Patrick West, in his work on social class and health in youth, also asserted that young people have yet to reach their final class position, and it may be more accurate to use the head of household's occupation as an indicator of their social class (West 1988). However, West was referring to the 12-19 years age group, and although a proportion of the subjects in the present study fall into this category, more than two-thirds were older than this and would perhaps be more likely to have attained at least a more stable class position.

Both the diabetic subjects and controls in this study demonstrated a high degree of commitment to the world of work, both in terms of financial gain and as an end in itself. Commitment was not influenced by either the experience of unemployment, or by the level of subjective competence in this domain. Neither parental nor subjects' social class differentiated between those who were and those who were not highly committed to employment.

The level of commitment that subjects felt towards their employment was unrelated to their felt competence in their work, and this confirms previous results reported by Warr et al (1979). These researchers developed a scale to measure 'work involvement', which was related to level of commitment to employment. They found that, although work involvement was correlated with job satisfaction, commitment to employment was usually unrelated to job performance except in higher grade occupations, such as professionals or managers, where there were more possibilities for shaping job activities.

In the present study, commitment to work was related to both financial gain and also the importance of the work itself. Work was important because it gave the individual a feeling of responsibility or independence, and improved one's chances of meeting new people. Finally, it helped to avoid the boredom associated with being unemployed.

The employment experiences of the young adults with diabetes and their matched controls were similar, and this confirms the findings of earlier studies by Ardron and colleagues (1987) and Hutchison (1983). For the total sample, both those diabetic subjects and their matched controls who were in the lower social classes experienced more unemployment compared with those in the higher social classes, which supports previous research (Wadsworth 1986). When the two groups of subjects were analysed separately, social class differences were still evident in the healthy control group. However social class was not associated with the experience of unemployment in the group with diabetes, suggesting that the effects of diabetes may override any social class influences.

Nearly half of the subjects with diabetes and the controls in the present study had experienced some unemployment in the past, but at the time of interview only four subjects (5%) were unemployed. Although prior experience of unemployment was unrelated to the current level of self-esteem, diabetic subjects who reported experiencing previous difficulties in obtaining employment were more likely to have low overall self-esteem (NES).

Rates of employment for people who have diabetes have been shown to vary, and some studies have indicated comparable rates for those with diabetes and the local population (Hutchison et al 1983, Ardron et al 1987, Tebbi et al 1990). However, in the first of these studies Hutchison (1983) showed that those with insulin-dependent diabetes were more likely to have been refused work or made redundant because of their diabetes.

In a recent study by Robinson et al (1990) carried out in 1985, young people under the age of 25 years with diabetes were more likely to be unemployed compared with matched controls. They also reported more difficulties in obtaining employment because of their condition compared to older subjects with diabetes. This may have been related to the type of diabetes, as the older subjects would be more likely to have non-insulin dependent diabetes. Unemployment rates in Robinson's investigation were higher for diabetic males compared with matched controls, but this difference was not evident for the females with and without diabetes. In the present study, diabetic subjects and controls of the same age as Robinson's subjects experienced comparable rates of unemployment, although the latter study covered many different areas of the UK which may have influenced these results.

A postal questionnaire study of young adults in the U.S. with diabetes aged 18 - 36 years, found that, although subjects had similar employment experiences compared to randomly recruited controls, the diabetic subjects reported more problems in performing their job and were more likely to worry about concentration problems at work (Tebbi et al 1990).

These latter authors also showed that 9% of their subjects had been rejected for work because of their diabetes. This was a much smaller proportion than the present study in which 30% reported being refused employment for the same reason. The wide discrepancy between this study and the present one may be associated with the methods used to obtain information; the more in-depth methods of the SESS would have almost certainly led to the recording of more detailed, and possibly more accurate information.

There may also be differences in terms of the experience of employment discrimination due to the different policy recommendations operating in the U.S. and the U.K. In 1982 the American Diabetes Association stated that "Any diabetic, whether insulin-dependent or non-insulin-dependent, should be able to accept any employment for which he or she is individually qualified" (Zagoria 1982). In the U.K., in 1984, the British Diabetic Association suggested that there were certain occupations which were not suitable for those with diabetes, particularly those with insulin-dependent diabetes (BDA 1984).

It has been previously suggested that unemployment is becoming a more acceptable aspect of young peoples' self-perceptions and self-identity, as the employment situation for school leavers deteriorates (Kelvin 1981, Coleman 1990). During the 1980's, school leavers were expected to join government training programmes, such as the Youth Training Scheme if they were unable to find employment. There were financial losses in terms of state benefits if they did not.

Coleman (1990) has pointed out that it is common and also accepted for young people to change jobs frequently at the start of their working life, not only for financial gain or upward mobility, but also in their search for greater job satisfaction in the light of the limited opportunities available. In the present study, it was common for the respondents to have been employed in several different jobs since leaving school. More than two-thirds of both subjects with diabetes and healthy controls had had two or more jobs since leaving school, and more than one-third of each group had had three or more jobs during this time.

Unemployment rates in the U.K. were high in the late 1980's, and this may have particularly affected young people with little experience or few qualifications. In this sample of young adults, although only 5% were unemployed at the time of interview, nearly half had experienced some unemployment since leaving school.

Recent government statistics showed that in 1988 10% of males aged 18 - 24 were unemployed in the U.K. and 7% of females (General Household Survey 1988). However, it is difficult to make comparisons between the unemployment rates obtained in the present study and those of these official statistics, as the latter are not area-specific and employment rates differ widely according to the area of residence. The Labour Force Survey of 1987 (published in 1989) reported the unemployment rate for Greater London, which was 4% for all 16 - 19 year olds, and 6% for all those aged between 20 and 24 years old. These findings do indicate therefore, that the unemployment rate for this study compares favourably with the official rates reported here.

An important aim of this study was to evaluate whether there was a relationship between state of health and the employment experiences of young adults with IDDM. In this investigation, those who had experienced unemployment had a higher mean Ghb level, compared to those who had remained employed, but this finding was not statistically significant.

The experience of unemployment may be less related to diabetes per se, but rather may be associated with the presence of complications. An American study of 158 insulin-dependent diabetic subjects of all ages, and their matched non-diabetic siblings, demonstrated that the primary factor associated with work disability was the presence of complications (Songer et al 1989). In the same investigation, those with diabetes were more likely to report job refusal and were less likely to be employed full-time, compared to their siblings.

In the present study although numbers were small, a somewhat greater proportion (46%) of those who had complications and who had left school had experienced unemployment compared to 35% of those who did not have complications. One quarter of the diabetic subjects in the study reported experiencing problems in obtaining employment, and this was associated with low self-esteem. This did not necessarily lead to an increased frequency of actual unemployment however; only one-third of those with problems had experienced unemployment and all were in the lower social classes, a risk factor for unemployment.

Although one-third of diabetic subjects reported that there were jobs they would like to do but could not, because of their disease, few hid their diabetes from potential employers due to a fear of discrimination. Those who had refused to inform their employer about their diabetes were often working in manual occupations, from which they had realised they would be barred if they had declared their illness.

It is important to recognise that both social class and level of self-esteem may have influenced reporting behaviour. In this investigation it was not possible to separate the effects of employment problems on self-esteem, from the influence of self-esteem on both experiences in the job market and on reporting behaviour. This is an issue which needs to be further investigated.

Social and family relationships.

The penultimate section of the results assessed the relationship between diabetes and social and family supports. The results have demonstrated that both people with diabetes and their healthy controls were equally committed to social arenas, that is to social activities outside the home, including both leisure or sports activities and time spent with friends. At the same time however, although commitment to social arenas in general was high, when more specific measures of social relationships were analysed, diabetic subjects were significantly more likely to be socially isolated and were less likely to report having someone they felt close to.

These two aspects were closely related in that for many, social isolation meant the absence of a VCO, rather than any other indicator of isolation. Absence of a VCO was not related to low self-esteem, although this may be related to the fact that a high proportion of both groups reported that they had someone in whom they could confide, even though this was not necessarily someone close to them.

Presence/absence of a confidant may be more importantly associated with self-esteem rather than merely the absence of someone they reported feeling very close to. Although subjects with diabetes and healthy controls did not differ in terms of the existence of boy/girlfriends (ie. partners), there was an association between the presence of low self-esteem and the lack of confiding in a partner or girl/boyfriend in diabetic subjects, although not for the healthy controls.

Actual concrete support, such as the opportunity to confide, has been shown to be related to self-esteem in a number of other studies (Brown et al 1990 ii). In one such investigation, the quality of young adults' attachments to both their peers and their parents, and the frequency of their utilisation, were significantly associated with self-esteem (Greenberg 1982). In a recent study, Brown et al (1990 ii) has shown in a study of working class women in London how negative interaction with VCO's may be related to low self-esteem; however in the present study, this was not the case.

Other researchers have also demonstrated how self-esteem may be influenced by level of social activity (Connolly et al 1987). Connolly suggested that socialising with peers can lead to high self-esteem because it is both a voluntary activity and a highly positive one.

Level of social activity as indicated by affiliation to a 'crowd' may decline during adolescence with one or more closer friends becoming more important as late adolescence is reached (Coleman and Hendry 1990). In the present study, this was especially the case for subjects who had left school and who did not have an easily accessible group of young people to socialise with. These young adults were passing through various life-stages which may have had an important impact on social relationships, as moves from school took place, leading to further education, employment or unemployment.

Type and frequency of social activity may differ according to sex, as well as with age and status. Although level of social activity was not directly measured in the present study females, both diabetic subjects and controls, were more likely to have true VCO's who were seen monthly or more, compared with males. Males with diabetes were the least likely to have a true VCO, compared with their controls. A study of younger adolescents aged 14 - 16 years, did not find any differences in the level of social activity between male and female subjects (Connolly et al 1987). However differences may not be apparent at this earlier age.

In cross-sectional studies, it is difficult to ascertain whether level of self-esteem is a result of decreased social interaction, or whether low self-esteem leads to fewer social contacts. It may be that positive self-evaluation may engender more social activity which in turn reinforces these positive feelings (Connolly et al 1987). This was possibly true for the present study, in which those with a more positive evaluation of self were more likely to report having someone they felt very close to.

Social activity may only be related to 'social' self-esteem, and it may also be worth considering how much importance is placed on this area of life in order to understand fully the relationship between social activity and self-esteem (Connolly et al 1987). In the present study, a high importance was placed on social arenas by both subjects with diabetes and controls. However diabetic subjects were significantly more likely to have high commitment but at the same time to experience social isolation, compared with their matched controls.

Young adults with diabetes were significantly more likely to exhibit attitudinal constraints towards eliciting care or comforting responses, and they were also more likely to demonstrate a fear of intimacy. These attitudes were not related to the sex of the subject (although females were more likely to have a VCO than males), but were related to low self-esteem.

Attitudinal constraints may be related to earlier experiences in social relationships which were not recorded in this study, or alternatively may be associated with the demands of their disease. Those with a chronic illness such as diabetes, which requires regular mealtimes, injections and a strict dietary regimen, tend to lead to a less spontaneous life-style, which could prohibit them from establishing close relationships.

Some of the respondents reported feeling constrained in terms of their social lives, having to plan their activities carefully, or having to take their insulin out with them, or remembering to eat at the correct time. At the same time, a direct association may exist between having diabetes and the presence of feelings which deter the development of close relationships, and this may be related to level of felt competence in social terms and overall level of self-esteem.

If having diabetes means less spontaneity, reduced peer-group participation, or experiencing feelings of 'not fitting in', then a reduced level of self-esteem may be the result. Feelings of unacceptability may be related to ideas about 'stigma', which refers to the discrediting attitudes of people. A stigma can be applied to any condition or attribute which marks out the individual as culturally unacceptable or inferior (Scambler 1984). Different diseases have varying acceptability, and this may depend to some extent on the visibility of the condition or its social impact. The present study has reported instances of the discrediting attitudes of others, such as the reactions of school friends to finding out about subjects' diabetes and the jokes made about their condition.

Some of these young adults reported their friends' shocked reaction and only one-third said that their friends were supportive or interested in their condition.

Various reactions to feeling stigmatised have been documented (Goffman 1963), and some of these different strategies were portrayed in the present study. For some, a strategy of concealment (Goffman termed this 'passing') was employed by those who reported that they did not tell anyone at school about their diabetes. When it came to mealtimes, they told their friends that they had already eaten, or they took sandwiches for lunch.

A second strategy has been referred to as 'covering' (Goffman 1963), which entails reducing the significance of their condition rather than denying that it exists (Scambler 1984). This can be done by fitting in or attempting to lead as 'normal' a life as possible, demonstrating to others that diabetes does not impact significantly on their individual capabilities. This can be illustrated using the case of the diabetic subject who was still able to 'drink his friends under the table'.

A third reaction to feeling stigmatised is withdrawal (Scambler 1984) or opting out of social activities. Whilst the subjects with diabetes in this study were more likely to be socially isolated and some of this group also portrayed marked feelings against the development of close relationships, it is difficult to link this with the strategy of withdrawal, as this was not directly addressed in the interview.

There is evidence however, of some subjects' social withdrawal apart from the necessary interactions taking place at school, and this may be indicative of the use of this strategy.

Hopper (1981) suggested that the potential for stigma in diabetes lies in the dramatic and often negative life-changes that this disease can bring. She illustrated this in terms of problems in metabolic control, which can interfere with the individuals capacity to function in society. In my study, half of the subjects reported testing their blood at least daily and often more frequently than that. A further quarter tested their blood at least once or twice each week, and the remainder admitted to extremely infrequent testing, if at all. Having to perform constant blood tests must seriously impact on day-to-day activities, and it is probably easy to see why some people do not carry them out.

In Hopper's study (1981) of adults with both insulin-dependent and non-insulin-dependent diabetes, feelings of being stigmatised led to increased anxiety. She concluded that stigmatisation can be experienced at work and in family and social relationships. This can interfere with patterns of self-care, which should be understood by physicians in their treatment of people with diabetes.

If the degree or quality of social activity influences level of self-esteem and low social competence is perceived, then people with diabetes, who were more likely to have low self-esteem, may be less likely to pursue a social life, and this may account for the higher level of social isolation in this group.

With the rapid progress made in terms of insulin delivery systems, which has led to the use of regimens which incorporate more frequent insulin injections, delivered by less obvious methods (such as the use of devices which look like fountain pens), the future looks brighter for those who opt to use this system.

In the present study, 18 (45%) of the diabetic subjects were using a pen-injector device. They were just as likely to have low self-esteem, and were only somewhat less likely to report employment difficulties. However they were much less likely to report problems at school, and were significantly more likely to have a boy/girlfriend, compared with those who remained on conventional therapy. A study in 1989 (Houtzagers et al) has shown the benefits of the pen-injector system for level of self-confidence.

The frequency with which young adults interact with their peers may be dependent on the quality of interaction with parents (Iacovetta 1975). In the present study few parents were described as very close by the diabetic subjects, and negative interaction with parents was higher in those people with diabetes than in the controls. At the same time, low levels of confiding in their parents about diabetes were reported. According to Iacovetta's argument, this would lead one to predict that these subjects would express a desire for the existence of other close confiding relationships; however this was not the case. Diabetic subjects were highly committed to social arenas in general, but had greater attitudinal constraints with regard to close relationships.

It has been suggested that relationships with peers may become more important than those with parents during adolescence (O'Donnell 1976), so that feelings towards parents may be less important to the adolescents' self-esteem compared with younger age groups. However, emotional and concrete support from parents may still be important for the well-being of young people (Burke 1979).

This latter study has shown how the quality of supportive relationships may be linked with both self-esteem and emotional and behavioural problems. Greenberg et al (1983) have also shown that the quality of parental attachment was more important than that of peers in terms of its impact on self-esteem.

This study has documented the nature of the relationships between parents and young adults, as reported by the study participants themselves. Equal proportions of both subjects with diabetes and healthy controls were still living at home with their parents, and this did not influence whether or not subjects regarded their relationships with their parents as very close, or whether they confided in their parents. In comparison with their matched controls, diabetic subjects also reported somewhat more negative interaction with their parents and less approval from their mothers, and these factors were related to low self-esteem.

None of those who had NES reported having either parent as VCO or confidant. These findings confirm earlier research in which Rosenberg (1965) demonstrated that degree of parental interest in areas such as academic achievement and friends, was related to later self-esteem.

In the present study most VCO's were friends rather than parents, and emotional support received from these was reported as being high. Although 68% of the subjects with diabetes reported that their parents were interested in their condition, only half of these also reported parental support, and only half of this same group also said that they discussed their diabetes with their parents. At the same time, few diabetic subjects hid their condition from their peers, with only 15% saying that they did not talk about it to their friends.

Burke (1979) has demonstrated that adolescents were more likely to report their feelings to peers rather than parents. However, in earlier research (Burke 1978) he demonstrated how adolescents' worries about school, social situations etc, were less likely to be associated with poor well-being if the adolescent was satisfied with support from both their parents and their peers.

Miller et al (1976) observed a relationship between greater physical and psychological symptoms and the absence of both casual, less intimate friends as well as closer ties. In the present study, subjects with diabetes were more likely to report the absence of lower confiding relationships compared with healthy controls, but this was not associated with self-esteem.

Support from both peers and family may have an important impact on physical and mental well-being, although it must be pointed out that the attitudes of parents may be difficult to infer from respondents' own reports. In the present study, although peers were more important than parents as 'very close others', diabetic subjects were also less likely to have one or more VCO and were more socially isolated. However, this did not lead to significant differences within the diabetic group in terms of metabolic control or the presence of complications.

