AN ASSESSMENT OF COPING IN ADULTS WITH TYPE 1 DIABETES

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Thesis submitted for the degree of PhD in Psychology

THE UNIVERSITY OF EDINBURGH

January 2002

To my parents
who have provided all the encouragement and support
that I could wish for.

THE UNIVERSITY OF EDINBURGH

ABSTRACT OF THESIS

(Regulation 3.5.13)

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Degree PH.D. *Date* 17 JANUARY 2002

Title of Thesis AN ASSESSMENT OF COPING IN ADULTS WITH TYPE 1 DIABETES

No. of words in the main text of Thesis 87,000

The development of Type 1 diabetes has a profound impact on many aspects of everyday life, health and well-being. In this thesis the literature relevant to different aspects coping with Type 1 diabetes is reviewed. The research described in the thesis includes (i) a prospective assessment of how psychosocial factors affect diabetes-related outcomes in adults following the onset of Type 1 diabetes, (ii) qualitative analysis of interviews that were conducted to explore the patient's perspective of what it means to cope with diabetes, and (iii) the development, pilot testing, and subsequent partial validation of a diabetes-specific questionnaire.

The Edinburgh Prospective Diabetes Study examines the relationships between psychosocial variables recorded at diagnosis and diabetes related outcomes recorded at four months ($n = 69$), 12 months ($n = 65$), 24 months ($n = 56$) and 36 months ($n = 40$) after diagnosis. The results showed that individuals who had a lower socio-economic status had consistently poorer glycaemic control at 24 months ($p < 0.001$) and at 36 months ($p < 0.01$) after diagnosis. Diabetes knowledge at four months after diagnosis was a significant predictor of glycaemic control at 12 months ($r = 0.35$, $p < 0.01$) and at 36 months after diagnosis ($r = 0.35$, $p < 0.05$). In adults, self-reported outcomes were significantly predicted by longstanding psychological (e.g. personality traits) and social factors (e.g. quality of life). There was some evidence to suggest that coping strategies have an intermediate position between psychosocial factors and diabetes-related outcomes. The results and their implications for future research are discussed in terms of existing theories of coping.

To date there are few psychometrically sound instruments capable of assessing how well a person is coping with their diabetes. With this in mind, the present research was undertaken to develop a new diabetes self-report measure termed the Diabetes Impact, Adjustment and Lifestyle Scales (DIALS). The development, pilot testing and partial validation of the DIALS are described. Semi-structured interviews ($n = 10$) were conducted to explore the patients' descriptions of their adjustment to diabetes and the impact that diabetes has on aspects of their daily life. A grounded theory approach (Strauss, 1987) was adopted to analyse the data. Several domains were established, from which items were generated. Two studies, a small pilot study ($n = 57$), and a large cross-sectional validation study ($n = 246$) were carried out to establish the underlying structure, internal consistency, partial validity, and stability of the DIALS. Principal components analysis of the DIALS identified five dimensions: Impact, Adherence, Information-seeking, Fear of complications and Diabetes-related distress. Overall, the results suggest that the DIALS is a valid, reliable and stable indicator of coping in adults with Type 1 diabetes. A hierarchal model of causal relationships between psychological constructs (i.e. personality traits and illness-related coping constructs) and the DIALS was formulated and tested formally using Structural Equation Modelling. There was considerable overlap in the constructs, with evidence for two latent variables relating to 'emotion-oriented' and 'task-oriented coping'. In summary, coping variables may be important mediators in the link between antecedent variables such as longstanding character traits (e.g. personality) and self-reported outcomes of diabetes.

Acknowledgements

I acknowledge with gratitude the following people who have assisted in the preparation of this thesis, and without whom this thesis would not have been possible.

Professor Ian Deary, as my supervisor, provided enormous support and personal encouragement throughout. His medical and psychological expertise, and constructive criticism were invaluable. I am especially grateful to him for his help with the statistical analysis, particularly with structural equation modelling, and the interpretation of results.

I am grateful for the advice provided by Dr Ann Gold and Dr Brian Frier, who along with Ian gave me enormous support in the preparation of the thesis.

I would like to thank Dr Andrew McKinlay for his help with the analysis and interpretation of the interviews.

My thanks also go out to the staff of the Department of Diabetes at the Royal Infirmary of Edinburgh, who were always helpful and accommodating, and to all the patients who willingly participated in this research, and whose perspectives I hope are reflected in this thesis.

Finally, I am grateful to my parents for their financial assistance, and to my family and all of my friends whose encouragement and support were invaluable.

Contents

PART II (continued)

Chapter 1 (continued)

PART III (continued)

Chapter 3 (continued)

APPENDIX

PART I

CHAPTER 1

Introduction to Type 1 Diabetes

Diabetes is a life long, chronic, and as yet incurable condition. The word *'diabetes'* comes from the ancient Greek, meaning syphon or fountain because the disease is often characterised by excessive thirst and urination. Mellitus was later added by Western writers in the 17th century and means honeyed (Shillitoe, 1988). In 1679, Thomas Willis was the first to provide a description in English when he wrote of the *'pissing evil'* and described the urine of diabetics as being *'wonderfully sweet'*. He speculated on the importance of *'unallyed wine' and 'prolonged sorrow'* as possible causes of the disease. This recognition of the importance of psychosocial factors was acknowledged even earlier by Hindu physicians who commented on the relevance of both behaviour and affluence, *'It is a disease of the rich and one that is brought about by the gluttonous over-indulgence in oil, flour and sugar'* (Zimmet, 1983). One hundred years later Matthew Dobson came closer to the truth in his observation that there was sugar in the blood of people with diabetes. This led him to the conclusion that glucose was being lost before it could be used in nutrition.

It wasn't until 1889 that Paul Langerhans identified cells in the pancreas that were not involved in other digestive processes. When these cells were damaged diabetes occurred. These cells became known as the Islets of Langerhans and it was believed that they held a chemical messenger (hormone) that would counteract diabetes. The Canadian surgeon Frederick Banting and his partner Charles Best were the first to name and isolate this hormone and they performed the first clinical trials. The hormone they extracted was called insulin. The exact cause of diabetes is still unknown although it has been suggested that the body makes antibodies that destroy the insulin producing cells. To date there is no known cure.

Disturbances in the metabolic regulation of glucose

Prior to the discovery and refinement of insulin medical treatment of diabetes consisted of little more than the passive supervision of the patient's gradual decline towards eventual death (Shillitoe, 1988). Insulin treatment has changed the prognosis dramatically because it provides an effective means of blood glucose control. Today people with Type 1 diabetes can have a near normal life expectancy. It is now known that insulin controls blood glucose levels and is needed to convert glucose into energy. Diabetes results from disturbances in the metabolic regulatory systems responsible for the storage of chemical energy released from food. The principal product of carbohydrate digestion is glucose. Glucose is absorbed into the blood stream and is a vital fuel for the brain and muscles. As foods are digested glucose rises in the blood stream and is the main source of energy. A proportion of glucose is also stored in the liver as glycogen, and any glucose left over is then converted into fat and stored as triglycerides. During a meal containing carbohydrates insulin levels rise. The primary function of insulin is to prevent an excessive rise of glucose in the blood by enhancing its conversion into fat and storage as glycogen. People who have Type 1 diabetes are unable to produce enough insulin naturally in the body which leaves blood glucose levels free to rise in a dangerously uncontrolled manner. These individuals are required to carry out careful monitoring of their own blood glucose levels on a daily basis using multiple injections of insulin.

Risk of complications

Controlling blood glucose levels well is important for people with Type 1 diabetes because poor glycaemic control has been linked to an increased risk of the development and progression of complications of the disorder in later life (DCCT, 1988). These include retinopathy leading to impaired vision and in some cases blindness, nephropathy (kidney damage) which can lead to kidney failure, and neuropathy (damage to nerve fibres). Damage to the peripheral nerves normally affects the feet of diabetics making them less aware of sensation and pain, and more susceptible to infection. On the other hand damage to the autonomic nervous system can affect blood pressure and may cause impotence (Kelleher, 1988).

For people with Type 1 diabetes the chances of developing complications related to diabetes are high. An American study revealed that the prevalence of retinopathy varies from as little as 17% in individuals who have had diabetes for less than five years to 97.5% in those who have had diabetes for more than fifteen years (Jarrett, 1986). For this reason it is important that patients are regularly screened for retinopathy to allow early recognition and treatment to reduce the damage. Other research on the incidence of kidney disease has shown that approximately 50% of people who have Type 1 diabetes will develop kidney disease at some stage of their life, and in 4-5% of cases this will be severe (Kelleher, 1988).

As quoted by Marble (1976), the discovery of insulin meant that diabetes was, *'unmasked, and forced to show its true colours, by virtue of having been granted a longer period of years to exert its effect'.* There are two hypotheses for the prevalence of complications. Firstly the genetic hypothesis, which suggests complications are genetically determined and secondly, the metabolic hypothesis which states that complications arise as a direct result of hyperglycaemia. Raskin and Ravenstock (1986) argued that these two hypotheses are not mutually exclusive and that the most likely condition may be those with hyperglycaemia and a genetic predisposition. Despite the controversy over the cause of complications good glycaemic control is a primary objective for patients with Type 1 diabetes, in an effort to avoid hyperglycaemia, but unfortunately this is not always achieved.

Hyperglycaemia occurs when low levels of insulin allow blood glucose to rise beyond normal levels. This causes excess glucose to spill into the urine giving rise to a number of symptoms. Symptoms include excessive urinating, thirst, genital itching, tiredness and weight loss. If this continues the body begins to find other sources of energy by breaking down proteins and fatty acids (gluconeogenesis). The prolonged breakdown of fatty acids can be dangerous because it produces ketones which are poisonous in large amounts. If ketones build up in the blood they can spill into the urine and result in *'ketoacidosis'*. One of the main concerns of diabetic treatment is to reduce blood glucose levels to within the normal range in order to reduce the symptoms of diabetes, and the risk of the development and progression of long-term complications of the disease.

Hypoglycaemia (low blood sugar) is one of the most common causes of fear for people who have Type 1 diabetes. Hypoglycaemia arises from a mismatch between insulin dose and energy expenditure (Deary, Hunter and Frier, 1997). It occurs when blood glucose leaves the bloodstream faster than it is replaced. People who have Type 1 diabetes are under the constant threat of hypoglycaemia in their everyday lives. Usually patients are alerted by warning symptoms that a *'hypo'* is imminent and can take action to prevent it. Many patients describe the initial manifestations as a vague feeling of apprehension, and a non-specific feeling of becoming unwell (Hepburn, cited in Fisher and Frier, 1993). The symptoms that alert the patient to the onset of hypoglycaemia can be subdivided into three groups based on their physiological mechanisms. First are those attributable to neuroglycopenic symptoms including dizziness, confusion, speech difficulty and lack of coordination. These symptoms are known to impair cognitive function (Gold, Deary and Frier, 1993). Second are those symptoms which result from activation of the autonomic nervous system (autonomic symptoms) including sweating, trembling, anxiety and nausea. These symptoms are caused by the release of counter-regulatory hormones like glucagon and adrenaline in the body's attempt to maintain homeostasis (Hepburn, cited in Fisher and Frier, 1993). The third category of symptoms are non-specific symptoms associated with malaise (Cooke, 1934; Hepburn, Deary, Frier, Patrick, Quinn and Fisher, 1991a). In the case of a serious episode of hypoglycaemia convulsions, unconsciousness and, rarely, death, can occur (Deary et al., 1997). The treatment of hypoglycaemia is simple in most cases. In the case of a mild attack, an oral carbohydrate (glucose sweets) or intravenous glucose is normally enough to restore glucose levels (Campbell and Macleod, 1924). In more severe cases a glucagon injection may be required. However, most episodes of hypoglycaemia are preventable and often occur due to the error of the individual: for example, failure to match insulin dose to carbohydrate intake, skipping meals, and poor injection techniques.

Psychological and social consequences

In order to avoid the development and progression of microvascular and macrovascular complications of diabetes the individual is required to adhere to the complex demands of a strict self-management routine on a daily basis. This routine includes regulation of diet, taking regular physical exercise, blood glucose monitoring and multiple injections of insulin. These self-management activities make coping with diabetes unique in comparison to other chronic diseases because it is one of the rare disorders that allows an individual to control their own well-being to a large extent. The psychological burden is increased because patients consider themselves responsible for their own health (Maes, Leventhal and Ridder, cited in Ziedner and Endler, 1996). This has considerable consequences for the individual's psychological and social functioning. The overall consequences for the patient's physical and psychological well-being are likely to be dependent on their ability to adapt to and control the disorder. In other words how well they cope.

PART 1 (continued)

CHAPTER 2

Coping with Diabetes

This chapter provides a review of previous literature on coping with diabetes. Firstly, a theoretical definition of the term 'coping' is provided followed by a review of relevant conceptual and measurement issues in health psychology. Then, a discussion of the various diabetes-related outcomes which may reflect optimal coping ability including the achievement of good glycaemic control and adherence to the demands of a complex self-management routine, having a comprehensive knowledge of diabetes, being satisfied with treatment, and having a good quality of life. The literature surrounding each of these outcomes will be discussed in turn with respect to their importance as independent coping outcomes.

Definition of coping

Historically, coping was defined in terms of a response to emotion and a "defence mechanism" (Freud, 1933). This was thought to be primarily an unconscious process. Nowadays coping strategies can be viewed as the cognitive and behavioural efforts used by an individual in response to a stressful condition (Lazarus and Folkman, 1984). According to Lazarus and Launier (1978) coping can be defined as *"efforts both action oriented and intrapsychic, to manage environmental and internal demands, and conflicts among them, which tax or exceed a person's resources"*. Previous research on coping suggests that coping is a psychologically normal (Costa, Somerfield and McCrae, 1996) and conscious process which involves a response to external stressful situations or negative events (Billings and Moos, 1981; Lazarus and Folkman, 1984). Moreover, cognitive factors are deemed as being of central importance in determining the impact of these stressful events and a person's emotional, physiological or behavioural reactions to the particular event in question

(Lazarus, 1966; Lazarus and Launier, 1978; Cohen and Lazarus, 1979). In the case of health problems, coping with health problems has been a major theme in recent years (Taylor and Aspinwall, 1990). Research to date suggests that adjustment to an illness may require considerable coping effort, and medical evidence has shown that despite the similarities between some conditions, patients appear to differ greatly in their adjustment and recovery (Cohen and Lazarus, 1979). Coping efforts, and in particular, controllability of the illness, have been suggested as one means of accounting for these differences (Felton and Revenson, 1984).

Theoretical framework and measurement of coping

Researchers often measure how individuals cope with the physical and emotional pressures of diabetes self-management in terms of models like the stress and coping model developed by Lazarus and Folkman (1984). The overriding assumption of this model is that coping strategies are important mediators in the link between psychological antecedents to disease (e.g. environmental stressors or personality traits) and health-related outcomes (Lazarus and Folkman, 1987; Deary, Clyde and Frier, 1997). According to Lazarus and Folkman (1987) individuals employ coping strategies in an effort to deal with the internal (emotional) and external (event-related) demands of the threat. This distinction led them to define two specific coping responses, (i) problem-focused coping, which deals directly with the external threat, (e.g. doing something to change the problem causing the threat), and (ii) emotion-focused coping, which is directed towards the emotional reactions of the individual (e.g. regulating distressing emotions). This distinction is widely documented in coping literature (Billings and Moos, 1981, 1984; Pearlin and Schooler, 1978).

By way of criticism of the stress and coping model it may be argued that it is too general in its conceptualisation of coping rather than describing coping with specific diseases. For example coping with the daily hassles of diabetes monitoring is different from suffering the traumatic experience of a severe attack of hypoglycaemia (Pennings-van der Eerden and Visser, 1986). The model also ignores the impact that other life events can have on coping processes. Lazarus himself has also acknowledged problems with the model in that it fails to account for an individual's situational demands and life goals (Lazarus, 1991). Despite these criticisms psychological knowledge and understanding of coping and adaptation to chronic illness has been largely expanded using this model, but it is apparent that more disease and situation-specific models, and psychometric instruments are necessary to advance current understanding of how people cope with different illnesses and health problems.

The model presented in Figure 1.1 is an elaboration of the stress and coping model (Zeidner and Endler, 1996). This model demonstrates how patient characteristics and other psychosocial and disease-related variables lead to coping responses, which in turn may have a causal influence on behavioural, physical and emotional outcomes.

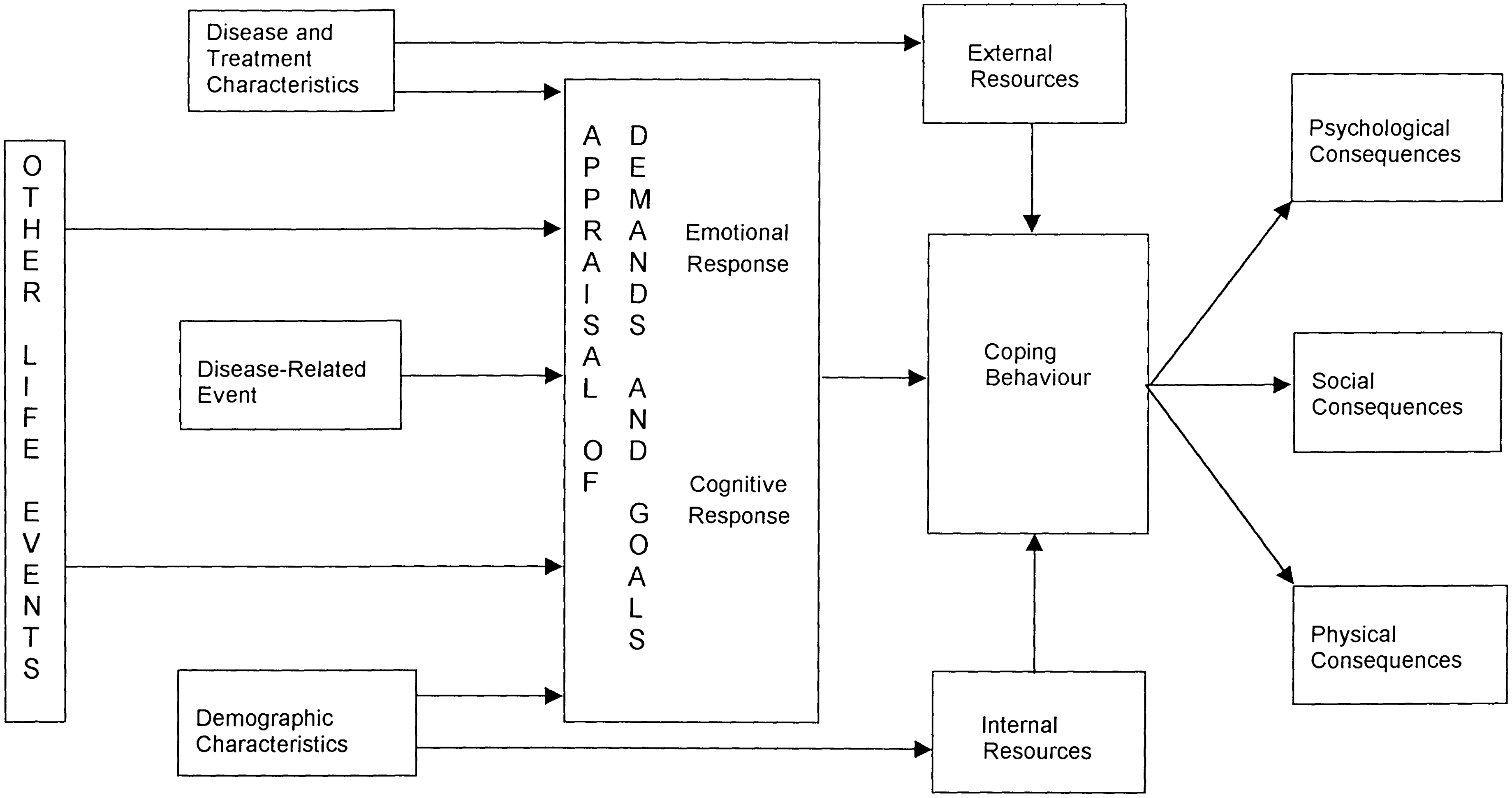


Figure 1.1: Schematization of the role of coping in chronic illness.
Adapted from Zeidner and Endler (1996), p. 229.

For many years coping has been understood in terms of the processes outlined in the theoretical framework provided by Lazarus and Folkman (1984). A central problem for researchers attempting to understand coping responses in terms of transactional models like this has been the lack of consensus regarding the dimensions of coping and their specific functions in different illnesses (Endler and Parker, 1990). According to Endler and Parker (1992) this limitation is a consequence, in part, of the "weak psychometric qualities" of many of the instruments that have been used to measure and conceptualise coping strategies.

The assessment of coping strategies in health psychology has adopted two main approaches which are defined as interindividual and intraindividual (Endler, Parker and Summerfeldt, 1993, 1998; Parker and Endler, 1992; Folkman, Lazarus, Dunkel-Schetter, Delongis and Gruen, 1986). The interindividual (dispositional) approach is generally concerned with identifying a person's general way of coping in a variety of encounters (Endler and Parker, 1990a). However, the intraindividual (situational) approach has focussed on measuring coping responses in particular stressful situations (e.g. chronic illness). In health psychology, research on coping has tended to follow the situational approach (Endler, Parker and Summerfeldt, 1998).

An example of a widely used intraindividual measure of coping is the Multi-dimensional Coping Inventory (MCI; Endler and Parker, 1990). The development of this scale followed on from previous studies which have concentrated on identifying the major coping dimensions (Billings and Moos, 1984; Folkman and Lazarus, 1980, 1985; Pearlin and Schooler, 1978). The MCI contained three pure factors; the traditional task and emotion oriented scales, and a third strategy, avoidance.

Avoidance was conceptualised as measuring an individual's avoidance of a particular stressful situation (e.g. seeking the comfort of others or engaging in other activities). This construct was similar to what Krohne (1986) termed as "attentional diversion coping". The MCI was found to be reliable, valid and had good factor structure, but despite the psychometric qualities of the scale some of the coping items may be inapplicable for people coping with chronic health problems such as diabetes.

To overcome the limitations of the previous global measures of coping Endler and colleagues have attempted to develop new measures of coping with better psychometric properties. These include the Coping Inventory for Stressful Situations (CISS; Endler and Parker, 1990a) and the Coping with Health Injuries and Problems scale (CHIP; Endler, Parker and Summerfeldt, 1998; Endler, 2000). The CISS is a general measure of coping that was designed to assess the interaction between stressful life events and the ways in which people cope with them (Endler and Parker, 1990a). More recently, Endler et al. (1998) developed a new scale that was capable of measuring general dispositions of coping with health problems and illness. The CHIP was devised to assess four distinct regions of coping behaviour; palliative, instrumental, distraction, and emotional pre-occupation coping, and is thought to be applicable across a broad range of health problems. Table 1.1 provides a description of the different subscales and examples of items relating to each dimension. The scale was found to be reliable, stable over time and adaptable to different medical populations (e.g. respiratory infections, fractures, cancer, and arthritis) (Endler, Summerfeldt and Parker, 1998). Early validation studies of this scale indicated that emotional preoccupation may be linked to maladaptive coping and poor psychological adjustment, however the reverse may be expected with instrumental coping (Endler, Parker and Summerfeldt, 1998). However, as these authors acknowledge additional validation of the CHIP is necessary, particularly with regard to examining the coping process over the course of the illness.

Table 1.1: Description of subscales and examples of items contained in the CHIP

Name of subscale	Description	Example items
Distraction	Describes the extent to which the respondent uses actions and cognitions that are aimed at avoiding preoccupation with the health problem. This involves thinking about other, usually more pleasant, experiences, engaging in unrelated activities, and being in the company of others.	5. Be with other people 21. Listen to music 25. Invite people to visit me 29. Surround myself with nice things (e.g. flowers)
Palliative	Describes the various "self-help" responses utilised to alleviate the unpleasantness of the situation. This type of coping response includes attempts at feeling better through, for example, making oneself comfortable by changing the surroundings, getting plenty of rest, etc. These responses may involve lay beliefs about illness.	6. Lie down when I feel tired 10. Get plenty of sleep 22. Make my surroundings as quiet as possible 26. Be as quiet and still as I can
Instrumental	Focuses on various *task-oriented* strategies used to deal with the illness. Such coping strategies can be categorized as active or problem-focused because they indicate that the individual is seeking help for the illness or trying to learn more about it.	15. Learn more about how my body works 23. Try my best to follow my doctor's advice 27. Be prompt about taking medications 31. Learn more about the most effective treatments available
Negative-emotion	Involves the extent to which an individual focuses on the emotional consequences of the health problem. These coping behaviours are related to *emotion-oriented* coping, and include responses like self-preoccupation and fantasising.	4. Wonder why it happened to me 8. Become angry because it happened to me 16. Feel anxious about the things I can't do 28. Feel anxious about being weak and vulnerable

Adapted from Endler (2000)

Previous research on coping with diabetes

Following the initial diagnosis of Type 1 diabetes many factors are likely to contribute towards a person's psychological distress, including the patient's uncertainty about outcomes, feelings of anger and self-blame with regard to the cause of the disease, feelings of helplessness and incompetence about the ability to adhere to the prescribed regimen, and an underlying fear about the future consequences of diabetes (Hamburg and Inoff, 1983). For example, early death, hypoglycaemia and complications such as the possibility of going blind or experiencing kidney problems are all potential threats. The psychological burden of the threats associated with the illness following diagnosis varies among individuals and coping efforts are likely to account for a large portion of these differences (Cohen and Lazarus, 1979).

Coping responses vary depending on the situation and are likely to be more or less effective depending on the type of stress faced, for example, emotion-focused coping styles are used more often than instrumental or problem-focused coping in health problems when the situation is uncontrollable (Folkman and Lazarus, 1980). One of the most prominent determinants of successful coping is controllability (Felton and Revenson, 1984). This is of primary importance in diabetes where the patient is required to control his or her own treatment to a large extent. Therefore it follows that a more problem-focused and instrumental approach would be most beneficial for these individuals. However, Marrero (1981, cited in Felton and Revenson, 1984), found problem-focused coping was more characteristic of diabetics in poor control than those who were well controlled. It may be that poor control is the cause rather than the consequence of this kind of active, problem-focused coping (Felton and

Revenson, 1984). However, this is difficult to establish in cross-sectional studies where coping has only been measured at one point in time.