Social and family support, or the absence of it, may have important implications for the management of the disease. Bury (1988) has suggested that in times of illness individuals may turn to their families for help, but it is not certain how appeals for help will be responded to. Different strategies for handling symptoms may be regarded more positively than others, and this may have important implications for the young adult with diabetes. Kelleher (1988) has described how some people with diabetes met with unsympathetic responses from other family members when having a hypoglycaemic attack.

The quality of family relationships may influence specific indicators of health for those with diabetes, such as the degree of metabolic control achieved, and may also influence whether or not the diabetic regimen is adhered to. In the present study however, neither current negative interaction with parents nor level of parental support was related to metabolic control or the presence of complications.

Approval from the father was related to current metabolic control, but only for those who were living away from the parental home. This finding could therefore, probably be explained by the older age of those who had left home, who were perhaps more likely to have attained better diabetic control, compared with younger subjects with diabetes. For males, the absence of approval from both parents was significantly associated with the presence of complications. These findings should be treated with caution, as for some of the older diabetic subjects, a considerable time-lag existed between the recording of Ghb used for this study, and the time period about which these subjects reported their relationships with their parents.

These difficulties in interpretation apply only to the measure of parental approval, and is overcome by looking only at the Ghb levels of subjects who were under the age of 18 years at the time of interview and were therefore reporting current parental approval. Although numbers were small in this group, father's approval was somewhat related to better levels of metabolic control. Overall, diabetic subjects in this age group were less likely to report their mother's approval during childhood compared with their controls. However, there was no detectable difference in mean Ghb between diabetic subjects with and without their mother's approval.

Less approval may be related to parental concerns about their child's adherence to their diabetic regimen. However, the present study has only found slight indications of a relationship between family relationships and metabolic control. This may be attributed to the small numbers involved. Adherence was not measured directly in this study, the only indication available is the level of metabolic control, and this may be influenced by other factors that are not related to adherence.

Earlier research has indicated that the presence of social and family supports can affect metabolic control, either by acting as a buffer against stresses or difficulties, or by affecting compliance or regimen adherence, which in turn affects glycaemic control (Schlenk 1984, Schafer et al 1986). Social supports, or rather the lack of them, may influence level of psychological well-being and adjustment to diabetes (Carpenter 1983), and the presence of family conflict has also been shown to have serious adverse consequences for diabetic control (Swift et al 1967, White et al 1984, Marteau et al 1987).

Any affect on overall adjustment to diabetes, or on degree of metabolic control may be mediated by the duration of diabetes (Hanson et al 1989). Hanson and colleagues have shown that in families where the adolescent has had diabetes for only a short time-period, family relations were important in determining metabolic control. For those who had a longer duration of diabetes, these factors were no longer important.

This was not explained by the age of the subject however, and Hanson argued that it may be related to physiological changes in the disease process itself. In the present study, duration of diabetes was not significantly associated with parental approval during childhood.

Marriage and parenthood.

The final part of the results section addressed the issue of the relationship between diabetes and both marriage and parenthood. Subjects with diabetes were significantly less likely to be married, and more likely to be cohabiting, compared with their matched controls, in spite of the fact that these two groups demonstrated comparable commitment to marriage. At the same time, subjects with diabetes were significantly less likely to be parents compared with their healthy controls, although once again, they exhibited comparable commitment to having children.

Little research has investigated this issue, although as the present study shows, young adults with diabetes do have some important concerns, such as their worries about pregnancy, and impotence. At the same time, one quarter said they felt that their diabetes would cause them some problems in the future.

In a study by Ahlfield and colleagues (1985), adults aged 20 - 35 years were questioned with regard to their attitudes towards marriage and children. More than one-third of females and nearly all the males found the disease a source of friction in their marriage.

Although none of the subjects in this American study reported making a conscious decision not to get married, nearly one-third of the females and one-quarter of the males had decided not to have children, and this decision was more common in those who had developed diabetes after the age of 13 years. None of the subjects in the present study reported that they had decided not to get married, but many of them showed concern about the difficulties associated with their ability to have children.

People with diabetes who had a high commitment to marriage, did not differ in terms of social class compared with those who had a low commitment, but when ethnic group was considered only one of the Asians with diabetes had a high commitment to marriage. This was an unexpected finding, given the importance placed on marriage by the Asian community. However, this importance may apply more to the parents of these young people, rather than to themselves. Low commitment to marriage may be related to the Asian subjects' current high commitment to furthering their education exhibited by these subjects. This may have influenced their feelings about marriage, at least with regard to the near future, especially if it meant giving up a career.

In conclusion, the results of this study have clearly demonstrated that subjects with diabetes suffered from a lower level of self-esteem compared with their matched controls. Although small scale, this investigation has highlighted some of the difficulties experienced by young people with diabetes, and has demonstrated that these problems were associated with the presence of low self-esteem.

Overall, subjects with diabetes and healthy controls reached comparable levels of educational achievement and any differences that did exist were more likely to be associated with social class and ethnic group rather than the presence of diabetes. However, when these factors were accounted for in the analysis, educational achievement was still related to level of self-esteem, especially for those subjects with diabetes.

The western world places great emphasis on educational credentials, as an end in themselves, as well as the means of acquiring high status employment, and some of the young adults with diabetes who participated in this study were clearly at a disadvantage. Although as a group subjects with diabetes did not experience greater unemployment, some of these young adults did report difficulties in obtaining employment and felt there were jobs they could not do because of their diabetes. These subjects were also more likely to have low self-esteem. Only a small proportion of diabetic subjects reported these employment difficulties however, and these subjects were also in the lower social classes, which gave them a greater risk of unemployment even without having diabetes.

The presence of diabetes may lead to reduced levels of social participation and may impact on parental relationships. Regardless of social class position, ethnic origin or sex, those who had diabetes were significantly less likely to feel very close to someone, and were less likely to have either parent as a VCO or a confidant.

Diabetic subjects were also less likely to be married, and had marked attitudinal constraints towards having close relationships. Many of these subjects reported a lack of understanding or support from both parents and peers, and this included the majority of those who had low self-esteem.

This was a cross-sectional study, and in order to establish whether self-esteem acts as a mediator in the relationship between chronic disease and educational and employment experiences, or whether self-esteem is a result of the young adults' experiences, can only be determined by a prospective investigation. Only small differences in the state of health of those with diabetes were detected in terms of these different psychosocial factors, and this was probably related to the small numbers involved.

One important avenue for further investigation might be to establish the existence of a sex difference in terms of the experiences of chronic disease. In certain aspects of this study, females fared less well than their male peers; they were more likely to have low self-esteem, and reported more problems in obtaining employment, in spite of the fact that they achieved comparable qualifications at school. How far these results reflect an accurate picture of women with diabetes experiencing difficulties in an environment where there are already difficulties for women, or how far these findings reflect differences in reporting behaviour or greater sensitivity to problems that are encountered, requires further investigation.

The approach taken in this study has been one in which both quantitative and qualitative methods were incorporated. Although I have reported findings from a relatively small number of subjects, it has been possible to illustrate the impact of diabetes on the lives of these young adults. The semi-structured interview technique enabled me to focus on the day-to-day effects of chronic disease, through the collection of qualitative information. At the same time, I have been able to report more quantitative results, in order to support this descriptive data. A further advantage of this study was that, unlike many other studies, a group of matched healthy controls was used. This made it possible for me to examine whether any observed differences were related to the presence of chronic disease, or could be explained by other factors such as social class or ethnic origin.

Those who participated in this study may not have been representative of the diabetic population in general, as not all young people with IDDM regularly attend diabetic out-patient clinics. However, the importance of this study lies in the nature of the information obtained, rather than in any possibilities for generalisation, which had not been an intention of the study. Having said this, a comparison of the state of health of those who did not attend clinic, with those who did regularly attend clinic, did not reveal any large differences between the two groups.

Those who attend out-patients may in general be more compliant, or they may be the most severe cases, in terms of metabolic control. However in the present study, the full range of Ghb measures was observed, with some in better control than others, and also a variety of complications were in evidence. If this sample of diabetic subjects consisted entirely of those who were in the poorest control or in the poorest state of health, these differences in terms of state of health may not have been observed.

By using the SESS, it has been possible to identify specific areas in the lives of young adults with IDDM which have been influenced more than others, such as the attitudes of peers towards diabetes, difficulties with diabetes at school, and feelings about having close relationships. All these aspects were associated with the presence of low self-esteem, and this detailed information would not have been obtained using a brief checklist method. This in-depth study has also shown how problems in obtaining employment were important for some of those with diabetes and possibly more important than the experience of actual unemployment, which may be seen as a 'normal' occurrence by young people today.

In a cross-sectional study such as this, it is not possible to determine the causal direction of these relationships, only to establish that in some way, various factors such as NES, may mediate the relationship between diabetes and education or employment experiences, or whether or not the individual is socially isolated. The effect of all these difficulties may be low self-esteem, although this can only be confirmed by the use of a prospective method of inquiry.

The findings of this study have implications for both future research, and for policy and practice in health care. Some people with diabetes do not attend their out-patient appointments, and prefer to go to their G.P. for their insulin supplies. In addition, there were comments made by some of the respondents regarding their experiences when they did attend clinic. Both these facts may indicate a certain amount of dissatisfaction about the nature of health care delivery, and how it is perceived by young adults with diabetes.

Little research has focussed on the requirements of young adults, and this is an area in which further research needs to be carried out. The present study has shown that those with diabetes were less likely to feel very close to their parents, and were less likely to confide in either of them. Parental relationships have been studied in young adolescents, but there is little information regarding the older adolescent or the young adult. Only half the diabetic subjects felt that they received their parents' support, and fewer than half discussed their condition with their parents. Although this study has been unable to show a direct relationship between these factors and degree of diabetic control, this may have been due to the small sample size, rather than the fact that this relationship did not exist. Other studies in younger people have indicated that family support is crucial, and, although peer support may be also influential, there is no reason to suggest that lack of family support will not have some impact at this older age.

Relations with other family members may also be important, and this is an area which has been neglected in research. There have been some suggestions in the literature that doctors should treat the whole family, rather than just the child with diabetes (Grey et al 1980). However, this may be more salient in the younger age groups and in those who are still living at home. Alternatively, total family support, rather than just that of the parents, may still be important in influencing the management of diabetes.

There is a need to encourage a better understanding of the issues that are important to young people with diabetes, and to address the common concerns of this group. The identification of the specific effects of diabetes can lead to more targeted intervention programmes, and to improved health care delivery. There may also be useful parallels with other illnesses, although what may be appropriate for those with diabetes may not necessarily be so for other patient groups.

Future initiatives must also take into consideration the role that both gender and ethnic group may play in mediating the effects of chronic disease on the lives of young adults. As mentioned before, in this study there were some specific effects of sex, with females having low self-esteem more often than males and reporting more problems in obtaining employment. Although in this investigation, Afro-Caribbean subjects achieved comparable educational qualifications to both Asians and Caucasian subjects, other research in this area has indicated otherwise, and this is clearly an area to be pursued.

Patients' worries with regard to marriage and parenthood need to be addressed by experts who can help to allay their fears. A greater awareness of the needs of those with chronic disease, on the part of both teachers and careers advisors, would help to orient their educational advice, and assist those with diabetes obtain employment and choose appropriate careers. Although only a small proportion of young adults with diabetes reported problems in obtaining employment, the future implications of this may be much greater. In ten or fifteen years time, these young people will be more likely to have diabetic complications, some of which will be severe. For those in manual occupations (although this applies to many other occupations) this could lead to difficulties, as disability leads to a greater risk of unemployment.

The two main issues raised here are firstly, how to improve patient services, and secondly, how to improve quality of life. These two related aspects may both affect metabolic control through their indirect effects on regimen adherence and self-care. Group therapy, social learning interventions, and self-help associations have all been shown to have some impact on diabetic control, and levels of psychological well-being, and the most successful of these have taken place out of the hospital setting (Tattersall et al 1985, Kaplan et al 1985, Aveline et al 1985).

The problem lies, not just in the establishment of these initiatives, but in the identification of young adults who require these services, as clearly not all those who have diabetes require support services, or indeed would wish to make use of them.

One possibility would be to develop a short-screen to identify those who have difficulties, which would also facilitate the use of larger patient groups. The main disadvantage of this would be the loss of detailed information, which is the major advantage of using a method such as the SESS. However, a larger study would also permit the use of multivariate analysis of the findings, in order to assess the relative importance of various factors. It was not possible to do this in the present study due to the sample size. Once the existence of particular problems has been established, appropriate interventions could then be designed.

Not only is it important to educate, support and inform those with diabetes, it is also crucial to inform those who provide medical care about the issues of relevance to young people with this condition. This dichotomous approach can only serve to improve patterns of care, which could lead to changes in metabolic control. This is the centre-point of diabetic management and could ultimately delay or even prevent the development of diabetic complications.

REFERENCES.

Ack M, Miller I, Weil WB. Intelligence of children with diabetes. *Pediatrics* 1961;Nov:764-770.

Ahlfield JE, Soler NG, Marcus SD. The young adult with diabetes: impact of the disease on marriage and having children. *Diabetes Care* 1985;8(1):52-56.

Ahnjso S, Humble K, Larsson Y, Settergren-Carlsson G, Sterky G. Personality changes and social adjustment during the first three years of diabetes in children. *Acta Paediatr Scand* 1981;70:321-327.

Allen DA, Affleck G, Tennon H et al. Concerns of children with a chronic illness: a cognitive-developmental study of juvenile diabetics. *Child Care Health & Development* 1984;10(4):211-218

Alsaker FD. Academic competence and global self-esteem. *School Psychology Int.* 1989;10:147-158.

Anderson R, Bury M (eds). *Living with chronic illness. The experience of patients and their families.* London, Unwin Hyman Ltd, 1988.

Anderson BJ, Miller JP, Auslander WF, Santiago JV. Family characteristics of diabetic adolescents: relationship to metabolic control. *Diabetes Care* 1981;4(6):586-594.

Antonucci T, Jackson J. Physical health and self-esteem. *Family Community Health* 1983;6:1-9

Ardron M, MacFarlane I, Robinson C. Educational achievements, employment and social class of insulin-dependent diabetics: a survey of a young adult clinic in Liverpool. Diabetic Med 1987;4:546-548

Armitage P. Statistical methods in medical research. Oxford, Blackwell, 1971;126-130.

Aveline MO, McCulloch DK, Tattersall RB. The practice of group psychotherapy with adult insulin-dependent diabetics. Diabetic Med 1985;2:275-282

Bagshaw E. Careers for diabetic girls in nursing. Br Med J 1980;280:1227.

Baker L, Minuchin S, Milman L, Leibman R, Todd T. Psychosomatic aspects of juvenile diabetes mellitus: a progress report. In: Laron Z (ed) Diabetes in juveniles: medical and rehabilitation aspects. Vol 12 of Modern Problems in Pediatrics. Karger Basel, New York 1975.

Bell RA, LeRoy JB, Stephenson JI. Evaluating the mediating effects of social support upon life events and depressive symptoms. Am J Commun Psychol 1982;10:325-340.

Berkman LF. Social networks, support and health: taking the next step forward. Am J Epidemiol 1986;123:559-562.

Berkman LF, Syme SL. Social networks, host resistance and mortality: a nine-year follow-up of Alameda County residents. Am J Epidemiol 1979; 109:186-204.

Berkman LF. The relationship of social networks and social support to morbidity and mortality. In: Cohen L, Syme SL (eds). Social Support and Health. London, Academic Press, 1981;241-262.

Bingley PJ, Gale EAM. The epidemiology of childhood onset diabetes: a review. Practical Diabetes 1990;7(1):7-11.

Bland M. An introduction to medical statistics. Oxford, Oxford University Press, 1987;268-269.

Bradley C. Stress and diabetes. In: Fisher S, Reason J. (eds). Handbook of life stress, cognition and health. London, J Wiley, 1988.

Brandaleone H. Employability of the diabetic. Ann New York Acad Sci 1959;82:258-265.

Brandaleone H, Friedman GJ. Diabetes in industry. Diabetes 1953;2(6): 448-453.

Brent Health Authority. Brent District health profile. 1988 (unpublished).

Brissett D. Toward a clarification of self-esteem. Psychiatry 1972;35:255-263.

British Diabetic Association. The employment of diabetics. Diabetic Med 1984;1:308.

- Brown GW, Andrews B, Bifulco A, Veiel H. Self-esteem and depression
i. Measurement issues and prediction of onset. Soc Psychiatry
Psychiatr Epidemiol 1990 i;25:200-209.
- Brown GW, Bifulco A, Veiel H, Andrews B. Self-esteem and depression.
ii. Social correlates of self-esteem. Soc Psychiatry Psychiatr
Epidemiol 1990 ii;25:225-234.
- Brown GW, Andrews B, Harris T, Adler Z, Bridge L. Social support,
self-esteem and depression. Psychol. Med 1986;16:813-831.
- Brown GW, Bhrolchain M, Harris T. Social class and psychiatric dis-
turbance among women in an urban population. Sociology 1975;9:225-
254.
- Bruhn JG. Self-concept and the control of diabetes. AFP
1977;15(3):93-97.
- Bruhn JG, Philips BU. Measuring social support: a synthesis of
current approaches. J Behav Med 1983;7:151-169.
- Bryman A. Quantity and quality in social research. London, Unwin
Hyman, 1990.
- Burke RJ, Weir T. Benefits to adolescents of informal helping
relationships with their parents and peers. Psychological reports
1978;42:1175-1184.
- Burke RJ, Weir T. Helping responses of parents and peers and
adolescent well-being. J Psychol 1979;102:49-62.

Burns KL, Green P, Chase HP. Psychosocial correlates of glycemic control as a function of age in youth with insulin-dependent diabetes. *J Adolesc Health Care* 1986;7:311-319.

Bury M. Chronic illness as biographical disruption. *Sociology of Health and Illness* 1982;4(2):167-182.