Research into the ways in which people cope with Type 1 diabetes is limited and most studies which have been conducted to date have been small cross-sectional studies, or have concentrated on children and adolescents with diabetes rather than adults (Kovacs, Brent, Steinberg, Paulauskas and Reid, 1986; Grey, Cameron, Lipman and Thurber, 1995; Kovacs, Feinberg, Paulauskas, Finkelstein, Pollock and Crouse-Novak, 1985; Hanson, Harris, Relyea, Cigrang, Carle and Burghen, 1989). A previous prospective investigation of the coping responses of children followed patients and their families across the first year after diagnosis, paying particular attention to the patient's life situation and emotional well-being. It was found that following diagnosis approximately one third of these patients experienced a brief period of emotional and psychological disturbance which included mild sadness, increased anxiety, and social withdrawal (Kovacs et al., 1985), but by the end of the first year self-ratings indicated fewer symptoms of depression and higher self-esteem. A substantial proportion of these children also reported using instrumental or problem-focused coping strategies (Kovacs et al., 1986).

More recently a six year follow-up study of children with newly diagnosed Type 1 diabetes showed that initial adjustment problems following diagnosis are predictive of subsequent psychosocial and self-management difficulties (Kovacs, Iyengar, Goldston, Stewart, Obrosky and Marsh, 1990), including an increased risk of psychiatric disorders (Kovacs, Mukerji, Drash and Iyengar, 1995). This implies that the burden of diabetes self-management may become more problematic over time in some individuals. It is therefore important for diabetes health professionals to be aware of those individuals who may be at risk of subsequent self-management and psychosocial difficulties from early on in the disease progression. Indeed, indications from a recent study, which assessed the clinical and psychological course of diabetes from adolescence through to young adulthood (n = 76), found that the outcomes of this cohort were generally poor. In particular, it appeared that behavioural problems in adolescence were important in influencing later glycaemic control (Bryden, Peveler, Stein, Neil, Mayou and Dunger, 2001).

To date there have been few attempts to assess coping prospectively in adults with Type 1 diabetes. This is surprising considering the lifelong challenges that diabetes poses on the individual. Coping behaviour used by adults with Type 1 diabetes may well differ from the coping responses observed in children and adolescents with diabetes because adults generally have more responsibilities and are more independent, and settled in their lives. Those studies which have examined the psychosocial impact of diabetes in adults suggest that young adults may be more socially isolated (Lloyd, Robinson, Andrews, and Fuller, 1993), have poorer well-being (Tebbi, Bromberg, Sills and Cukierman, 1990), and lower self-esteem (Jacobson, Hauser, Willet, Wolpert, Dvorak, Herman and de Groot, 1997) than aged matched control groups.

The patterns of adjustment observed in the above studies have implications for future research on coping styles. Firstly, they draw attention to the importance of prospective studies for the identification of predictors of coping and disease-related outcomes, and secondly they highlight the fact that there may be distinct and important stages involved in the adjustment process following diagnosis which should be examined more closely. For example, Kubler-Ross (1969) provided a detailed description of the five stages of bereavement which can be summarised as denial, anger, bargaining, depression and finally acceptance. It may be possible to apply such a framework to patients' adjustment following diagnosis of Type 1 diabetes.

Coping and diabetes-related outcomes

According to Hanson, Harris, Relyea, Cigrang, Carle and Burghen (1989), few studies have attempted to identify the relationships among coping styles and objective health outcomes in people with diabetes. In an attempt to over come this problem these authors examined the relationships between coping styles and diabetes-related outcomes in a sample of youths, paying particular attention to family environment and individual characteristics in predicting coping. They found that ventilation and low family cohesion were related to avoidance coping, and that avoidance coping was strongly predictive of poor adherence, but failed to find any relationship between coping and metabolic control. In a similar investigation coping styles were not associated with adherence except in the case of timing of meals which was associated with active and avoidance coping (Frenzel, McCaul, Glasgow and Schafer, 1988). Instead both coping styles were related to poor control (Frenzel, McCaul, Glasgow and Schafer, 1988; Delamater, Kurtz, Bubb, White and Santiago, 1987). These findings suggest that individuals in poor control may experience more stress related to their illness and therefore draw on coping strategies to reduce the psychological burden of the disorder. This claim is supported by evidence which suggests that coping strategies buffer the effect of stress on glycaemic control, and effective coping strategies have been shown to protect individuals from the damaging effects of stress (Peyrot and McMurry, 1992). While it is not always possible for individuals to avoid stress, helping them to learn to recognise and cope with particular stressors may help them to maintain good glycaemic control and improve their general well-being.

So far, interventions which have attempted to implement coping skills training and education programmes have produced promising results. In a sample of adolescents with Type 1 diabetes coping skills training combined with intensive diabetes management was successful in producing improvements in metabolic control and quality of life (Grey, Boland, Davidson, Chang Yu, Sullivan-Bolyai and Tamborlance, 1998). Furthermore, these improvements were evident one year later (Grey, Boland, Davidson, Li and Tamborlane, 2000). Similar findings have been observed in adults with diabetes. For example, interventions aimed at increasing the patients' sense of empowerment and self-care activities had a positive effect on diabetes-related outcomes including self-efficacy, self care behaviours, glycaemic control, and quality of life (Anderson, Funnell, Butler, Arnold, Fitzgerald, Feste, 1995; Pieber, Brunner, Schnedl, Schattenberg, Kaufman and Krejs, 1995). In addition blood glucose awareness training has been shown to reduce the frequency of severe hypoglycaemia episodes, ketoacidosis and fear of hypoglycaemia in adult patients with Type 1 diabetes (Cox, Gonder-Frederick, Polonsky, Schlundt, Julian and Clarke, 1995). More recently a randomised control trial aimed to investigate whether interventions that involved monitoring and discussing psychological well-being were effective in producing improvements in the patients' mood and HbA_{1c} (Pouwer, Snoek, Van der Ploeg, Ader and Heine, 2001). The results revealed that monitoring and discussing psychological well-being was an effective way of improving the mood of patients but did not affect their HbA_{1c} values.

The above studies provide collective evidence to suggest that behavioural interventions are an effective and necessary way to improve glycaemic control, self-management difficulties and coping ability in people with diabetes. However, the monitoring and discussing of psychological well-being as part of routine diabetes care may be more effective in producing improvements in the mood and subjective well-being of patients with Type 1 diabetes. A review of the literature on the effectiveness of psychosocial therapies in diabetes concluded that more research is needed to identify specific psychosocial factors that influence regimen adherence and glycaemic control in adults with Type 1 diabetes, and recommended using longitudinal designs to account for how psychosocial factors affect health over time (Delamater, Jacobson, Anderson, Cox, Fisher, Lustman, Rubin and Wysocki, 2001).

Multi-dimensional aspects of coping

Previous literature in health psychology has been surrounded by the ongoing controversy regarding the major dimensions of coping, and their specific functions in different illness. Despite this confusion most researchers today distinguish between task-oriented (active) coping and emotion-focussed (passive) coping, and more recently avoidance coping. In general, most research studies indicate that active coping styles are associated with positive disease outcomes (Cox and Gonder-Frederick, 1992; Kovacs et al., 1990, Smari and Valtysdottir, 1997), and emotion-oriented coping to negative disease outcomes (Felton and Revenson, 1984). For example, an investigation of coping responses to the threat of hypoglycaemia (Cox, Irvine, Gonder-Frederick, Nowacek and Butterfield, 1987) revealed that worrying about hypoglycaemia was related to negative-emotion coping. However, in contrast hypoglycaemic avoidance behaviour was associated with more instrumental and avoidance coping strategies (Deary, Hunter and Frier, 1997). As a result Deary et al. (1997) suggested that specific coping styles may have distinct associations with health-related worries and health-related actions.

In conclusion, it is important to note that although the evidence is indicative of the need to promote problem-focused coping styles more prospective research from the time of diagnosis of diabetes is necessary to (i) determine developmental changes in coping strategies over time, (ii) to examine whether changes in coping behaviour result in different outcomes at different stages of the illness, and (iii) to examine this sequence in adults as well as children and adolescents with Type 1 diabetes. It is suggested that the present conceptual framework of 'coping' provides one way to disentangle the relationships between psychosocial variables and health-related outcomes of diabetes, and the study of coping as a process may elaborate on what is already known about normal or atypical responses at various points throughout the illness.

Assessment of risk factors for poor glycaemic control

The primary aim of insulin therapy is to achieve near normal glycaemic control, with minimal episodes of hypoglycaemia, and as little disruption to daily living as possible. This is not an easy task, especially in the early stages of the disease, and requires an individual to draw on coping mechanisms to help them deal with the psychological and physical challenges of diabetes. Perhaps most important is the fact that patients must comply with the demanding requirements of insulin therapy while knowing that the eventual onset of complications is almost inevitable (Cox and Gonder-Frederick, 1992).

The Diabetes Control and Complications Trial (DCCT, 1986, 1987, 1993) was a large, multicentre, randomised clinical trial designed to compare intensive and conventional diabetes therapy. This research was designed to examine whether two treatment regimens would result in differences in chronic blood glucose control, and clinical differences in the appearance and progression of vascular complications (DCCT, 1993). Prior to the DCCT some (Keiding, Root and Marble, 1952; Hardin, Jackson and Johnson, 1956; Johnsson, 1960; Job, Eschwege, Guyot-Argenton, Aubry and Tchobroutsky, 1976, Pirart, 1978) but not all (Dolger, 1947) studies found that elevated blood glucose levels caused or contributed to microvascular complications in patients with Type 1 diabetes. The DCCT Research Group extended these findings by showing the importance of long term glycaemic control in minimising the risk of the development and progression of microvascular complications of diabetes (DCCT, 1993), but failed to reveal any adverse psychological outcomes in patients who achieved good control over their diabetes. More recently the DCCT research group have demonstrated that intensive therapy, in patients in the early stages of Type 1 diabetes, prolongs their ability to produce endogenous insulin as well as lowering their risk of diabetic complications (DCCT, 1998). However, the patients in this study were young, mostly well-educated and highly motivated and could not be considered representative of the general population.

Despite the results of the DCCT, most small, cross-sectional studies have failed to elucidate the direct determinants of glycaemic control and have produced contradictory findings. Identifying the strategies to prevent poor glycaemic control remains a priority for health professionals but the factors that determine which patients will achieve good glycaemic control are likely to be multiple and may include, pre-morbid personality, psychiatric well-being, cognitive ability, coping strategies, an individual's social and work environment, in addition to the education received at the diabetic clinic.

Previously it has been difficult to measure long term glycaemic control but recent advances have enabled researchers to make more reliable and valid estimates. The best measure of long term glycaemic control available to date is a patient's HbA_1 concentration (glycated haemoglobin) which is a short-lived protein that becomes altered by the attachment of glucose molecules (Cox and Gonder-Frederick, 1992). HbA_{1c} provides a good biochemical marker of glucose control over the previous six to eight weeks.

To date much research has focused on diabetes knowledge, beliefs and attitudes but little research has been done on the social environment in which the patient lives and copes with diabetes (Glasgow and Osteen, 1992). For example, perceived social support and higher levels of family cohesion are associated with better adherence and hence glycaemic control in adolescents (Hanson, De Guire, Schinkel and Kolterman, 1995; Hanson, Henggeler and Burghen, 1987). Hanson et al. (1987) hypothesised that psychosocial variables have an indirect effect on glycaemic control through their impact on diabetes-related regimen adherence behaviours and proposed a conceptual model based on five domains; life stress, social competence, family relations, family knowledge about diabetes, and age of the adolescent (Figure 1.2).

As shown in Figure 1.2, family knowledge about diabetes ($r = .28$, $p < 0.01$), age ($r = -.21$, $p < 0.05$) and family relationships ($r = .32$, $p < 0.001$) were all related to adherence. However, in multiple regression analyses, family knowledge about diabetes was the only variable that was significantly associated with adherence when the effects of the other variables were controlled. Adherence and metabolic control were also related ($r = -.30$, $p < 0.01$), and stress was related to control ($r = .24$, $p < 0.01$) but not adherence.

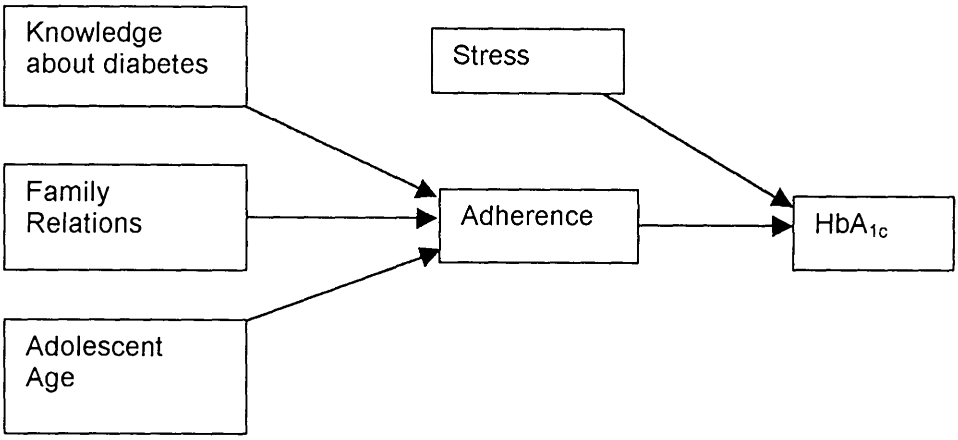


Figure 1.2: Model to show the relationship between psychosocial variables, adherence, and metabolic control .
Adapted from Hanson, Henggeler and Burghen (1987).

This model supports the existing evidence that social support (Peyrot and Rubin, 1994), psychological stress (Peyrot and McMurray, 1992; Lloyd, Dyer, Lancashire, Harris, Daniels and Barnett, 1999) and knowledge about diabetes (Bott, Jorgens, Grusser, Bender, Muhlhauser and Berger, 1994) are significant determinants, albeit perhaps indirectly, of eventual glycaemic control. However the predictive power of this model should not be over interpreted as it only accounts for 14.5% of the variance in predicting metabolic control. This is likely to be due to the conceptual restraints of the study and future investigations need to consider broader issues of individual differences in psychosocial factors such as personality, coping and well-being.

Evidence regarding the relationship between personality traits such as extraversion and neuroticism, and objective disease-related factors has provoked considerable disagreement (Lane, Stabler, Ross, Morris, Litton and Surwit, 1988; Fonagy, Moran, Lindsay, Kurtz and Brown, 1987; Lloyd, Matthews, Wing and Orchard, 1991). More recently an investigation was made into the relationship between Eysenck's Personality Questionnaire and HbA_{1c} (Gordon, Fisher, Wilson, Fergus, Paterson and Semple, 1993). This investigation revealed a correlation between neuroticism and glycaemic control ($r = .43$, $p < 0.01$) but this result was not replicated in subsequent research (Hepburn, Langan, Deary, MacLeod and Frier, 1994). Instead the best predictors of glycaemic control were age at onset of diabetes ($r = -.37$, $p < 0.001$) and duration of diabetes ($r = .19$, $p < 0.05$). As Hepburn et al. (1994) acknowledge, it may be true that older patients have a greater coping capacity than younger patients, and patients with more experience of diabetes rely on coping strategies less, therefore experiencing less stress related to their illness, which in turn leads to better quality of glycaemic control. If the association between neuroticism and glycaemic control reported by Gordon et al. (1993) had been replicated it would represent one of the only correlations between personality and diabetes control, but it is likely that their results were flawed due to the small sample size ($n =40$).

Similar disagreement surrounds the claim that the psychiatric well-being of patients may be linked to glycaemic control. The incidence of depression in people with diabetes is high, currently three times greater than in the general population (Gavard, Lustman and Clouse, 1993). Whilst we know that depression can have adverse effects on psychological functioning and quality of life in people with diabetes (Jacobson, de Groot and Samson, 1997; Lustman, Freedland, Griffith, Barnes, Miller, Anderson, McGill, Rubin and Clouse, 1999) the exisiting literature concerning the association between psychiatric well-being and glycaemic control is not clear. Some research suggests that patients with poor control are more likely to have a history of psychiatric illness (Fonagy, Moran, Lindsay, Kurtz and Brown, 1987; Lustman, Griffith, Clouse and Cryer, 1986; Cohen, Welch, Jacobson, de Groot and Samson, 1997). In particular these individuals are more likely to report high levels of anxiety and depression (Mazze, Lucido, and Shamoon, 1984). However, the results of a study of children with Type 1 diabetes showed that between 1/4 and 1/3 of children with Type 1 diabetes are psychiatrically disturbed, but such disturbances did not predict poor control. In fact, anxious children were more diligent in monitoring their blood glucose levels (Fonagy, Morgan, Lindsay, Kurtz and Brown, 1987). This result was replicated in a recent study which revealed that there was a tendency for emotional problems, such as anxiety and depression, to be associated with lower glycaemic control in young adults with diabetes (Bryden, Peveler, Stein, Neil, Mayou and Dunger, 2001).

Bryden et al. (2001) followed up a cohort of adolescents with Type 1 diabetes (aged 11- 18) through to young adulthood (aged 20-28; n = 65), and found a similarly high prevalence of psychiatric morbidity at baseline and at follow-up. Furthermore, in this study referrals for psychiatric morbidity were observed most often in patients who had recurrent hospital admissions for diabetic ketoacidosis (Bryden et al., 2001). These results indicate those individuals who have poorly controlled diabetes may be at increased risk of psychological morbidity. A recent meta-analysis performed to assess the reliability and strength of the association between depression and glycaemic control found conclusive evidence for an association between depression and hyperglycaemia, but the directional nature of this relationship remains unclear (Lustman, Anderson, Freedland, de Groot, Carney and Clouse, 2000). Prospective studies are therefore necessary to establish whether it is the patient's psychological profile that has influenced their diabetes control or whether it is the diabetes that has altered the patient's psychological profile.

Some investigations have demonstrated that diabetes-specific measures of individual differences in psychosocial variables may be better predictors of glycaemic control than global measures. For example, a recent study of individual differences in Diabetes Locus of Control suggested that patients with a good external network achieve better control and that clinic oriented control does not always achieve the best results (Peyrot and Rubin, 1994). Chance locus of control has been associated with worse metabolic control (Bradley, Brewin, Gamsu and Moses, 1984). Internality on the other hand has been associated with better (Dobbins and Eaddy, 1986) and worse control (Burns, Green and Chase, 1986). Assessment using the Diabetes Locus of Control scale has established two types of internal, the autonomous individual who takes responsibility for their diabetes and another group who believe they can control their diabetes but do not. This leads to self-blame and hence poor adherence and control (Peyrot and Rubin, 1994). Based on these findings it is likely that optimal control is achieved in individuals who combine an autonomous approach with a willingness to take advantage of their available support networks. However, the contradictory nature of the relationships between locus of control and adverse outcomes in people with diabetes has prompted the need to develop more complex appraisals of the multidimensional aspects of a person's psychological sense of control (Surgenor, Horn, Hudson, Lunt and Tennent, 2000).

Most research to date has failed to draw any firm conclusions with regard to the direct determinants of glycaemic control in adults with Type 1 diabetes and no one theory has yet convinced researchers. Although some modest psychological predictors have been found, many of the observed correlations are too small to be of practical value in predicting individuals who may be vulnerable to poor control. Such discrepancies regarding the nature of the relationships between psychological and social factors and glycaemic control highlight the need to determine those aspects of the individual at the time of diagnosis, which are subsequently associated with the quality of control at different stages of the disorder. This can only be achieved by serial assessment of individual differences in the methods by which people cope with diabetes.

The importance of diabetes self-management

Diabetes self-management or what is commonly known as adherence (compliance) is important because adoption of a healthy lifestyle is assumed to produce better control which leads to a reduced risk of long-term complications (Toobert and Glasgow, 1994). It is therefore hypothesised that the diverse associations observed between psychosocial factors and diabetes control are perhaps mediated by an individual's response to the demands of their diabetes self-management routine.

Previously researchers have often found it difficult to demonstrate any relationships between adherence and level of control (Cox, Taylor, Nowacek, Holley-Wilcox, Phol and Guthrow, 1984). This problem may be caused, in part, by the complexity of diabetes self-care and metabolic problems. Adherence behaviours are difficult to measure because they are based on a number of behavioural tasks aimed at regulating metabolic processes which are normally performed automatically. These tasks can be summarised into four components: taking medication (e.g. injections of insulin), dietary regulation, exercise regimens and self-monitoring of blood glucose (Cox and Gonder-Frederick, 1992). Until recently there was an absence of reliable, valid and unbiased indices to assess diabetes self-care activities, and those scales which have been developed are based on self-report questionnaires (Glasgow, 1994; Toobert and Glasgow, 1994; Toobert, Hampson and Glasgow, 2000) and structured interviews (Harris, Wysocki, Sadler, Wilkinson, Harvey, Buckloh, Mauras and White, 2000) which may not always provide truthful reflections of regimen adherence.

A few years ago Glasgow (1994) defined what he refers to as *'barriers to self-care'* which include factors like cost, time, social pressures and competing demands whilst trying to follow one's regimen. This theory developed from applying social learning theory to the study of psychosocial factors involved in predicting diabetes outcomes (Glasgow and McCaul, 1982). As these authors acknowledge previous investigations have often *'thrown in everything but the kitchen sink'* which has merely added to the *'conceptual haziness'* of the field. Social learning theory overcomes this problem by emphasising the interaction of personal and environmental influences in determining self-regulatory behaviour (Glasgow and McCaul, 1982). Immediate support for this theory can be obtained from the investigations discussed previously which reveal the importance of social support in predicting adherence and control (Hanson, Henggeler and Burghen, 1987). Health professionals may provide another important source of information and support for overcoming barriers to self-care. Some research suggests that an individual's interaction with health professionals is related to self-care behaviour (Rost, 1989) and improvements in glycaemic control (Greenfield, Kaplan, Ware, Yano and Frank, 1988). However, the role of health-care providers has been somewhat neglected in previous research.

More recently, research has focused on expanding the ‘barriers’ concept with some promising results (Glasgow, Hampson, Strycker and Ruggiero, 1997). For example, in a study by Glasgow et al. (1997), personal models were shown to be more important than perceived barriers to self-management in a large cross-sectional study of a representative sample of people with diabetes. Recent research by Hampson and colleagues complements these findings and suggests that personal models of diabetes are associated with self-management outcomes including regulation of diet and exercise, both concurrently and prospectively in adults with diabetes (Hampson, Glasgow and Foster, 1995; Hampson, Glasgow and Toobert, 1990), and have also been shown to relate to adolescents’ self-management (Skinner and Hampson, 1998). Personal models refer to patients’ representations of their illness, and are thought to include beliefs, experiences and emotions concerning a person’s health condition (Petrie and Weinman, 1997, cited in Hampson, Glasgow and Strycker, 2000). The finding that personal models of diabetes are predictive of self-management behaviours, particularly, dietary self-management has important implications for future research in diabetes. However, further work is necessary to investigate whether or not other factors such as demographic, medical and psychosocial variables also contribute to diabetes self-management outcomes.

Despite the efforts of previous investigations the adherence-control relationship is not well established. There are several reasons for this. One problem is that many of the studies to date have been cross-sectional and therefore give little information about the time-specific effects of behaviour on adherence and glycaemic control. For example, one investigation found that 25% of the variance in self-care behaviours could be explained by psychosocial and demographic variables, especially social support, but in contrast psychosocial variables did not predict glycaemic control (Wilson, Ary, Biglan, Glasgow, Toobert and Campbell, 1986). A second problem is that adherence to one aspect of a regimen is not necessarily related to adherence to other aspects (Schafer, Glasgow, McCaul and Dreher, 1983). For example, it is known that adherence is higher for medication taking and glucose testing than for regimen tasks which require lifestyle modifications such as control of diet and exercise (Glasgow, McCaul and Schafer, 1987) which are perceived to be more difficult (Hanestad and Albrektsen, 1991). Such findings support the theory that it is difficult to measure and conceptualise global adherence (Glasgow and McCaul, 1982), and future investigations need to consider adherence behaviours in the context of factors which may influence glycaemic control (e.g. stress, individual metabolic factors, social influences and appropriateness of the regimen) rather than assuming that a one to one relationship exists.

In summary, it may be wrong to assume that good control is a direct result of good self-management and vice versa, but in the past this has often been the case. Metabolic control is in fact often a poor indicator of behaviour (Johnson, 1992). In order to assess which factors are directly responsible for predicting good metabolic control behavioural assessments (Glasgow, Fisher, Anderson, LaGreca, Marrero, Johnson, Rubin and Cox,

1999) and interventions (Hampson, Skinner, Hart, Storey, Gage, Foxcroft, Kimber, Cradock and McEvilly, 2000) are necessary. This may allow health professionals to identify those individual patients who are at risk of poor self-management, and to determine which patients appear more vulnerable to being poorly controlled.

Diabetes knowledge, attitudes and beliefs

Ensuring that people with Type 1 diabetes have a comprehensive knowledge of their diabetes, its management and potential complications is essential if they are to successfully cope with the complex demands of diabetes of self-care activities and the various lifestyle changes associated with the disorder. The goal for diabetes health professionals is, therefore, to enable the patient to become an active participant in their own diabetes care.

Previous research suggests that diabetes knowledge deficits are associated with a number of adverse outcomes of the disorder including excess hospital admissions for diabetes-related problems, increased morbidity (Geller and Butler, 1981; Clement, 1995) and poor self-management skills (Miller, Goldstein and Nicolaisen, 1978). In contrast, there is some evidence to suggest that diabetes self-management education programmes are effective in producing improvements in blood glucose control (Kronsbein, Jorgens, Muhlhausen, Scholz, Venhaus and Berger, 1988; Rubin, Peyrot and Saudek, 1991), and that intensive therapy can delay the onset and progression of microvascular complications of diabetes (DCCT, 1993). Despite these findings a national study of adults in America found that more than 50% of people with diabetes received little or no diabetes self-management education (Coonrod, Betschart and Harris, 1994).

In the late 1970's diabetes education programs were introduced to ensure that patients were provided with sufficient knowledge and understanding of their diabetes. Subsequently, this led to the development of questionnaires to assess diabetes knowledge, but the content of these scales was often inconsistent and their reliability and validity were not well established (Collier and Etzwiler, 1971). Since then researchers have attempted to measure the effectiveness of diabetes self-management education programs using more concise measures with better psychometric properties (Beeney, Dunn and Welch, 1994). Validation studies using these scales have produced contradictory findings. For example, age has been positively (Maxwell, Hunt and Bush, 1992) and negatively (Dunn, Bryson, Hoskins, Alford, Handelsman and Turtle, 1984) correlated with diabetes knowledge, and significantly higher scores were observed in patients with lower socio-economic status ($r = -.33$) (Beeney et al., 1994). As expected, diabetes knowledge scores have been associated with a tendency to read more articles about diabetes ($r = .52$), more frequent exercise ($r = 0.48$) (Beeney et al., 1994), and better adherence ($r = .28$) (Hanson, Henggeler and Burghen, 1987).