Bury M. Meanings at risk: the experience of arthritis. In: Anderson R, Bury M (eds). *Living with chronic illness. The experience of patients and their families*. London, Unwin Hyman Ltd, 1988;89-116.

Capelli M, McGrath PJ, Heick CE, et al. Chronic disease and its impact; the adolescent's perspective. *J Adolesc Health Care* 1989;10(4):283-288.

Carpenter BN, Hansson RO, Rountree R, Jones WH. Relational competence and adjustment in diabetic patients. *J Social Clinical Psychol* 1983;1(4):359-369.

Cassel J. The contribution of the social environment to host resistance. *Am J Epidemiol* 1976;104(2):107-123.

Cernelc D, Hafner G, Kos S, Cenlec P. Comparative study of social and psychological analyses in asthmatic, rheumatic and diabetic children. *Allergie Immunol* 1977;23:214-220.

Cerreto MC, Travis LB. Implications of psychological and family factors in the treatment of diabetes. *Paed Clin North Am* 1984;31:689-710.

- Challen AH, Davies AG, Williams RJW, Haslum MN, Baum JD. Measuring psychosocial adaptation to diabetes in adolescence. *Diabetic Med* 1988;5:739-746.
- Chazan BI, MacLaren A, Shetty YP, Tooley E, Moore A, Wilkinson E. The effect of locus of control and socio-economic status on control of diabetes in adolescents. *Pediatr Adolesc Endocr* 1982;10:39-42.
- Citrin WS, Kleiman GA, Skyler JS. Emotions: a critical factor in diabetic control. In: Mayer B Davidson. *Diabetes mellitus, diagnosis and treatment*. New York, J Wiley, 1981;ch.9.
- Close H, Davies AG, Price DA, Goodyer IM. Emotional difficulties in diabetes mellitus. *Arch Dis Child* 1986;61:337-340
- Cohen S, Wills TA. Social support and the buffering hypothesis. *Psychological Bull* 1985;98(2):310-357.
- Collier BN Jr. Comparisons between adolescents with and without diabetes. *Personnel and Guidance Journal* 1969, Mar:679-684.
- Coleman JC, Hendry L. *The nature of adolescence*. London, Routledge, 1990;162-214.
- Committee on Employment 1955-6. Analysis of a survey concerning employment of diabetics in some major industries. *Diabetes* 1957; 6(6):550-554.
- Connolly J, White D, Stevens R, Burstein S. Adolescent self-reports of social activity: assessment of stability and relations to social adjustment. *J Adolesc* 1987;10:83-95.

Coopersmith S. A method for determining types of self esteem. J Abnorm Soc Psychol 1959;59:87-95.

Coopersmith S. The antecedents of self-esteem. California, Consulting Psychologists Press Inc, 1981;1-18.

Cox DJ, Taylor AG, Navacek G et al. The relationship between psychosocial stress and insulin-dependent diabetic blood glucose control: preliminary investigations. Health Psychology 1984;3(1):63-75.

Cruickshank JK. Diabetes: contrasts between peoples of black (West African) , Indian and white European origin. In: Cruickshank JK, Beavers DG (eds). Ethnic factors in health and disease. London, Butterworth & Co., 1989;289-304.

Davis DM, Shipp JC, Pattishall EG. Attitudes of diabetic boys and girls towards diabetes. Diabetes 1965;14(2):106-109.

Davis Wk, Hess GE, Van Harrison R, Hiss RG. Psychological adjustment to and control of diabetes mellitus: differences by disease type and treatment. Health Psychol 1987;6:1-14.

DCCT Research Group. Diabetes control and complications trial (DCCT). Update. Diabetes Care 1990;13(4):427-433.

Dean A, Lin N. The stress-buffering role of social support. J Nerv and Ment Dis 1977;165:403-416.

Debono J, Johnson C, Betts P. Juvenile diabetes and social class. Lancet 1983;May 14:1113-1114.

Delbridge L. Educational and psychological factors in the management of diabetes in childhood. Med J Aust 1975;2:737-739.

Denzin NK. The research act. London, Prentice Hall, 1989;3-33.

Department of Education and Science. School Examination Survey 1988-1989. Statistical Bulletin. London, H.M.S.O. 1991.

Dublin LI, Marks HH. The diabetic in industry and his employer. Indust Med & Surg 1950;19:279-283.

Dunn SM, Smartt HH, Beeney LJ, Turtle JR. Measurement of emotional adjustment in diabetic patients: validity and reliability of ATT39. Diabetes Care 1986;9(5):480-489.

Edelstein J, Linn MW. Locus of control and control of diabetes. The Diabetes Educator 1985;13(1):51-54.

Evans C, Hughes IE. The relationship between diabetic control and individual and family characteristics. J Psychosom Research 1987;31(3):367-374.

Fallstrom K. On the personality structure in diabetic schoolchildren. Acta Paediatr Scand Suppl 1974;251:5-71.

Ferrari M. Chronic illness: psychosocial effects on siblings - I. Chronically ill boys. J Child Psychol Psychiat 1984;25(3):459-476.

Fleiss JL. Statistical methods for rates and proportions. New York, J Wiley, 1973;72-77.

- Fowler MG, Johnson MP, Atkinson MS. School achievement and absence in children with chronic health conditions. J Pediatr 1985;106(4):683-687.
- Franks DD, Marolla J. Efficacious action and social approval as interacting dimensions of self-esteem: a tentative formulation through construct validation. Sociometry 1976;39(4):324-341.
- Friis R, Nanjundappa G. Diabetes, depression and employment status. Soc Sci Med 1986;23:471-475.
- Funch DP, Marshall JR, Gebhardt GP. Assessment of a short scale to measure social support. Soc Sci Med 1986;23:337-344.
- Gale E, Tattersall R. Brittle diabetes. Br J Hosp Med 1979;22:589-597
- Gath A, Smith MA, Baum JD. Emotional, behavioural and educational disorders in diabetic children. Arch Dis Child 1980;55:371-375.
- Gendron D. Sick/well self-concept adaptations in adults with diabetes. Nurs Pap 1984;16:26-37.
- General Household Survey Series GHS no.17. Social Survey Division, Office of Population and Census Surveys. London, H.M.S.O. 1988.
- Gil R, Frish M, Amir S, Galatzer A. Awareness of complications among juvenile diabetics and their parents. Pediat. Adolesc. Endocr. 1977;3:59-63
- Gilberts R. The evaluation of self-esteem. Family Community Health 1983;6:29-49.

Glasgow RE, Toobert DJ. Regimen adherence and social environment among Type II patients. Diabetes Care 1988;11(5):377-386.

Goffman E. Stigma: notes on the management of spoiled identity. New York, Prentice Hall, 1963.

Goldstein DE. Is glycosylated haemoglobin clinically useful? N Eng J Med 1984;310:384-5

Gortmaker SL, Walker DK, Weitzman M, Sobol AM. Chronic conditions, socio-economic risks, and behavioural problems in children and adolescents. Pediatrics 1990;85(3):267-276

Gould BJ, Hall PM. Measurement of glycosylated haemoglobin using an affinity chromatography method. Clin Chim Acta 1982;125:41-48

Gray RS, Duncan LP, Clarke BF. Seasonal onset of insulin-dependent diabetes in relation to sex and age at onset. Diabetologia 1979;17:29-32.

Greenberg MT, Siegel JM, Leitch CJ. The nature and importance of attachment relationships to parents and peers during adolescence. J Youth Adolesc 1983;12:373-386

Grey MJ, Genel M, Tamborlane WV. Psychosocial adjustment of latency-aged diabetics: determinants and relationship to control. Pediatrics 1980;65(1):69-73.

Greydanus DE, Hofmann AD. Psychological factors in diabetes mellitus. Am J Dis Child 1979;133:1061-1066.

Grossman HY, Brink S, Hauser ST. Self-efficacy in adolescent girls and boys with insulin dependent diabetes mellitus. Diabetes Care 1987; 10(3):324-329.

Hanson CL, Henggeler SW, Burghen GA. Social competence and parental support as mediators of the link between stress and metabolic control in adolescents with insulin-dependent diabetes mellitus. J Consult Clin Psychol 1987;55(4):529-533

Hanson CL, Henggeler SW, Burghen GA. Model of associations between psychosocial variables and health outcome measures of adolescents with IDDM. Diabetes Care 1987a;10:752-758.

Hanson CL, Henggeler SW, Harris MA. Family system variables and the health status of adolescents with insulin-dependent diabetes mellitus. Health Psychology 1989;8(2):239-253

Hanson F, Wilks M. Mobile patients in an inner London practice. Br Med J 1984;288:1579-1582

Hauenstein EJ, Marvin RS, Snyder AL, Clarke WL. Stress in parents of children with diabetes mellitus. Diabetes Care 1989;12(1):18-23

Hauser ST, Jacobson AM, Wertlieb D, et al. Children with recently diagnosed diabetes: interactions with their families. Health Psychology 1986;5(3) 273-296.

Hauser ST, Pollets D, Turner BL, Jacobson A, Powers S, Noam G. Ego development and self-esteem in diabetic adolescents. Diabetes Care 1979;2(6):465-471.

- Head J, Fuller JH. International variations in mortality among diabetic patients: the WHO Multinational Study of Vascular Disease in Diabetics. *Diabetologia* 1990;33:477-481
- Henderson AS. Interpreting the evidence of social support. *Soc Psychiatry* 1984;19:1-4.
- Henderson S, Byrne DG, Duncan-Jones P, Adcock S, Scott R, Steele GP. Social bonds in the epidemiology of neurosis: a preliminary communication. *B J Psychiat* 1978;132:463-466.
- Hewitt JP. Self and society. A symbolic interactionist social psychology. Massachusetts, Allyn and Bacon Inc., 1976;59-104.
- Hie NH. SPSSX Users guide. New York, McGraw Hill Book Company, 1983.
- Hoffman RG, Guthrie D, Speelman D, Childs L. Self-concept changes in diabetic adolescents. *Pediatr Adolesc Endocr* 1982;10:32-38.
- Hopper S. Diabetes as a stigmatised condition: the case of the low-income clinic patients in the United States. *Soc Sci Med* 1981;13:11-19.
- House JS, Robbins C, Metzner HL. The association of social relationships and activities with mortality: prospective evidence from the Tecumseh Community Health Study. *Am J Epidemiol* 1982;116: 123-140.
- Houtzagers CMGJ, Visser AP, Berntzen H et al. Multiple daily insulin injections improve self-confidence. *Diabetic Med* 1989;6:512-519
- Hutchison SJ, Kesson CM, Slater SD. Does diabetes affect employment prospects? *Br Med J* 1983;287:946-947.

Iacovetta RG. Adolescent-adult interaction and peer-group involvement. *Adolescence* 1975;10:327-36

Ireland JT, Viberti GC, Watkins PJ. The kidney and renal tract. In: Keen H, Jarrett RJ (eds), *Complications of diabetes*. London, Edward Arnold, 1982;99-150.

Jacobson AM, Adler AG, Wolfsdorf JI, Anderson B, Derby L. Psychological characteristics of adults with IDDM. Comparison of patients in poor and good glycemic control. *Diabetes Care* 1990;13(4):375-381

Jacobson AM, Hauser ST, Wertlieb D, Wolfsdorf JI, Orleans J, Vieyra M. Psychological adjustment of children with recently diagnosed diabetes mellitus. *Diabetes Care* 1986;9(4):323-328.

Jamison RN, Lewis S, Burish TG. Psychological impact of cancer on adolescents' self-image, locus of control, perception of illness and knowledge of cancer. *J Chronic Dis* 1986; 39(8):609-17

Jarman B. Identification of underprivileged areas. *Br Med J* 1983;286:1705-1709

Jarrett RJ, McCartney P, Keen H. The Bedford survey. Ten-year mortality rates in newly diagnosed diabetics and normoglycaemic controls and risk indices for coronary heart disease in borderline diabetics. *Diabetologia* 1982;22:79-84.

Jenny JL. A comparison of four age groups' adaption to diabetes. *Canadian J Public Health* 1984;75:237-244

- Jensen SB. Emotional aspects in a chronic disease: a study of 101 insulin treated diabetics. *Int J Rehab Research* 1986;9(1):13-20
- Johansen K. Does strict metabolic control prevent long-term diabetic complications? *Practical Diabetes* 1988;5(1):10-14.
- Johansson E, Larsson Y, Ludvigsson J. Social adaptation in juvenile diabetes. *Acta Paediatr Scand Suppl* 1979;275:85-87.
- Johnson SB. Psychosocial factors in juvenile diabetes: a review. *J Behav Med* 1980;3(1):95-116.
- Johnson SB. Psychological aspects of childhood diabetes. *J Child Psychol Psychiat* 1988;29(6):729-738.
- Kannel WB, McGee DL. Diabetes and cardiovascular disease. The Framingham Study. *JAMA* 1979;241:2035-2038.
- Kantrow AH. Employment experiences of juvenile diabetics. Some observations based on a survey. *Diabetes* 1961;10(6):476-481.
- Kaplan HB. Social class and self derogation: a conditional relationship. *Sociometry* 1971;34:41-64.
- Kaplan BH, Cassel JC, Gore S. Social support and health. *Medical Care* 1977;15(5):47-58
- Kaplan RM, Chadwick MW, Schimel LE. Social learning intervention to promote metabolic control in type 1 diabetes mellitus: pilot experiment results. *Diabetes Care* 1985;8(2):152-155

- Kaye R. Psychological aspects of management of juvenile diabetes.
In: Report of the National Commission on diabetes Vol III.
Washington DC, U.S. Govt Ptg Office, 1976;4:129-136.
- Kelleher D. Coming to terms with diabetes, coping strategies and non-compliance. In: Anderson R, Bury M (eds) Living with chronic illness. The experience of patients and their families. London, Unwin Hyman Ltd, 1988;137-155.
- Kelleher D. Diabetes. London, Routledge, 1988a.
- Kellerman J, Zeltzer L, Ellenberg L, Dash J, Rigler D. Psychological effects of illness in adolescence. I. Anxiety, self-esteem and perception of control. J Pediatrics 1980;97(1):126-131.
- Kelvin P. Work as a source of identity; the implications of unemployment. Br J Guidance Counselling 1981;9:2-11
- Kemmer FW, Bisping R, Steingruber HJ, Baar H, Hardtmann F, Schlaghecke R, Berger M. Psychological stress and metabolic control in patients with type 1 diabetes mellitus. New Eng J Med 1986;314:1078-1084.
- Khurana RC, White P. Juvenile onset diabetes; problems in managing 16 to 22 year olds. Post Grad Med 1971;119:123
- Knowles HC Jr. The problem of the relation of the control of diabetes to the development of vascular disease. Trans Amer Clin Climatol Ass 1964;76:142.

Koski ML. The coping processes in childhood diabetes. Acta Paediatr Scand Suppl 1969;198:7-56.

Koski ML, Kumento A. The interrelationship between diabetic control and family life. Pediatr Adolesc Endocr 1977;3:41-45.

Kovacs M, Brent D, Steinberg TF, Paulauskas S, Reid J. Children's self-reports of psychologic adjustment and coping strategies during the first year of insulin dependent diabetes mellitus. Diabetes Care 1986;9(5):472-478.

Krosnick A. Psychiatric aspects of diabetes. In: Ellenberg M, Rifkin H (eds). Diabetes mellitus: theory and practice. London, McGraw-Hill, 1970;920-933.

Labour Force Survey 1987. OPCS Series LFS number 7. H.M.S.O. 1989.

Laing W, Williams R. Diabetes. A model for health care management. London, Office of Health Economics, 1989.

Lane JD, Stabler B, Ross SL, Morris MA, Litton JC, Surwit RS. Psychological predictors of glucose control in patients with IDDM. Diabetes Care 1988;11(10):798-800.

Laron Z. Psychosocial problems of diabetic children and adolescents. Acta Diabet Lat 1984;21:35.

Laron Z, Karp M, Frankel JJ. A study of the rehabilitation of juvenile and adolescent diabetics in the central region of Israel. Final report. Petach-Tiqua, Israel 1972.

Leslie ND, Sperling MA. Relation of metabolic control to complications in diabetes mellitus. J Pediatr 1986;108:491-497.

Lin N, Dean A, Ensel WM. Social support scales: a methodological note. Schizophr Bull 1981;7:73-89.

Lister J. The employment of diabetics. Br Med J 1983;287:1087-1088.

Lloyd CE, Matthews K, Wing RR, Orchard TJ. Psychosocial factors and the complications of insulin-dependent diabetes mellitus: the Pittsburgh epidemiology of diabetes complications study. Diabetes Care 1991 (submitted for publication).

Lonsdale S. Women and disability. London, Macmillan Education Ltd, 1990.

Ludvigsson J. Socio-psychological factors and metabolic control in juvenile diabetes. Acta Paediatr Scand 1977;66:431-437.

Lyons JS. Perceived social support from family and friends: measurement across disparate samples. J Personality Assess. 1988;52(1):42-47.

Mac An Ghaill M. Young gifted and black. Milton Keynes, Open University Press, 1988.

Marteau TM, Bloch S, Baum JD. Family life and diabetic control. J Child Psychol Psychiat 1987;28(6):823-833.

Mason C. The production and effects of uncertainty with special reference to diabetes mellitus. Soc Sci Med 1985;21:1329-1334.

Mastbaum L. Medical vs economic progress for diabetics. Minn Med 1974; 221-222.

Mastbaum, Tetrick, Alexander. Physicians guidelines for employment and placement of the diabetic in industry - an update. J Occup Med 1980;22(9):601-602.

Mazze RS, Lucido D, Shamoon H. Psychological and social correlates of glycaemic control. Diabetes Care 1984;7:360-366.

Mead GH. Mind, self and society. Chicago, University of Chicago Press, 1934.

Meldman LS. Diabetes as experienced by adolescence. Adolescence 1987; 22(86):433-444.

Metcalfe A, Baum JD. National survey of childhood-onset diabetes 1988:interim report. Balance 1990;115:69-71.

McAnarney ER. Social Maturation. J Adolesc Health care 1985;6(2):90-101.

McCraw RK, Travis LB. Psychological effects of a special summer camp on juvenile diabetics. Diabetes 1973;22(4):275-278.

McFarlane AH, Norman GR, Streiner DL. The process of social stress: stable, reciprocal and mediating relationships. J Health Soc Behav 1983;24:160-173.

McFie J, Thompson JA. Intellectual abilities of immigrant children. 1970;1:348-351.

McGregor M. Juvenile diabetics growing up. The Lancet 1977;April 30: 944-945.

Miller PM, Ingham JG. Friends, confidants and symptoms. Social Psychiatry 1976;11:51-58.

Mills JW, Sanders KM, Martin FIR. Socioeconomic problems of insulin dependent diabetes. Med J Aust 1973;Dec:1040-1044.

Moore RH, Buschbom RL. Work absenteeism in diabetics. Diabetes 1974; 23:957-961.

Mok JYK, Laing IA, Farquhar JW. Young diabetics; memories, current lifestyles and attitudes. Diabetic Med 1984;1:227-230.

Nelms BC. Emotional behaviours in chronically ill children J Abnorm Child Psychol 1989: 17(6);657 -68.

Norris J, Kunes-Connell M. Self-esteem disturbance. Nurs Clin North America 1985;20(4):745-761.

O'Connor P, Brown GW. Supportive relationships: fact or fancy? J Soc Pers Relationships 1984;1:159-195.

O'Donnell WJ. Adolescent self-esteem related to feelings toward parents and friends. J Youth Adolesc 1976;5(2):179-185.

Office of Population and Census Surveys. Classification of occupations 1980. London H.M.S.O. 1980.

Ohwovoriole AE, Omolulu CB. Personality and control of diabetes. Br J Med Psychol 1986;59:101-104.

Olafsson O, Svensson PG. Unemployment related life-style changes and health disturbances in adolescents and children in western countries. Soc Sci Med 1986;22(11):1105-1113.

O'Malley PM, Bachman JG. Self-esteem: change and stability between the ages 13 and 23. Devel Psychol 1983;19(2):257-268.

Orchard TJ, Dorman JS, Maser RE et al. Prevalence of complications in IDDM by sex and duration. Pittsburgh epidemiology of diabetes complications study II. Diabetes 1990;39:1116-1124.

Orr DP, Golden MP, Myers, Marrero DG. Characteristics of adolescents with poorly controlled diabetes referred to a tertiary care centre. Diabetes Care 1983;6(2):170-175.

Orth-Gomer K, Unden AL. The measurement of social support in population surveys. Soc Sci Med 1987;24:83-94.

Partridge JW, Garner AM, Thompson CW, Cherry T. Attitudes of adolescents toward their diabetes. Am J Dis Child 1972;124:226-229.

Patrick DL, Morgan M, Charlton J. Psychosocial support and change in the health status of physically disabled people. Soc Sci Med 1986;22(12):1347-1354.

Patterson CC, Thorogood M, Smith PG, Heasman MA, Clarke JA, Mann JI. Epidemiology of type 1 (insulin-dependent) diabetes in Scotland 1968-1976: Evidence of increasing incidence. Diabetologia 1983;24:238-243.

Pearlin LI, Turner HA. The family as a context of the stress process. In: Kasl SV, Cooper CL (eds) Stress and health: issues in research methodology. New York, J Wiley, 1987;156-164.

Pearson A, Carr J Halliwell M. The self-concept of adolescents with spina bifida. Z Kinderchir 1985;40(Suppl)27-30.

Pell S, D'Alonzo CA. Sickness absenteeism in employed diabetics. Am J Public Health 1967;57(2):253-260.

Peyrot M, McMurry JF. Psychosocial factors in diabetes control; adjustment of insulin-treated adults. Psychosomatic Medicine 1985; 47(6):542-557.

Petrides P. Socio-medical problems of diabetes and their possible solutions. Internist 1980;22:242-246,

Piers EV. Piers-Harris childrens self-concept scale, revised manual. Los Angeles, Western Psychological Services 1984.

Pilisuk M, Froland C. Kinship, social networks, social support and health. Soc Sci Med 1978;12:273-280.

Pless IB, Heller A, Belmonte M, Zvagulis I. Expected diabetic control in childhood and psychosocial functioning in early adult life. Diabetes Care 1988;11(5):387-392.

Pless IB, Roghmann KJ. Chronic illness and its consequences: observation based on three epidemiologic surveys. J Pediatrics 1971; 79(3):351-359.

Pless IB, Satterwhite B. A measure of family functioning and its application. Soc Sci Med 1973;7:613.

Pond H. Parental attitudes towards the diabetic child. Diabetes Care 1979;2:425-431.

Popkess-Vawter S. The adult living with diabetes mellitus. Nurs Clin North America 1983;19(4):777-789.

Porter JR, Washington RE. Black identity and self-esteem: a review of studies of black self-concept 1968-1978. In: Rosenberg M, Kaplan HB (eds). Social psychology of the self-concept. USA, Harlan Davidson Inc, 1982.

Reeves F, Chevannes M. The ideological construction of black underachievement. In: Woodhead M, McGrath A (eds) Family, school and society. London, Open University Press, 1988;178-196.

Rewers M, LaPorte RE, King H, Tuomilehto J. Trends in the prevalence and incidence of diabetes: insulin-dependent diabetes mellitus in childhood. World Health Statistics Quarterly 1988;41:179-189.

Rihmer Z, Arato M. Depression and diabetes mellitus. Neuropsychobiology 1982;8:315-318.

Riley K. Black girls speak for themselves. In: Woodhead M, McGrath A (eds) Family, school and society. London, Open University Press, 1988.

Robson PJ. Self-esteem - a psychiatric view. Br J Psychiatry 1988; 165:6-15.

Robinson N, Bush L, Protopapa LE, Yateman NA. Employers' attitudes to diabetes. Diabetic Med 1989a;6:692-697.

Robinson N, Fuller JH, Edmeades SP. Depression and diabetes. Diabetic Med 1988;5:268-274.

Robinson N, Lister J, Knibbs S. A nursing career for people with diabetes. Br Med J 1988;296:1506-1507.

Robinson N, Yateman NA, Protopapa LE, Bush L. Employment problems and diabetes. Diabetic Med 1990;7:16-22.

Robinson N, Yateman NA, Protopapa LE, Bush L. Unemployment and diabetes. Diabetic Med 1989;6:797-803.

Rosenberg M. Society and the adolescent self-image. Princeton, Princeton University Press 1965.

Rosenberg M. Conceiving the self. New York, Basic Books, 1986.

Rosenberg RG, Simmons FR. Sex differences in the self-concept in adolescence. In: Rosenberg M, Kaplan HB (eds), Social psychology of the self-concept. USA, Harlan Davidson Inc, 1982.

Rovet JF, Ehrlich RM, Hoppe M. Intellectual deficits associated with early onset of insulin-dependent diabetes mellitus in children. Diabetes Care 1987;10(4):510-515.

Ryan CM, Atchison J, Puczynski S, Puczynski M, Arsianian S, Becker D. Mild hypoglycaemia associated with deterioration of mental efficiency in children with insulin-dependent diabetes mellitus. J Pediatr 1990;117(1):32-38.

- Ryan C, Longstreet C, Morrow L. The effects of diabetes mellitus on the school attendance and school achievement of adolescents. *Child Care Health Devel* 1985;14:229-240.
- Ryan CM, Morrow LA. Self-esteem in diabetic adolescents: relationship between age at onset and gender. *J Consult Clinical Psychol* 1986;54 (5):730-731.
- Ryan C, Vega A, Longstreet C, Drash A. Neuropsychological changes in adolescents with insulin-dependent diabetes. *J Consult Clin Psychol* 1984;52(3):335-342.
- Samanta A, Burden AC, Jones GR et al. Prevalence of insulin-dependent diabetes mellitus in Asian children. *Diabetic Med* 1987;4:65-67.
- Sanders K, Mills J, Martin FIR, Delthorne DJ. Emotional attitudes in adult insulin-dependent diabetics. *J Psychosom Research* 1975;19:241-246.
- Sarason IG, Levine HM, Basham RB, Sarason BR. Assessing social support: the social support questionnaire. *J Person Soc Psychol* 1983; 44:127-139.
- Savvides S. Education and ethnic minorities. PhD Thesis, University of London 1987.
- Scambler G. Perceiving and coping with stigmatising illness. In: Fitzpatrick R (ed). *The experience of illness*. London, Tavistock 1988;ch.10.

Scambler G. Deviance, labelling and stigma. In: Patrick DL, Scambler G (eds) Sociology as applied to medicine. England, Bailliere Tindall, 1984. 184-192.

Schafer LC, McCaul KD, Glasgow RE. Supportive and non-supportive family behaviours: relationships to adherence and metabolic control in persons with type 1 diabetes. Diabetes Care 1986;9:179-185.

Schlenck EA, Hart LK. Relationship between health locus of control, health value, and social support and compliance of persons with diabetes mellitus. Diabetes Care 1984;7(6):566-574.

Schlieper A. Chronic illness and school achievement. Devel Med Child Neurol 1985;27:69-79.

Schoenbach VJ, Kaplan BH, Fredman L et al. Social ties and mortality in Evans County, Georgia. Am J Epidemiol 1986;123:577-591.

Shillitoe RW. Psychology and diabetes. Psychosocial factors in management and control. London, Chapman and Hall, 1988.

Silverman D. Qualitative methodology and sociology. London, Gower Press, 1985.

Simonds JF. Psychiatric status of diabetic youth matched with a control group. Diabetes 1977;26:921-925.

Simmons D. Prevalence and age of onset of type 1 diabetes in adult Asians in the Coventry diabetes study. Diabetic Med 1990;7:238-241.

Simmons RJ, Corey M, Cowen L, Keenan N et al. Emotional adjustment of early adolescents with cystic fibrosis. Psychosom Med 1985;47(2):111-22.

Simmons D. Prevalence and age of onset of type 1 diabetes in adult Asians in the Coventry diabetes study. Diabetic Med 1990;7:238-241.

Skyler JS. Diabetes in adolescence: the forgotten years. In: Podolsky J (ed) Clinical diabetes: modern management. New York, Appleton-Century-Crofts 1980;463-479.

Songer TJ, LaPorte RE, Dorman JS, Orchard TJ, Becker DJ, Drash AL. Employment spectrum of IDDM. Diabetes Care 1989;12(9):615-622.

Sonksen PH. The employment of diabetics. Br Med J 1982;288:239.

Stabler B, Morris MA, Litton J, Feinglos MN, Surwit RS. Differential glycaemic response to stress in type A and type B individuals with IDDM. Diabetes Care 1986;9:550-551.

Stabler B, Surwit RS, Lane JD, Morris MA, Litton JD, Feinglos MN. Type A behaviour pattern and blood glucose control in diabetic children. Psychosom Med 1987;49:313-316.

Stankowska E, Firlik M, Westfal I. Self-perception in patients with lung cancer and chronic bronchitis. Pneumon Pol 1990; 58(2-3); 92-7.

Sterky G. Family background and state of mental health in a group of diabetic schoolchildren. Acta Paediatrica 1963;52:377-390.

Stewart-Brown S, Haslum M, Butler N. Evidence for increasing prevalence of diabetes mellitus in childhood. Br Med J 1983;286:1855-1857.

Strauss A, Glaser B. Chronic illness and the quality of life. St Louis, Mosby, 1975.

Sullivan BJ. Adjustment in diabetic adolescent girls. I. Development of the diabetic adjustment scale. Psychosom Med 1979;41(2):119-126.

Sullivan BJ. Adjustment in diabetic adolescent girls: II adjustment, self-esteem and depression in diabetic adolescent girls. Psychosom Med 1979a;41(2):127-138.

Surridge DHC, Williams Erdahl DL, Lawson JS et al. Psychiatric aspects of diabetes mellitus. B J Psychiatry 1984;145:269-276.

Swift C, Seidman F, Stein H. Adjustment problems in juvenile diabetics. Psychosom Med 1967;29(6):555-571.

Tarn AC, Gorsuch AN, Spencer KM. Diabetes and social class. Lancet 1983; 631-632.

Tattersall RB, McCulloch DK, Aveline M. Group therapy in the treatment of diabetes. Diabetes Care 1985;8(2):180-188.

Tchobroutsky G. Relation of diabetic control to development of microvascular complications. Diabetologia 1978;15:143-152.

- Tebbi CK, Bromberg C, Sills I, Cukierman J, Piedmonte M. Vocational well-being of young adults with IDDM. *Diabetes Care* 1990;13(2):98-103.
- Tetrick L, Colwell JA. Employment of the diabetic subject. *J Occup Med* 1971;13(8):380-383.
- Tomlinson S. Ethnic minorities in British schools. A review of the literature, 1960-1982. London, Heinemann Educational Books, 1983.
- Troyna B, Carrington B. Education, racism and reform. London, Routledge. 1990.
- Troyna B. Fact or artefact? The 'Educational underachievement' of black pupils. *Br J Sociol Educ* 1984;5(2):153-166.
- Unger RH. Meticulous control of diabetes. Benefits, risks and precautions. *Diabetes* 1982;31:479-483.
- Vandenburgh RL, Sussman KE, Titus CC. Effects of hypnotically induced acute emotional stress on carbohydrate and lipid metabolism in patients with diabetes mellitus. *Psychosom Med* 1966;28:383-390.
- Varni JW, Babani L, Wallander JL, Roe TF, Frasier SD. Social support and self-esteem effects on psychological adjustment in children and adolescents with insulin-dependent diabetes mellitus. *Child & Family Behaviour Therapy* 1989;11(1):1-16.
- Viberti GC, Hill RD, Jarrett RJ et al. Microalbuminuria as a predictor of clinical nephropathy in insulin-dependent diabetes mellitus. *Lancet* 1982;1:1420-1432.

Wacklawski ER. Employment and diabetes: a survey of the prevalence of diabetic workers known by occupational physicians and the restrictions placed on diabetic workers in employment. Diabetic Med 1989;6:16-19.

Waclawski ER. Sickness absence among insulin-treated diabetic employees. Diabetic Med 1990;7:41-44.

Wade L. Diabetes in industry. Diabetes 1959;8(2):143-148.

Wadsworth MEJ. Serious illness in childhood and its association with later-life achievement. In: Wilkinson RG (ed). Class and health: research and longitudinal data. London, Tavistock Pub. 1986;50-74.

Wallander JL, Varni JW. Social support and adjustment in chronically ill and handicapped children. Am J Community Psychol 1989;17(2):185-201.

Walsh A, Walsh PA. Love, self-esteem and multiple sclerosis. Soc Sci Med 1989;29(7):793-798.

Warr P, Cook J, Wall T. Scales for the measurement of some work attitudes and aspects of psychological well-being. J Occup Psychol 1979;52:129-148.

Weil WB, Ack M. School achievement in juvenile diabetes mellitus. Diabetes 1964;13(3):303-306.

Weinstock M, Haft JI. The effect of illness on employment opportunities. Arch Environ Health 1974;29:79-83.

Weitzman M. School and peer relations. Paed Clin North Am 1984;31(1):59-69.

Welin L, Svardsudd K, Ander-Perciva S et al. Prospective study of social influences on mortality. The study of men born in 1913 and 1923. Lancet 1985;1:915-918.

Wertlieb D, Hauser ST, Jacobson AM. Adaptation to diabetes: behaviour symptoms and family context. J Pediatr Psychol 1986;11(4):463-479.

West P. Inequalities? Social class differentials in health in British youth. Soc Sci Med 1988;27(4):291-296.

White K, Kolman ML, Wexler P, Polin G, Winter RJ. Instable diabetes and unstable families: a psychosocial evaluation of diabetic children with recurrent ketoacidosis. Pediatrics 1984;73(6):749-755.

World Health Organisation Expert Committee on Diabetes Mellitus. Second Report. W.H.O. Geneva 1980;49-50.

World Health Organisation. International classification of impairments, disabilities and handicaps. W.H.O. Geneva 1980.

Wing RR, Epstein LH, Blair E, Nowalk MP. Psychologic stress and blood glucose levels in non-diabetic subjects. Psychosom Med 1985;47:558-564.

Winter WE, Maclaren NK, Riley WJ et al. Maturity-onset diabetes of youth in black Americans. New England J Med 1987;316(6):285-291.

Wylie RC. The self-concept. Vol 2, Revised edition. U.S., University of Nebraska Press, 1979.

Yancey WL, Rigsby L, McCarthy JD. Social position and self-evaluation: the relative importance of race. Am J Sociol 1972;78:338-359.

Yule W, Berger M, Rutter M, Yule B. Children of West Indian immigrants - II. Intellectual performance and reading attainment. J Child Psychol Psychiat 1975;16:1-17.

Zagoria RB. Your right to work. Diabetes Forecast 1982;20-23.

Zeltzer L, Ellenberg L, Rigler D. Psychologic effects of illness in adolescence. II. Impact of illness in adolescents - crucial issues and coping styles. J Pediatrics 1980;97(1):132-138.

Zimmerman E, Carter ME, Sears JH et al. Diabetic Camping: effect on knowledge, attitude and self-concept. Issues in Comprehensive Pediatric Nursing 1987;10:99-111.

Dear

We are interested in looking at the way health may affect young peoples' employment prospects, their life style and how they cope in general. We are interviewing young people with diabetes, and we would especially like to hear your views on subjects such as education and employment. Your contribution to this study would be very valuable in helping us to understand some of the issues that affect young people today.