Although studies have identified improvements in diabetes knowledge following diabetes education programmes (Wise, Dowlatshahi, Farrant, Fromson and Meadows, 1986; Beeney and Dunn, 1990), there is little evidence to suggest that diabetes knowledge is directly related to improvements in glycaemic control (Dunn, Beeney, Hoskins and Turtle, 1990; Hanson et al., 1987); rather a person's level of understanding of their diabetes appears to be linked to an increase in diabetes health-specific behaviours, a decreased sense of burden, and positive quality of life outcomes (Watkins, Connell, Fitzgerald, Klem, Hickey and Ingersoll-Dayton, 2000).

However, a study of individual differences in multiple dimensional aspects of diabetes knowledge has shown a relationship between glycaemic control and a particular component of diabetes knowledge which has been attributed to a lack of general background knowledge provided by a formal education. This factor appeared to be distinct from the more specific knowledge of diabetes treatment and symptoms (Robinson, Al-Bustan, Bitar, Al-Asousi and Majeed, 1997). The implication of these findings is that the relationship between diabetes knowledge and glycaemic control may be explained, in part, by individual differences in cognitive ability. Further support for this claim is provided by a study of children with Type 1 diabetes which demonstrated that the mother's score on a test of psychometric intelligence was significantly correlated with the child's quality of glycaemic control (Ross, Frier, Kelnar and Deary, 2001). Following the results of these studies the relationship between diabetes knowledge and glycaemic control warrants further investigation.

Diabetes knowledge is an important outcome of diabetes self-management. However, research into the relationships between social and psychological factors and diabetes knowledge are not well established, and there is a lack of theoretical frameworks in health psychology into which the diabetes knowledge construct can be incorporated. Recent research into the determinants of individual differences in knowledge in areas other than health have been investigated using the theory of adult intellectual development (Ackerman, 2000; Ackerman and Rolfhus, 1999). This model is called the Intelligence-as-Process, Personality, Interests, and Intelligence-as-Knowledge (PPIK) (Ackerman, 1996). The PPIK is an investment theory, with the underlying assumption that an individual chooses to invest their cognitive resources to acquire knowledge about the world. The intensity of this investment is controlled by other aspects of the individual such as their personality traits, interests and abilities. The PPIK model has useful applications in health psychology because the broader construct of intelligence-as-knowledge expands the traditional theory of fluid and crystallised intelligence (Horn and Cattell, 1966) by taking into account a person's normal experiences of adult life including school, jobs, family life, and hobbies, as well as academic knowledge. Prior research using this model holds promise for future investigations. For example, it has already been demonstrated that gender, age, personality, interests and abilities are important determinants of knowledge in general (Ackerman, 2000; Ackerman and Rolfhus, 1999). It is hypothesised here that some of these factors may also be important determinants of more specific health-related knowledge. Identifying the determinants of health knowledge in adults with Type 1 diabetes is an important step towards the development of future recommendations aimed at increasing the information and support provided to vulnerable groups of patients.

Diabetes Quality of life, treatment satisfaction and well-being

The assessment of how well an individual is doing with their diabetes is reflected by a number of psychological and behavioural factors as well as metabolic control (Glasgow, Fisher, Anderson, LaGreca, Marrero, Johnson, Rubin and Cox, 1999). In order to provide a level of supportive care which promotes well-being, while attempting to minimise the risk of complications, diabetes care teams must ensure that the educational, social and psychological needs of the individual are addressed (Glasgow, Ruggiero, Eakin, Dryfoos and Chobanian, 1997). For example, having a comprehensive personal knowledge of diabetes is often associated with an improvement in self-regulatory behaviour (Jacobson, 1996; Rubin, Peyrot and Saudek, 1991; Robinson, Al-Bustan, Bitar, Al-Asousi and Majeed, 1997; Hanson, Henggeler and Burghen, 1987; Glasgow, 1994) and reduced admission to hospital for diabetes-related problems (Clement, 1995), but may not be as successful in producing important lifestyle changes which are associated with the person's quality of life and well-being (Rubin, Peyrot and Saudek, 1991).

Until recently generic measures such as the Sickness and Impact Profile and the Medical Outcome Survey have been widely used (Littlefield, Rodin, Murray and Craven, 1990; Stewart, Greenfield, Hays, Wells, Rogers, Berry, McGlynn and Ware, 1989) to assess a person's psychosocial functioning and well-being. These global measures of health-related quality of life and well-being have often been used because they allow for easy comparison of the impact of treatment and health-related outcomes across different disease groups. This is useful when making decisions about the effectiveness of health care programmes within different health care settings (Kaplan and Bush, 1982). However, these measures may not be sensitive to the effects of particular treatments especially diabetes treatment where the therapy requires extensive self-management and inevitably results in a change in lifestyle.

Studies that have compared generic and disease-specific measures have produced evidence to suggest that there may be some clinical value in the use of generic measures to assess the patient's experience of living with diabetes (Anderson, Fitzgerald, Wisdom, Davis and Hiss, 1997), quality of life related to non-diabetic factors such as marital status and social relationships (Parkerson, Connis, Broadhead, Patrick, Taylor and Tse, 1993), and functional health status (Jacobson, de Groot and

Samson, 1994). Generic scales may, however, be less effective in measuring the impact of acute complications associated with diabetes, or a person's response to the demands of a complex regimen (Anderson et al., 1997). Therefore, disease-specific measures may be more appropriate in clinical trials in which specific interventions are being monitored (DCCT, 1988; 1996). Perhaps the optimal situation for future behavioural assessments of people with diabetes is to use a combination of disease-specific and generic measures of quality of life and well-being, but to date there is a shortage of psychometrically valid instruments available to measure a person's diabetes-specific outcomes.

In recent years psychometric instruments with better psychometric properties have been developed. For example, the Diabetes Quality of Life (DQOL) measure was originally developed to evaluate the burden of an intensive diabetes treatment regimen (Jacobson and DCCT Research Group, 1994), and covers issues relevant to diabetes and its treatment including satisfaction with diabetes-related quality of life, the impact of diabetes, and worry about the future effects of diabetes and social or vocational issues (DCCT, 1988). In addition, there is also an overall well-being item. Following the development of the Diabetes Quality of Life scale reliability testing revealed that the scale had high test re-test correlations in the .78 to .92 range based on re-test scores after approximately one week (DCCT, 1988). Validation studies of the scale led the authors to conclude that the scale is valid and sensitive to the effects of changes in treatment (Selam, Micossi, Dunn, and Nathan, 1992), and improvements in quality of life following pancreatic transplantation (Nathan, Fogel, Norman, Russell, Tolkoff-Rubin, Delmonico, Auchinloss, Camuso and Cosimi, 1991). Further testing indicated that increasing severity of diabetes and the number of complications a person had were associated with lower satisfaction and greater impact of diabetes. However, the worry scale was less related to complications (Jacobson, de Groot and Samson, 1994). These results have since been replicated in patients taking part in the Epidemiology of Diabetes Complications Study (EDC) (Lloyd, Matthews, Wing and Orchard, 1991). The findings of this study suggested that patients with macrovascular disease or nephropathy reported significantly poorer quality of life and well-being compared to those free of complications (Lloyd et al., 1991).

Further scales are now available to assess a person's satisfaction with their diabetes treatment regimen (Bradley, 1994; Lewis, Bradley, Knight, Boulton, and Ward, 1988) and well-being (Bradley, 1994). The Diabetes Treatment Satisfaction (DTSQ) scale was developed to assess satisfaction with changes in treatment regimens and comparison of satisfaction levels across different treatments (Bradley, 1994). To date these scales have often been used to evaluate the effects of new methods of insulin delivery such as subcutaneous insulin infusion (Bradley, Meadows, and Snowden, 1992, cited in Bradley, 1994; Jennings, Lewis, Murdoch, Talbot, Bradley and Ward, 1991) insulin for patients with table-treated diabetes (Bradley and Lewis, 1990), and the effects of education programmes (Lewis, 1994, cited in Bradley, 1994). However, as acknowledged by Bradley (1994), future studies should attempt to interpret scores on the DTSQ in light of other important outcomes measures such as metabolic control and well-being. Validation studies of the DTSQ indicate that the scale is highly reliable, valid, and adaptable to people undergoing a variety of treatment regimens (Bradley, 1994).

Whilst we know that factors such as diabetes quality of life, satisfaction with treatment, and well-being are important outcomes of diabetes self-management (Glasgow, Ruggiero, Eakin, Dryfoos and Chobanian, 1997; Petterson, Lee, Hollis, Young, Newton and Dornan, 1998; Leplege and Hunt, 1997; Lewis, Bradley, Knight, Boulton and Ward, 1988; Jacobson, de Groot and Samson, 1994; DCCT Research Group, 1988; Watkins, Connell, Fitzgerald, Klem, Hickey and Ingersoll-Dayton, 2000) the psychological and social correlates of these measures have seldom been reported, nor how these affect an individual's ability to cope with diabetes. A recent investigation represents one of the first attempts to examine the physical, psychological and social determinants of quality of life (Rose, Burkert, Scholler, Schirop, Danzer and Klapp, 1998). The results of this study revealed that social support had an independent influence on global quality of life and served as a buffer to negative emotions. Following from these findings the authors presented a conceptual interactive model based on the covariation observed between an individual's physical condition, psychological state, level of independence and social support, and quality of life (Figure 1.3). In this model secondary illnesses had a causal effect on a patient's emotional well-being and daily functioning, and social support was an independent predictor of global quality of life.

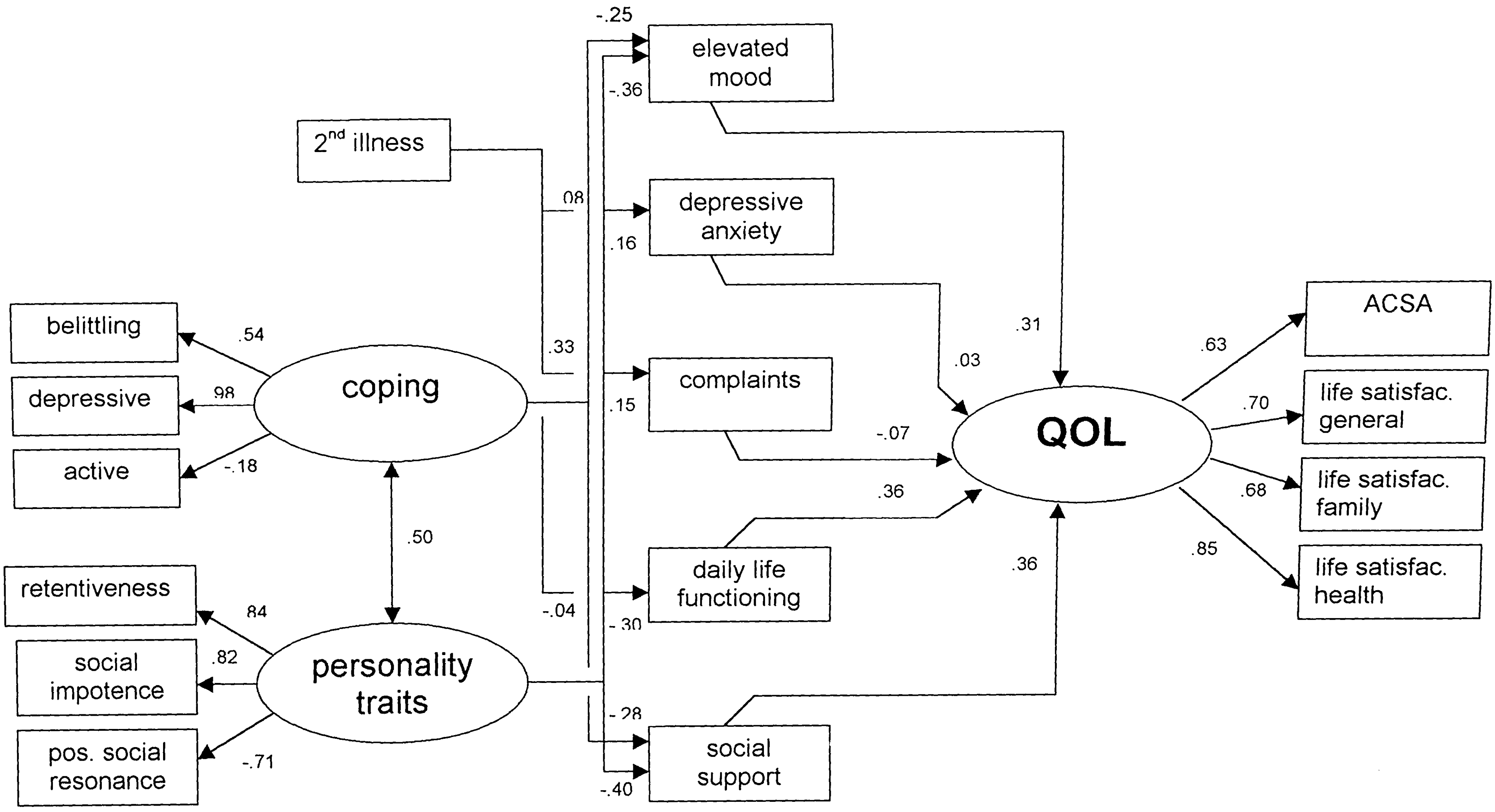


Figure 1.3: An interactive model to show the relationships between coping and personality traits, and multidimensional aspects of quality of life. Figures represent squared regression coefficients.
Adapted from Rose et al. (1998) (p.1883)

On the basis of their results Rose et al. (1998), concluded that socially less competent and emotionally reserved patients cope less well with their diabetes and report more negative emotions, greater physical ailments and less social support. In contrast, those with more active coping strategies report better scores on all dimensions of quality of life, irrespective of physical health. According to some researchers quality of life should be regarded as a feedback loop where more active coping leads to improved quality of life, hence greater therapy adherence and a more positive illness progression (Testa and Simonson, 1996). These findings highlight the need to pay more attention to the role of personality and coping variables when assessing quality of life and well-being.

In general, the determinants of diabetes-related quality of life, treatment satisfaction and well-being are not well established. Furthermore most of the relationships between psychosocial factors and self-reported outcomes of diabetes which have been documented have not been replicated. Research to date suggests it is important for researchers to concentrate on both subjective and objective indicators of health and well-being rather than merely concentrating on a patient's metabolic control. Indeed it has been suggested that HbA_{1c} is not associated with quality of life or any other psychosocial variables in adolescents with type I diabetes (Grey, Boland, Yu, Sullivan-Bolyai and Tamborlane, 1988). In designing future studies investigators should pay more attention to the social, physical and psychological functioning of individuals and attempt to identify the direct determinants of subjective treatment-related and quality of life outcomes, while providing further validation for diabetes-specific measures of these constructs.

PART I (continued)

CHAPTER 3

The Way Forward

Over recent years behavioural research in diabetes has grown progressively more sophisticated and has provided some insight into the relationships between behavioural and psychological antecedents of disease, and health-related outcomes. However, many studies to date have been based on children and adolescents with diabetes rather than adults (Kovacs, Brent, Steinberg, Paulauskas and Reid, 1986; Hanson, Harris, Relyea, Cigrang, Carle and Burghen, 1989) and have often been small cross-sectional studies which tell us little about changes in the patient's psychological profile over time. How well an individual copes with their diabetes following diagnosis is likely to be predicted by a number of psychosocial factors, and coping styles have been suggested as mediating variables between antecedents to disease (e.g. personality traits) and diabetes-related outcomes (Lazarus and Folkman, 1984, 1987). Future research now needs to introduce more prospective designs to examine the coping process, and to concentrate on a wider range of educational, behavioural and psychosocial variables, as well as glycaemic control, including quality of life, diabetes knowledge, and treatment satisfaction.

To date there have been few prospective studies which have attempted to address predictive factors for good glycaemic control in adults with Type 1 diabetes. Following the results of the DCCT (1993) it is important for health professionals to work together with the patient to help optimise glycaemic control. The present investigation aims to identify the psychological and social factors that determine which patients will respond well to diabetes education and to identify those patients who appear vulnerable to being poorly controlled which may allow 'targeting' of such patients from the time of diagnosis.

Past research has often focused on metabolic control because good control is the primary aim of insulin therapy. However, many attempts to predict glycaemic control have been unsuccessful and the few associations that have been found have been difficult to replicate. Previous literature indicates that psychosocial behaviours have an influence on patient's self-care (Glasgow and McCaul, 1982) and that adherence may have an indirect influence on control (Hanson, Henggeler and Burghen, 1987). The relationship between adherence and glycaemic control therefore warrants further investigation.

According to the stress and coping model of illness reporting proposed by Lazarus and Folkman (1984, 1987) physical and psychological (e.g. personality traits) stressors are assumed to act via mediating variables to produce health-related outcomes. Using the stress and coping model (Figure 1.2) as a hypothetical framework, one of the objectives of the present thesis is to explore the role of illness-related coping (Endler, Parker and Summerfeldt, 1998) in adults with Type 1 diabetes to (i) examine the influence of individual differences in psychological and social factors recorded shortly after diagnosis on illness-related coping outcomes over time, and (ii) investigate, prospectively, the influence of illness-related coping strategies on objective (e.g. HbA_{1c}) and subjective (e.g. quality of life) indicators of diabetes-related outcomes.

One of the problems facing researchers is that there is an absence of well-validated psychometric instruments available to measure diabetes-specific outcomes. Many of the scales which do exist are relatively new and have not yet reached statistical sophistication. Research should now focus on developing and standardising new diabetes-specific instruments which are capable of capturing how individuals with Type 1 diabetes cope with the burden of diabetes and its effects on their daily life and well-being. One of the objectives of the present research is to evaluate coping with diabetes from the patient's perspective in order to derive those aspects of coping which are important to the individuals themselves. This may allow for the eventual development of more precise and valid estimates of coping in people with Type 1 diabetes in the future.

In summary, the overall objectives of this thesis are: i) to contribute to existing research into the complex relationships between psychosocial factors and diabetes-related outcomes following initial diagnosis of Type 1 diabetes, ii) to enhance current understanding of the role of coping, and the ways in which particular strategies relate to objective and subjective indicators of physical and psychological well-being in Type 1 diabetes across time, and finally, iii) to work towards providing a more sensitive, disease-specific measure of coping which can be used to assess the psychological impact of diabetes and adjustment-related coping strategies in adults with Type 1 diabetes.

PART II: The Edinburgh Prospective Diabetes Study

CHAPTER 1

Research Design and Methodology

Introduction

The development of Type 1 diabetes has a profound impact on many aspects of everyday life. How individuals cope with managing this disorder poses a question which may refer to a combination of at least four different outcomes. Optimal coping ability may mean (i) achieving good metabolic control, (ii) having a comprehensive knowledge of the disorder, (iii) being satisfied with treatment, and (iv) having a good self-reported quality of life. Once such outcomes have been defined the issue arises of whether individual differences in these outcomes can be predicted by socio-psychological factors or by some other aspect of the individual. This may influence the type of education and supportive care that can be offered to newly diagnosed patients.

To date few prospective studies have addressed predictive factors for the achievement of good control of diabetes in an adult sample. Although the large prospective Diabetes Control and Complications Trial (DCCT, 1993) has demonstrated the importance of glycaemic control in minimising the risk of development and progression of diabetic complications, the majority of small cross-sectional studies have failed to elucidate the determinants of glycaemic control and have often provided contradictory findings. In particular, correlations observed between HbA_{1c} and extraversion (Bradley and Cox, 1978; Lane, Stabler, Ross, Morris, Litton and Surwit, 1988) were not replicated in subsequent research (Hepburn, Langan, Deary, MacLeod and Frier, 1994), and the relationship between neuroticism and glycated haemoglobin has also been disputed (Hepburn et al., 1994; Fonagy, Moran, Lindsay, Kurtz and Brown, 1987; Lloyd, Matthews, Wing and Orchard; 1991; Gordon, Fisher, Wilson, Fergus, Paterson and

Semple, 1993; Deary, Strickland, Frier and Gold, 1998). Similar disagreement surrounds the claim that the psychiatric well-being of patients may be linked to HbA_{1c}, and that patients who have poor glycaemic control are more likely to have a history of a psychiatric illness (Lustman, Griffith, Clouse and Cryer, 1986). However, evidence to the contrary was demonstrated in children where psychiatric disturbances were found to correlate with good glycaemic control (Fonagy et al., 1987). Such discrepancies highlight the need to determine the psychological factors which are associated with quality of glycaemic control at different stages of the disorder. This can be achieved by serial assessment of individual differences in the methods by which people cope with diabetes over time.

How well an individual is adjusting to diabetes may be reflected by long term psychological and behavioural factors as well as by quality of glycaemic control (Glasgow, Fisher, Anderson, La Greca. Marrero, Johnson, Rubin and Cox, 1999; Hampson, Glasgow and Strycker, 2000). Individual differences in a person's psychological responses are often apparent soon after initial diagnosis (Kovacs, Brent, Steinberg, Paulauskas and Reid, 1986) when many people experience a series of "predictable crises" (Hamburg and Inoff, 1983) and a sense of loss or bereavement which may constitute measurable stages of psychological adjustment (Kubler-Ross, 1969). This is supported by a prospective study of children which identified a critical period two years after diagnosis and may represent a risk phase in some patients (Grey, Lipman, Cameron and Thurber, 1995). More attention is therefore required to assess the social and psychological consequences of the disease in individual patients. However, it is only recently that psychosocial factors such as aspects of diabetes-related quality of life and treatment satisfaction have become recognised as outcomes of diabetes self-management in their own right (Glasgow, Ruggiero, Eakin, Dryfoos and Chobanian, 1997; Guttman-Bauman, Flaherty, Strugger and McEvoy, 1998; Glasgow et al., 1999; Petterson, Lee, Hollis, Young, Newton and Dornan, 1998). While it has been established that the number of diabetes complications developed by an individual and the severity of the disorder are associated with quality of life (Jacobson, de Groot and Samson, 1994; DCCT, 1988; Stewart, Greenfield, Hays, Wells, Rogers, Berry, McGlynn and Ware, 1989; Glasgow et al., 1997), social and environmental correlates of quality of life have seldom been reported, nor how these affect an individual's ability to cope with diabetes.

In order to provide a level of education and supportive care which promotes well-being, while attempting to minimise the risk of complications, diabetes care teams must ensure that the educational, social and psychological needs of the individual are addressed (Jacobson, 1996). Having a comprehensive personal knowledge of diabetes is associated with an improvement in self-regulatory behaviour (Rubin, Peyrot and Saudek, 1991; Robinson, Al-Bustan, Bitar, Al-Asousi and Majeed, 1997; Hanson, Henggeler and Burghen, 1987) and reduced admission to hospital for diabetes-related problems (Clement, 1995) but may not be as successful in producing important lifestyle changes which are associated with the person's quality of life (Rubin et al., 1991). Studies now need to determine the predictors that identify which individuals will benefit from educational programs and focus on developing strategies which help people to overcome the social and psychological 'barriers' to adherence (Glasgow, 1994).

To answer the question of who copes well and who does not following the development of Type 1 diabetes, more insight is required into the risk factors for poor adjustment in individual patients. To date no prospective studies have characterised predictive factors for good glycaemic control in adults with Type 1 diabetes, nor have they examined the coping process in this life-long chronic disorder. The few studies that have examined psychological adjustment have concentrated principally on children and adolescents with diabetes (e.g. Kovacs et al., 1986; Grey et al., 1995) and have often been small cross-sectional studies. The Edinburgh Prospective Diabetes Study (EPDS) is a medium-sized prospective study established to surmount these problems by focusing on the relationships between a wider range of psychosocial variables and diabetes-related outcomes in a cohort of adults with Type 1 diabetes, and to examine how these variables change over time. The early identification of those individuals who are at risk of poor glycaemic control, or psychological well-being, may enable such patients to receive particular support from the onset of treatment.

The EPDS was developed in 1995, and was originally designed by Dr. Ann Gold and Professor Ian Deary. Further input was obtained from colleagues and staff working within the diabetic outpatient clinic at The Royal Infirmary of Edinburgh. The third year follow-up stage of the study is now complete and a five year follow-up is already underway. Whilst I was not involved in the design stages of the EPDS, I have been responsible for the smooth running and progression of this study since October 1998 when I was given the opportunity to become involved in this research. This includes model conception and the incorporation of a coping perspective, the design of the third wave of the study, and the design and execution of the statistical analysis. Other activities involved in the day to day management of the study included: keeping track of the participants in the study and following them up at each periodic review, either by sending a questionnaire by post, or when they attended the diabetic outpatient clinic for their routine appointment, scoring and filing the returned questionnaires and entering the data into a computerised database, maintaining the database and checking for errors, following up patients who either did not attend the clinic or return the questionnaire within six weeks, by telephone, and if necessary sending out a second questionnaire, writing drafts of manuscripts intended for publication, and doing oral presentations at large British and European conferences.

Aims and objectives

The Edinburgh Prospective Diabetes Study was designed to monitor the progress of a cohort of adults following initial diagnosis of Type 1 diabetes. The aims of the study are as follows:

i) To examine how biochemical, social and psychological aspects of the person change following initial diagnosis and to monitor prospectively the stability of individual differences in these diabetes-related factors from the time of diagnosis of Type 1 diabetes.

ii) To measure prospectively, in adults, from the time of diagnosis of Type 1 diabetes, the relationships between psychosocial predictors and diabetes-related outcome variables which include glycaemic control (HbA_{1c}), diabetes knowledge, satisfaction with diabetes treatment, and diabetes quality of life.

iii) To date there have been few prospective studies which have attempted to address predictive factors for good control in adults with Type 1 diabetes. Following the results of the DCCT (1993) it is the responsibility of diabetes specialist care workers to optimise glycaemic control. The present investigation aims to identify the psychological and social factors that determine which patients will respond well to diabetes education and to identify those patients who appear vulnerable to being poorly controlled which may allow 'targeting' of such patients from the time of diagnosis.

(iv) It has been acknowledge that 'doing well' represents more than metabolic control and an absence of complications (Glasgow et al., 1999). Therefore the EPDS aims to concentrate on the behavioural and social functioning of the individual as independent outcomes in an effort to provide a broader definition of what it means to cope well with diabetes following initial diagnosis.

Ethical permission

Permission for the study was granted by the Lothian Health Board Ethics of Medical Research Subcommittee for Medicine and Clinical Oncology.

Recruitment

All patients with newly diagnosed Type 1 diabetes aged 16 years or above presenting to the Department of Diabetes at the Royal Infirmary of Edinburgh between June 1995 and October 1998 were invited to participate. The patients were given an information sheet explaining the nature of the study, and written consent was obtained if they agreed to participate. Of the 93 patients approached, 84 (48 men, 36 women) took part - a 93% recruitment rate making the final sample a relatively unselected cohort. Reasons for not taking part included being too busy at work or transfer to a different clinic or centre for treatment. One patient did not want their General Practitioner to know about the study and another died shortly after initial diagnosis. Two patients agreed to take part initially but failed to return the questionnaires. Two patients declined without reason.

Patient characteristics

The social and educational characteristics of the sample are shown in Table 2.1. All of the participants were native English speakers. The median (range) age of the patients at diagnosis was 30.8 (17 - 51) years and the number of years spent in education was 12 (10 - 24) years. At the time of diagnosis occupational details were obtained for 82 of the 84 respondents. Of these 24 (28.6%) patients were defined as professionals (high and low grade professionals and self-employed), 39 (47.3%) as non-manual employees (routine non-manual employees in administration and commerce, service workers, small proprietors, farmers and low grade technicians), 14 (16.7%) as being manual workers (skilled and semi-skilled manual workers and agricultural workers) and 5 (6.0%) participants were currently unemployed (Goldthorpe, 1987).

The majority of respondents (n = 45, 53.6%) were single, 35 (41.7%) were married or engaged, and 4 (4.7%) were divorced or separated from their spouse. Of the total sample 22 (26.2%) people reported having a first degree relative with diabetes who was receiving insulin therapy. Alcohol and tobacco consumption were documented. The median (range) number of units of alcohol consumed per week was 8 (0 - 70). A large percentage (45.2%) of the sample were current smokers, 16.7% were ex-smokers and 36.9% had never smoked.

Table 2.1: Socio-demographic details of the sample recorded shortly after diagnosis.

	N	%	Median	Range
Age (yrs)	84		29	17 - 51
Gender				
male	48	57.1		
female	36	42.9		
Educational background (yrs)	80		12	10 - 24
Marital status				
single	45	53.6		
married/cohabiting	30	35.7		
divorced/separated	9	10.8		
widowed	0	0		
Occupational details				
professionals	24	28.6		
non-manual employees	39	47.3		
manual employees	14	16.7		
unemployed	5	6.0		
missing values	2	2.4		
Living arrangements				
spouse/partner	27	32.1		
parents	16	19.0		
alone	13	15.5		
other (e.g. flatmates)	28	33.3		
Family history of diabetes	22	26.2		
Co-morbid problems	9	11.0		
Number of patients admitted to hospital at diagnosis	18	21.4		
Body Mass Index (kg/m^2)	74		22	18 - 49
Glycated Haemoglobin (HbA$_{1c}$)	69		11.3	6.5 - 16.8
Alcohol (units per week)	82		8	0 - 70
Tobacco usage				
- never	31	36.9		
- ex-smoker	14	16.7		
- current smoker	38	45.2		
- *missing values*	1	1.2		
Exercise (times per week)	84		1	0 - 7
Happiness	84		8	2 - 10

At the time of diagnosis 18 (21.4%) patients were admitted to hospital and 66 (78.6%) were treated as outpatients. The departmental policy is generally not to admit patients to hospital unless they have evidence of significant metabolic decompensation. Nine of the participants had additional co-morbid problems which included Graves disease, asthma, psoriasis, peptic ulcer disease, allergies (e.g. Hayfever), and hypertension.

Procedure

Each participant was asked to complete a series of self-administered questionnaires shortly after diagnosis. All of the questionnaires had been validated previously, with the exception of the Diabetes Knowledge Questionnaire (DKNQ) which was designed specifically for this study. The questionnaires were presented at intervals so as not to overload the patients at what was potentially a time of stress. The initial scales were presented at diagnosis and further questionnaires were administered at subsequent visits to the clinic at three to six weeks and four months after diagnosis, and at annual reviews thereafter. The questionnaires were completed either in the outpatient clinic or at home and returned by post. Where a questionnaire was not returned within six weeks the individual was contacted by telephone and sent another questionnaire. Body mass index and glycated haemoglobin were measured at each clinic visit. The questionnaires presented at each periodic review (at diagnosis, three to six weeks, four months, 12 months, 24 months and 36 months) are described below, and shown in Table 2.2.

Individual difference measures

The National Adult Reading Test (NART; Nelson and Wilson, 1991)

Cognitive ability was assessed at a routine clinic visit three to six weeks after diagnosis using the National Adult Reading Test (NART). The NART has been found to correlate closely with the Wechsler Adult Intelligence Scale-Revised (Crawford, Stewart, Cochrane, Parker and Besson, 1989), and is relatively resistant to the effects of organic brain damage (Nelson and Willison, 1991). The NART requires subjects to pronounce 50 irregular words and the number of correctly pronounced words is recorded.

Eysenck Personality Questionnaire - Revised Short Form (EPQ-R; Eysenck and Eysenck, 1975; Eysenck, Eysenck and Barrett, 1985)

Current theories suggest that the associations between personality and illness may represent associations between psychological factors and subjective health reports (Deary, Clyde and Frier, 1997). It has been widely established that neuroticism is a robust measure of illness reporting (Smith and Williams, 1992) and may form part of a broad dimension of negative affectivity (Watson and Pennebaker, 1989; Deary, Strickland, Frier and Gold, 1998). In the present study individual differences in personality were assessed using Eysenck's Personality Questionnaire (revised short form) to establish whether personality has a direct effect on objective diabetes-related outcomes or whether it is an indicator of more subjective negative health reports. The EPQ-R consists of 48 items and measures three personality dimensions; Extraversion (E) (sociability and optimism), Neuroticism (N) (negative emotions, anxiety and moodiness) and Psychoticism (P) (solitary, hostile and lacking empathy). In addition there is a Lie scale (L) which detects socially desirable responding patterns. Respondents are asked to circle 'yes' or 'no' for each item and responses for each dimension are scored out of a maximum of 12. A high score on a particular dimension indicates that the dimension is highly descriptive of the individual.

Conscientiousness (Goldberg, 1981)

The conscientiousness scale was adapted from Goldberg's adjective scales which measure the traits considered to be characteristic of normal personality. These include conscientiousness, openness, agreeableness, neuroticism and extraversion. The conscientiousness scale was adapted for use in this study because this characteristic may be important in predicting self-management behaviour. Individuals who obtain high scores on this scale are expected to be more conscientious with regard to monitoring their blood glucose levels and adhering to their regimen. The scale requires respondents to rate a list of adjectives on a 1-7 scale depending on how well they feel the adjective describes what they are really like. Low scores indicate low levels of conscientiousness.

Coping with Health Injuries and Problems scale (CHIP; Endler, 2000; Endler, Parker and Summerfeldt, 1998)

The Coping with Health Injuries and Problems scale (CHIP) assesses how individuals cope with illness and health problems in a general sense. There is some evidence to suggest that task oriented coping is associated with positive disease outcomes and emotion-oriented coping is associated with negative outcomes (Felton and Revenson, 1984; Smari and Valtydottir, 1997; Cox and Gonder-Frederick; 1992) but there have been few documented attempts to assess the role of coping prospectively in an adult sample. The EPDS explores the role of coping in diabetes prospectively following diagnosis of Type 1 diabetes, and also examines the psychological predictors of particular coping styles at follow-up. The scale contains 32 items which measure four dimensions of coping. These comprise of palliative coping which refers to self-help responses used to alleviate the unpleasantness of the illness, such as getting plenty of sleep and keeping warm and comfortable. Instrumental (or problem-focused) coping refers to task-oriented responses such as finding out more information about the illness and following professional advice. A further coping style assessed by the CHIP is Distraction which involves thinking about other activities such as the 'good times', making surroundings pleasant or enjoying the company of family and friends, and finally Negative-emotion coping which is characterised by worry, anxiety, and wishing that the problem had never happened. Individuals who use negative-emotion focused coping tend to become preoccupied with the emotional consequences of the illness. The CHIP requires individuals to give their typical reactions to illness in general and not just the current problem. Respondents circle a number from 1 to 5 for each item indicating how much they have engaged in these types of activities when they have encountered health problems. Responses range from 1 'not at all' to 3 'moderately' and 5 'very much'.

General Health Questionnaire (GHQ; Goldberg and Hillier, 1979)

The General Health Questionnaire (GHQ) is a generic measure that gives a good indication of a person's psychiatric morbidity during recent weeks. Previous studies have found evidence to suggest that an individual's psychiatric well-being is associated with glycaemic control (Lustman, Griffith, Clouse and Cryer, 1986). The scale contains 28 questions and the patients were instructed to answer all the questions by underlining one of four statements which most accurately described how their health had been in general over the preceding two weeks. High scores indicate increased levels of psychiatric distress.

Diabetes Locus of Control (DLOC; Peyrot and Rubin, 1994)

Diabetes-specific locus of control is an important psychological predictor of diabetes-related outcomes. It has been claimed that patients with a good external network achieve better control and that clinic-oriented control does not always achieve the best results (Peyrot and Rubin, 1994). These authors recently examined the structure and correlates of the DLOC scale. They found that the scales measuring internals and powerful others each contained two components which accounted for both negative and positive diabetes-related outcomes. Chance also appeared to be related to a variety of health-related problems. This scale was included in the EPDS in an effort to assess its predictive value in relation to diabetes outcomes and its stability over time. The DLOC contains eighteen items which address five subscales; Internal Autonomy (IA), Internal Blame (IB), Chance (C), External Health-Professionals (EHP) and External Non-Health Professionals (ENHP). Respondents are required to circle the number which corresponds to the way they feel about each item on a six point Likert scale, where 1 = 'strongly disagree' and 6 = 'strongly agree'. High scores indicate more agreement with the type of control orientation being measured.

'Happiness' visual analogue scale

The participants were asked to indicate on a visual analogue scale ranging from 1 to 10 how happy they were with their present life at home.

Diabetes-related outcome measures

Glycaemic Control

Glycated haemoglobin (HbA_{1c}) provides an estimate of a person's average blood glucose level over the past six to eight weeks. Glycated haemoglobin was measured in all patients at each clinic visit. The assay for HbA_{1c} used high performance liquid chromatography based on an ion-exchange, reverse-phase partition method for which the local non-diabetic range is 5.0 - 6.5%.

Diabetes Knowledge Questionnaire (DKNQ; Gold et al. 1995)

The Diabetes Knowledge Questionnaire (DKNQ) was developed specifically for use in this study. The scale contains 24 diabetes-related multiple choice questions which pay particular attention to diet (6 items), insulin therapy (7 items), knowledge of diabetes (7 items), and dealing with intercurrent illness (4 items). A mark is scored for each correct response and a total score is derived for analyses.

Diabetes Treatment Satisfaction Questionnaire (DTSQ; Lewis, Bradley, Knight, Boulton and Ward, 1988; Bradley, 1994)

The Diabetes Treatment Satisfaction Questionnaire (DTSQ) was designed specifically to measure a person's satisfaction with their diabetes treatment regimen (Lewis, Bradley, Knight, Boulton and Ward, 1988; Bradley, 1994). Scores on the DTSQ should also be considered in light of other outcomes such as metabolic control and quality of life. According to Bradley (1994) the ideal situation would be to have someone who is highly satisfied with their treatment, has a low HbA_{1c} and high levels of self-reported well-being. However, it is important to be aware of patients who are highly satisfied but have poor control or where metabolic control is achieved at the expense of satisfaction. The DTSQ has eight items which are rated on a seven point Likert scale, six of which (1 and 4 - 8) are summated to give an estimate of satisfaction with treatment. The scores range from 0 (very dissatisfied) to 36 (very satisfied). The remaining two items are treated individually. Item 2 gives an indication of Perceived Frequency of Hyperglycaemia and item 3 measures Perceived Frequency of Hypoglycaemia where scores range from 0 (none of the time) to 6 (most of the time).

Diabetes Quality of Life (DQOL; The Diabetes Control and Complications Research Group, 1988)

The Diabetes Quality of Life (DQOL) measure covers a range of issues directly relevant to diabetes and its treatment. It was developed for use in the Diabetes Control and Complications Trial (DCCT, 1998) to evaluate the burden of an intensive diabetes treatment regimen, and the patient's personal experience of diabetes care. This is a particularly useful scale in the present study because it is concerned with diabetes-specific outcomes and provides a reliable indicator of the overall effects of diabetes treatment on an individual's daily functioning. The DQOL is composed of a Diabetes Life Satisfaction scale containing 15 items, where high scores indicate more satisfaction, Impact of Diabetes scale, containing 20 items, and a Diabetes Worry scale of 11 items, which addresses issues related to the future effects of diabetes and social issues. High scores on the Impact and Worry subscales represent negative ratings. A formula is used to convert raw scores to a 100 point scale (IRC, 1991). In addition, an individual item of general health-related well-being is included where respondents are asked to rate their perceived health status on a four point scale from 1 (excellent) to 4 (poor).

Table 2.2: Summary of the information collected at each review

	Diagnosis	3-6 weeks	4 months	12 months	24 months	36 months
Individual Difference Measures						
National Adult Reading Test		54 (64)				
Body Mass Index (kg/m^2)	77 (92)		56 (67)	55 (65)	38 (45)	24 (29)
Exercise pattern	84 (100)		66 (79)	63 (75)	51 (61)	39 (46)
Eysenck's Personality Questionnaire	80 (95)					39 (46)
Conscientiousness scale	78 (93)					
General Health Questionnaire		66 (79)	67 (80)	65 (77)	56 (67)	41 (49)
Diabetes Locus of Control		69 (82)	68 (81)	64 (76)	55 (66)	41 (49)
"Happiness" visual analogue scale	84 (100)		66 (79)	63 (75)	53 (63)	39 (46)
Coping with Health Injuries and Problems	77 (92)			64 (76)	56 (67)	41 (49)
Diabetes-Related Outcome Measures						
Glycated Haemoglobin (HbA$_{1c}$)	72 (86)		74 (88)	66 (79)	52 (62)	39 (46)
Diabetes Knowledge Questionnaire			69 (82)	66 (79)	56 (67)	40 (48)
Diabetes Treatment Satisfaction			69 (82)	65 (77)	55 (66)	41 (49)
Diabetes Quality of Life		70 (83)	69 (82)	65 (77)	55 (66)	41 (49)
Additional Outcomes (at 36 months)						
Hypoglycaemic Fear Survey						41 (49)
Summary of Self-Care Activities						39 (46)
The Well-being Questionnaire						41 (49)
Total number of responses (%)	84 (100)	72 (86)	69 (82)	66 (79)	56 (67)	41 (49)

Figures indicate the number of original participants (%) who completed the measure

Additional diabetes-related outcomes at 36 months after diagnosis

The Well-being Questionnaire (Bradley, 1994)

The Well-being Questionnaire was originally designed to measure depressed mood, anxiety and aspects of positive well-being in a study evaluating new treatments for the management of diabetes (WHO, 1982, cited in Bradley, 1994). The scale is thought to be particularly sensitive to cognitive symptoms and to avoid where possible somatic symptoms associated with the disease, or situational factors (e.g. weight loss) which may be common in poorly controlled diabetes (Bradley, 1994). In the present study the WHO is being used to assess psychological outcomes while avoiding confusing them with symptoms of diabetes or quality of glycaemic control. The WHO contains twenty-two items which address four subscales labeled as Depression (six items), Anxiety (six items), Positive well-being (six items) and Energy (four items). Each item is scored on a 0 to 3 Likert scale ranging from 0 which indicates that the respondent felt that the item applied to them 'not at all' over the past few weeks and 3 indicating that it applied 'all the time'. Complete ratings for each subscale are summed after reverse scoring where necessary. A high score on each subscale indicates more of the mood described. A general well-being total score can be obtained by summing the scores from each subscale after reversing the scores of the Anxiety and Depression subscales.

Summary of Self-Care Activities Questionnaire (SSCAQ; Toobert and Glasgow, 1994)

Diabetes self-management is important because adoption of a healthy lifestyle is assumed to produce better control which leads to a reduced risk of complications (Toobert and Glasgow, 1994). However, until recently there was an absence of reliable and valid measures to assess self-care behaviours in individuals with diabetes. Those measures which do exist are based on self-reports which may not always provide truthful reflections of regimen adherence (Hepburn, Deary, MacLeod and Frier, 1994). Despite the efforts of recent investigations the adherence-control relationship has not been well established, and it may be wrong to assume that good control is a direct result of good self-management and vice versa. The present study aims to further investigate adherence behaviours in the context of factors which may influence control rather than assuming that a one to one relationship exists. The Summary of Self-Care Activities Questionnaire (SSCAQ) is a self-report measure of the frequency with which individuals have completed different regimen activities over the preceding seven days. These activities include diet, exercise, glucose monitoring and diabetes medication taking. The SSCAQ was constructed to assess absolute levels of self-care behaviour as well as an individual's perceived adherence to their individual prescriptions. The scale consists of twelve items and respondents are instructed to answer the questions as honestly and accurately as possible. The first five items relate to levels of diet self-care and adherence. The first two items are referred to as diet amount items (adherence) and require subjects to indicate the amount of time they successfully adhered to their regimen on a five point scale. The following three items are referred to as diet type items (absolute) and are concerned with the percentage of meals which included high fibre foods, high fat foods, sweets and desserts. These items are also assessed on a five point scale. Items 6 to 8 assess how often and the amount of time individuals spent exercising in the past week (absolute activity levels) and how much the individual adhered to their prescribed exercise regimen (adherence). The final two sections of the questionnaire relate to glucose testing and medication taking to control diabetes. Glucose testing is assessed by two items, one which assesses the absolute number of tests taken and a second item which records the percentage of activities recommended by the doctor which were actually performed. Diabetes medication taking also contains two items, individuals are asked to indicate the number of insulin injections and pills they took which were recommended over the last seven days. Scores for each regimen behaviour are calculated by giving items with different scales equal weighting. These scores are then transformed into percentage scores for analysis.

Hypoglycaemic Fear Survey (HFS; Cox, Irvine, Gonder-Frederick, Nowacek, and Butterfield, 1987; Irvine, Cox and Gonder-Frederick, 1994)

Hypoglycaemia is one of the most common causes of fear in patients with Type 1 diabetes and represents a constant threat in their daily lives. The consequences of hypoglycaemia are often aversive and can be life threatening providing ample reason for many patients to fear and avoid episodes. Symptoms vary between individual patients but can include; dizziness, sweating, trembling and confused thinking, and in more serious cases convulsions, unconsciousness and rarely, death can occur. The Hypoglycaemic Fear Survey (HFS) was developed to measure the degree of fear experienced with respect to a variety of aspects of hypoglycaemia, in particular, behavioural reactions to hypoglycaemia and an exploration of the events that precipitate fear. The HFS contains 23 items which are split into two sections labeled Behaviour and Worry. The Behaviour sections instructs respondents to circle the number next to each item that best describes what they do during their daily routine to avoid low blood sugar e.g. 'Eating large snacks at bedtime' or 'Avoid exercise when I think my blood sugar is low'. The Worry section provides a list of concerns which people with diabetes may have. Patients are required to circle the number that best describes how often they worry about each item because of low blood sugar e.g. 'Passing out in public' or 'Appearing stupid or drunk'. For both scales responses are given on a five point Likert scale ranging from Never (0) to Always (4).

Statistical analysis

Statistical analysis was carried out using the Statistical Package for the Social Sciences (SPSS) version 10.0 for Windows. Test re-test reliabilities of the diabetes-related outcomes were examined using Pearson product moment correlation coefficients. The internal consistency of the Diabetes Knowledge Questionnaire was assessed by Cronbach's alpha computed at the four month assessment. Independent samples t-tests and analysis of variance were used to investigate the effect of socio-demographic factors on diabetes-related outcomes across time. Paired samples t-tests and analysis of variance were used to assess changes within individuals across time. The Scheffe test (a conservative post hoc test) was used where multiple comparisons were employed. Univariate associations among psychosocial variables and diabetes-related outcomes recorded at each annual review were examined using Pearson's and, where appropriate, Spearman's correlation coefficients. Multiple (stepwise) regression was used to ascertain which variables contributed significant, independent amounts of variance to self-reports and diabetes-related outcomes. With an n of 66 (the number of subjects at 12 months after diagnosis) there is 82% power to detect an $r = 0.35$ (αlpha = .05, 2 tailed). In linear multiple regression analysis there is 80% power to detect a squared multiple correlation of 0.15 with three covariates (alpha = .05, 2 tailed).

PART II (continued): The Edinburgh Prospective Diabetes Study

CHAPTER 2

Psychosocial Predictors of Glycaemic Control, Diabetes Knowledge, and Subjective Well-being in Adults Following Initial Diagnosis of Type 1 Diabetes

The EPDS is the first study to monitor, prospectively, the relationships between psychosocial variables and diabetes-related outcomes in adults from the time of initial diagnosis of Type 1 diabetes. Previous literature reviewed in the introduction suggests that the factors that determine who copes well with Type 1 diabetes are likely to be multiple and may include personality traits, cognitive ability, coping styles, locus of control, as well as a person's social and work environment. With this in mind, the present study aims to examine the natural history of diabetes, from the time of diagnosis, in a relatively unselected sample of adults. In order to ensure that the multiple determinants of coping in diabetes were addressed a diverse range of psychological and social variables were incorporated into the study. However, due to the large number of variables it is acknowledged that type 1 errors are likely to occur. Therefore the preliminary results of the study presented here will need to be replicated, and future follow-ups of longer duration will be necessary.

In this chapter the results from the first 36 months of prospective assessment of the participants in the Edinburgh Prospective Diabetes Study (EPDS) are presented. The aims are as follows:

(i) To assess the stability of individual differences and detect changes in psychosocial variables and diabetes-related outcomes over time.

(ii) To examine the relationships between psychosocial factors recorded shortly after diagnosis, and diabetes-related outcomes recorded at four months, 12months, 24 months and 36 months after diagnosis.

(iii) To identify the independent predictors of subjective (e.g. quality of life) and objective (e.g. HbA_{1c}) diabetes-related outcomes at each successive follow-up.

The means and standard deviations for all measures presented at each assessment are displayed in Table 2.3(a) and 2.3(b).

Response rate

At three to six weeks after diagnosis responses were available for 71 (84.5%) of the original 84 participants, 69 (82.1%) and 66 (78.6%) responses were obtained at four months and at 12 months after diagnosis, respectively. At 12 months after diagnosis four of the respondents had relocated, two people had transferred to another diabetes centre, one person no longer wished to participate in the study, and eleven people failed to attend follow-up clinic appointments and/or could not be contacted subsequently.

Independent samples t-tests revealed that individuals who were admitted to hospital for a greater number of days at the time of diagnosis were significantly less likely to complete the follow-up questionnaire at the initial review four months after diagnosis ($t [82] = 2.45$, $p < 0.05$). Those individuals who had a greater body mass index at diagnosis were also less likely to complete and return the questionnaires four months after diagnosis (t

[75] = 3.03, $p < 0.01$). There were no significant baseline differences between those individuals who responded and those who did not respond at 12 months after diagnosis.

At 24 months after diagnosis responses were obtained from 56 (67%) of the participants, and at 36 months after diagnosis 41 (49%) responses were available for analysis. T-tests showed that there were no significant baseline differences between those individuals who responded and those individuals who did not respond at the 24 month and 36 month follow-up reviews.

Individual difference measures

The number of participants available for each variable across all time points varied due to the number of individuals who took part in the study at each review. The exact number of responses available for each measure is shown in Table 2.3(a). Correlations between socio-demographic variables recorded at diagnosis and each individual difference measure at baseline (diagnosis and three to six weeks) were examined.

Body mass index

Body mass index remained highly stable across the epoch (all $r = .82$ to $.98$, $p < 0.001$). However, analysis of variance revealed that there was a significant increase in mean levels of body mass index between diagnosis and follow-up at four months, 12 months, 24 months, and 36 months after diagnosis (all $p < 0.001$). Baseline social and educational characteristics were not significantly correlated with body mass index at diagnosis.

Exercise

The number of times an individual reported taking exercise per week remained moderately stable across all follow-ups (all r's between .37 and 69, $p < 0.05$). There were no significant differences in mean levels of exercise across time. Exercise pattern was inversely correlated with HbA_{1c} at diagnosis ($r = -.34$, $p < 0.01$). None of the other baseline socio-demographic variables were associated with exercise.

Cognitive ability

Correlations between baseline socio-demographic variables and the National Adult Reading Test (NART) recorded shortly after diagnosis were examined. Educational background and high socio-economic status were significantly associated with high scores on the NART ($r = .46$ and $-.48$, respectively, both $p < 0.001$).

Personality

Test re-test reliabilities of the dimensions of Eysenck's Personality Questionnaire revised short form (EPQ-R) over a three year period indicated that extraversion ($r = .71$, $p < 0.001$) remained highly stable over time. Neuroticism and social desirability were also fairly stable across this time interval ($r = .46$ and $.41$, respectively, both $p < 0.01$). Psychoticism at diagnosis was not a reliable indicator of psychotcism at 36 months after diagnosis. Mean levels of psychoticism declined significantly between diagnosis and 36 months after diagnosis ($t [39] = 4.96$, $p < 0.001$). There were no significant changes in mean levels of neuroticism, extraversion or social desirability during the three year interval between assessments. There was an inverse correlation between neuroticism and extraversion ($r = -.31$, $p < 0.01$) at diagnosis. No other relationships existed between the dimensions of personality. Alcohol consumption (units/week) was inversely correlated with neuroticism at diagnosis ($r = -.36$, $p < 0.01$).

Coping

The test retest reliability coefficients of the dimensions of the Coping with Health Injuries and Problems (CHIP) scale were calculated. Instrumental coping (all r's between .33 and .69, $p < 0.05$), negative emotion coping (all r's between .46 and .76, $p < 0.01$), and distraction coping (all r's between $r = .36$ and .61, $p < 0.05$) were moderately stable across all follow-ups. Palliative coping at diagnosis was not significantly correlated with palliative coping at 12 months after diagnosis, but had good within subjects stability between diagnosis and 24 months after diagnosis ($r = .51$, $p < 0.01$), and between diagnosis and 36 months after diagnosis ($r = .41$, $p < 0.05$). In general, the temporal stability of the CHIP ratings was moderate to high across a 36 month period.