If you agree to be involved, you would be invited to take part in a confidential interview (approx. 1 hr) in your own home or at the diabetes unit at Central Middlesex Hospital, if you prefer.

As in all studies of this sort, you are perfectly free to change your mind and withdraw at any time, should you wish.

We hope that you will be able to help us with your time. If you have any questions about what is involved, please phone us.

We will contact you shortly to see if you are willing to help us.

Yours sincerely,

Cathy Lloyd

Research Assistant

Dear

You may have received a letter from the Diabetes Epidemiology Unit, asking if you would like to take part in a confidential interview for a research study, looking at the ways health can affect people in their employment and life style in general.

I have been appointed as the interviewer for the study, and would be most grateful if you could spare approximately one hour in the next few weeks, during which time I can meet you to conduct an interview.

If you are willing to help me, please fill in the slip below and return it in the pre-paid envelope with this letter. Alternatively, you are free to phone me on the above number (office hours only) and we can arrange a date for us to meet.

Thank you once again for your help.

Yours sincerely,

Cathy Lloyd
Research Assistant

I.....(name) am willing to take part in your research study.

Date and time preferred:.....(this can be in the evening).

Place of interview: Home ☐ or Research Office ☐ (please tick box).

Phone number (if available) Home:..... Work:.....

Dear

We are interested in looking at the way health may affect young peoples' employment prospects, their life style and how they cope in general.

We are interviewing young people at this practice, and we would especially like to hear your views on subjects such as education and employment. Your contribution to this study would be very valuable in helping us to understand some of the issues that affect young people today.

If you agree to be involved, you would be invited to take part in a confidential interview (approx. 1 hr) in your own home or at the health centre (if you prefer).

As in all studies of this sort, you are perfectly free to change your mind and withdraw at any time, should you wish.

We hope that you will be able to help us with your time. If you have any questions about what is involved, please phone us.

We will contact you shortly to see if you are willing to help us.

Yours sincerely,

Dr S Gellert
MB, DRCOG

Dr A Craig
MB, DRCOG

Dr P Wallace
MB, BSc, MRCGP

Dr S Gillam
BA, DCH, MRCP(UK), MRCGP

1st March 1990

Dear

You may have received a letter from Craven Park Health Centre, asking if you would like to take part in a confidential interview for a research study, looking at the ways health can affect people in their employment and lifestyle in general.

I have been appointed as the interviewer for this study and would be most grateful if you could spare approximately one hour in the next few weeks, during which time I can meet you to conduct an interview.

If you are willing to help me, please fill in the slip below and return it in the pre-paid envelope with this letter. Alternatively, you are free to phone me on the above number (office hours only) and we can arrange a date for us to meet.

Thank you once again for your help.

Yours sincerely

Cathy Lloyd
Research Assistant

I, (name) am willing to take part in your research study.

Date and time preferred:.....(this can be in the evening)

Place of interview: Home ☐ or Research Office ☐ (please tick box)

Phone number (if available) Home:..... Work:.....

BRENT HEALTH AUTHORITY

Agreement to participate in research project

I, (name of subject)

of (address).....

.....

agree to take part in the research project:

PSYCHOSOCIAL FACTORS AND DIABETES

(name of research project)

I confirm that the nature and demands of the research have been explained to me, and I understand and accept them. I also understand that I may withdraw from the research project if I find that I am unable to continue for any reason.

Signed..... Date.....

Investigators statement:

I have explained the nature and demands of the above research project to the subject.

Signed..... Date.....

THE SELF-EVALUATION AND SOCIAL SUPPORT QUESTIONNAIRE

DEMOGRAPHIC SECTION

I would like to ask a few general questions about your background if I may.

A. Background Factors

First of all, how old are you?

What is your date of birth?

Where were you born?

When was your diabetes diagnosed?

Have you ever had any other illness or medical problems?

B. Present Household

Can you tell me who's living in your household at the present time?

Describe household members:

(i.e. who share meals together)

What is your father's occupation?

What is your mother's occupation?

At what age did your father leave school?

At what age did you mother leave school?

Do your parents own their own house, or rent it? (Council?) Do you have your own room?

QUESTIONS FOR THOSE LIVING APART FROM PARENTS

Do you rent your flat/house?

IF YES: is it council owned?

(if no) - do you own it yourself?

How many rooms do you have (including bedrooms, living rooms and kitchen if used for eating in)?

How long have you been living in this area?

C. Marital Status

QUESTIONS FOR THOSE LIVING WITH PARENTS

Have you always lived with your parents?

(if no) - who were you living with before?
(Prove for marital status and for dates
of marriages. cohabs. and separations).

(if living apart from father) - where is he living now?

QUESTIONS FOR THOSE LIVING APART FROM PARENTS

(If not already clear):

Are you married or living with anyone?

IF YES: What age were you when you got married? (started living
with your partner?)

What job does your partner do?

Have you been married or lived with anyone else before? (probe for
dates of marriages, cohabs and separations).

D. Children - ASK QUESTIONS ONLY IF IT SEEMS APPROPRIATE AT THIS
STAGE.

Do you have any children

IF YES: How many children have you got?
(ascertain whether boys or girls)

What age are they?

Are they living with you?
(ever separated, when) (get details of where living)

How old were you when you had your first child?

Any stillbirths, terminations, deaths? (dates).

APPENDIX VI

E. Childhood

(if not already clear):

Are both your parents still alive?

(if no) - How old was your Father when he died?

How old were you when your father died?

Were you adopted? (age at adoption?)

Were you ever separated from either parent before age 17?

(Probe for mother and father)

(IF YES) - what age were you?

- what was the reason for separation?

(PROBE: parents divorce, parents work, Subjects illness, parents illness, Subjects own choice, other).

What was the length of separation?

SIBLING POSITION

Do you have any brothers and sisters?

How many?

Are they older or younger than you?

(probe for where living - if not in Subjects' household)

Do you have any half or step brothers and sisters?

How many?

(half siblings are blood relatives and have one parent in common).

Have you had a brother or sister that has died?

How old were you?

F. Education and Work History

Are you still at school or college

(if not) - what age were you when you left? (probe for date)

What type of school did you go to?
(e.g. comprehensive, grammar, technical, secondary modern, private).

Have you taken (did you take) any exams at school?
(e.g. CSE, GCE 'O' and 'A' level)

IF YES: - what exams have you passed?

QUESTIONS FOR THOSE STILL AT SCHOOL

Do you do any part-time work outside school?
(probe for Saturday job, evening work - only rate regular work)

QUESTIONS FOR THOSE WHO HAVE LEFT SCHOOL

Have you had any training since you left school?

IF YES: - what did you do?
(probe for college, apprenticeship, YTS)

When was that?
How long did it go on?
(probe for time periods and dates)

Are you working at present?
(Registered disabled? if not, have you ever considered this?
Would it help you in any way? eg if you had the trouble getting a job?)

IF YES: - Is it full-time or part-time?

How many hours do you work?

What do you do in your present job?

When did you start this job?
(probe for dates)

Is this your first job since leaving school?

(if not) - What other jobs have you had?
(probe for full and part-time, time periods, dates).

APPENDIX VI

Have you had any periods out of work?

When was that?
(probe for time periods, dates).

IF NOT CURRENTLY EMPLOYED:

Have you been getting any Social Security benefits?

Have you done any paid work since leaving school?

IF YES: when was that?
(probe for time periods, dates, type of work)

APPENDIX VI

SELF SECTION

I'd like to ask a few questions about how you see yourself as a person and the things that are important to you.

Self acceptance	<u>Is there anybody you know that you would like to change places with?</u> IF YES, SPECIFY WHO. Why would you like to change places with them? (PROBE: Because of the kind of life they have? (for DM's: Because of your diabetes?) The kinds of things they do? Because of the kind of people they are? In what way?) How happy are you with yourself? The way you are? <u>Do you think anybody might like to change places with you?</u> IF YES: Why? IF NOT: Why not? (PROBE: Because of the kind of life you have, the kind of things you do? Because of the kind of person you are? (DM's: Because of your diabetes?))
Commitments (Role Performance)	<u>Thinking of your own life now - what do you think matters most to you?</u> Why do you say that? (PROBE: For some people, a husband or wife and child(ren) are their whole world - while for others they are only a part of it. What about you? IF A PART, what else is part of your world?)
Role conflict	<u>Do you ever feel any conflict or strain about your different roles or responsibilities?</u> Do you feel any conflict over the things that are important to you?
Self attributes	<u>What kind of person do you like to think you are?</u> <u>How would you describe yourself?</u>

APPENDIX VI

	<u>Do you think you are better or worse than other people? In what way?</u>
Self acceptance	<u>Is there anything about yourself that you would like to be different? (What about your health?)</u>
Self attributes	<u>Do you feel you are a sympathetic person/or do you tend to be a bit hard?</u>
	(ESTABLISH WHETHER THEY WOULD PREFER TO BE DIFFERENT FOR THIS AND FOLLOWING TRAITS)
Self acceptance	<u>Do you think you are an efficient person or do you just seem to muddle through?</u>
Self attributes	<u>Do you put yourself first or do you give way to other people?</u>
	Are you the sort of person who says what you think or not? Are you happy with this?
	<u>Do you feel you are an intelligent person or not particularly?</u>
	Would you like to change this?
	<u>Do you think you are attractive or not particularly?</u>
	Do you wish you were? (e.g. How do you feel when you're dressed up to go out?)
Other focussed basis of self-evaluation	<u>Do you care about what other people might think about you?</u>
	<u>Is that the same for most people or just some people you know?</u>
	Do you worry about the effect you might have on others?
	<u>If someone is critical of you, does it make you feel bad?</u>
	<u>Is that the same for most people or just some people you know?</u>

PARENTHOOD SECTION

A. QUESTIONS FOR THOSE WITH NO CHILDREN

(for those who have children proceed to section B)

Commitment to
parenthood

In your ideal world, many
children would you like to have?

(PROBE: How would you feel if you were
unable to have children for some reason?)

Is having children in the future something
you think about or do you feel it doesn't
concern you at the moment?

For those with
diabetes:

(PROBE: Do you think you are too young to
think about it?)

Has having diabetes changed your
views on having children? (in what
way?)

B. QUESTIONS FOR THOSE WHO HAVE CHILDREN

Commitment to
parenthood

In your ideal world, how
many children would you like to have?

Do you think you will have any more
children in the future?

For those with
diabetes:

Did having diabetes change your
views on having children? (in what
way?) (what about after you had
your child/children)

Commitment

How far do you see yourself as being a
mother/father?

IF APPROPRIATE:

Do you prefer to think of yourself as a
mother/father or a wife/husband?

Do you like talking to people about your
children?

Can you imagine not being a mother/father?

(PROBE: Can you imagine never having had
children?)

APPENDIX VI

How would you have felt if you had been
unable to have children for some reason?

APPENDIX VI

	<u>Since you've been a mother/father, do you feel that you are a different sort of person in any way?</u>
	Better in any way? Worse?
	(PROBE: More responsible? More or less interesting?)
Competence (Role Performance)	<u>Would you say that looking after children is something which takes a lot of skill or ability any kind, or not really?</u>
	At this stage how would you say it compares with your present/last job?
	(PROBE: More or less challenging? More or less interesting?)
Competence	<u>Overall how good would you say you are as a mother/father?</u>
	Compared with your own mother/father - are you better in any ways? Not as good?
Competence (Role Performance)	<u>ALL: Do you ever find yourself unable to cope with all the demands of being a mother/father - when it's just too much for you?</u>
	IF YES: Is this most of the time? What do you do when you're feeling like this? Is there anything that helps?
	IF NO: Do you think you're better at doing this than most mothers/fathers? Why/why not?
Competence (Role Performance)	<u>ALL: How patient would you say you are with the children/baby?</u>
Negative Interaction	(PROBE: Do you feel you are <u>too sharp</u> or irritable with them? Or that you smack them even when they don't deserve it?)

APPENDIX VI

	<u>How about in comparison to other mothers/fathers?</u>
Competence (Role Performance)	<u>IF APPROPRIATE: How well do you think you manage to keep the children in check?</u> Are the children well-behaved? Or do they play you up? (PROBE: Can you influence them when they are like this? Do you think this has anything to do with the way they have been brought up?)
Competence (Role Performance)	<u>ALL: Do you feel you give the children/baby enough time and affection - or do you find this difficult?</u> <u>Does anyone such as your wife/husband/partner/boyfriend/ girlfriend notice the kind of mother/ father you are?</u>
Partner's Negative evaluation of S	<u>IF YES: What do they think?</u> Is that often? (PROBE: That you're too soft/strict? That you're very patient/too irritable with them?)
Security characteristics	<u>Are any of your children (the baby) a worry to you for any reason?</u>
Self Acceptance	<u>Many people would like their children to be different from themselves in some ways.</u> Do you feel this way? (PROBE: In what ways?) <u>Are there any ways you would like them to be the same as you?</u> (PROBE: In what ways?)
Quality of interaction	<u>What is it like when you are with the children/baby? What sort of atmosphere is there?</u> (PROBE: A bit boring? Tense? Fun? Do you talk much or have a laugh? Is there much fighting or arguing?)

MARRIAGE SECTION

A. QUESTIONS FOR THOSE NOT MARRIED OR COHABITING

Now I'd like to ask you a few general questions on your feelings about marriage.

Commitment Compared with married women/men, do you think single women/men miss out on anything important?

(PROBE: family, companionship security?)
Would you like to get married (again) eventually?

Is getting married something you ever think about or doesn't it concern you at the moment?

(PROBE: Do you think you're too young to think about it?)

For those with
Diabetes:

Has having diabetes changed your views on getting married at all?

Do you feel having diabetes might affect your future plans in any way? (how?) Do you think having diabetes might cause you any problems if you got married? (what sort?)

Do you have a boyfriend/girlfriend at the moment?

IF RELEVANT:

Commitment Is marriage something you ever talk(ed) about with him/her?

Is it something you considered since you have been (when you were) seeing each other, even if you haven't (didn't) discuss(ed) it with him.

APPENDIX VI

B. QUESTIONS FOR THOSE MARRIED OR COHABITING

Now I'd like to ask you a few general questions about marriage and then a bit about you and your husband/wife/boyfriend/girlfriend.

Optional
Demographic
Questions

Where was your Husband/wife/partner born?

What is your husband/wife/partner's occupation?

Is he/she self employed?

Is he/she a Manager/Supervisor?

Did he have any training for that job?

ALL:

Commitment

Compared with married women/men do you think single women/men miss out on anything important?

(PROBE: a family? Companionship? Security?)

Would you want to be single again?

Why/why not?

(PROBE: Do you think people generally feel sorry for people who never marry or that there is something odd about them?)

For those with
diabetes

Has having diabetes changed your views on getting married at all? Do you feel that having diabetes might affect your future plans in any way? (how?) Do you think having diabetes might cause you any problems in your marriage? (In what way?)

QUESTIONS FOR THOSE MARRIED - i.e. NOT COHABITING

Commitment
(self evaluation)

Would you say 'being a wife' is important to the way you see yourself or not?

In what way?

(PROBE: Do you like to think of yourself as married? Why/why not?)

APPENDIX VI

Can you imagine not having married/being married? Why/why not?

How would you feel? (PROBE: left on the shelf?)

FOR THOSE COHABITING

Commitment to
marriage/
cohabiting

Do you see yourself as being married?
Would you like to be married?

Self evaluation

ALL:
Do you think being married (being in this
relationship) has made a difference to the sort
of person you are?

(PROBE: more/less confident? More/less easy-going?)

(PROBE: Do you feel it is a change for the better or for the worse?)

Competence
(Role performance)

Thinking of other women/men you know,
how do you think you compare as a
husband/wife/partner?

Are you better in any ways? Or worse?

Partner's
Negative
Evaluation

How about your husband/wife/partner,
what sort of a wife/partner does he/she
think you are?

APPENDIX VI

EMPLOYMENT SECTION

QUESTIONS FOR THOSE STILL IN FULL TIME EDUCATION

(If no longer in full-time education proceed to section B)

I'd like to ask you some questions about work.

Commitment

How important is it to you to have a job?

Would you prefer to be working when you leave school, or are you not bothered?

Are you looking forward to working when you leave school/college?

(IF NO: Why is that?)

Have you thought about the sort of work you want to do? Made any plans?

How do you feel about getting a job?

(PROBE: Terrible? Great?)

For those with diabetes:

Has becoming diabetic meant you've had to alter your views on employment or the type of job you can do?

EMPLOYMENT SECTION

B. QUESTIONS FOR THOSE NO LONGER IN FULL-TIME EDUCATION

SECTION I: FOR THOSE NOT CURRENTLY WORKING

(If S is working proceed to Section II)

Commitment to
other areas

How do you feel about not having a job?
(PROBE: Like it? Dislike it? In what way?)

What is the best thing about not having a job?

(PROBE: Being your own boss? Having time to
spend on other things? Anything else?)
Have you been looking for work during the year?

Commitment

What is the worst thing about not having a job?

(PROBE: Having no money of your own? Being
stuck in the house? Being on your own a lot of
the time? Not being able to help out with
extras/running a car/holidays etc? Anything
else?)

Commitment

How do you feel about the idea of getting a job?

(PROBE: Terrible? Great?)
Why do you say that?

Have you thought about taking a job now?
Part-time? Full-time? Or at any stage in the
future

SECTION II - FOR THOSE CURRENTLY WORKING

What do you actually do in your job?

Do you have someone under you? What about over
you? Do you work for someone else?)

Do you do shift work?

Commitment

How do you feel about having a job?
(PROBE: Like/not like it? In what way?)

APPENDIX VI

What is the best thing about having a job?

(PROBE: Getting out of the house? Being with other people? Having a bit of independence? Having a routine? Money of your own? Being able to help out with extras/running the car/holidays? etc)

Commitment What's the worst thing?

(PROBE: Having to be at work at a fixed time? Never having time to relax?

Self evaluation Do you see yourself as a worker?

(PROBE: Can you imagine yourself not being one? Not having a job?)

Commitment How would you feel if you didn't have a job?

(PROBE: A bit lost/relieved? Disoriented?)

Commitment Do you expect to continue working over the next ten years?

How do you feel about that?

Have you ever thought about stopping work?

(PROBE: When? How serious were you about it? What changed your mind?)

What are your career plans?

Self evaluation Does having a job make any difference to your feelings about yourself?

In what way?

(PROBE: Has it brought you out of yourself in any way? Made you feel more confident? Better able to get on with people?)

APPENDIX VI

How does it compare with other jobs you
have had?

(PROBE: Better/worse job? In what way?
More/less important? Skilled? Interesting?)

Do you get paid holidays?

What about sick pay? Pensions?
(Paid time off for clinic appointments?)

Do you have much time to talk to the people you
work with?

(PROBE: Can you? Do you?)

What is the atmosphere like at work?

(PROBE: Is there much laughing and joking? What
about a bit of tension or just a bad atmosphere?
Do you ever get on each other's nerves? Often?)

Competence
(Role performance)

How good/bad do you think you are at your job?

PROBE: Are you able to keep up with
work each day? Or not really? Do you ever feel
proud of your day's work? When was the last
time you felt this way?

EDUCATION SECTION

A. QUESTIONS FOR THOSE STILL IN FULL-TIME EDUCATION

(If no longer in full-time education proceed to section B)

These questions are about how you are getting on at school and about education in general.

Commitment to
school

How important do you think it is to have
a good education?

Is it something that is important for you?

Do you think people who haven't done well at
school are at a disadvantage when they get out
into the world?

(PROBE: How? In what sort of ways?)

Do you work hard at school/college?

Is it important for you to do well in class and
in exams?

Do you ever take time off school/college to do
other things?

(Probe for "bunking off")

WHERE APPROPRIATE:

Do you plan to stay on into the sixth year?

Are you going to do your 'A' levels?
(IF YES) - what about after that?
(Probe for plans)

Competence
(Role performance)

In general how well do you think you are
doing at school/college?

What sort of student do you think you are?

What sort of subjects do you enjoy?

Is there anything you are particularly good at?

Anything you are really not very good at?

APPENDIX VI

How about other subjects?
(Probe for Sport, Music, Drama, Art)

IF APPROPRIATE:

For Sport

Have you competed in any supporting events? Won any medals?

Drama & Music

Have you taken part in any school entertainments? Do you play a musical instrument?

Art

Have you had any of your artwork on show? (Probe for where?)

ASK ALL:

Have you taken on any extra responsibilities?

Competence
and commitment

IF APPROPRIATE:

Are you a prefect or a class representative?

Do you belong to any school/college societies?

(How involved have you become?)

Do you sit on any school committees or anything like that?

B. QUESTIONS FOR THOSE NOT IN FULL-TIME EDUCATION

These questions are about education in general and about how you got on at school.

Commitment
to
Further Education

How important is it to have a good education?

Do you think people who have not been well educated are at a disadvantage in life?

(PROBE: How? In what sort of ways?)

APPENDIX VI

Are there any subjects you were interested in at school that still interest you?

(PROBE: For what subjects)
Are you still interested in learning more about it (them)?
Do you go to any evening classes?

Do you go to the library?

What sort of books do you get out?
Do you ever go to museums or art galleries/theatres and concerts?
What about other subjects?

Have you any plans to do further training?
Anything that might help you start a career?

(Probe for secretarial skills, computer training, etc), any other training, etc.

Do you think you did well at school/college?

What sort of student do you think you were?

Competence/
Incompetence

What sort of subjects did you do well in? Was there anything you were particularly good at? How about other subjects? (Probe for Sport, Music, Drama, Art?) (Did you take any exams? (How did you do?)

IF APPROPRIATE:

Did you ever compete in any sporting events?
Win any medals?
Did you ever take part in any school entertainments? Do you play a musical instrument (how good were you - probe for music grades)
Did you ever have any of your artwork on show? (probe for where)

Did you take on any extra responsibilities?
Were you a prefect or a class-representative?
Did you belong to any school or college societies or committees?
Or anything else like that?

APPENDIX VI

SOCIAL CONTACTS AND EXTERNAL ARENAS

I'd like to ask a few general questions about your social life, family and friends.

Commitment

How often do you see your close relatives?

Social
Isolation

(Probe for Mother/father,
brothers/sisters)
Where do they live?
What about telephoning?
Is this regular?
Any other relative you see regularly?

(Probe for in-laws if married/cohabiting)

Do you have any friends you see regularly?

How often do you see them?
Do you telephone?
(How often)

Involvement in
peer group

Do you have a group of friends that you
go around with?

(IF YES:) Is it important to you to belong to
this group?

Would you say you are very influenced by what
your friends do?

(PROBE: In what sort of ways? Do you all wear
the same sort of clothes?)

(If they want to drink a lot or smoke or take
drugs will you do that too?)

For those with
Diabetes:

Do your friends know you have diabetes?
Do you discuss your diabetes with your
friends?

How did they first react when you first told
them you had diabetes?
Were you embarrassed/did you find it hard to
talk to them about it? Are they ever embarrassed
about it?

(PROBE: injecting in front of friends, refusing
certain foods).

APPENDIX VI

	Do they ever make comments about your health? (Do they understand?)	
Positive & negative evaluation peer group	<u>How popular would you say you are with your friends?</u> <u>Do any of them ask your opinion on things that are important to them?</u> (PROBE: What sorts of things?) <u>Do they value your opinion?</u> Would you say you are a leader among your group of friends? (PROBE: What sort of position do you have in the group) <u>Do your friends ever make any comments on the way you look, or the clothes you wear?</u> (PROBE: What sorts of things do they say?) Do they ever make any critical or hurtful comments? <u>How long have you been going around with the friends you are involved with at present?</u> Security increasing & decreasing characteristics of peer group	<u>Have you ever had times when you've been unpopular with your group of friends?</u> When they haven't wanted to know you? How long did that go on for? <u>Has anyone in the group ever been in trouble with the police?</u> (PROBE: What was that about?) <u>Do you and your friends like to go out drinking?</u> Do you ever get very drunk? <u>Do any of you take any drugs? Do you smoke?</u> What about glue sniffing?

APPENDIX VI

Are there any other things that you do that might get you into trouble with the police?

(PROBE: Do any of you ever break things or destroy property. What about stealing or getting into fights?

ALL:

Commitment Is it important to you to have friends to go and see and talk to?

Do you look forward to it?

Is it important to you to have a social life?

Would you miss it if it did not happen?

Quality of interaction What sort of an atmosphere is there when you are with your friends?

(PROBE: Fun? Bit boring? Exciting? Tense? Just a bad atmosphere? Does the time seem to go quickly, or fairly slowly?)

Self evaluation Would you say you were a sociable person?

Do you think people find it easy or difficult to get along with you in social situations?

(PROBE: Do you think they enjoy being with you or not particularly?)

Commitment Do you do any sports or hobbies that require skill?

Self evaluation IF RELEVANT: Are you good at it or not really?

Social Isolation Do you belong to any clubs or organisations?

Do you belong to church?

How often? What denomination?

APPENDIX VI

Attitudinal
constraints

Some people we speak to feel that its
best not to be too close to anyone
(other than their husband/wife and
children) While others do not agree.
What do you think?

Fear of
intimacy

Can you think of anyone you feel very close to?

Do you have anyone like that at present?
Who? Anyone else?

Is having someone close important to you?

Have you ever felt hurt or rejected by anyone
you've been close to?

Does the fear of being hurt stop you getting too
close to people?

Do you find it hard to get very close to people?

(IF YES OR NO)

Is that the same for most people or just some
people you know?

(PROBE: for males, females, family, friends)

(IF YES:) Why do think this is?

(PROBE: Are you shy? Hard to get to know?)

Does it ever make you feel uncomfortable to be
too close to people?

Is that the same for most people or just some
people you know?

(Probe for males, females, family)

Do you ever back off if you find yourself
getting too close to someone?

(PROBE: Who? Why is that?)

Fear of
intimacy

Do you think you can see too much of
your friends or family?

APPENDIX VI

Do you find it easy to ask people for help?

(Can you go to others for advice if you have a problem?)

Do you find it difficult to confide in others?
(IF YES:) Why do you think this is?

How do you feel when someone wants to confide in you?

(PROBE: Do you ever feel uneasy? Why is that?)

Is that the same for most people or just some people you know?

(Probe for males, females, family)

Camberwell
Confiding
question

If you had a problem of some sort, who would be the first person you would want to discuss it with?

Who else? Can you confide in about personal things or worries?

(PROBE: parents, husband/boyfriend, parents, friends, relatives etc.)

VERY CLOSE OTHERS

ASK FOR A MAXIMUM OF 3 RELATIONSHIPS

Exclude children under age 12. Take hierarchy of first 3 others that S feels closest to. It is not necessary to ask these questions for mothers, or fathers named as VCO's as the same questions are covered in the parent section.

Now I'd like to ask you a little bit about the people (person) you feel very close to.

First of all how old is ... (probe for first name if not already reported)

IF APPROPRIATE: Is she/he married?
Does she (he) have children? What age are they?

Security
characteristics

How long have you known ...?
Have you ever been closer than you are at present?

How did things change?

Have there been any times when you've not got on so well?

Quality of
interaction

(PROBE: Times when there was a bit tension or bad feeling between you? When you get on each others' nerves? Times when you rowed or quarrelled?) How often does this happen?

Confiding

Do you confide in ...?

IF YES: What sorts of things do you confide in them about?

(PROBE: About things that worry or upset you? Do you just touch on it or do you go into detail? Easily? With difficulty?)

Other's
emotional
support

Did you confide in them about ...?
(EVENT OR DIFFICULTY)

What did/do they do when you confide?

(PROBE: Did/do they take your side or were/are they a bit critical?)

APPENDIX VI

Sympathetic? Did/do they offer any advice? How about telling you what to do?)

Do you think they were interested? Or not particularly?

Other's evaluation of S Would you say ... has a good opinion of you? Does she/he think you're a good friend?

Is there anything she/he admires about you or anything she/he'd like to be different?

Dependency Did/do you rely on their support/sympathy/advice in making up your mind?

Or not really?

Do you think they told anyone afterwards?

Or thought any less of you?

Confiding **IF NOT ALREADY CLEAR:**

What about personal things?

Do you talk to them about things like that?

What about money matters? Sex? Pregnancy?

(PROBE: Or if there was trouble between you and your husband/boyfriend? Say a serious argument? Or things that bother you about your relatives?)

Or, anything that might make them think badly of you?

 Such as ...?

Confiding Are there any thing that you would not talk to them about?

 Why/why not?

Active emotional support Do they ever help you out?

GET DETAILS OF THE LAST TIME

APPENDIX VI

Do you think ... worries about you?

(PROBE: If you are not feeling well? Have problems? How do they show it?)

Frequency of contact Have you seen ... at all during the past week?

 About how often do you meet?

Security characteristics Do you meet pretty regularly or does it vary a lot?

What about being in touch by phone?

 Has this changed at all in the last year?

ESTABLISH FREQUENCY AND DURATION

Do you feel free to call in on them without notice?

 Do they?

Dependency Would you like to see them more often or do you see enough of each other?

 (PROBE: Rely on their company?)

Quality of interaction What is it like when you are together?

 (PROBE: Do you have much to say to each other? Is there much laughing and joking? Do you ever get a bit bored when you are with them?)

 Do you quarrel? How often?

IF NOT SEEN OFTEN

Dependency Do you feel sad when it's time for you to go?

Felt attachment Where is ... living now?

How would you feel about her/him living further away?

 (Say up North?)

If you saw ... only a few times a year, do you think it would make any difference to your relationship?

 In what way?

APPENDIX VI

(PROBE: Would you just drift apart? Why/why not?)

Is it important to you just to know that ... is there?

Dependency
Felt attachment How would you feel if she/he wasn't there?

(PROBE: A bit lost? A bit afraid? Uneasy because they would not be there when you really needed them?)

Felt attachment At the moment, do you think ... would be willing to help you if you really needed it?

Security characteristics Are there any kinds of situations where you feel you just could not rely on them?

Have there been any times when they did not put themselves out for you?

APPENDIX VI

CHILDHOOD AND PARENTS SECTION

A. QUESTIONS FOR THOSE STILL LIVING AT HOME

I'd like to ask you about your childhood and how you get on with your parents now.

(ask for each family arrangement)

Identify with
parents

To begin with what sort of person do you think your mother/father is, how would you describe her/him (ask for both parents)?

(PROBE: Is there anything about her/him you admire? Anything that embarrasses you?)

Do you think you're more like one parent than the other?

(PROBE: In what ways?)

Were you very close to either your mother or father say up to the time you were a teenager?

Antipathy to
Mother

In what way?

(PROBE: Was she fairly distant - or did she tend to hug and kiss you a lot?)

Did your parents have their favourites?

Up to now (you were 17) have you felt your parents have always had time for you and taken an interest?

Indifference

Have your parents always spend much time with you?

Have you always felt you could go to your parents if you were upset or unhappy?

Having things changed at all since you've got older?

Did you ever feel neglected? (in what way?)

Were you well looked after materially as far as food, clothes, etc. were concerned.

APPENDIX VI

Did your parents take an interest in who
your friends were?

Were they interested in how you did at school?
(e.g. read reports, see teachers).

Did they help you look for your first job?

Do you feel that your parents take an interest
in your health? What about your diabetes?

Ever feel overprotected?

Do either of your parents come to your out-
patient appointments with you?

Do you ever discuss your diabetes with either of
your parents?

Do either of your parents take an interest or
help you with:

- a) Your diet
- b) Taking insulin
- c) Testing your urine (blood)

(probe for criticism, encouragement on diet,
insulin, tests and general self-care)

Do you confide in your parents now?

Current
Confiding and
Emotional
Support

One more than the other?

IF YES: What sorts of things do you confide in
her/him about?

(PROBE: Can you tell them about personal
things. Do you just touch on it or go into
detail?)

Are there many things you would not talk to them
about?

What do they say? (when you confide)

(PROBE: Do they take your side or are they a
bit critical? sympathetic? Do they offer advice?
Do you think they are interested or not
particularly?)

APPENDIX VI

Is one of your parents more sympathetic than the other?

Do you think your parents worry about you?

(probe for surrogate parents).

Current
Dependency

Do you rely on mother's/father's support/sympathy and advice in making up your mind?

Or not really?

Approval/
Disapproval

Do you think your parents approve of you?

What about your mother, does she think highly of you?

Does she praise you?

(What does she say?)

Has she been easy or hard to please?

(ask same questions for father)

What about when you were younger, have things changed?

Have either of them been disapproving?

What about your mother, has she ever made critical or hurtful comments?

(PROBE: About the way you look or the things you do) Has your father ever been critical or hurtful?

Are your parents very strict?

Do they ever punish you or did they when you were younger?

In what ways?

Parental
Control

Have they been strict about things like manners at table?

When you were younger would they let you play out in the street?

APPENDIX VI

Have they been strict about you going out with boys/girls?

What about if you came home late?

Have they been strict about clothes and make-up?

(If S has lived with both parents) - How have your parents got on together?

Discord
Tension

Has it always been like that?

Have they ever argued much?

(probe for interaction with surrogate parents where appropriate)

(How often is that? What is it like?
(probe for raised voices, throwing things, violence, etc.)

Quality of
Interaction

Was that in front of you?

Have your brothers and sisters ever got involved in family arguments?

Has there been a lot of tension?

Have there ever been periods of time when members of your family have stopped talking to one another?

Has there ever been any violence in the home?

(probe for frequency, get description)

IF YES: Who was involved? (parents, sibs, Subjects themselves).

Did any serious injuries result (e.g. hospitalisations)

APPENDIX VI

Have the police ever been called?

(if relevant) - Have you ever been in an institution? (local authority care or borstal)

(probe for age periods - question about longest stay)

IF YES: ASK QUESTIONS AT THE END OF THIS SECTION (PAGE) AFTER HAVING COMPLETED THIS SECTION.

Quality of
interaction

What is it like when you're with your
parents now?

What kind of atmosphere is there?

Do you have much to say to each other?

How would you feel about leaving home?

Dependency
Felt Attachment

Do you think you could cope without your
mother/father?

How would you feel?

It is important to you just to know that your
mother is there?

What about your father?

How would you feel if they weren't there?

At the moment do you think both your parents
would be willing to help you if you really
needed it?

Is that the same for both your parents?

Felt Attachment
Security

Are there any kinds of situations where
you feel you just could not rely on either of
them?

Have there been times when either of them did
not put themselves out for you?

APPENDIX VI

B. QUESTIONS FOR THOSE WHO HAVE LEFT HOME

I'd like to ask you about your childhood and how you get on with your parents now.

(ask for each family arrangement)

Identify with
parents

To begin with what sort of person do you think your mother/father is, how would you describe her/him (ask for both parents)?

(PROBE: Is there anything about her/him you admire? Anything that embarrasses you?)

Do you think you're more like one parent than the other?

(PROBE: In what ways?)

Were you very close to either your mother or father say up to the time you were a teenager?

Antipathy to
Mother

In what way?

(PROBE: Was she fairly distant - or did she tend to hug and kiss you a lot?)

Did your parents have their favourites?

Up to now (you were 17) have you felt your parents have always had time for you and taken an interest?

Indifference

Have your parents always spend much time with you?

Have you always felt you could go to your parents if you were upset or unhappy?