Using paired samples t-tests overall mean scores for instrumental coping were significantly greater than for any of the other dimensions of coping and this difference was consistent across all follow-ups (all $p < 0.001$). Mean levels of instrumental coping declined significantly between diagnosis and 12 months ($t [35] = 2.52$, $p < 0.05$), 24 months ($t [35] = 3.20$, $p < 0.01$), and 36 months after diagnosis ($t [35] = 3.37$, $p < 0.01$). There was no significant change in mean levels of distraction coping between diagnosis and 12 months after diagnosis, but mean levels of distraction coping declined significantly in the longer term between diagnosis and 24 months after diagnosis (t [34]

$= 2.53$, $p < 0.05$) and between diagnosis and 36 months after diagnosis ($t [34] = 3.13$, $p < 0.01$). Negative-emotion coping declined significantly between diagnosis and 12 months ($t [36] = 3.17$, $p < 0.01$), 24 months ($t [36] = 3.61$, $p < 0.001$) and 36 months ($t [36] = 3.00$, $p < 0.01$) after diagnosis. However, all of these effect sizes were small. There were no significant changes in mean levels of palliative coping during the 36 months post diagnosis. These results show an overall reduction in self-reported coping styles following diagnosis of Type 1 diabetes.

Intercorrelations between the dimensions of the CHIP were examined using Pearson's product moment correlation coefficients at the time of diagnosis. There was a positive relationship between instrumental coping and distraction coping ($r = .50$, $p < 0.01$). There were no significant relationships between the remaining constructs at baseline. The limited intercorrelations of the CHIP subscales provide supportive evidence for the multi-dimensionality of the measure.

Psychiatric distress

The stability of individual differences in psychiatric distress was fairly high between diagnosis and follow-up at four months, 12 months, 24 months and 36 months after diagnosis (all r's between .43 and .57, $p < 0.01$). There were no significant changes in mean levels of psychiatric distress during the 36 months following diagnosis of Type 1 diabetes. None of the baseline socio-demographic variables were significantly related to psychiatric distress at diagnosis.

Diabetes Locus of Control

The Diabetes Locus of Control (DLOC) questionnaire contains five subscales; internal autonomy, internal blame, chance, external health professionals, and external non-health professionals. Test retest reliability coefficients were calculated to establish the stability of individual differences for each subscale across time. Internal autonomy (all r's between .51 and .69, $p < 0.01$) and internal blame (all r's between .37 and .70, $p < 0.05$) remained stable across all follow-ups. Chance locus of control had good within subjects stability throughout the period of investigation (all r's between .63 and .83, $p < 0.001$). External health professional locus of control was fairly stable across successive follow-ups (all r's between .38 and .68, $p < 0.05$) but had less reliable longer term stability, for example, there was no significant correlation between external health professional locus of control between four months and 36 months after diagnosis, or between 12 months and 36 months after diagnosis. External non-health professional locus of control had moderate stability across time (all r's between .36 and .68, $p < 0.05$). There were no significant changes in mean scores of the subscales of the DLOC questionnaire over time.

Intercorrelations between the subscales of the DLOC questionnaire were examined at the four month review. External health professional locus of control and external non-health professional locus of control were positively correlated ($r = .44$, $p < 0.05$). There were no significant relationships between the remaining subscales.

Happiness

Happiness at diagnosis was a good indicator of happiness at follow-up reviews at four months, 12 months, 24 months, and 36 months after diagnosis (all r's between .38 and .72, $p < 0.05$). There were no significant changes in self-reported happiness over time. The number of days spent in hospital at the time of diagnosis was significantly correlated with happiness self-ratings ($r = -.23$, $p < 0.05$).

Table 2.3(a): Means (SD) of socio-demographic variables and individual difference measures recorded at each review

Variable	Scale/Metric	N	Baseline	3-6 weeks	4 months	12 months	24 months	36 months	Anova (p)
Socio-demographics									
Age	years	84	30.8 (8.5)						
Education	years	80	13.0 (2.8)						
NART	1 - 50	54		30.9 (7.8)					
BMI	kg/m^2	26	23.6 (4.9)		25.8 (4.5)*	25.9 (4.4)*	25.8 (4.3)*	26.1 (4.1)*	0.001
Exercise	times/week	31	1.4 (1.9)		1.8 (1.6)	2.1 (1.8)	2.0 (2.1)	1.8 (2.1)	
Alcohol	units/week	82	11.3 (12.7)						
Individual Differences									
Personality (EPQ-R)									
Extraversion	1 - 12	38	8.4 (3.4)					8.0 (3.7)	
Neuroticism	1 - 12	39	5.1 (3.1)					4.3 (3.4)	
Psychoticism	1 - 12	39	4.5 (2.0)					2.4 (1.8)*	0.001
Lie	1 - 12	39	5.0 (2.6)					4.1 (2.6)	
Conscientiousness		78	36.0 (6.3)						
Psychiatric distress (GHQ)	0 - 28	31		4.6 (5.0)	3.6 (6.2)	3.3 (5.6)	4.1 (6.6)	2.8 (5.7)	
Coping styles (CHIP)									
Palliative	8 - 40	37	23.8 (4.4)			22.4 (4.6)	23.5 (3.8)	24.3 (4.1)	
Instrumental	8 - 40	36	31.1 (5.2)			28.7 (4.7)*	28.4 (4.0)*	28.2 (3.5)*	0.001
Distraction	8 - 40	35	25.1 (4.4)			23.7 (4.8)	23.0 (4.3)*	22.5 (4.3)*	0.01
Negative-emotion	8 - 40	36	23.3 (6.8)			20.0 (6.5)*	19.3 (6.0)*	20.2 (6.2)*	0.001
Diabetes Locus of Control									
Internal autonomy	6 - 18	34		15.1 (2.1)	14.7 (1.9)	14.8 (1.8)	14.9 (1.9)	14.7 (1.9)	
Internal blame	6 - 18	33		11.5 (3.1)	12.1 (3.2)	11.5 (3.0)	11.3 (3.1)	11.4 (3.1)	
Chance	6 - 36	34		13.4 (4.7)	12.4 (4.4)	12.1 (4.2)	12.5 (4.7)	12.4 (4.2)	
Health prof	6 - 24	33		12.9 (3.6)	12.5 (3.1)	12.9 (3.3)	12.8 (2.6)	12.2 (2.5)	
Non-health prof	6 - 12	34		5.8 (1.7)	5.6 (1.8)	5.8 (2.2)	5.4 (1.5)	5.2 (1.8)	
Happiness	1 - 10	32	7.6 (2.5)		6.7 (2.5)	7.2 (2.5)	6.7 (2.9)	7.2 (2.5)	

Means (SD) are based on listwise comparisons of each variable. Exact N for each variable is shown in the table.
Symbols represent significant changes in mean levels across time: * change since diagnosis

Table 2.3(b): Means (SD) of diabetes-related outcome measures recorded at each review

Variable	Scale/Metric	N	Baseline	3-6 weeks	4 months	12 months	24 months	36 months	Anova (p)
Diabetes-related Outcomes									
Glycaemic control (HbA_{1c})	%	30	11.0 (1.9)		7.1 (1.2)*	7.7 (1.8)* †	8.2 (1.3)* †	8.8 (1.3)* †δ #	0.001
Diabetes knowledge	0 - 24	36			20.5 (3.1)	21.1 (2.9)	20.9 (2.6)	20.6 (3.0)	
Treatment satisfaction	0 - 36	35			26.2 (6.9)	27.6 (5.1)	27.1 (6.1)	27.3 (6.8)	
Perceived hyperglcaemia	0 - 6	36			2.1 (1.5)	2.6 (1.5)	2.6 (1.6)	3.0 (1.3)†	0.05
Perceived hypoglycaemia	0 - 6	35			2.3 (1.3)	2.0 (1.4)	2.2 (1.3)	1.9 (1.1)	
Diabetes Quality of Life									
Satisfaction	%	34		70.9 (17.2)	66.1 (18.4)	71.5 (17.1)†	71.6 (16.2)†	70.1 (17.1)†	0.05
Impact	%	34		72.8 (11.3)	71.8 (11.6)	70.2 (12.2)	70.5 (11.5)	72.0 (11.3)	
Worry	%	20		68.9 (21.3)	71.5 (20.3)	73.2 (15.0)	71.1 (18.3)	71.9 (16.7)	
General well-being	1 - 4	30		2.5 (0.9)	2.3 (0.9)	2.4 (0.9)	2.4 (0.6)	2.5 (0.8)	
Additional Outcomes									
Well-being: total	0 - 66	41						46.5 (12.7)	
Depression	0 - 18	41						4.4 (3.3)	
Anxiety	0 - 18	41						4.5 (3.4)	
Energy	0 - 12	41						7.6 (2.6)	
Positive well-being	0 - 18	41						11.5 (4.4)	
Hypoglycaemia Fear Survey	0 - 92	41						33.7 (12.3)	
Behaviour	0 - 40	41						17.4 (6.0)	
Worry	0 - 52	41						16.2 (9.2)	
Self-care activities									
Diet	%	38						64.8 (13.3)	
Exercise	%	37						36.4 (31.8)	
Glucose monitoring	%	38						81.2 (27.9)	
Medication taking	%	39						96.1 (9.1)	

Means (SD) are based on listwise comparisons of each outcome variable. Exact N for each variable is shown in the table.
Symbols represent significant changes in mean levels across time: * change since diagnosis,
† change since four months after diagnosis
δ change since 12 months after diagnosis
change since 24 months after diagnosis

Predicting diabetes-related outcomes after diagnosis from baseline and four month psychosocial variables

Correlations between psychosocial variables recorded at baseline and four months after diagnosis, and diabetes-related outcomes measures at each review are shown in a series of tables. Each correlation is based the number of individuals available for each comparison. The independent predictors of diabetes-related outcomes measured at a series of periodic reviews (at four, 12, 24 and 36 months after diagnosis) were examined using stepwise multiple regression analyses. The number of participants available for analysis for each outcome is shown in the appropriate table. This analytic approach is now applied in turn to the various aspects of 'coping' with diabetes identified in the introduction: glycaemic control, diabetes knowledge, diabetes treatment satisfaction and diabetes quality of life.

Glycaemic control

Achieving good glycaemic control is important if individuals who have Type 1 diabetes are to avoid the risk of the development and progression of long term complications of diabetes in later life (DCCT, 1988, 1993). To date there have been few prospective studies that have attempted to assess predictive factors of long term glycaemic control in an adult sample from the time of initial diagnosis. Prospective studies of this kind are clearly important as in cross-sectional studies it is not possible to determine how individual differences in glycaemic control change over time, or to identify individuals who are more vulnerable to being poorly controlled. By identifying the psychological and social risk factors for poor glycaemic control early on it may be possible to 'target' such patients from the time of diagnosis, and to provide educational interventions to help to optimise glycaemic control.

This section provides a prospective assessment of glycaemic control recorded at series of periodic reviews following initial diagnosis of Type 1 diabetes.

Stability of individual differences and changes in mean levels of HbA_{1c} across time

Test-retest reliabilities indicated that glycaemic control at diagnosis was not significantly correlated with glycaemic control at four months, 12 months, 24 months or 36 months after diagnosis, reflecting the interventions over the period following diagnosis of diabetes. Individual differences in HbA_{1c} showed moderate stability between four months and 12 months after diagnosis ($r = .49$, $p < 0.01$), and between 24 months and 36 months after diagnosis ($r = .54$, $p < 0.01$) but there was no relationship between HbA_{1c} recorded at 12 months and at 24 months after diagnosis.

There were significant changes in mean levels of HbA_{1c} across time (Table 2.3(b)). Bonferroni post hoc analysis revealed a decline in HbA_{1c} following the onset of insulin therapy. This decline was significant at each follow-up (all $p < 0.001$). Despite the overall decline in HbA_{1c} resulting from the intervention of insulin therapy, there was a significant increase in HbA_{1c} between four months and 24 months after diagnosis ($t [28] = -4.63$, $p< 0.001$), four months and 36 months after diagnosis ($t [28] = -5.74$, $p < 0.001$), 12 months and 36 months after diagnosis ($t [28] = -3.59$, $p < 0.01$), and 24 months and 36 months after diagnosis ($t [28] = -2.42$, $p < 0.05$). These findings suggest that the within subjects stability of glycaemic control remains fairly high across time with the exception of the period between 12 months and 24 months after diagnosis. However, the overall quality of glycaemic control achieved begins to decline approximately one year following initial diagnosis of Type 1 diabetes.

Effect of socio-demographic variables on glycaemic control across time

An independent samples t-test revealed that current smokers had poorer glycaemic control at four months after diagnosis than those individuals who had never smoked (t [59] = -2.65, $p < 0.01$) but smoking had no significant effect on glycaemic control in later follow-ups.

Being admitted to hospital at the time of diagnosis was predictive of poorer glycaemic control at 24 months (t [50] = -.3.67, $p < 0.001$) and at 36 months (t [37] = -2.78, $p < 0.01$) after diagnosis. In addition, individuals who had a poorer socio-economic status also had poorer glycaemic control at 24 months (F [8, 50] = 3.64, $p < 0.01$) and at 36 months (F [8, 38] = 3.89, $p < 0.01$) after diagnosis. Poor health status at diagnosis and low socio-economic status were consistent long-term predictors of poor glycaemic control.

Correlations between baseline psychosocial variables and diabetes outcomes at four months after diagnosis, and glycaemic control across time

Correlations between psychosocial variables recorded at baseline and outcomes recorded at each follow-up (at four, 12, 24 and 36 months) are shown in the top part of Table 2.4.

Younger participants and those individuals who took more regular exercise at diagnosis were more likely to have good glycaemic control at four months after diagnosis ($r = .27$ and $-.26$, respectively, both $p < 0.05$). The perceived frequency of hyperglycaemia recorded at four months after diagnosis was also significantly correlated with glycaemic control at four months after diagnosis ($r = .48$, $p < 0.01$), indicating that individuals were moderately accurate in their perceptions of their glycaemic control. The perceived frequency of hyperglycaemia at four months after diagnosis was not a reliable predictor of long-term glycaemic control.

Participants who reported consuming a greater number of units of alcohol per week had poorer glycaemic control at 12 months after diagnosis ($r = .31$, $p < 0.05$). High neuroticism at diagnosis was significantly correlated with the achievement of good glycaemic control ($r = -.25$, $p < 0.05$) at 12 months after diagnosis. None of the remaining psychosocial variables recorded at baseline were significantly correlated with the quality of glycaemic control at four months or at 12 months after diagnosis.

The intercorrelations between the diabetes-related outcome measures recorded at four months after diagnosis and glycaemic control at each review are shown in the bottom half of Table 2.4. Having a comprehensive knowledge of diabetes at four months after diagnosis was a good predictor of glycaemic control at 12 months after diagnosis ($r = -.35$, $p < 0.01$) and this relationship was also present at 36 months after diagnosis ($r = -.35$, $p < 0.05$). Diabetes knowledge was a good long-term predictor of glycaemic control but this relationship was not consistent across all follow-ups. None of the remaining diabetes-related outcome measures recorded at four months after diagnosis were predictive of glycaemic control during the first 12 months after diagnosis.

Table 2.4: Correlations between psychosocial variables recorded at diagnosis and four months after diagnosis, and glycaemic control recorded at a series of periodic reviews

	HbA$_{1c}$ 4	HbA$_{1c}$ 12	HbA$_{1c}$ 24	HbA$_{1c}$ 36
Baseline				
Age	**.267***	.143	-.020	-.001
Education	-.005	-.004	-.054	-.178
NART	.090	-.143	-.267	-.273
Social class	-.101	.043	.047	.064
BMI	-.006	-.115	-.236	-.112
Exercise	**-.263***	-.158	-.195	.050
Alcohol intake	.132	**.311***	-.068	-.165
EPQ: N	-.206	**-.251***	.151	.189
EPQ: E	.027	.225	.045	-.023
EPQ: P	-.139	-.048	-.012	-.025
Consc	-.135	-.115	-.137	**-.322***
GHQ	-.078	.159	.164	**.415***
Happiness	-.009	-.129	-.153	**-.375***
CHIP: P	-.213	-.237	-.070	-.078
CHIP: I	-.132	-.026	-.189	-.065
CHIP: D	-.173	-.094	.019	-.055
CHIP: NE	-.132	-.171	-.045	.128
DLOC: IA	.020	.052	.039	-.054
DLOC: IB	.021	.104	**.310***	.223
DLOC: C	.107	.027	**.328***	.242
DLOC: EHP	.040	.019	.050	-.058
DLOC: ENHP	-.144	-.185	-.006	-.010
4 Months				
DKNQ	-.093	**-.350****	-.215	**-.354***
DTSQ: Total	-.154	.045	-.099	-.277
DTSQ: Hyper	**.484****	.105	.151	.208
DTSQ: Hypo	-.207	-.069	.079	.258
DQOL: S	-.052	.032	-.156	-.263
DQOL: I	-.048	-.060	-.131	**-.364***
DQOL: W	.187	.126	-.054	-.269
DQOL: G	.048	.154	.137	**.390***
N Range	51 - 74	50 - 66	40 - 52	33 - 40

Note: ** $p < 0.01$; * $p < 0.05$ (2-tailed)

Correlations for Social Class are based on Spearman's r co-efficients

Abbreviations: NART = National Adult Reading Test; BMI = Body mass index; EPQ = Eysenck's Personality Questionnaire; N = Neuroticism; E = Extraversion; P = Psychoticism; Consc = Conscientiousness; GHQ = Psychiatric distress; CHIP = Coping with Health Injuries and Problems; P = Palliative; I = Instrumental; D = Distraction; NE = Negative-emotion; DLOC = Diabetes Locus of Control; IA = Internal autonomy; IB = Internal blame; C = Chance; EHP = External health professional; ENHP = External non-health professional; DKNQ = Diabetes Knowledge Questionnaire; DTSQ = Diabetes Treatment Satisfaction Questionnaire; Hyper = Perceived hyperglycaemia; Hypo = Perceived hypoglycaemia; DQOL = Diabetes Quality of Life; S = Satisfaction; I = Impact; W = Worry; G = General well-being.

Relationships between self-reported psychosocial variables recorded at baseline and diabetes-related outcomes at four months after diagnosis, and long-term glycaemic control were present but these correlations were not consistent across successive follow-ups. High levels of internal blame and chance locus of control at diagnosis were significantly correlated with poor glycaemic control at 24 months after diagnosis ($r = .31$ and $.33$, respectively, both $p < 0.05$). High conscientiousness ($r = -.32$, $p < 0.05$), happiness ($r = -.37$, $p < 0.05$), and low levels of psychiatric distress ($r = .41$, $p < 0.05$) at diagnosis were significantly predictive of good glycaemic control at 36 months after diagnosis. DQOL impact of diabetes and general well-being recorded at four months after diagnosis were also predictive of glycaemic control at 36 months after diagnosis ($r = -.36$ and $.39$, respectively, both $p < 0.05$).

Predictors of glycaemic control

The results of multiple regression analyses to determine the independent predictors of glycaemic control at each review are displayed in Table 2.5.

Table 2.5: Multiple regression to show the baseline and four months predictors of glycaemic control across time.

Step/Variable	Adjusted R^2	R^2 Increment	*F* Change (*p*)	Part Corr. (*p*)
HbA$_{1c}$ 4 months (N = 63)	.29			
Perceived hyperglycaemia		.22	18.98 (.001)	.49 (.001)
Age		.07	14.07 (.001)	.28 (.01)
HbA$_{1c}$ 12 months (N = 58)	.18			
Diabetes Knowledge		.11	8.19 (.006)	-.37 (.003)
Neuroticism		.07	7.55 (.001)	-.29 (.05)
HbA$_{1c}$ 24 months (N = 46)	.09			
DLOC: Chance			5.43 (.05)	.33 (.05)
HbA$_{1c}$ 36 months (N = 38)	.08			
DQOL: General well-being			4.31 (.05)	.32 (.05)

At 4 months: The perceived frequency of hyperglycaemia reported at four months after diagnosis accounted for 22% of the independent variance in glycaemic control at four months after diagnosis. Age at diagnosis accounted for a further 7% of the variance; younger individuals and those participants who perceived themselves as having less frequent episodes of hyperglycaemia had better glycaemic control at four months after diagnosis.

At 12 months: Having a comprehensive knowledge of diabetes at four months after diagnosis accounted for 11% of the variance in glycaemic control at 12 months after diagnosis. A further 7% of the variance was added by the personality dimension neuroticism.

At 24 months: Chance locus of control recorded at three to six weeks after diagnosis was a significant independent predictor of glycaemic control at 24 months after diagnosis, accounting for 9% of the variance. None of the other psychosocial variables recorded at baseline or diabetes-related outcomes at four months after diagnosis were significant independent predictors of glycaemic control at 24 months after diagnosis.

At 36 months: Poor self-reported well-being at four months after diagnosis was a significant independent predictor of poor glycaemic control at 36 months after diagnosis. DQOL: general well-being alone accounted for 8% of the variance in glycaemic control at 36 months after diagnosis.

Summary

There was an initial decline in HbA_{1c} shortly after diagnosis reflecting the intervention with insulin therapy during this period. After diagnosis the temporal stability of individual differences in glycaemic control was fairly good, with the exception of the period between 12 months and 24 months after diagnosis. The overall quality of glycaemic control began to decline approximately one year following diagnosis.

Younger adults and those who took more regular exercise were most likely to have good glycaemic control in the first few months following diagnosis, while smoking and regular alcohol consumption were identified as early risk factors for poor glycaemic control during the first 12 months of diabetes self-management. However these relationships were not consistent across time and had disappeared in later follow-ups.

The best long-term predictors of glycaemic control were whether or not the individual had been admitted to hospital for ketoacidosis at diagnosis (i.e. poorer objective health status) and socio-economic background recorded at diagnosis. These differences were consistent at 24 months and at 36 months after diagnosis. In addition, there was evidence for a direct link between having a comprehensive knowledge of diabetes at four months after diagnosis and subsequent glycaemic control at 12 months and at 36 months after diagnosis. These findings suggest that educational interventions put in place shortly after diagnosis may be effective in producing improvements in the quality of glycaemic control achieved.

In conclusion, the results of the EPDS suggest that, in adults, self-reported psychological variables (e.g. personality and psychiatric distress) recorded at diagnosis, and social factors (e.g. quality of life) recorded at four months after diagnosis are not reliable predictors of glycaemic control during the first few months following diagnosis of Type 1 diabetes but may be important long-term predictors of glycaemic control. Future follow-ups of longer duration are therefore required to replicate the present findings, and to further examine the temporal relationships between psychological and social factors and glycaemic control in adults with Type 1 diabetes.

Diabetes knowledge

Another important indicator of how well a person is 'coping' with their diabetes is reflected by how much they know about their diabetes. Having a comprehensive knowledge of diabetes, its management and complications will allow individuals who have diabetes to manage the disorder more efficiently, and may help them to overcome at least some of the potential 'barriers' to diabetes self-care. In the present study diabetes knowledge was assessed using the Diabetes Knowledge Questionnaire (DKNQ) which was developed specifically for this study (Gold et al., 1995). The first psychometric data relating to the reliability and validity of this measure are presented here as well as a prospective examination of the psychological and social predictors of diabetes knowledge across time.

Internal consistency, stability, and changes in mean scores on the DKNQ across time

The internal consistency of the Diabetes Knowledge Questionnaire was acceptable ($\alpha = .66$) based on the results obtained at the four month review, and individual differences in the Diabetes Knowledge Questionnaire total scores were moderately stable across time ($r = .66$ to $.83$, $p < 0.001$). There were no significant changes in mean levels of diabetes knowledge throughout the 36 month follow-up period (Table 2.3(b)).

Effect of socio-demographic factors on diabetes knowledge

Individuals who were defined as working class had poorer knowledge of their diabetes than those defined as service class at four months ($F\ [2, 67] = 3.49$, $p < 0.05$) and at 24 months ($F\ [2, 53] = 5.03$, $p < 0.01$) after diagnosis. Independent samples t-tests revealed that women had significantly better knowledge of their diabetes than men (t [67] = 2.50, $p < 0.05$) at four months after diagnosis but this difference had disappeared at subsequent follow-ups.

Psychosocial correlates of diabetes knowledge

Correlations between baseline psychosocial variables and knowledge of diabetes at 12 months, 24 months and 36 months after diagnosis were examined. These relationships are displayed in the top half of Table 2.6.

Participants who had a higher socio-economic status at diagnosis had a more comprehensive knowledge of their diabetes at four months ($r = -.30$, $p < 0.05$), at 12 months ($r = -.28$, $p < 0.05$) and at 24 months ($r = -.33$, $p < 0.05$) after diagnosis. Despite the initial consistency of these correlations, this relationship did not persist at 36 months after diagnosis. Similarly, cognitive ability at diagnosis was a consistent predictor of diabetes knowledge during the first 12 months after diagnosis; high scores on the National Adult Reading Test (NART) were significantly correlated with having a good knowledge of diabetes at four months ($r = .38$, $p < 0.01$) and at 12 months ($r = .36$, $p < 0.01$) after diagnosis. The number of years spent in education was predictive of diabetes knowledge at four months after diagnosis ($r = .35$, $p < 0.01$) but this relationship had disappeared in subsequent follow-ups. Those participants who reported taking more regular exercise at diagnosis had a more comprehensive knowledge of diabetes at four months and at 36 months after diagnosis ($r = .35$, $p < 0.01$, and $r = .36$, $p < 0.05$, respectively).

Table 2.6: Correlations between baseline psychosocial variables and diabetes knowledge across time.