Have things changed at all since you've got older?

Did you ever feel neglected? (in what way?)

Were you well looked after materially as far as food, clothes, etc. were concerned.

Did your parents take an interest in who your friends were?

APPENDIX VI

Were they interested in how you did at school?
(e.g. read reports, see teachers).

Did they help you look for your first job?

Do you feel that your parents take an interest
in your health? What about your diabetes?

Ever feel overprotected?

Do either of your parents come to your out-
patient appointments with you?

Do you ever discuss your diabetes with either of
your parents?

Do either of your parents take an interest or
help you with:

- a) Your diet
- b) Taking insulin
- c) Testing your urine (blood)

(probe for criticism, encouragement on diet,
insulin, tests and general self-care)

Do you confide in your parents now?

Current
Confiding and
Emotional
Support

One more than the other?

IF YES: What sorts of things do you confide in
her/him about?

(PROBE: Can you tell them about personal
things. Do you just touch on it or go into
detail?)

Are there many things you would not talk to them
about?

What do they say? (when you confide)

(PROBE: Do they take your side or are they a
bit critical? sympathetic? Do they offer advice?
Do you think they are interested or not
particularly?)

Is one of your parents more sympathetic than the
other?

APPENDIX VI

	<u>Do you think your parents worry about you?</u> (probe for surrogate parents).
Current Dependency	<u>Do you rely on mother's/father's support/sympathy and advice in making up your mind?</u>
	<u>Or not really?</u>
Approval/ Disapproval	<u>Do you think your parents approve of you?</u> What about your mother, does she think highly of you? Does she praise you? (What does she say?) Has she been easy or hard to please? (ask same questions for father) <u>What about when you were younger, have things changed?</u> <u>Have either of them been disapproving?</u> What about your mother, has she ever made critical or hurtful comments? (PROBE: About the way you look or the things you do) Has your father ever been critical or hurtful? <u>Are your parents very strict?</u> Do they ever <u>punish you</u> or did they when you were younger? In what ways?
Parental Control	Have they been strict about things like <u>manners</u> at table? When you were younger would they let you <u>play out in the street?</u> Have they been strict about you going out <u>with boys/girls?</u>

APPENDIX VI

What about if you came home late
Have they been strict about clothes and make-up?

(If S has lived with both parents) - How have
your parents got on together?

Discord
Tension

Has it always been like that?

Have they ever argued much?

(probe for interaction with surrogate parents
where appropriate)

(How often is that? What is it like?
(probe for raised voices, throwing things,
violence, etc.)

Quality of
Interaction

Was that in front of you?

Have your brothers and sisters ever got involved
in family arguments?

Has there been a lot of tension?

Have there ever been periods of time when
members of your family have stopped talking to
one another?

Has there ever been any violence in the home?

(probe for frequency, get description)

IF YES: Who was involved? (parents, sibs,
Subjects themselves).

Did any serious injuries result (e.g.
hospitalisations)

Have the police ever been called?

(if relevant) - Have you ever been in an
institution? (local authority care or borstal)

(probe for age periods - question about longest
stay)

**IF YES: ASK QUESTIONS AT THE END OF THIS SECTION
(PAGE) AFTER HAVING COMPLETED THIS SECTION.**

APPENDIX VI

How close are you to your parents now?

Do you confide in either of them?

(PROBE: one more than the other)

IF YES: What sorts of things do you confide in her/him about?

Confiding

(PROBE: about things that worry or upset you? Do you just touch on it or do you go into detail?)

Can you tell them about personal things?

(PROBE: one more than the other?)

Are there many things you would not talk to them about?

Emotional
Support

What do you say? (when you confide)

(PROBE: do they take your side or are they a bit critical? Sympathetic? Do they offer advice? Do you think they are interested or not particularly?)

Is one of your parents more sympathetic than the other?

Do you think your parents worry about you?

CHECK FOR FREQUENCY OF CONTACT IF NOT ALREADY ESTABLISHED

Would you like to see them more often or do you see enough of each other?

Depending

Do you rely on your mother's/father's support/sympathy and advice in making up your mind?

Or not really?

APPENDIX VI

Quality of
Interaction

What is it like when you are with your
parents now?

What sort of atmosphere is there?

(PROBE: Do you have much to say to each other?
Is there much laughing and joking? Do you ever
get a bit bored when you are with them?)

Difficulty

Do you quarrel? How often?

How would you say your parents got on together?
Are there any difficulties between them?

Security

Have you ever been closer to either of them?
How are you at present?

How did things change?

Dependence and
Felt Attachment

How would you feel about your mother/
father living further away?

If you saw them only a few times a year do you
think it would make any difference to your
relationship?

In what way?

(PROBE: Would you just drift apart? why/why
not?)

How do you feel about living alone?

Is it important to you just to know your mother
is there?

What about your father?

At the moment do you think your parents would be
willing to help you if you really needed it?

Is it the same for both your parents?

Security
Support

Are there any kinds of situations where
you feel you just could not rely on either of
them?

Have there been times when either of them did
not put themselves out for you?

Further Questions for those with diabetesEducation section:

- Did you have any problems at school with your diabetes?

- Such as
 - with physical activities
 - with taking your insulin
 - with other peoples' attitudes
 - with your diet or doing your tests

(probe for problems with examinations, hypos, eating times, etc)

- Do/did you feel that your friends treated you differently in any way, because of your diabetes?

Employment section:

- Has having diabetes meant that you have had to alter your views on employment, or the type of job you can do?

- Do you do shift work?

- Do you get paid time off for clinic appointments?

- Does your employer know you have diabetes?

- Do your colleagues know you have diabetes?

- Have you ever had trouble getting work because of your health?

- Have you ever lost a job because of ill health?

- Are there jobs you would like to do, but cannot? Why is this?

- Has having diabetes meant that you have had to alter your views on employment, or on the type of job you can do?

- If you changed jobs, would you say that you had diabetes?

- Have you ever had to change the type of job you do because of your diabetes, or other health problems?

- Have you had any trouble getting pensions or insurance?

SELF ACCEPTANCE

The extent to which the subject accepts him/herself and/or feels happy or unhappy with the kind of person he/she is.

Indicators:

- (i) Whether there is anyone they would like to change places with because of some admired personal characteristic. Disregard statements concerning changing places with people because of their superior social situation.
- (ii) Whether there is anything about themselves that they would like to be different - either expressed directly, or inferred by the rater from expressions of guilt etc. about the impact of their personality on others.
- (iii) Whether there are any ways that they would like the children to be like or unlike them.
- (iv) Spontaneous comments that they are happy or unhappy about the kind of person they are, or that other people would or would not like to change places with them because of the kind of person they are.
- (v) Whether positive, self-accepting, statements are frequent and strong enough to reduce a rating based on rejecting statements, bearing in mind that most weight is given to the latter.

- 1 - marked
- 2 - moderate
- 3 - some
- 4 - little/none

Justification of rating:

DEGREE OF SELF ACCEPTANCE: _____

SELF-DEFINITION - ATTRIBUTED SELF: POSITIVE AND NEGATIVE

Statements about the kind of person the subject thinks they are in general terms -e.g. physical attributes (pretty, healthy, strong etc), emotional and intellectual attributes (brainy, moody, quiet, affectionate etc), non-social performance attributes (competent, tidy etc), social attributes (bossy, helpful, sociable, sympathetic etc) - and moral attributes (keeping '10 commandments,' strong principles etc).

Indicators:

- (i) Evaluative statements about their personal attributes - would like to be fatter/thinner, more/less easy going, more competent etc. (Check for relevant information on self-acceptance sheet).
- (ii) Comparisons made between their personal attributes and those of others - e.g. they feel they are as easy going, as competent, as brainy as others.
- (iii) Their assessment of their personal attributes in terms of their own standards - either expressed directly or implied by statements indicating pride, embarrassment etc.

- 1 - marked
- 2 - moderate
- 3 - some
- 4 - little/none

Justification of rating:

POSITIVE EVALUATION OF PERSONAL ATTRIBUTES: _____

NEGATIVE EVALUATION OF PERSONAL ATTRIBUTES: _____

SELF SECTION

ID _____

GENERAL SELF-DEFINITION AND EVALUATION OF SELF:

Subjects' description of self in terms of attributes (see previous rating sheet) and in terms of positions, (e.g. "I'm just a mum/wife/friend" etc, or "I've always been a hard worker", or class position) and activities e.g. I'm the sort of person who likes housework/needs a break etc).

Indicators:

- (i) Evaluative statements about their performance in tasks/roles or just their occupancy of positions - e.g. they are a good/bad housewife/worker/ parent/ spouse, would like to be better/ different at different tasks, feel they have done well to get a particular job.
- (ii) Comparisons made between their own performances and other's - e.g. they feel the same/better/worse.
- (iii) Their assessment of their performance in terms of their own standards.
- (iv) Subjects' assent to others' positive/ negative evaluation of their performances.

N.B. Check rating sheets on felt competence/ incompetence in marital, parenthood, homemaking, work and education domains for possibly relevant material that may have been missed.

- 1 - marked
- 2 - moderate
- 3 - some
- 4 - little/none

Justification of rating:

POSITIVE EVALUATION OF GENERAL SELF-DEFINITION: _____

NEGATIVE EVALUATION OF GENERAL SELF-DEFINITION: _____

OTHER-FOCUSED BASIS OF SELF-EVALUATION

The extent to which the judgements and feelings of the subject about themselves are influenced by the opinions and standards of others.

Indicators:

- (i) The extent to which they react to positive and negative feedback bothers, whether imagined or real by feeling proud, pleased, guilty, ashamed or unbothered or indifferent.
- (ii) The extent to which behaviour is geared to please others so as to be accepted by them as against avoiding contact for fear of what others will think.
- (iii) Whether they spontaneously compare themselves to others or to external standards or cannot find others to compare self with.
- (iv) Whether they refer to other's opinions when asked what they think and the extent to which they incorporate or disregard others opinions and perceptions about themselves.

Give greater weight to feelings about others in general and less to the impact of one particular person.

- 1 - marked: highly other focused with evidence of generalisation to most people.
- 2 - moderate: moderately other-focused. Influence limited to 'significant others' and/or generally less markedly influenced by others.
- 3 - some: somewhat other-focused.
- 4 - little/none: others seem to have little or no influence on feelings and judgements about self.

Justification of rating:

MARRIAGE SECTION

ID _____

COMMITMENT TO MARRIAGE

The extent to which being married (or cohabiting without marriage), rather than being single is an important focus for the subject. Emotional and behavioural commitment are rated separately. Behavioural commitment involves plans and activities that increase the chance of marrying/cohabiting and staying in that role. Emotional commitment is concerned only with thoughts and feelings related to being married/cohabiting.

Indicators

- (i) The extent to which the position of being married/cohabiting is important to the subject. That she thinks marriage/cohabiting is important for people in general (as long as she does not opt self out), likes to think of herself as married, would not want to be single, thinks she would have felt left on the shelf or less needed if she hadn't married or cohabited, thinks single people miss out on things she considers important e.g. companionship, having a family, security etc. For behavioural commitment take into account whether she has done anything to jeopardise the relationship (e.g. by having affairs), whether her plans for the future are to stay married/cohabiting and the degree to which she 'works at' the relationship.
- (ii) For those not married/cohabiting the extent to which the idea of cohabiting or getting married and settling down is an important focus. For behavioural commitment, take into account whether the subject has someone she would like to marry or live with and, if so, whether she conveys this to him. If there is no one at present, whether she is actively looking for someone to marry or live with.

- 1 - marked
 2 - moderate
 3 - some
 4 - little/none

Justification of rating:

LEVEL OF COMMITMENT TO MARRIAGE: _____

CONFIDING IN PARTNER

The extent to which the subject has talked with her partner about their personal feelings, crises and emotionally charged topics.

Indicators:

- (i) Whether or not they have actually confided about things that have come up in the course of the interview that have worried or upset them, made them feel guilty or ashamed, or conversely have made them feel pleased or happy.
 - (ii) The presence of emotionally significant areas or topics about which they know they could not confide.
- 1 - marked: Confides in all emotionally significant areas with only the occasional minor exception; and feels there is very little that he/she could not talk about.
 - 2 - moderate: Confides most things, the amount of confiding outweighs the exceptions.
 - 3 - some: Confides somewhat, but not the majority of things.
 - 4 - little/none: Confides little or not at all.

Justification of ratings:

CONFIDING IN PARTNER: _____

MARRIAGE SECTION

ID _____

ACTIVE EMOTIONAL SUPPORT BY PARTNER

The extent to which the partner has responded to confidences, strong personal feelings and/or crises in a sympathetic, helpful and understanding way. The rating is made on the basis of the frequency and strength of such supportive behaviour:

Indicators:

- (i) What the partner said/did in the specific crisis or ongoing situation in which the subject confided about positive or negative experiences.
- (ii) What the partner said/did in other potentially support-seeking situations e.g. when they had a bad day; just did not know how to deal with a particular situation.
- (iii) Any other potentially supportive technique e.g. explicit or tacit siding with the subject by criticising those who criticise them.

Note: an attempt should be made to take into account not only the actual level of support provided but also situations where the possibility for support existed, but was not given.

- 1 - marked
- 2 - moderate
- 3 - some
- 4 - little/none

Justification of rating:

ACTIVE EMOTIONAL SUPPORT BY PARTNER: _____

COMMITMENT TO PARENTHOOD

The extent to which the position of being a parent is an important focus for the subject. Take into account:

Indicators:

- (i) The extent to which the position of being a parent is important to the subject and that it is important to people in general. Whether they like to think of themselves as a parent, would not like to have been unable to have children and feels that people who do not have children miss out.
- (ii) For those with children: The extent the children are a focus of concern and planning - i.e. their level of emotional involvement/concern in the children's welfare, and the extent she is planning on having more children. Extent of time and energy they want to devote to them. The extent to which they like to talk about the children.
- (iii) For those without children: The extent to which plans for children in the future is an important focus in both emotional and behavioural terms.

- 1 - marked
- 2 - moderate
- 3 - some
- 4 - little/none

Justification of rating:

LEVEL OF COMMITMENT TO PARENTHOOD _____

CURRENT LEVEL OF COMMITMENT TO WORK/LABOUR MARKET:

Work is basically defined as a paid activity (but including serious voluntary i.e. unpaid activities), whether or not they are formally registered as employed and however they define it.

Commitment to be rated according to the importance of having a job in their eyes and how far their current and future life derives focus and intelligibility from it. Note a person does not have to have a job for such commitment.

Indicators:

- (i) Types of commitment. The following examples of different types of commitment should be treated in principle as equal, although each type of commitment will be influenced by the other indicators, which of course, also have to be taken into account in making the rating.
 - (a) Career commitment or commitment to a particular chosen occupation (or particular level of job).
 - (b) Instrumental commitment to the labour market.
- (ii) Present work situation
- (iii) Work as part of their future

Rating - 4 point scale

- 1 - Marked
- 2 - Moderate
- 3 - Some
- 4 - Little/None

Justification of rating:

CURRENT LEVEL OF COMMITMENT TO WORK _____

FELT COMPETENCE/INCOMPETENCE AS A WORKER

The extent to which performance as a worker is evaluated positively or negatively. Take into account both general evaluation of performance in the work role, the frequency with which they have bad days and her general ability to keep up with the work each day.

Indicators:

- 1 - marked
- 2 - moderate
- 3 - some
- 4 - little/none

Justification of rating:

FELT COMPETENCE AS A WORKER:

FELT INCOMPETENCE AS A WORKER:

APPENDIX VIII

SOCIAL CONTACTS

ID _____

COMMITMENT TO EXTERNAL INTERESTS/ARENAS:

The importance of social and recreational activities in the subject's eyes and the extent to which they see themselves, their current or future life in these terms. Rate commitment to contact with family and friends outside the domestic arena and other external interests (such as sports or hobbies).

Indicators:

- (i) Statements concerning the importance of time for self or generally for external outlets (other than work) in the subject's life and/or in their ideas of who they are; and the conditionality of such statements (e.g. if partner or children don't mind etc.)
- (ii) The existence of a strong desire for some (or more) of these outlets or just time for themselves/or their feelings of strong regret/loss etc. in its partial or total absence.
- (iii) The existence, strength and concreteness of plans to create, retain and develop social and recreational activities, as well as current degree of participation.
- (iv) Behavioural indicators of current willingness/ unwillingness to overcome difficulties (e.g. time, money, childcare, partner's opposition etc.) in order to have such outlets.

- 1 - marked
- 2 - moderate
- 3 - some
- 4 - little/none

Justification of rating:

EMOTIONAL COMMITMENT TO EXTERNAL ARENAS: _____

BEHAVIOURAL COMMITMENT TO EXTERNAL ARENAS: _____

SOCIAL ISOLATION

The scale measures the subjects' lack of social participation. Take into account only situational material - do not rate feelings concerning social isolation.

Indicators:

- (i) The number of 'very close others' and 'confidants.'
- (ii) The size of the subject's social circle.
- (iii) The existence, significance and proximity of parents and other close family members.
- (iv) Frequency of contact with friends and family.
- (v) Whether they confide in their partner.
- (vi) The quality of 'friendly' contacts at work.
- (vii) The significance of parents.

- 1 - marked
- 2 - moderate
- 3 - some
- 4 - little/none

Justification of ratings:

SOCIAL ISOLATION: _____

ATTITUDINAL CONSTRAINTS REGARDING PRIMARY/CONFIDING RELATIONSHIPS

The existence of attitudinal blockages inhibiting the development or maintenance of primary/confiding relationships outside the relationship with husband and children.