	DKNQ 4	DKNQ 12	DKNQ 24	DKNQ 36
Baseline				
Age	-.168	-.218	-.055	-.291
Education	**.346****	.246	.193	.253
NART	**.385****	**.360****	.110	.321
Social class	**-.300***	**-.277***	**-.329***	-.167
BMI	.016	-.004	.051	-.066
Exercise	**.348****	.193	.093	**.359***
Alcohol	-.066	.068	-.107	-.003
EPQ: E	.142	.135	.056	.107
EPQ: N	-.151	**-.322****	-.189	-.083
EPQ: P	.068	**.294***	.240	**.372***
Consc	.229	.175	.191	.017
GHQ	-.051	-.173	-.017	-.149
Happiness	.099	.189	.100	.220
CHIP: P	-.107	-.099	-.181	-.085
CHIP: I	.016	-.214	-.171	-.082
CHIP: D	.156	.000	.008	.123
CHIP: NE	-.211	**-.400****	**-.270***	-.279
DLOC: IA	.124	.175	-.019	.074
DLOC: IB	-.054	.010	-.067	.134
DLOC: C	**-.276***	**-.407****	**-.348***	-.227
DLOC: EHP	-.247	-.126	-.196	-.291
DLOC: ENHP	-.111	-.125	-.121	-.082
4 Months				
HbA_{1c}	-.093	-.148	-.122	-.061
DTSQ: Total	.077	.086	.032	-.012
DTSQ: Hyper	.066	-.019	.021	.172
DTSQ: Hypo	-.037	.035	.107	.079
DQOL: S	.067	.092	.032	-.014
DQOL: I	.048	.107	.059	-.107
DQOL: W	-.034	-.070	.023	-.106
DQOL: G	-.225	**-.308***	-.087	-.204
N Range	51 - 74	50 - 66	43 - 56	31 - 40

Note: ** $p < 0.01$; * $p < 0.05$ (2-tailed)

Correlations for Social Class and Days Admitted are based on Spearman's r co-efficients

Abbreviations: NART = National Adult Reading Test; BMI = Body mass index; EPQ = Eysenck's Personality Questionnaire; N = Neuroticism; E = Extraversion; P = Psychoticism; Consc = Conscientiousness; GHQ = Psychiatric distress; CHIP = Coping with Health Injuries and Problems; P = Palliative; I = Instrumental; D = Distraction; NE = Negative-emotion; DLOC = Diabetes Locus of Control; IA = Internal autonomy; IB = Internal blame; C = Chance; EHP = External health professional; ENHP = External non-health professional; HbA_{1c} = Glycaemic control; DTSQ = Diabetes Treatment Satisfaction Questionnaire; Hyper = Perceived hyperglycaemia; Hypo = Perceived hypoglycaemia; DQOL = Diabetes Quality of Life; S = Satisfaction; I = Impact; W = Worry; G = General well-being.

Self-reported psychosocial variables recorded shortly after diagnosis were also predictive of diabetes knowledge. In particular, those individuals with high scores on the personality trait neuroticism were likely to have poorer knowledge of their diabetes at 12 months after diagnosis ($r = -.32$, $p < 0.01$) whereas high psychoticism scores were consistently correlated with better knowledge of diabetes at 12 months and at 36 months after diagnosis ($r = .29$ and .37, respectively, both $p < 0.05$). Negative-emotion focussed coping was inversely correlated with diabetes knowledge at 12 months ($r = -.40$, $p < 0.01$) and at 24 months after diagnosis ($r = -.27$, $p < 0.05$). Individuals who obtained high scores on DLOC chance had poorer knowledge of their diabetes at four months ($r = -.28$, $p < 0.05$), at 12 months ($r = -.41$, $p < 0.01$) and at 24 months ($r = -.35$, $p < 0.05$) after diagnosis.

The intercorrelations between diabetes-related outcome variables recorded at four months after diagnosis and diabetes knowledge are shown in the bottom half of Table 2.6. The diabetes-related outcome measures were not significantly correlated with diabetes knowledge across time, with the exception of DQOL general well-being which had a small but significant correlation with diabetes knowledge at 12 months after diagnosis ($r = -.31$, $p < 0.05$). Participants who perceived themselves as having poorer health status at four months after diagnosis had poorer knowledge of their diabetes at 12 months after diagnosis.

Predictors of diabetes knowledge

Using multiple regression analyses the independent predictors of diabetes knowledge were examined. These results are displayed in Table 2.7.

Table 2.7: Multiple regression analyses to identify the independent predictors of diabetes knowledge across time, after the exclusion of four month levels of the same variable.

Step/Variable	Adjusted R^2	R^2 Increment	*F* Change (*p*)	Partial Corr. (*p*)
DKNQ 4 months (N = 42)	.33			
Social class		.16	9.01 (.005)	-.52 (.001)
Exercise		.17	11.32 (.001)	.43 (.002)
DKNQ 12 months (N = 37)	.14			
Psychoticism			7.13 (.01)	.41 (.01)
DKNQ 24 months (N = 48)	.23			
DLOC: Chance		.11	6.95 (.01)	-.38 (.004)
Social class		.12	8.34 (.001)	-.37 (.005)
DKNQ 36 months (N = 39)	.12			
Psychoticism			6.09 (.02)	.37 (.02)

At 4 months: High socio-economic status at diagnosis was an independent predictor of diabetes knowledge at four months after diagnosis. Social class accounted for 16% of the variance in the first step of the analyses. A further 17% of the variance was added by exercise at diagnosis. Together these variables were able to account for 33% of the significant variance in knowledge of diabetes at four months after diagnosis.

At 12 months: The personality dimension, psychoticism, recorded at diagnosis was predictive of diabetes knowledge at 12 months after diagnosis. Psychoticism alone accounted for 14% of the variance in diabetes knowledge at 12 months after diagnosis.

At 24 months: Low levels of chance locus of control and high socio-economic status at diagnosis were significant independent predictors of diabetes knowledge at 24 months after diagnosis. These variables explained 23% of the variance, 11% of the variance was accounted for by chance locus of control and a further 12% was added by social class.

At 36 months: Psychoticism alone accounted for 12% of the variance in diabetes knowledge at 36 months after diagnosis.

Summary

The results of the EPDS provide evidence to suggest that the Diabetes Knowledge Questionnaire (DKNQ) is reliable. The measure has good internal consistency, and the within subjects stability of the DKNQ was high throughout the 36 month duration of the study.

At four months after diagnosis women had greater average diabetes knowledge scores than men but this advantage had disappeared in later follow-ups. As expected, there were highly consistent relationships between a person's social background and cognitive ability at the time of diagnosis, and diabetes knowledge scores across time. In particular, individuals who had higher socio-economic status, better pre-morbid IQ scores and who reported taking more regular exercise were more likely to have a good personal knowledge of their diabetes.

There was some evidence to suggest that individual differences in self-reported psychological variables were predictive of diabetes knowledge across time. Chance locus of control and negative emotion coping measured shortly after diagnosis were consistent predictors of poor diabetes knowledge scores. Participants who obtained high scores on the personality trait psychoticism at diagnosis were likely to have a good knowledge of their diabetes.

In conclusion, the results of the EPDS provide support for the internal and temporal reliability of the DKNQ over a 36 month duration. In adults, socio-economic status, and individual differences in personality traits (e.g. psychoticism) may be reliable long-term predictors of diabetes knowledge.

Diabetes treatment satisfaction

A third way of measuring how well a person is coping with their diabetes is how satisfied they are with their current treatment regimen. This can be measured using the Diabetes Treatment Satisfaction Questionnaire (DTSQ; Bradley, 1994). The DTSQ provides an overall score relating to each participant's satisfaction with their current diabetes treatment (DTSQ total score). In addition there are two individual items which measure an individual's perceived frequency of hyperglycaemia and hypoglycaemia. The DTSQ has been used in previous research and has been found to have good reliability, construct validity, discriminatory power and sensitivity to change (Bradley and Lewis, 1990; Bradley, 1994).

Being satisfied with diabetes treatment is an important outcome of diabetes self-management due, in part, to the burden that the treatment of diabetes places on the individual. People who have Type 1 diabetes are required to follow a strict daily routine in order to remain healthy which includes, regulation of diet, taking regular exercise, monitoring of blood glucose levels, and multiple injections of insulin. The complex and repetitive nature of these tasks can have negative implications for an individual's treatment satisfaction. It is therefore important to establish instances when patient satisfaction (self-reported outcome) is achieved at the expense of glycaemic control (actual health outcome) or vice versa.

In this section the reliability and validity of the DTSQ will be explored further and the relationships between baseline psychosocial variables and the DTSQ will be investigated across a series of periodic reviews (four months, 12 months, 24 months and 36 months) after diagnosis.

Stability of individual differences and changes in mean levels of the Diabetes Treatment Satisfaction Questionnaire across time

There were no significant changes in mean scores on the Diabetes Treatment Satisfaction Questionnaire (DTSQ) across time. Mean levels of the individual item which measures the perceived frequency of hyperglycaemia increased significantly between four months and 36 months after diagnosis (F [1, 35] = 7.61, $p < 0.01$); indicating that whilst overall satisfaction with diabetes treatment does not alter, there is a general decline in the perceived quality of glycaemic control. The perceived frequency of hypoglycaemia did not change significantly across time. These results are displayed in Table 2.3(b).

Individual differences in the DTSQ total scores were stable throughout the period of study (all r's between .60 and .76, $p < 0.001$). The individual item that measures the perceived frequency of hyperglycaemia remained moderately stable between four months and 12 months after diagnosis ($r = .33$, $p < 0.05$), and four months and 24 moths after diagnosis ($r = .35$, $p < 0.05$) but there was no significant relationship between the perceived frequency of hyperglycaemia between four months and 36 months after diagnosis. The perceived frequency of hypoglycaemia was significantly stable during the initial follow-up period between four and 12 months after diagnosis ($r = .44$, $p < 0.01$), but there was no significant relationship between the perceived frequency of hypoglycaemia between four months and 24 months after diagnosis. However there was a significant correlation between an individual's estimates of the perceived frequency of hypoglcyaemia between four months and 36 months ($r = 38$, $p < 0.05$), and between 12 months and 24 months ($r = .48$, $p < 0.01$) after diagnosis.

Intercorrelations between DTSQ total scores, the perceived frequency of hyperglycaemia, and the perceived frequency of hypoglycaemia

Intercorrelations between the DTSQ total scores and the two individual items between four months after diagnosis and subsequent follow-up at 12 months, 24 months and 36 months were examined. There was an inverse correlation between DTSQ total scores at four months after diagnosis and the perceived frequency of hyperglycaemia at 12 months ($r = -.52$, $p < 0.01$), at 24 months ($r = -.61$, $p < 0.001$) and at 36 months ($r = -.50$, $p < 0.01$) after diagnosis; participants who were satisfied with their treatment at four months reported less frequent episodes of hyperglycaemia. There was no significant correlation between DTSQ total scores at four months and the perceived frequency of hypoglycaemia across time. The perceived frequency of hypoglycaemia at four months after diagnosis was positively correlated with greater perceived hyperglycaemia at 12 months ($r = .46$, $p < 0.01$) and 24 months ($r = .41$, $p < 0.05$) after diagnosis. This relationship had disappeared at 36 months after diagnosis.

The effect of socio-demographic characteristics on Diabetes Treatment Satisfaction across time

Single people were consistently less satisfied with their treatment both at 12 months (F [2, 62] = 4.62, $p < 0.01$) and at 36 months (F [2, 40] = 5.31, $p < 0.01$) after diagnosis than individuals who were married or cohabiting at the time of diagnosis. Independent samples t-tests revealed that female participants reported more frequent episodes of perceived hyperglycaemia at 24 months after diagnosis than males (t [54] = 3.05, $p < 0.01$).

Those participants who had additional health problems at the time of diagnosis had lower DTSQ total scores at 24 months after diagnosis (t [52] = 3.33, $p < 0.01$), and individuals who were admitted to hospital at diagnosis reported more frequent episodes of perceived hyperglycaemia at 36 months after diagnosis (t [39] = -2.23, $p < 0.05$) None of the remaining social and educational factors had a significant effect on treatment satisfaction.

Psychosocial correlates and independent predictors of the Diabetes Treatment Satisfaction Questionnaire across time

The relationships between baseline psychosocial variables and the subscales of the Diabetes Treatment Satisfaction Questionnaire (DTSQ) recorded at 4 months, 12 months 24 months and 36 months after diagnosis were examined using Pearson's and where appropriate Spearman's correlation coefficients. These results are displayed in the top half of Table 2.8. The intercorrelations between diabetes-related outcomes recorded at four months after diagnosis and diabetes-related outcomes across time are shown in the bottom half of Table 2.8. Multiple regression analyses was used to identify the independent predictors of DTSQ total scores, the perceived frequency of hyperglycaemia and the perceived frequency of hypoglycaemia at each follow-up (Table 2.9). The number of participants available for each regression model is shown in the table.

DTSQ total scores

Older adults had greater DTSQ total scores that younger adults at 12 months after diagnosis ($r = .31$, $p < 0.05$), and high socio-economic status was a significant predictor of high DTSQ total scores at 24 months after diagnosis ($r = -.27$, $p < 0.05$).

Neuroticism was a highly consistent long-term predictor of DTSQ total scores across all follow-ups; individuals who reported high levels of neuroticism at diagnosis had lower DTSQ total scores at four months, 12 months, 24 months and at 36 months after diagnosis (all r's between -.26 and -.32, all $p < 0.05$). Happiness and negative-emotion coping recorded at diagnosis were also consistent long-term predictors of DTSQ total scores at four months ($r = .33$ and -.44, respectively, both $p < 0.01$), at 24 months ($r = .33$, $p < 0.05$ and $r = -.41$, $p < 0.01$, respectively) and at 36 months ($r = .31$, $p < 0.05$ and $r = -.40$, $p < 0.01$, respectively) after diagnosis. These two variables were not significantly correlated with DTSQ total scores at 12 months after diagnosis. High levels of palliative coping and greater internal blame at diagnosis were significantly predictive of low DTSQ total scores at 4 months ($r = -.27$ and -.29, respectively, both p

< 0.05) and at 36 months ($r = -.33$ and $-.37$, respectively, both $p < 0.05$) after diagnosis, however these relationships were not present at 12 months or at 24 months after diagnosis. Participants who reported greater psychiatric distress and more chance locus of control at the time of diagnosis obtained lower DTSQ total scores at four months after diagnosis ($r = -.34$, $p < 0.05$ and $r = -.38$, $p < 0.01$, respectively), but these relationships did not persist in future follow-ups. There was an inverse relationship between external health professional locus of control at diagnosis and treatment satisfaction at 24 months after diagnosis.

The intercorrelations between diabetes-related outcome measures at four months after diagnosis and DTSQ total scores recorded at each review were examined (Table 2.8). There were no significant relationships between early glycaemic control and diabetes knowledge recorded at four months after diagnosis, and DTSQ total scores across time. The dimensions of the Diabetes Quality of Life (DQOL) recorded at four months after diagnosis were highly correlated with DTSQ total scores over time. The DQOL satisfaction, impact and worry subscales recorded at four months after diagnosis were positively correlated with DTSQ total scores at 4 months, 12 months, 24 months and 36 months after diagnosis (all r's between .33 and .74, $p < 0.05$). DQOL general well-being was positively correlated with the DTSQ total scores at 4 months, at 24 months and at 36 months after diagnosis, but this relationship was not present at 12 months after diagnosis. These results suggest that total scores on the Diabetes Treatment Satisfaction Questionnaire are highly related to the dimensions of the Diabetes Quality of Life measure.

Using multiple regression analyses the independent predictors of DTSQ total scores at each review were examined (Table 2.9).

At four months: The Diabetes Quality of Life (DQOL) life satisfaction subscale recorded at four months after diagnosis was a highly significant predictor of DTSQ total scores at four months after diagnosis, accounting for 53% of the variance. Palliative coping recorded at diagnosis accounted for a further 3% of the variance.

At 12 months: Younger participants, and those who reported high DQOL impact of diabetes at four months after diagnosis were less satisfied with their treatment at 12 months after diagnosis. Collectively these variable accounted for 25% of the variance in DTSQ total scores at 12 months after diagnosis. The DQOL impact of diabetes scale recorded at four months after diagnosis accounted for 19% of the variance in DTSQ total scores at 12 months after diagnosis. A further 6% of the variance was added by age at diagnosis.

At 24 months: DQOL impact of diabetes recorded at four months after diagnosis was the only significant independent predictor of DTSQ total scores at 24 months after diagnosis. DQOL impact of diabetes accounted for 54% of the variance.

At 36 months: DQOL worry and DQOL satisfaction at four months after diagnosis were significant independent predictors of DTSQ total scores at 36 months after diagnosis. Together these variables accounted for 62% of the variance. DQOL worry accounted for 52% of the variance in the first step of the analysis and a further 10% of the variance was added by DQOL satisfaction; individuals who express more worry about the future effects of diabetes and who reported less diabetes-related life satisfaction at four months were less satisfied with their diabetes treatment at 36 months after diagnosis.

DTSQ Perceived Frequency of Hyperglycaemia

Younger participants and those who had spent a greater number of years in education reported more frequent episodes of hyperglycaemia at 12 months after diagnosis ($r = -.28$, $p < 0.05$ and $r = .34$, $p < 0.34$, $p < 0.01$). Individuals who reported consuming a greater number of units of alcohol (per week) at diagnosis also reported more frequent episodes of hyperglycaemia at 12 months after diagnosis ($r = .29$, $p < 0.05$). None of the remaining socio-demographic variables were predictive of DTSQ perceived hyperglycaemia.

Diabetes Locus of Control (DLOC) internal blame recorded shortly after diagnosis was a good initial predictor of more frequently perceived episodes of hyperglycaemia during the first 24 months following diagnosis of Type 1 diabetes. Participants who reported greater internal blame perceived themselves as having significantly poorer glycaemic control at 4 months ($r = .30$, $p < 0.05$), at 12 months ($r = .26$, $p < 0.05$), and at 24 months ($r = .29$, $p < 0.05$) after diagnosis. This relationship was of a similar magnitude but no longer significant at 36 months after diagnosis ($r = 0.28$, $p = \text{ns}$).

In addition, DLOC chance locus of control recorded shortly after diagnosis was correlated with more frequently perceived hyperglycaemia at 4 months and at 24 months after diagnosis, and DLOC external non-health professional was correlated with perceived hyperglycaemia at 24 months after diagnosis. These relationships suggest that DLOC may be a reliable predictor of perceived control during the initial 24 months following diagnosis. In addition, chance locus of control recorded shortly after diagnosis was correlated with more frequently perceived hyperglycaemia at 4 months ($r = .29$, $p < 0.05$) and at 24 months ($r = .33$, $p < 0.05$) after diagnosis, and DLOC external non-health professional was correlated with perceived hyperglycaemia at 24 months after diagnosis ($r = .32$, $p < 0.01$). These relationships suggest that those individuals who blame themselves for the outcomes of their diabetes and participants who believe that the outcomes of their diabetes are due to chance or fate, are significantly more likely to report poorer perceived glycaemic control throughout the 24 months following diagnosis.

Table 2.8: Correlations between baseline psychosocial variables and diabetes-related outcomes at four months, and the DTSQ across time.

	DTSQ4	DTSQ 12	DTSQ 24	DTSQ 36	Hyper 4	Hyper 12	Hyper 24	Hyper 36	Hypo 4	Hypo 12	Hypo 24	Hypo 36
Baseline												
Age	.012	**.309***	.187	.289	.003	**-.278***	.059	-.085	**-.256***	-.229	-.159	-.173
Education	-.209	-.092	-.104	-.264	.050	**.336****	.066	.290	.155	.006	-.121	-.002
NART	-.119	-.228	.029	-.114	-.017	.152	-.060	.185	-.116	.156	**-.315***	.109
Social class	-.010	-.151	**-.271***	-.251	-.027	.143	-.003	.117	-.036	-.073	.054	.066
BMI	-.011	.107	.027	-.126	-.033	-.036	.010	-.131	.131	.101	.063	-.008
Exercise	.114	-.176	.044	-.009	-.064	-.085	-.168	-.094	-.056	-.007	.078	-.175
Alcohol	.054	-.059	-.168	-.199	.092	**.299***	-.129	.221	-.027	-.010	-.098	-.011
EPQ: E	.059	.129	.185	-.040	.046	-.008	.078	-.026	.037	.119	.163	.172
EPQ: N	**-.263***	**-.272***	**-.321***	**-.317***	.043	.143	.063	.168	.225	.134	-.232	.036
EPQ: P	-.051	.029	.206	-.130	-.103	-.022	-.110	-.017	-.138	-.208	-.118	.115
Consc	.083	-.207	.053	.101	-.125	-.002	-.105	-.304	.031	-.008	.002	.139
GHQ	**-.338***	-.061	-.236	-.257	.241	-.007	**.338***	.246	.138	.029	.032	-.065
Happiness	**.335****	.184	**.327***	**.313***	-.137	-.149	-.141	**-.356***	.051	.129	**.272***	.218
CHIP: P	**-.274***	-.220	-.265	**-.333***	.036	.157	**.332***	.184	**.273***	.245	-.158	.079
CHIP: I	.032	.196	.104	.060	-.038	**-.346****	.145	-.113	.064	.048	**.293***	.278
CHIP: D	.160	.053	.127	.119	.049	-.007	.088	.003	.144	.195	.124	.221
CHIP: NE	**-.438****	-.238	**-.406****	**-.405****	.204	.052	**.301***	**.417****	.175	.136	-.155	-.003
DLOC: IA	.143	.159	.222	.007	-.258	.010	.055	-.040	-.199	-.051	-.174	.111
DLOC: IB	**-.287***	-.163	-.151	**-.367***	**.300***	**.259***	**.287***	.280	.128	-.019	.019	.151
DLOC: C	**-.377****	-.201	-.204	-.001	**.293***	.098	**.329***	.029	.233	.133	-.017	.032
DLOC: EHP	-.019	.011	**-.348***	-.048	.120	.029	.251	.022	.069	.060	.085	-.035
DLOC: ENHP	-.119	.025	-.036	-.099	.118	.057	**.321***	.099	.163	.146	-.067	.087
4 months												
HbA_{1c}	-.154	.050	.085	.128	**.484****	.159	.066	.156	-.207	-.087	.109	-.079
DKNQ	.077	-.116	.104	-.061	.066	.175	-.167	-.105	-.037	.159	.081	-.007
DQOL: S	**.698****	**.464****	**.560****	**.737****	**-.278***	**-.337***	**-.414***	**-.494****	**-.260***	-.238	-.070	-.081
DQOL: I	**.686****	**.468****	**.667****	**.654****	**-.425****	**-.367****	**-.352****	**-.386***	**-.269***	**-.301***	-.107	-.084
DQOL: W	**.541****	**.331***	**.533****	**.723****	-.199	-.195	**-.306***	**-.364***	-.190	-.178	-.003	-.108
DQOL: G	**-.346****	-.217	**-.465****	**-.480****	.156	.081	**.322***	**.370***	.051	.059	-.027	-.081
N Range	68-50	65-49	55-42	41-31	69-51	65-49	55-43	41-31	69-51	64-48	56-43	41-31

Note: ** $p < 0.01$; * $p < 0.05$ (2-tailed). Correlations for social class are based on Spearman's correlation coefficients

Abbreviations: NART = National Adult Reading Test; BMI = Body mass index; EPQ = Eysenck Personality Questionnaire; N = Neuroticism; E = Extraversion; P = Psychoticism; Consc = Conscientiousness; GHQ = Psychiatric distress; CHIP = Coping with Health Injuries and Problems; P = Palliative; I = Instrumental; D = Distraction; NE = Negative-emotion; DLOC = Diabetes Locus of Control; IA = Internal autonomy; IB = Internal blame; C = Chance; EHP = External health professional; ENHP = External non-health professional; HbA_{1c} = Glycaemic control; DKNQ = Diabetes Knowledge Questionnaire; DQOL = Diabetes Quality of Life; S = Satisfaction; I = Impact; W = Worry; G = General well-being.

Table 2.9: Multiple regression analyses to identify the independent predictors of DTSQ total scores, perceived hyperglycaemia and perceived hypoglycaemia across time.

Step/Variable	Adjusted R^2	R^2 Increment	*F* Change (*p*)	Part Corr. (*p*)
DTSQ 4 months (N = 42)	.56			
DQOL: Satisfaction		.53	48.33 (.001)	.71 (.001)
CHIP: Palliative		.03	28.12 (.001)	-.21 (.05)
DTSQ 12 months (N = 51)	.25			
DQOL: Impact		.19	12.99 (.001)	.40 (.002)
Age		.06	9.45 (.001)	.27 (.05)
DTSQ 24 months (N = 40)	.54			
DQOL: Impact			47.58 (.001)	.74 (.001)
DTSQ 36 months (N = 33)	.62			
DQOL: Worry		.52	36.60 (.001)	.36 (.002)
DQOL: Satisfaction		.10	27.85 (.001)	.33 (.004)
Hyper 4 months (N = 53)	.36			
HbA$_{1c}$		.22	16.01 (.001)	.49 (.001)
DQOL: Impact		.09	12.82 (.001)	-.28 (.02)
DLOC: Internal blame		..05	10.95 (.001)	.25 (.05)
Hyper 12 months (N = 49)	.32			
DQOL: Impact		.14	9.11 (.004)	-.39 (.002)
Age		.10	8.78 (.001)	-.31 (.01)
Education		.08	8.60 (.001)	-.29 (.02)
Hyper 24 months (N = 37)	.25			
DQOL: Impact		.18	8.82 (.005)	-.38 (.01)
DLOC: External non-prof.		.07	6.99 (.003)	.30 (.05)
Hyper 36 months (N = 32)	.34			
Happiness			17.25 (.001)	-.60 (.001)
Hypo 4 months (N = 65)	.11			
DQOL: Impact			8.72 (.004)	-.35 (.004)
Hypo 12 months (N = 59)	.08			
DQOL: Impact			5.78 (.02)	-.30 (.02)
Hypo 24 months (N = 41)	.13			
CHIP: Instrumental			7.25 (.01)	.39 (.01)

Individual differences in illness-related coping ability at diagnosis were related to the perceived frequency of hyperglycaemia following diagnosis. Instrumental coping was inversely correlated with the perceived frequency of hyperglycaemia at 12 months after diagnosis ($r = -.35$, $p < 0.01$); individuals who used more problem-focussed coping at diagnosis perceived themselves as having better glycaemic control at 12 months after diagnosis. This relationship did not persist in future follow-ups. Negative-emotion focussed coping was significantly correlated with greater perceived frequency of hyperglycaemia at 24 months ($r = .30$, $p < 0.05$) and this relationship increased in magnitude at 36 months ($r = .42$, $p < 0.01$) after diagnosis. Palliative coping at diagnosis was significantly correlated with the perceived frequency of hyperglycaemia at 24 months after diagnosis ($r = .33$, $p < 0.05$). These results suggest that individuals who used more task-oriented coping initially are more likely to report good perceived glycaemic control after 12 months. In contrast respondents who reported high emotion-focussed coping at diagnosis were at risk of poorer perceived glycaemic control in later follow-ups at 24 months and at 36 months after diagnosis.

Less psychiatric distress at diagnosis was correlated with less perceived hyperglycaemia at 24 months after diagnosis ($r = .34$, $p < 0.05$), and individuals who were happier at diagnosis reported experiencing less frequent episodes of hyperglycaemia at 36 months after diagnosis ($r = -.36$, $p < 0.05$).

Intercorrelations between diabetes-related outcomes at four months after diagnosis and the perceived frequency of hyperglycaemia at each periodic review were examined (Table 2.8). Poor glycaemic control at four months after diagnosis was significantly correlated with greater perceived frequency of hyperglycaemia at four months after diagnosis ($r = .48$, $p < 0.01$). DQOL satisfaction and DQOL impact of diabetes were significantly correlated with the perceived frequency of hyperglycaemia reported at all follow-ups (all r's between -.28 and -.49, $p < 0.05$). DQOL worry and DQOL general well-being recorded at four months after diagnosis were significantly correlated with the perceived frequency of hyperglycaemia in later follow-ups at 24 months ($r = -.31$ and .32, respectively, both $p < 0.05$) and at 36 months ($r = -.36$ and .37, respectively, both $p < 0.05$) after diagnosis.

Multiple regression analyses were used to identify the independent predictors of the perceived frequency of hyperglycaemia at each review. These results are displayed in Table 2.9.

At 4 months: Glycaemic control at four months after diagnosis accounted for 22% of the variance in the perceived frequency of hyperglycaemia at four months after diagnosis; objective measures of glycaemic control (HbA_{1c}) were significantly related to subjective perceptions of glycaemic control in the early stages of diabetes self-management. DQOL impact of diabetes at four months after diagnosis and DLOC internal blame recorded at diagnosis accounted for a further 14% of the variance in the perceived frequency of hyperglycaemia at four months after diagnosis. DQOL impact of diabetes accounted for 9% of the variance and a further 5% was added by DLOC internal blame.

At 12 months: Instrumental coping at diagnosis was an independent predictor of less frequently perceived episodes of hyperglycaemia at 12 months after diagnosis, accounting for 14% of the variance. Age and educational background accounted for a further 10% and 8% of the variance, respectively. Older adults and those participants who had spent longer in education reported less frequent episodes of perceived hyperglycaemia at 12 months after diagnosis.

At 24 months: DQOL impact of diabetes at four months after diagnosis accounted for 18% of the variance in the perceived frequency of hyperglycaemia at 24 months after diagnosis. DLOC external non-health professional recorded at 3-6 weeks after diagnosis added a further 7% of the variance.

At 36 months: Happiness at diagnosis was an independent predictor of the perceived frequency of hyperglycaemia at 36 months after diagnosis. Happiness alone accounted for 34% of the variance; happier individuals at diagnosis were less likely to perceive themselves as having poor glycaemic control.

Perceived Frequency of Hypoglycaemia

Older adults reported less frequent episodes of perceived hypoglycaemia than younger adults at four months after diagnosis ($r = -.26$, $p < 0.05$). This relationship was not significant in later follow-ups. High scores on the National Adult Reading Test at diagnosis were predictive of less frequently perceived episodes of hypoglycaemia at 24 months after diagnosis ups ($r = -.31$, $p < 0.05$), but this relationship did not persist at 36 months after diagnosis.

Palliative coping was positively correlated with the perceived frequency of hypoglycaemia at four months after diagnosis ($r = .27$, $p < 0.05$). This relationship did not remain consistent in future follow-ups, however, at the 12 month review the magnitude of the correlation coefficient was similar to that at four months ($r = .24$) but was not significant. This is likely to be due to a reduction in the power available to detect a significant effect. Instrumental coping and happiness were positively correlated with the perceived frequency of hypoglycaemia at 24 months ($r = .27$ and $.29$, respectively, both $p < 0.05$) after diagnosis and had similar but non-significant correlation coefficients at 36 months after diagnosis ($r = .22$ and $.28$, respectively, $p =$ ns). These results suggest that individuals who take a problem-focussed approach to managing their diabetes at diagnosis may be more at risk of perceived low blood sugar but not perceived high blood sugar. This was perhaps a result of their efforts to maintain blood glucose levels within the normal (non-diabetic) range. None of the baseline psychological and social factors were significant predictors of the perceived frequency of hypoglycaemia at 12 months or at 36 months after diagnosis.

The relationships between diabetes-related outcomes at four months after diagnosis and the perceived frequency of hypoglycaemia across each review were examined (Table 2.8). Glycaemic control and diabetes knowledge were not significantly correlated with the perceived frequency of hypoglcyaemia. DQOL impact of diabetes was a consistent predictor of the perceived frequency of hypoglycaemia at four months ($r = -.27$, $p < 0.05$) and at 12 months ($r = -.30$, $p < 0.05$) after diagnosis, but this relationship had diminished at the 24 months and 36 month reviews. DQOL life satisfaction was significantly correlated with the perceived frequency of hypoglycaemia at four months after diagnosis ($r = -.26$, $p < 0.05$). The results suggest that self-reported quality of life, in particular, high life satisfaction and low impact of diabetes during the first 12 months after development of the disorder are predictive of less frequently perceived episodes of hypoglycaemia. None of the diabetes-related outcomes recorded at four months after diagnosis were long-term predictors of the perceived frequency of hypoglycaemia at 24 months or at 36 months after diagnosis.

Using multiple regression analyses it was possible to identify significant independent predictors of the perceived frequency of hypoglycaemia at each follow-up (Table 2.9).

At 4 months: DQOL impact of diabetes at four months accounted for 11% of the variance in the perceived frequency of hypoglycaemia at four months after diagnosis; those who reported that diabetes placed a greater burden on their quality of life were more likely to report frequent episodes of hypoglycaemia.

At 12 months: The DQOL impact of diabetes subscale alone accounted for 8% of the variance in the perceived frequency of hypoglycaemia.

At 24 months: Those participants who reported more instrumental focussed coping at diagnosis reported greater perceived hypoglycaemia at 24 months after diagnosis. Instrumental coping accounted for 13% of the variance.

At 36 months: There were no significant independent predictors of the perceived frequency of hypoglycaemia at 36 months after diagnosis.

Summary

The results of the EPDS have shown that DTSQ has good temporal stability over a three year period. The individual items that measure the perceived frequency of hyperglycaemia and hypoglycaemia remained moderately stable initially but had poor reliability over longer durations. Intercorrelations between the subscales of the DTSQ revealed that treatment satisfaction is inversely correlated with the perceived frequency of hyperglycaemia, but there was no relationship between treatment satisfaction and the perceived frequency of hypoglycaemia.

Social and educational factors were related to the DTSQ but there were no consistent predictors of DTSQ across all follow-ups. In general, older adults and people who were married or living with a partner were more satisfied with their diabetes treatment and reported less frequent episodes of hyperglycaemia than younger adults at 12 months after diagnosis. In later follow-ups the relationship between age and treatment satisfaction did not persist, but the presence of a spouse or partner at home may be a good long term predictor of treatment satisfaction up to as long as 36 months after diagnosis.

Low socio-economic status and additional health problems at diagnosis were predictive of less treatment satisfaction at 24 months after diagnosis. None of the social and educational factors recorded at diagnosis were associated with treatment satisfaction at 36 months after diagnosis.

Psychological factors were important predictors of a person's satisfaction with their insulin therapy. In particular, high neuroticism was a consistent predictor of treatment satisfaction across the whole duration of the study. Other long term predictors of treatment satisfaction included a person's self-rated happiness and their use of negative-emotion focussed coping at diagnosis. These relationships were consistent across the follow-up waves with the exception of the 12 month review. Correlations between the individual difference measures recorded at diagnosis and the individual items were less uniform. Diabetes Locus of Control appeared to be a good predictor of the perceived frequency of hyperglycaemia. For example, high internal blame at diagnosis was a consistent predictor of the perceived frequency of hyperglycaemia between diagnosis and 24 months after diagnosis and the results indicated that negative-emotion coping at diagnosis may be a risk factor for poorer perceived control beyond the first year of treatment.

In adults, individual differences in diabetes-related quality of life recorded shortly after diagnosis was an excellent predictor of overall treatment satisfaction across all follow-ups. In particular, the correlations between the DQOL satisfaction and DQOL impact of diabetes subscales, and DTSQ total scores were moderate to high in magnitude (all r's above .46). In multiple regression analyses, these measures shared common variance. Taken independently, DQOL satisfaction and DQOL impact of diabetes were able to account for over 50% of the variance in DTSQ total scores at 4 months and at 24 months after diagnosis, respectively. The perceived burden of insulin therapy at four months after diagnosis was also an independent predictor of the perceived frequency of hyperglycaemia across time, accounting for as much as 18% of the variance, and the perceived frequency of hypoglycaemia during the first 12 months of insulin therapy.

Diabetes quality of life

The fourth aspect of coping referred to in the introduction is a person's diabetes-related quality of life. The best measure of diabetes-specific quality of life available is the Diabetes Quality of Life (DQOL) measure which was developed in the 1980's for use in the Diabetes Control and Complications Trial (DCCT, 1986, 1987, 1988). The scale was intended to measure a range of issues directly relevant to diabetes and its treatment. The DQOL measure contains three core dimensions; diabetes life satisfaction, impact of diabetes, and worry about the future effects of diabetes and social/vocational issues. In addition there is an individual item which measures general (health-related) well-being.

Prior to the development of the DQOL there were no readily available diabetes-specific measures of quality of life. Therefore previous measurements of quality of life had often relied on generic scales such as the Sickness Impact Profile (Bergner, Bobbitt, Carter and Gibson, 1981) and the Quality of Well-being Scale (Bush and Kaplan, 1982) which are applicable to other disease groups. One of the problems with this approach is that these instruments may not be sensitive to the disease-specific demands of treatment and changes in lifestyle that are brought about as a result of diabetes self-management.

Since the development of the DQOL it has been used in a variety of studies. The studies to date provide support for the scale's reliability (DCCT, 1988), validity (DCCT, 1988; Jacobson, de Groot and Samson, 1994) and sensitivity to change (Nathan et al., 1991; Selam et al., 1992). It is the aim of the present study to add further evidence to support the reliability and validity of this measure, and to provide the first assessment of the natural history of diabetes-specific quality of life, in adults, from the time of diagnosis of Type 1 diabetes.

Stability of individual differences and changes in mean levels of the dimensions of the Diabetes Quality of Life measure across time

There was no significant difference in the mean scores of the DQOL satisfaction subscale between diagnosis and four months after diagnosis, however, DQOL satisfaction increased significantly between four months and 12 months (t [33] = -.3.30, $p < 0.01$), four months and 24 months (t [33] = -.2.75, $p < 0.01$) and four months and 36 months (t [33] = -2.30, $p < 0.05$) after diagnosis. There were no significant changes in the mean levels of DQOL impact of diabetes, DQOL worry and DQOL general well-being over the 36 months duration of the study.

The stability coefficients of the DQOL subscales across successive follow-ups were examined (between baseline and four months, four and 12 months, 12 and 24 months, and 24 and 36 months). DQOL satisfaction ($n = 34$) remained highly stable throughout the period of study (all r's between .69 and .86, $p < 0.001$). DQOL impact of diabetes ($n = 34$) also had good within subjects stability across time (all r's between .71 and .90, $p < 0.001$). The stability coefficients for DQOL worry about the future affects of diabetes ($n = 20$) and DQOL general well-being ($n = 30$) were high across the epoch (all r's between

.66 and .86, $p < 0.001$). These results provide evidence of excellent within subjects stability of the dimensions of the DQOL throughout 36 months duration.

Intercorrelations between the dimensions of the Diabetes Quality of Life measure across time

Intercorrelations between the dimensions of the DQOL measure at four months after diagnosis and at subsequent follow-ups at 12 months, 24 months and 36 months after diagnosis were examined. The four month review was used for each comparison rather than the baseline measurement to ensure that the participants scores for each dimension were based on sufficient experience of diabetes self-management.

There was considerable overlap in the dimensions of the DQOL measure and evidence to suggest that these relationships were highly consistent across time. In particular, the three subscales DQOL satisfaction, DQOL impact and DQOL worry recorded at four months after diagnosis were highly related (all r's between .69 and .75, $p < 0.01$), and these relationships remained consistent across successive follow-ups at 12 months, 24 months and 36 months after diagnosis (all r's between .49 and .80, $p < 0.01$).

The individual item that measured DQOL general well-being at four months after diagnosis was inversely correlated with DQOL satisfaction and DQOL impact of diabetes across all follow-ups (all r's between -.48 and -.60, $p < 0.01$). DQOL general well-being at four months after diagnosis was also inversely correlated with DQOL worry at four months ($r = -.68$, $p < 0.01$) and at 12 months ($r = -.70$, $p < 0.01$) after diagnosis but this relationship did not persist at 24 months or at 36 months after diagnosis.

The effect of socio-demographic characteristics of the individual at diagnosis on the dimensions of Diabetes Quality of Life

Female participants reported poorer DQOL general well-being at 36 months after diagnosis than males ($t [37] = 2.26$, $p < 0.05$). There were no other significant sex differences in diabetes quality of life.

Those participants who were admitted to hospital at the time of diagnosis of Type 1 diabetes reported having a poorer quality of life during the four months following diagnosis than individuals who were treated as outpatients. Independent samples t-tests revealed that individuals who were admitted to hospital at diagnosis experienced greater impact of diabetes ($t [67] = 2.85$, $p < 0.01$), and poorer general well-being ($t [61] = -2.97$, $p < 0.01$) four months later than did those individuals who were not admitted to hospital. At 12 months after diagnosis no significant differences were observed between these groups. However, individuals who were admitted to hospital at diagnosis reported significantly poorer DQOL general well-being at 24 months after diagnosis ($t [49] = -2.37$, $p < 0.05$) and this relationship was consistent at 36 months after diagnosis ($t [37] = -2.07$, $p < 0.05$). Being admitted at diagnosis was also predictive of greater DQOL worry at 36 months after diagnosis ($t [29] = 2.50$, $p < 0.05$). The results suggest that being admitted to hospital at diagnosis has a long lasting effect on an individual's subjective health-related well-being.

Individuals who had additional comorbid problems at the time of diagnosis were also at risk of poor self-reported quality of life. Having comorbid problems at diagnosis was a consistent predictor of DQOL general well-being at four months (t [60] = -2.79, $p < 0.01$), 12 months (t [57] = -2.69, $p < 0.01$), 24 months (t [48] = -3.59, $p < 0.001$) and 36 months (t [37] = -2.70, $p < 0.01$) after diagnosis. The magnitude of the effect of comorbid problems on DQOL general well-being was greatest at 24 months after diagnosis. Those who had comorbid problems at diagnosis were significantly more likely to worry about the future effects of diabetes at 4 months (t [58] = 2.60, $p < 0.05$) and at 12 months (t [44] = 2.53, $p < 0.05$) after diagnosis, but this relationship was not present at 24 months and at 36 months after diagnosis. In addition, the presence of comorbid problems at diagnosis was predictive of DQOL impact of diabetes at four months after diagnosis (t [66] = 2.39, $p < 0.05$) and at 24 months (t [52] = 2.39, $p < 0.05$) after diagnosis but this relationship was not present at 12 months or at 36 months after diagnosis. None of the remaining social and demographic characteristics measured in this study were predictive of diabetes quality of life.

In general these results provide evidence to suggest that individuals who are more sick at diagnosis, either due to ketoacidosis requiring admission to hospital or additional illnesses aside from diabetes, are at risk of having poorer quality of life including a greater perceived burden of the illness and poor self-rated well-being. Furthermore these differences in self-reported well-being in particular, are consistent across time and are present up to 36 months after diagnosis.

Psychosocial correlates and independent predictors of Diabetes Quality of Life at 4, 12, 24 and 36 months after diagnosis

The relationships between psychosocial variables recorded at diagnosis and the dimensions of the Diabetes Quality of Life (DQOL) measure are shown in the top half of Table 2.10. The intercorrelations between the four month outcomes of diabetes described in the introduction and the dimensions of the DQOL measure across each review are shown in the bottom half of Table 2.10. Multiple regression analyses were used to identify the baseline and four month predictors of the dimensions of the DQOL measure at each review. These results are shown in a series of tables (Tables 2.11 to 2.14). The numbers of individuals included in each regression analysis is provided in the appropriate table.

DQOL Satisfaction

Educational background (years) was negatively correlated with DQOL satisfaction at four months after diagnosis ($r = -.30$, $p < 0.05$) but this relationship had disappeared in future follow-ups. None of the remaining socio-demographic factors were significantly correlated with DQOL satisfaction.

Individual differences in psychological factors at diagnosis including neuroticism (all r's between -.33 and -.40, $p < 0.01$), happiness (all r's between .37 and .49, $p < 0.01$) and negative-emotion focussed coping (all r's between -.29 and -.36, $p < 0.05$) were reliable long term predictors of DQOL satisfaction across all follow-ups. Palliative coping was inversely correlated with DQOL satisfaction across time (all r's between -.28 and -.34, $p < 0.05$) with the exception of the 24 month review. Greater psychiatric distress at three to six weeks after diagnosis was significantly correlated with poor DQOL satisfaction at four months ($r = -.39$, $p < 0.01$), 12 months ($r = -.36$, $p < 0.01$) and 24 months ($r = -.32$, $p < 0.05$) after diagnosis but there was no significant relationship between these variables at the 36 month review. Individuals who scored highly on the personality trait, conscientiousness, at diagnosis had high scores on DQOL satisfaction at four months after diagnosis ($r = .29$, $p < 0.05$) but this relationship was not present in later follow-ups. High internal blame at diagnosis was negatively correlated with DQOL satisfaction at four months after diagnosis ($r = -.30$, $p < 0.05$) but there was no significant relationship between these variables at 12 months, 24 months or at 36 months after diagnosis. Chance locus of control was inversely correlated with DQOL satisfaction at 12 months after diagnosis ($r = -.30$, $p < 0.05$). In general these results suggest that psychological factors such as high scores on the personality dimension neuroticism and emotion focussed coping at diagnosis are reliable indicators of poor self reported life satisfaction following diagnosis of Type 1 diabetes.

Investigation of the relationships between diabetes-related outcomes at four months after diagnosis and DQOL satisfaction across time revealed that glycaemic control and diabetes knowledge were not significantly correlated with diabetes-related life satisfaction throughout the 36 months post diagnosis. However, Diabetes Treatment Satisfaction Questionnaire total scores at four months after diagnosis were consistently and highly related to DQOL satisfaction scores across all follow-ups (all r's between .62 and .70, $p < 0.01$) indicating that these measures may share some common variance. The individual items of the DTSQ which measure the perceived frequency of hyperglycaemia and the perceived frequency of hypoglycaemia were negatively correlated with DQOL satisfaction at four months ($r = -.28$ and -.26, respectively, both $p < 0.05$) and at 12 months ($r = -.28$ and -.29, respectively, both $p < 0.05$) after diagnosis but not at 24 months and 36 months after diagnosis. These results suggest that i) the DTSQ and the DQOL satisfaction scale are highly related, and ii) in the early stages of diabetes self-management treatment perceptions and perceived glycaemic control may be important predictors of DQOL satisfaction.

The independent predictors of DQOL satisfaction at four months, 12 months, 24 months and 36 months after diagnosis are discussed below. These results are displayed in Table 2.11.

At four months: DTSQ total scores recorded at four months after diagnosis were significantly predictive of DQOL satisfaction accounting for 46% of the variance.

Conscientiousness and educational background recorded at diagnosis were also predictive of DQOL satisfaction throughout the four months following diagnosis. These variables explained 11% of the variance; 4% of the variance was accounted for by conscientiousness and a further 7% was added by educational background.

At 12 months: High treatment satisfaction at four months after diagnosis and greater happiness at diagnosis were predictive of high scores on DQOL satisfaction at 12 months after diagnosis. Collectively these variables accounted for 48% of the variance in DQOL satisfaction. DTSQ total scores explained 42% of the variance in the first step of the analysis and happiness added a further 6% of the variance.

At 24 months: DTSQ total scores at four months after diagnosis and happiness at diagnosis accounted for 47% of the independent variance in DQOL satisfaction at 24 months after diagnosis; DTSQ accounted for 36% of the variance and a further 11% of the variance was added by happiness.

At 36 months: DTSQ total scores at four months after diagnosis accounted for 38% of the variance in DQOL satisfaction at 36 months after diagnosis. The personality dimension, neuroticism, was also predictive of DQOL satisfaction at 36 months after diagnosis accounting for a further 10% of the variance. Collectively these variables explained 48% of the variance.

DQOL Impact of diabetes

The correlations between baseline psychosocial variables and DQOL impact of diabetes are provided in Table 2.10. The DQOL impact of diabetes scale is scored so that higher ratings indicate less self-reported burden of the illness.

Participants who had spent longer in education reported more DQOL impact of diabetes at 24 months after diagnosis ($r = -.29$, $p < 0.05$). None of the other socio-demographic characteristics were significantly correlated with DQOL impact of diabetes. Individuals who reported high levels of psychiatric distress (all r's between -.46 and -.59, $p < 0.01$), less happiness (all r's between .48 and .53, $p < 0.01$), greater negative-emotion focussed coping (all r's between -.43 and -.57, $p < 0.01$), and greater palliative coping (all r's between -.28 and -.40, $p < 0.05$) at diagnosis, experienced greater DQOL impact of diabetes. These correlations were highly consistent and significant across all follow-ups (at four months, 12 months, 24 months and 36 months) after diagnosis. Individuals who obtained high scores on the personality trait, neuroticism, reported greater DQOL impact of diabetes at 4 months ($r = -.36$, $p < 0.01$), 12 months ($r = -.30$, $p < 0.01$) and 24 months ($r = -.28$, $p < 0.01$) after diagnosis but this relationship was significant at 36 months after diagnosis. DLOC internal autonomy was predictive of less DQOL impact of diabetes, whereas DLOC chance was predictive of greater DQOL impact of diabetes at four months ($r = .31$, $p < 0.05$ and $r = -.41$, $p < 0.01$, respectively), and 12 months ($r = .27$, $p < 0.05$ and $r = -.31$, $p < 0.01$, respectively) after diagnosis but these relationships did not persist at 24 months and 36 months after diagnosis. In adults, individual differences in longstanding psychological factors such as coping ability, psychiatric well-being and personality are consistently related to the perceived burden of the diabetes throughout the 36 months following initial diagnosis of Type 1 diabetes.

The relationships between diabetes-related outcomes recorded at four months after diagnosis and DQOL impact of diabetes at each review are shown in the bottom half of Table 2.2.8. DTSQ total scores at four months after diagnosis were strongly associated with less DQOL impact of diabetes across all follow-ups (all r's between .69 and .72, $p < 0.01$). The consistency of these correlations was high and their magnitude increased over time. The perceived frequency of hyperglycaemia at four months after diagnosis was a consistent predictor of greater DQOL impact of diabetes at all follow-ups (all r's between -.36 and -.43, $p < 0.05$). The perceived frequency of hypoglycaemia was predictive of high DQOL impact of diabetes at 4 months ($r = -.27$, $p < 0.05$), 12 months ($r = -.48$, $p < 0.01$) and 24 months ($r = -.54$, $p < 0.01$) after diagnosis but not at 36 months after diagnosis. HbA_{1c} and diabetes knowledge were not significantly correlated with self-reported DQOL impact of diabetes.

The results of the multiple regression analyses to identify the independent predictors of DQOL impact of diabetes are shown in Table 2.12.

At four months: DTSQ total scores recorded at four months after diagnosis and self-rated happiness at diagnosis accounted for 55% of the variance in DQOL impact of diabetes at four months after diagnosis. DTSQ total scores accounted for the majority of the variance (50%) in the first step of the analyses, a further 5% was added by happiness.

At 12 months: Individuals who reported less treatment satisfaction, greater psychiatric distress, more frequent episodes of hypoglycaemia, and who were less happy shortly after diagnosis, reported experiencing a greater psychological burden of diabetes at 12 months after diagnosis. Collectively these variables accounted for 67% of the variance in DQOL impact of diabetes. DTSQ total scores at four months after diagnosis accounted for 42% of the variance, a further 14% of the variance was accounted for by recent psychiatric distress recorded at three to six weeks after diagnosis. The frequency of perceived hypoglycaemia at four months after diagnosis, and happiness at diagnosis added a further 6% and 5% of the variance respectively.

At 24 months: DTSQ total scores, psychiatric distress, educational background and the perceived frequency of hypoglycaemia were predictive of DQOL impact of diabetes at 24 months after diagnosis. These variables accounted for 69% of the variance. DTSQ total scores accounted for 54% of the variance in the first step of the analysis, a further 6% was added by psychiatric distress, the remaining 9% of the variance was explained by educational background and perceived hyperglycaemia.

At 36 months: The independent predictors of DQOL impact of diabetes at 36 months after diagnosis were DTSQ total scores at four months after diagnosis and happiness. DTSQ total scores accounted for 56% of the variance and a further 10% was added by happiness at diagnosis.