Indicators:

- (i) General statements about attitudes to having 'very close others' and frequency, strength and spontaneity of such statements and statements about not getting involved emotionally with other people.
- (ii) Statements about not talking to people about things that have nothing to do with them, taking into account the number of areas mentioned (e.g. money, sex, arguments with partner, relatives etc.)
- (iii) The number of people or categories of people (e.g. kin/neighbours/friends) who are partially or totally excluded by such barriers.

- 1 - marked
- 2 - moderate
- 3 - some
- 4 - little/none

Justification of rating:

ATTUDINL CONSTRNTS RE PRIM RLTSHPs: _____

ATTITUDINAL CONSTRAINTS REGARDING 'CARE ELICITING'

The existence of attitudinal blockages about evoking help, concern and comforting responses in the other.

Indicators:

- (i) The number of areas, e.g. money, time, childcare where such barriers exist.
- (ii) The strength of the statements regarding any barrier.
- (iii) The number and categories of people, e.g. kin/neighbour/friends who are partially or totally excluded by such barriers.
- (iv) The conditions (if any) under which this barrier would be waived, e.g. the acceptability of reciprocal help from family or close friends.
- (v) A general reluctance to be 'seen' in need of comfort, active emotional support, dependency etc.

- 1 - marked
- 2 - moderate
- 3 - some
- 4 - little/none

Justification of rating:

ATTUDNL CONSTRNTS RE CARE ELICITING: _____

SOCIAL CONTACTS

ID _____

FEAR OF INTIMACY

This scale goes further than those dealing with attitudinal constraints to ascertain the extent to which the subject reports an actual fear of closeness.

Indicators:

- (i) The extent to which they feel uncomfortable or anxious when others try to get close to them. Whether they feel they have to distance themselves from others once they start to get too close.
- (ii) Discomfort or fear of self-disclosure and also discomfort when others try to confide in her.
- (iii) The extent to which past adverse experiences are adding to their fear of getting close to people.
- (iv) The extent to which such fear or discomfort is generalised to all others or whether certain categories of people are excluded, e.g. members of their family, men.

- 1 - marked
- 2 - moderate
- 3 - some
- 4 - little or none

Justification of rating:

FEAR OF INTIMACY: OVERALL

WITH FEMALES IN FAMILY

WITH MALES IN FAMILY

WITH FEMALES NON-FAMILY

WITH MALES NON-FAMILY

CLOSE RELATIONSHIP RECORD

ID _____

**CLOSE RELATIONSHIP RECORD
FOR VCO'S AND PARENTS WHO ARE NOT VCO'S**

Brief description of person to be rated

Identification of other person (number 1 to 5)
(Give preference to VCOs) _____

Type of Relationship _____

- 1 = Very close relationship. (VCO)
2 = non-VCO parent
3 = non-VCO step/surrogate parent

Relationship of other person to subject _____

- 1 = mother.
2 = father/step father.
3 = sib: female.
4 = sib: male.
5 = other relative: female.
6 = other relative: male.
7 = non-relative: female.
8 = non-relative: male.

Frequency of contact

- 1 = daily.
2 = less than daily, more than weekly.
3 = weekly.
4 = less than weekly, more than monthly.
5 = monthly.
6 = less than monthly, more than 4 months.
7 = less than 4 months, more than 7 months.
8 = at least yearly,
9 = less often.

Visual _____

Visual

& non-visual _____

APPENDIX VIIICLOSE RELATIONSHIP RECORD

ID _____

Place of Residence _____

- 0 = in same household as subject.
- 1 = within immediate neighbourhood.
- 2 = within 10 minutes.
- 3 = within 1/2 hour.
- 4 = elsewhere in London.
- 5 = elsewhere in UK.
- 6 = outside UK.

Approximate age of other person relative to the subject

- 1 = same or almost the same age. _____
- 2 = older.
- 3 = younger.

Life-stage of other person _____

- 1 = under 35, unmarried.
- 2 = under 35, married no children.
- 3 = married youngest child under 5.
- 4 = married youngest child 6-14.
- 5 = married youngest child 15+.
- 6 = over 35 never married.
- 7 = over 35 married, no children at home.

Marital status of other person _____

- 1 = Single - never married/cohabited.
 - 2 = Married.
 - 3 = Cohabiting.
 - 4 = Widowed.
 - 5 = Divorced/separated.
 - 6 = Remarried/cohabiting - previously divorced/separated.
 - 7 = Remarried/cohabiting - previously widowed.
- Note: Cohabiting in past should have been for at least six months.

Duration of relationship _____

- 0 = under one year.
- 1 = 1 year.
- 2 = 2 years etc.

CLOSE RELATIONSHIP RECORD

ID _____

CONFIDING IN OTHER PERSON: GENERAL AND INTIMATE

- A. General confiding The extent to which the subject talks to the other about any and all aspects of their life - ranging from dramatic events to trivial worries and her own general feelings of frustration, unhappiness, discontent etc.

Indicators:

- (i) Whether or not they have actually confided about things that have come up in the course of the interview, and the range and depth of such confiding.
- (ii) Whether they have confided about specific topics popularly regarded as 'intimate' e.g. money matters, sexual matters, serious arguments between themselves and partner and trouble with relatives and about other things which the interview suggests are intimate to them.

- B. Intimate Confiding (sub-rating) the extent to which the subject confides about those topics which seem likely to be intimate for all respondents and those which are 'intimate' to them i.e. indicator (ii) above.

- 1 - marked: Confides in all emotionally significant areas with only the occasional minor exception; and feels there is very little that she could not talk about.
- 2 - moderate: Confides most things, the amount of confiding outweighs the exceptions.
- 3 - some: Confides somewhat, but not the majority of things.
- 4 - little/none: Confides little or not at all.

Justification of rating:

GENERAL CONFIDING IN OTHER PERSON: _____

INTIMATE CONFIDING IN OTHER PERSON: _____

CLOSE RELATIONSHIP RECORD

ID _____

ACTIVE EMOTIONAL SUPPORT BY OTHER PERSON

The extent to which the other person has responded to confidences, strong personal feelings and/or crises in a sympathetic, helpful and understanding way. The rating is made on the basis of the frequency and strength of such supportive behaviour:

Indicators:

- (i) What the other person said/did in the specific crisis or ongoing situation in which the subject confided about positive or negative experiences.
- (ii) What the other person said/did in other potentially support-seeking situations e.g. when they had a bad day; just did not know how to deal with a particular situation.
- (iii) Any other potentially supportive behaviour - e.g. explicit or tacit siding with the subject by criticising those who criticise them.

Note: in making a rating on this scale an attempt should be made to take into account not only the actual level of support provided but also the existence of situations where the possibility for support existed, but was not given.

- 1 - marked
- 2 - moderate
- 3 - some
- 4 - little/none

Justification of rating:

ACTIVE EMOTIONAL SUPPORT BY OTHER PERSON: _____

EDUCATION SECTION

ID _____

LEVEL OF COMMITMENT TO SCHOOL/COLLEGE

RATE SECTION ONLY FOR SUBJECTS STILL IN FULL TIME EDUCATION

The extent the position of being a pupil/student is an important focus to S. An overall rating of marked commitment cannot be made without at least moderate behavioural commitment: that is committed participation in school and educational activities.

Indicators:

- (i) Whether S thinks having a good education is important for young people in general (as long as does not opt self out), feels people without an education miss out on things she considers important.
- (ii) Extent to which S is personally committed to doing well at school/college in terms of making sure homework is done on time, doing extra work/revision for exams etc. Take into account whether S has truanted from school, taken time off to pursue other interests etc. Also whether S plans to (has) stay(ed) on at school past 16 and whether S plans to continue (has continued) into higher education.
- (iii) Involvement with school in terms of joining school societies, sitting on committees, taking on extra responsibilities.

- 1 - marked
- 2 - moderate
- 3 - some
- 4 - little/none

Justification for rating:

LEVEL OF COMMITMENT TO SCHOOL/COLLEGE: _____

FELT COMPETENCE/INCOMPETENCE AT SCHOOL: _____

EDUCATION SECTION

ID _____

The extent to which performance at school is evaluated positively and/or negatively in terms of the subject's own standards and in comparison with others. Include evaluation in specific areas as well as overall performance. Rate felt competence and incompetence separately. Specific areas covered should include:

- (i) Traditional academic school subjects
- (ii) Non-academic activities such as sports, drama, artwork and musical ability
- (iii) Roles of responsibility such as prefect, class representative, etc.

For those at school rate present felt competence/incompetence only. For those no longer at school rate past competence/incompetence caring last 2 years at school.

- 1 - marked
- 2 - moderate
- 3 - some
- 4 - little/none

Justification of rating:

FELT COMPETENCE AT SCHOOL: _____

FELT INCOMPETENCE AT SCHOOL: _____

EDUCATION SECTION

ID _____

FOR THOSE NO LONGER IN FULL-TIME EDUCATION

Subjects' Level of Commitment to Further Education: extent to which the idea of further education and "bettering oneself" is an important focus to them. This scale is for those who are no longer in full time academic education and takes into account:

- (i) Whether they think having a good education is important for people in general (as long as do not opt self out), feels people without an education miss out on things they consider important.
 - (ii) Whether they are on or are planning to enrol in any further education courses including evening classes in areas that could further their career or "better" them in some way - e.g. secretarial training, computer course, etc.
 - (iii) Whether they have interests that could further their knowledge in some way, without necessarily leading to any formal qualifications - e.g. an interest in literature, regular visits to museums, art galleries etc.
- 1. High
 - 2. Moderate
 - 3. Some
 - 4. Little/None

Justification for rating:

LEVEL OF COMMITMENT TO FURTHER EDUCATION _____

PARENTAL CARE SECTION

ID _____

**PARENTAL CARE IN CHILDHOOD
Self Esteem Project**Arrangement NoAge when arrangement began (losses only)Type of loss (preceding this particular arrangement)

- 0 = No loss, no change in quality care quality of care
- 1 = Death of mother
- 2 = Death of father
- 3 = Death of both
- 4 = Separation of mother
- 5 = Separation of father
- 6 = Separation both (independent)
- 7 = Separation surrogate parent
- 8 = Death surrogate parent
- 9 = Qualitative change in care
- 10 = Separation of both (possibly independent)

Parental Indifference

(to rate 1 & 2 there must be evidence of neglect and indifference over and above feelings of being unwanted). Give interviewers estimated rating.

Where parents act differently give weight to mothers behaviour.

DESCRIBE

- 1 - high
- 2 - moderate
- 3 - some
- 4 - little or none

Parental Control

To rate 3 there must be evidence 3. Low of actual lack of control, supervision and discipline) - estimated rating.

DESCRIBE

- 1 - high
- 2 - moderate
- 3 - some

PARENTAL CARE SECTION

ID _____

Family Structure

- 1 = Both real parents
- 2 = Mother alone
- 3 = Father alone (including sister as surrogate mother)
- 4 = Parent and step-parent
- 5 = Parent and surrogate parent (relative)
- 6 = Parent and surrogate parent (non relative)
- 7 = Surrogate parent (relative) only
- 8 = Surrogate parent (non-relative) only
- 9 = Other
- 10 = Mother and Grandmother

Surrogate sibs in household

(Note: Half-sibs are blood relatives with one parent in common.
Step-sibs are not blood relatives).

- 0 = No
- 1 = Half-sibs
- 2 = Step-sibs
- 3 = Both
- 4 = Other e.g. cousins
- 5 = Mixture of above

Number of children in householdSubjects' sib position including sibs and surrogate sibs in household

- 1 = Eldest/only
- 2 = Middle
- 3 = Youngest

Subjects' sibling position: Full sibs only

- 1 = Eldest/only
- 2 = Middle
- 3 = Youngest

Discord/tension in the home

(only rate '0' when the tension is marked such as when parents won't talk to each other for long periods of time).

- 0 = Marked Tension only
- 1 = Marked discord
- 2 = Moderate discord
- 3 = Some discord
- 4 = Little/No discord

PARENTAL CARE SECTION

ID _____

People involved in Discord/TensionDESCRIBE:

- 1 = Parents only
- 2 = Parent(s) & sibs but not subjects
- 3 = Whole family including subjects
- 4 = Subjects and at least one parent
- 5 = Subjects and sibs
- 6 = Subjects used as family scapegoat

Felt Approval/Disapproval from Mother/surrogate motherDESCRIBE:

- 1 = Marked
- 2 = Moderate
- 3 = Some
- 4 = Little/None

Approval _____

Disapproval _____

Felt Approval/Disapproval from Father/Surrogate FatherDESCRIBE:

- 1 = Marked
- 2 = Moderate
- 3 = Some
- 4 = Little/None

Approval _____

Disapproval _____

CONFIDENTIAL

For Office
Use onlyYOUNG/ADULTS WITH DIABETES STUDY - CLINICAL INFORMATION
(Hospital Notes)

1/ Today's Date _____

2/ Serial Number _____

3/ Clinic : 1. Willesden
2. Central Middlesex _____

4/ Sex 1. Male 3. Female _____

5/ Ethnic Group 1. Caucasian 3. Asian
2. West Indian _____

6/ Date of Diagnosis of diabetes _____

7/ Date of Birth _____

8/ Current therapy _____

9/ Date of last clinic visit _____

10/ Number of clinic visits in last year _____

11/ Number of 'did not attend' in last year _____

Presence of diabetic complications at up to and including last clinic visit

12a/ Retinopathy (fundi) 0. None
1. Background
2. Proliferative _____
3. Cataracts
4. Combination of 1-3

12b/ Visual acuity 0. Normal
1. Impaired _____
2. Blind

13/ Proteinuria albustix +ve (do not include "trace")
(present for last 2 clinic visits)
1. Yes 2. No _____

14/	Hypertensive treatment	1. Yes	2. No	_____
	Presence of, or past history of:-			
15/	Cataracts	1. Yes	2. No	_____
16/	Myocardial infarction	1. Yes	2. No	_____
17/	Intermittant claudication	1. Yes	2. No	_____
18/	Angina	1. Yes	2. No	_____
19/	Cerebrovascular disease/stroke	1. Yes	2. No	_____
20/	Foot ulcer/gangrene	1. Yes	2. No	_____
21/	Amputation	1. Yes	2. No	_____
22/	Impotence	1. Yes	2. No	_____
23/	Renal Failure	1. Yes	2. No	_____
24/	Any symptoms of autonomic neuropathy	1. Yes	2. No	_____
25/	Any symptoms of peripheral neuropathy	1. Yes	2. No	_____
26/	Any other serious conditions (please specify)			_____

27/	No. of hypoglycaemic attacks requiring hospital admission in last year.			_____

28/	No. of clinic visits where dosage increased in last year			_____
29/	Last Ghb			_____
30/	Date of last Ghb measure			_____

Details of hospital admissions in last year
(Code -1 if not applicable)

31/ Date 1st hospital admission
(nearest to clinic date) _____

32/ Diagnosis (ICD code) _____

33/ Operation, if any _____

34/ Date 2nd hospital admission _____

35/ Diagnosis (ICD Code) _____

36/ Operation, if any _____

37/ Date 3rd hospital admission _____

38/ Diagnosis (ICD Code) _____

39/ Operation, if any _____

40/ Date 4th hospital admission _____

41/ Diagnosis (ICD Code) _____

42/ Operation, if any _____

43/ Date 5th hospital admission _____

44/ Diagnosis (ICD Code) _____

45/ Operation, if any _____

Last recorded measurements

46/ Blood pressure _____ Date _____

47/ Weight _____ Date _____

48/ Height _____ Date _____

49/ Blood glucose _____ Date _____

50/ Urine protein _____ Date _____

51/ Urine glucose _____ Date _____

52/ Ketones _____ Date _____

53/ Other drugs _____ Date _____

Young Diabetics Employment Study - Clinical Information For Office

1/	Today's Date	_____		
2/	Serial Number	_____		
3/	GP Practice	_____		
4/	Sex	1. Male 2. Female		
5/	Ethnic Group	1. Caucasian 3. Asian 2. West Indian 4. Other-specify _____		
6/	Date of birth	_____		
7/	Date of last visit	_____		
8/	No. of visits in last year	_____		
9/	Past Medical History			
	Presence of following diseases/conditions:-			
	(code -3 if not known/not recorded)			
a/	Heart trouble	1. Yes 2. No		
b/	High blood pressure	1. Yes 2. No		
c/	Chest complaints (inc. asthma)	1. Yes 2. No		
d/	Epilepsy	1. Yes 2. No		
e/	Diabetes	1. Yes 2. No		
f/	Cystitis	1. Yes 2. No		
g/	Allergies	1. Yes 2. No		
h/	Period problems	1. Yes 2. No		
i/	Skin problems (e.g. acne)	1. Yes 2. No		
j/	Headaches/Migraine	1. Yes 2. No		
k/	Gastro-intestinal disease (e.g. colitis)	1. Yes 2. No		
l/	Psychiatric trouble (e.g. depression, anorexia)	1. Yes 2. No		
m/	Handicapped	1. Yes 2. No		

10/ Any other illnesses 1. Yes 2. No

☐

Specify with date
of diagnosis if
appropriate

11/ Smoker

1. Yes 2. No

☐

Details of any GP visits in the last year
(code -1 if not applicable)

12/ Date of 1st visit

Symptoms

Diagnosis

Treatment

13/ Date of 2nd visit

Symptoms

Diagnosis

Treatment

14/ Date of 3rd visit

Symptoms

Diagnosis

Treatment

15/ Date of 4th visit

Symptoms

Diagnosis

Treatment

16/ Date of 5th visit

Symptoms

Diagnosis

Treatment

17/ Date of 6th visit _____

Symptoms _____

Diagnosis _____

Treatment _____

Last recorded measurements

18/ Blood pressure _____ Date _____

19/ Weight _____ Date _____

20/ Height _____ Date _____

21/ Occupation _____

22/ Social Class _____

23/ Any other relevant information