Table 2.10: Correlations between baseline psychosocial variables and diabetes-related outcomes at four months, and the dimensions of the Diabetes Quality of Life measures across time

	DQOL: Satisfaction				DQOL: Impact				DQOL: Worry				DQOL: General well-being			
Months:	4	12	24	36	4	12	24	36	4	12	24	36	4	12	24	36
Baseline																
Age	.088	.091	.051	.079	.034	.103	.114	.018	.016	.058	.163	-.097	.194	.123	.150	.077
Education	**-.300***	-.220	-.215	-.225	-.198	-.182	**-.291***	-.231	**-.335***	-.157	-.263	**-.434***	.082	.001	.167	.199
NART	-.040	.009	-.122	-.152	-.118	-.065	-.163	-.180	-.126	-.186	-.358	-.339	-.015	.154	.206	.170
Social class	-.088	-.108	-.124	-.178	-.056	.009	-.036	-.197	-.015	.018	.224	.335	.018	-.006	-.047	-.192
BMI	-.206	-.158	-.015	-.158	-.113	-.200	-.017	.019	**-.352****	-.213	-.173	-.091	.178	.155	.255	.229
Exercise	.106	-.043	.008	.085	.011	-.026	.029	.106	-.208	-.233	**-.355***	.001	-.101	.011	-.020	.001
Alcohol	.094	-.087	.058	-.212	.043	-.028	-.111	-.144	.123	.048	.023	.069	-.048	-.014	.091	.093
EPQ: E	-.010	.187	.187	.100	.061	.033	-.031	-.021	-.010	**.297***	**.343***	.018	-.125	-.086	.122	.183
EPQ: N	**-.334****	**-.402****	**-.371****	**-.403****	**-.359****	**-.301****	**-.283***	-.183	**-.301***	**-.459****	**-.348***	-.033	**.286***	**.259***	.212	.180
EPQ: P	.010	.070	.113	-.145	.116	.142	.229	.052	.054	.071	.050	-.008	-.199	-.150	-.216	-.143
Consc	**.288***	.191	.110	.246	.239	.200	.113	.097	.105	.081	.088	**.355***	-.213	.050	.056	-.177
GHQ	**-.395****	**-.363****	**-.324***	-.242	**-.468****	**-.590****	**-.460****	**-.475****	**-.353***	-.245	-.117	-.116	**.505****	**.532****	**.490****	**.456****
Happiness	**.367****	**.493****	**.464****	**.419****	**.494****	**.534****	**.479****	**.518****	**.505****	**.598****	**.445****	.208	**-.668****	**-.527****	**-.358****	**-.552****
CHIP: P	**-.285***	**-.307***	-.246	**-.336***	**-.293***	**-.282***	**-.403****	**-.333***	**-.363****	**-.400****	-.208	-.045	.212	.212	**.308***	.079
CHIP: I	.145	.047	-.125	.138	.108	-.025	-.059	-.050	.072	-.080	-.130	.197	-.034	.007	-.009	-.073
CHIP: D	.083	.071	.111	.255	.048	-.032	-.030	.077	-.128	-.028	-.143	.167	-.122	-.129	.036	-.059
CHIP: NE	**-.362****	**-.352****	**-.295***	**-.362***	**-.511****	**-.426****	**-.475****	**-.572****	**-.455****	**-.531****	**-.348****	-.184	**.394****	**.338****	.255	**.327***
DLOC: IA	.110	.195	.026	-.060	.312*	**.272***	.171	.141	.167	.094	.159	.160	-.318*	-.267	-.122	-.282
DLOC: IB	**-.303***	-.204	-.227	-.257	-.200	-.218	-.187	-.186	-.126	-.149	.007	.155	.038	.118	.161	-.066
DLOC: C	-.245	**-.301***	-.211	.065	**-.406****	**-.311****	-.221	-.147	-.214	-.214	-.215	-.093	.132	.226	.046	-.117
DLOC: EHP	.040	-.063	-.104	-.023	-.019	-.092	-.092	-.043	-.068	-.011	-.056	.067	-.225	-.054	-.073	-.167
DLOC: ENHP	-.115	-.033	.080	-.033	-.165	-.152	-.069	-.092	-.285*	-.186	-.176	-.315	-.009	-.052	-.100	-.063
4 months																
HbA1c	-.052	.089	.074	.082	-.048	.112	.138	.054	.187	.185	.186	.078	.048	-.054	.040	.015
DKNQ	.067	.063	.195	.113	.048	.026	.099	.097	-.034	-.040	**-.337***	-.210	-.225	.035	-.011	.011
DTSQ	**.698****	**.675****	**.645****	**.629****	**.686****	**689****	**.721****	**.725****	**.541****	**.425****	.295	.182	**-.346****	**-.481****	**-.410****	**-.357***
Hyper	**-.278***	**-.281***	-.166	-.115	**-.425****	**-.432****	**-.401****	**-.357***	-.199	-.279	-.122	-.051	.156	**.276***	**.343***	.280
Hypo	**-.260***	**-.295***	-.217	-.048	**-.269***	**-.484****	**-.545****	-.305	-.190	-.226	**-.368***	-.109	.051	.151	.192	.252

Table 2.11: Multiple regression analyses to identify the independent predictors of the DQOL satisfaction across time.

Step/Variable	Adjusted R^2	R^2 Increment	*F* Change (*p*)	Part Corr. (*p*)
Satisfaction 4 months (N = 48)	.57			
DTSQ total		.46	41.42 (.001)	.61 (.001)
Conscientiousness		.04	25.33 (.001)	.27 (.01)
Education		.07	22.05 (.001)	-.27 (.01)
Satisfaction 12 months (N = 49)	.48			
DTSQ total		.42	36.02 (.001)	.55 (.001)
Happiness		.06	23.97 (.001)	.28 (.01)
Satisfaction 24 months (N = 44)	.47			
DTSQ total		.39	29.60 (.001)	.52 (.001)
Happiness		.08	20.33 (.001)	.29 (.01)
Satisfaction 36 months (N = 38)	.48			
DTSQ total		.38	24.24 (.001)	.58 (.001)
Neuroticism		.10	18.22 (.001)	-.33 (.01)

Table 2.12: Multiple regression analyses to identify the independent predictors of the DQOL impact of diabetes across time.

Step/Variable	Adjusted R^2	R^2 Increment	*F* Change (*p*)	Part Corr. (*p*)
Impact 4 months (N = 51)	.55			
DTSQ total		.50	50.94 (.001)	.62 (.001)
Happiness		.05	31.73 (.001)	.24 (.01)
Impact 12 months (N = 50)	.67			
DTSQ total		.42	37.84 (.001)	.34 (.001)
GHQ		.14	32.77 (.001)	-.27 (.002)
Perceived hypoglycaemia		.06	28.25 (.001)	-.29 (.001)
Happiness		.05	26.78 (.001)	.24 (.005)
Impact 24 months (N = 42)	.69			
DTSQ total		.54	50.45 (.001)	.45 (.001)
GHQ		.06	32.71 (.001)	-.25 (.006)
Education		.05	27.63 (.001)	-.22 (.01)
Perceived hypoglycaemia		.04	24.54 (.001)	-.20 (.02)
Impact 36 months (N = 34)	.66			
DTSQ total		.56	45.06 (.001)	.63 (.001)
Happiness		.10	34.60 (.001)	.33 (.002)

Table 2.13: Multiple regression analyses to identify the independent predictors of the DQOL worry about the future affects of diabetes and social/vocational issues across time.

Step/Variable	Adjusted R^2	R^2 Increment	*F* Change (*p*)	Part Corr. (*p*)
Worry 4 months (N = 43)	.59			
DTSQ total		.32	20.91 (.001)	.37 (.001)
Neuroticism		.12	17.63 (.001)	-.37 (.001)
Education		.10	17.67 (.001)	-.31 (.003)
Body mass index		.05	16.34 (.001)	-.24 (.02)
Worry 12 months (N = 40)	.54			
Happiness		.39	26.25 (.001)	.41 (.001)
Neuroticism		.11	20.79 (.001)	-.33 (.004)
DTSQ total		.04	16.79 (.001)	.23 (.04)
Worry 24 months (N = 33)	.42			
Happiness		.22	10.29 (.003)	.42 (.003)
DTSQ total		.10	8.75 (.001)	-.38 (.007)
Exercise		.10	9.03 (.001)	-.34 (.02)
Worry 36 months (N = 28)	.16			
Education			6.26 (.02)	-.43 (.02)

Table 2.14: Multiple regression analyses to identify the independent predictors of the DQOL general well-being across time.

Step/Variable	Adjusted R^2	R^2 Increment	*F* Change (*p*)	Part Corr. (*p*)
General well-being 4 months (N = 47)	.53			
Happiness			54.77 (.001)	-.74 (.001)
General well-being 12 months (N = 48)	.54			
Happiness		.35	27.35 (.001)	-.33 (.002)
DTSQ total		.13	23.47 (.001)	-.31 (.003)
GHQ		.06	19.42 (.001)	.24 (.02)
General well-being 24 months (N = 42)	.48			
Happiness		.25	14.76 (.001)	-.32 (.006)
DTSQ total		.17	16.32 (.001)	.40 (.001)
GHQ		.06	14.13 (.001)	.27 (.02)
General well-being 36 months (N = 33)	.31			
Happiness			16.06 (.001)	-.58 (.001)

DQOL Worry about the future effects of diabetes and social/vocational issues

The DQOL subscale 'worry' is thought to measure some aspect of a patient's diabetes-related psychological distress (DCCT, 1988). Validation of the DQOL worry subscale has previously been done using children and adolescents with diabetes. However, as acknowledged by the authors and developers of this scale, many of the items refer to an individual's social development (e.g. "How often do you worry about whether you will get married?" and "How often do you worry about whether you will not get a job you want?"). Items such as these may not apply to adult samples who are more settled in their lives. For this reason the present study has calculated DQOL worry independently of DQOL satisfaction and DQOL impact of diabetes rather than calculating an overall DQOL total score.

The correlations between psychosocial variables recorded at diagnosis and three to six weeks after diagnosis are shown in the top half of Table 2.10. High scores on the DQOL worry subscale indicate less worry.

Educational background was a significant predictor of DQOL worry at four months ($r = -.33$, $p < 0.05$) and at 36 months ($r = -.43$, $p < 0.05$) after diagnosis; the more years an individual had spent in education the more likely they were to worry about the future effects of diabetes and social issues. High body mass index at diagnosis was significantly correlated with greater DQOL worry at 4 months after diagnosis ($r = -.35$, $p < 0.01$) but this relationship was not present in later follow-ups. Taking more regular exercise at diagnosis was predictive of less DQOL worry at 24 months after diagnosis ($r = -.35$, $p < 0.05$).

Individuals who scored highly on extraversion were less likely to worry about the future affects of diabetes and social issues at 12 months and at 24 months after diagnosis ($r = .30$ and $.34$, respectively, $p < 0.05$). In contrast, those individuals who reported high levels of neuroticism reported greater DQOL worry. Neuroticism (r's between -.30 and -.46, $p < 0.05$), happiness (r's between .44 and .60, $p < 0.01$), and negative-emotion focussed coping (r's between -.35 and -.53, $p < 0.01$) at diagnosis had the most consistent relationships with DQOL worry across time; at four months, at 12 months and at 24 months after diagnosis, but these relationships did not persist at 36 months after diagnosis. However, this may be due in part to the decline in the power available to claim a significant effect. Psychiatric distress at 3-6 weeks after diagnosis was a good predictor of DQOL worry initially, at the four month review ($r = -.35$, $p < 0.05$) but was not a long term predictor of DQOL worry. Palliative coping at diagnosis was significantly associated with greater DQOL worry at the four months ($r = -.36$, $p < 0.01$) and 12 months ($r = -.40$, $p < 0.01$) reviews but this relationship did not persist at 24 months or at 36 months after diagnosis.

The relationships between diabetes-related outcomes at four months after diagnosis and DQOL worry are shown in the bottom half of Table 2.10. There was no significant relationship between HbA_{1c} at four months after diagnosis and DQOL worry across time. Diabetes knowledge at four months after diagnosis was a significant predictor of DQOL worry at 24 months after diagnosis; participants who had better knowledge of their diabetes at four months were more likely to worry about the future affects of their diabetes and social issues at 24 months after diagnosis ($r = -.34$, $p < 0.05$). DTSQ total scores were significantly correlated with DQOL worry at four months and at 12 months after diagnosis ($r = .54$ and $.42$, respectively, both $p < 0.01$), but this relationship did not persist at 24 months and at 36 months after diagnosis. In addition, the relationships that did exist between DTSQ total scores and DQOL worry were smaller in magnitude than those obtained for DQOL: satisfaction and DQOL: impact of diabetes. Greater perceived frequency of hypoglycaemia at four months after diagnosis was predictive of greater DQOL worry at 24 months after diagnosis ($r = -.37$, $p < 0.05$).

In summary, health-related lifestyle factors such as exercise and body mass index appear to play a significant role in predicting DQOL worry. The most consistent predictors of DQOL worry were baseline psychological factors such as happiness, emotion-focussed coping and neuroticism. Treatment satisfaction at four months was also related to DQOL worry, but not in later follow-ups. This suggests that DQOL worry may differ from DQOL satisfaction and DQOL impact of diabetes by tapping more directly into a broad dimension of diabetes-related negative affectivity.

Multiple regression analyses was used to attempt to identify the independent predictors of DQOL worry across time, and to shed more light on the nature of the relationships between psychological factors and DQOL worry.

At four months: Individuals who were least satisfied with their treatment at four months after diagnosis, and those participants who scored highly on the personality dimension, neuroticism, reported more worry about the future affects of their diabetes and social issues at four months after diagnosis. DTSQ total scores accounted for 32% of the variance in the first step of the analysis, and neuroticism accounted for a further 12% of the variance. Educational background and body mass index at diagnosis also accounted for independent amounts of variance in DQOL worry about the future affects of their diabetes and social issues at four months after diagnosis. Educational background accounted for 10% of the variance, and a further 5% of the variance was added by body mass index. Collectively these variables accounted for 64% of the variance in DQOL worry at four months

At 12 months: Happiness at diagnosis was the strongest predicator of DQOL worry at 12 months after diagnosis accounting for 39% of the variance. Those participants who were less happy at diagnosis were more likely to worry about the future affects of diabetes and social issues at 12 months after diagnosis. Neuroticism was also an independent predictor of DQOL worry at 12 months after diagnosis, accounting for 11% of the variance. DTSQ total scores added a further 4% of the variance.

At 24 months: Happiness at diagnosis accounted for 22% of the variance in DQOL worry at 24 months after diagnosis. High treatment satisfaction at four months and regular exercise at diagnosis were predictive of less DQOL worry. DTSQ total scores accounted for 10% of the variance and a further 10% of the variance was added by exercise.

At 36 months: Educational background at diagnosis was a significant predictor of DQOL worry at 36 months after diagnosis, accounting for 16% of the variance. Participants who had spent longer in education had a tendency to be more worried about the future affects of diabetes and social issues at 36 months after diagnosis. There were no other significant independent predictors of DQOL worry at 36 months after diagnosis.

DQOL General well-being

The individual item DQOL general well-being asks individuals to rate their general health status on a four point scale. High scores indicate poorer self-rated well-being. Correlations between psychosocial variables recorded at baseline and general well-being are displayed in the top half of Table 2.14.

None of the social and demographic variables recorded at diagnosis were significantly correlated with DQOL general well-being in this study.

Highly consistent relationships were found between psychiatric distress (all r's between .46 and .53, $p < 0.01$) and happiness (all r's between -.36 and -.67, $p < 0.01$) at diagnosis, and DQOL general well-being across time. Negative-emotion focussed coping was also consistently correlated with DQOL general well-being at four months ($r = .39$, $p < 0.01$), 12 months ($r = .34$, $p < 0.01$) and 36 months ($r = .33$, $p < 0.05$) after diagnosis but these correlations were smaller in magnitude. The personality dimension neuroticism was significantly correlated with DQOL general well-being initially, at the four month and 12 months reviews ($r = .29$ and .26, respectively, both $p < 0.05$) but this relationship did not persist at 24 months or 36 months after diagnosis. High levels of DLOC internal autonomy were associated with good DQOL general well-being at four months after diagnosis ($r = -.32$, $p < 0.05$) but this relationship was not consistent across later follow-ups. Palliative coping was predictive of DQOL general well-being at 24 months after diagnosis ($r = .31$, $p < 0.05$).

The intercorrelations between diabetes-related outcomes at four months after diagnosis and DQOL general well-being are shown in the bottom half of Table 2.10. DTSQ total scores were moderately correlated with DQOL general well-being (all r's between -.35 and -.48, $p < 0.05$). This relationship was highly consistent across time; high treatment satisfaction at four months was predictive of good self-rated well-being up to 36 months after diagnosis. Greater perceived frequency of hyperglycaemia was predictive of poorer well-being at 12 months and at 24 months after diagnosis ($r = .27$ and .34, respectively, both $p < 0.05$). Glycaemic control and diabetes knowledge were not significantly correlated with DQOL general well-being.

The results of multiple regression analyses to identify the independent predictors of DQOL General well-being are shown in Table 2.14.

At four months: Self-rated happiness at diagnosis was a highly significant predictor of DQOL general well-being at four months after diagnosis. Happiness alone accounted for 53% of the variance.

At 12 months: Happiness at diagnosis, DTSQ total scores at four months after diagnosis and psychiatric distress at 3-6weeks after diagnosis were significant independent predictors of DQOL general well-being at 12 months after diagnosis. Happiness at diagnosis explained 35% of the variance. DTSQ total scores and psychiatric distress added a further 13% and 6 % of the variance respectively.

At 24 months: Happiness at diagnosis accounted for 25% of the independent variance in DQOL general well-being at 24 months after diagnosis. DTSQ total scores and psychiatric distress added a further 17% and 6 % of the variance respectively.

At 36 months: Happiness at diagnosis was a significant independent predictor of DQOL general well-being at 36 months after diagnosis, accounting for 31% of the variance. No other variables were significant independent predictors of DQOL general well-being in the present study.

Summary

The EPDS has examined the natural history of diabetes-quality of life in adults with newly diagnosed Type 1 diabetes throughout the first 36 months of insulin therapy. The results have provided considerable evidence to support the reliability and validity of the Diabetes Quality of Life measure (DQOL). In the present study the DQOL had excellent within subjects stability across all follow-up reviews (all r's above .66). Diabetes-related satisfaction scores increased significantly following the initial adjustment period between diagnosis and four months after diagnosis and this increase was significant at each follow-up thereafter. None of the remaining dimensions of DQOL changed significantly across time.

Intercorrelations between the core dimensions of the DQOL revealed that the satisfaction, impact and worry subscales had considerable overlap (all r's above .69 at the four month review). This implies that the subscoring of the dimensions of the DQOL may not be justified and that in future investigations a DQOL total score may provide a valid single measure of diabetes-related quality of life. In addition, the Diabetes Treatment Satisfaction Questionnaire was highly related to the dimensions of the DQOL. The relationships between DTSQ total scores, and the DQOL satisfaction and the DQOL impact subscales were particularly high at all follow-ups (all r's above .63); these measures share common variance.

Patients who were admitted to hospital at the time of diagnosis and those participants who had other illnesses in addition to their diabetes reported consistently poorer general well-being across all follow-ups. This is an important finding and one that should be recognised by health professionals so that extra support can be provided for this vulnerable group of individuals from the time of diagnosis.

In general, the results of the EPDS have highlighted a group of overlapping psychological and health-related variables that appear to be consistently related to the dimensions of the DQOL measure. In particular, high neuroticism, greater psychiatric distress, less happiness, greater emotion-focussed coping and palliative coping at diagnosis were highly consistent predictors of the DQOL satisfaction and the DQOL impact of diabetes subscales.

In multiple regression analyses diabetes treatment satisfaction at four months was the best independent predictor of DQOL satisfaction and DQOL impact at each review (all $p < 0.001$) and smaller amounts of variance were added by psychological factors such as happiness, psychiatric distress, and neuroticism. These results indicate that diabetes life satisfaction and the burden of diabetes during the 36 months following diagnosis are largely dependent on an individual's reaction to their diabetes treatment, and to a lesser extent individual differences in longstanding psychological factors (e.g. personality). However, the results of the present study suggest that the DQOL worry scale and the individual item that measures general well-being may differ from DQOL satisfaction and DQOL impact of diabetes. The DQOL worry scale appears to be measuring some additional aspect of the individual's diabetes-related psychological distress, whereas happiness at diagnosis was a consistent predictor of DQOL general well-being.

Further follow-up of longer duration is required to replicate these findings and to further investigate the temporal relationships between psychosocial variables and diabetes-related quality of life.

General summary of findings

The key findings of the EPDS are summarised below:

- Health-related behaviours (i.e. smoking and alcohol consumption) recorded at diagnosis may be early risk factors for poor glycaemic control
- Diabetes knowledge recorded at four months after diagnosis was predictive of glycaemic control at 12 months and at 36 months after diagnosis. This suggests that educational interventions put in place shortly after diagnosis my be effective in improving the quality of glycaemic control that is achieved
- Patients requiring admission to hospital at diagnosis were at risk of poor glycaemic control and self-reported quality of life in future follow-ups
- Social class and pre-morbid IQ were consistent early predictors of diabetes knowledge
- In general, the within subjects stability of the psychosocial factors and diabetes-related outcomes was high
- There was considerable overlap in self-report measures which suggests that these variables are measuring a common source of latent variance and may reflect a broad dimension of 'negative affectivity'
- Longstanding psychological factors (e.g. personality and psychiatric distress) can in part predict individual differences in treatment satisfaction and quality of life up to 36 months after diagnosis

Discussion

The Edinburgh Prospective Diabetes Study (EPDS) was established to determine whether individual differences in diabetes-related outcomes, including diabetes control, knowledge of diabetes, satisfaction with the treatment for diabetes, and diabetes-related quality of life, can be explained by psychological factors and social factors recorded shortly after diagnosis of Type 1 diabetes.

According to the results of the EPDS, smoking and alcohol consumption may be early risk factors for poor glycaemic control. The association between smoking and HbA_{1c} is well documented (Lundman, Asplund and Norberg, 1990; Muhlhauser, 1990) and has also been associated with an increased risk of complications (Muhlhauser, 1990). In the present study smoking had an effect on both HbA_{1c} and an individual's perceived frequency of hyperglycaemia at four months after diagnosis but these relationships did not persist in later follow-ups; smoking was not a reliable long-term predictor of either subjective or objective measures of glycaemic control.

The present study found little evidence for any consistent relationships between patients' psychosocial variables recorded at baseline and subsequent glycaemic control during the 36 months following initial diagnosis. However, significant correlations were observed between age and exercise, and HbA_{1c} at four months after diagnosis; younger people who take more regular exercise have better glycaemic control during the early stages of diabetes self-management but these relationships do not persist in later follow-ups.

Previous research suggests that psychosocial variables may have an indirect causal effect on control via their impact on adherence to a therapeutic regimen (Glasgow, Fisher, Anderson, LaGreca, Marrero, Johnson, Rubin and Cox, 1999; Hanson, Henggeler and Burghen, 1987). The correlation between exercise pattern and glycaemic control offers broad support to the claim that adherence to self-care behaviours is predictive of good glycaemic control.

Previous investigations have shown that having a comprehensive knowledge of diabetes is associated with an improvement in self-regulatory behaviour (Jacobson, 1996; Rubin, Peyrot and Saudek, 1991; Robinson, Al-Bustan, Bitar, Al-Asousi and Majeed, 1997; Hanson, Henggeler and Burghen, 1987; Clement, 1995) and may have an indirect effect on glycaemic control via adherence (Robinson et al., 1997). The EPDS adds to past research by demonstrating that individual differences in diabetes knowledge present as early as four months after diagnosis may independently account for up to 11% of the variance in subsequent glycaemic control at 12 months after diagnosis, providing some evidence for a link between diabetes knowledge and subsequent glycaemic control. The recurrence of a significant relationship between diabetes knowledge at four months after diagnosis and glycaemic control at 36 months after diagnosis adds further support to this claim. This implies that by increasing a person's knowledge using educational interventions shortly after diagnosis, it may be possible to produce a subsequent improvement in the quality of glycaemic control achieved up to 36 months after diagnosis.

In conjunction with previous studies, it is apparent that the relationships between psychosocial factors such as personality (Hepburn, Langan, Deary, Macleod and Frier, 1994; Fonagy, Moran, Lindsay, Kurtz and Brown, 1987; Lloyd, Matthews, Wing and Orchard, 1991; Gordon, Fisher, Wilson, Fergus, Paterson and Semple, 1993), levels of psychiatric distress (Fonagy et al., 1987; Lustman, Griffith, Clouse and Cryer, 1986; Cohen, Welch, Jacobson, de Groot and Samson, 1997), diabetes-related quality of life (Glasgow, Ruggiero, Eakin, Dryfoos and Chobanian, 1997; Grey, Boland, Yu, Sullivan-Bolyai and Tamborlane, 1998), and diabetes knowledge (Jacobson, 1996; Robinson et al., 1997) and recent glycaemic control are as yet ill-defined. In the present investigation there was a small but significant inverse correlation between neuroticism at diagnosis and subsequent glycaemic control 12 months later ($r = -.25$). However this relationship did not persist in future follow-ups. This finding adds more information to the question of the relationship between neuroticism and objective heath status (Hepburn et al., 1994; Fonagy et al., 1987; Lloyd et al., 1991; Gordon et al., 1993), and indicates that neuroticism may be an unreliable predictor of long-term glycaemic control in adults.

A recent meta-analysis by Lustman et al. (2000) has provided conclusive evidence for the much disputed relationship between depression and hyperglycaemia (Mazze, Lucido an Shamoon, 1984; Lustman, Griffith, Clouse and Cryer, 1986; Cohen, Welch, Jacobson, de Groot and Samson, 1997; Fonagy, Moran, Lindsay, Kurtz and Brown, 1987), but was unable to establish the directional nature of this relationship. In the present study there was a significant association between psychiatric well-being recorded shortly after diagnosis and the quality of glycaemic control achieved at 36 months after diagnosis ($r = .41$, $p < 0.05$). This suggests that poor psychological well-being shortly after diagnosis may be a risk factor for poor glycaemic control in adults.

It is perhaps not surprising that few reliable predictors of glycaemic control can be identified at this early stage of the disorder because the majority of individuals are likely to be in the 'honeymoon period'. This is a period of remission when many patients with adult-onset of Type 1 diabetes retain significant endogenous secretion of insulin (Grajwer, Pildes, Horwitz and Rubenstein, 1977; Madsbad, Faber, Binder, McNair, Christiansen and Transbot, 1978). The 'honeymoon period' can last from a few months to several years; achieving good glycaemic control is relatively easy during this time and severe hypoglycaemia or metabolic decompensation are rare. In the EPDS, plasma C-peptide was not measured to correlate residual insulin secretory capacity to glycaemic control and insulin requirement. It is therefore suggested that further assessment is necessary to clarify the nature of any existing temporal relationship after a longer duration of diabetes.

According to the Intelligence-as-Process, Personality, Interests and Intelligence-as-Knowledge (PPIK) theory (Ackerman, 2000; Ackerman and Rolfhus, 1999) discussed previously in the Introduction (see Part I, Chapter 2), an individual chooses to invest their cognitive resources to acquire knowledge about the world. The PPIK model expands the traditional theory of fluid and crystallized intelligence (Horn and Cattell,

1966) by taking into account a person's normal experiences of adult life. For example previous research suggest that gender, age, personality traits, interests and abilities are important determinants of knowledge in general (Ackerman, 2000; Ackerman and Rolfhus, 1999). In the present study the PPIK model has been applied as a theoretical framework in which to understand the most important determinants of diabetes-related knowledge. The findings of the EPDS offer broad support for the PPIK model. In addition, to pre-morbid IQ, high occupational social class, low scores on the personality trait neuroticism, less negative-emotion-coping and low levels of chance-oriented locus of control were significant determinants of diabetes knowledge. These factors may be important early risk factors which can be used to identify those patients who may benefit from increased information and support following diagnosis of Type 1 diabetes.

Evidence from the first three years of prospective investigation suggests that there may be individual differences in how people respond following the development of Type 1 diabetes. In general, key psychosocial variables recorded at diagnosis and the diabetes-related outcomes recorded at four months after diagnosis were associated substantially with self-reported outcomes recorded at 12 months, at 24 months and at 36 months after diagnosis. The distinct pattern of these associations suggests that there may be a group of overlapping, health-related constructs that relate to the reporting of negative affects shortly after diagnosis (Deary, Clyde and Frier, 1997). For example, the personality construct, neuroticism, was consistently associated with low levels of satisfaction with diabetes-related quality of life, greater perceived burden of the illness and a tendency to worry about the future effects of diabetes. This tendency of some patients to report negatively with regard to self-reported aspects of illness is well documented and is often referred to as 'a broad dimension of negative affectivity' (Watson and Pennebaker, 1989; Adler and Matthews, 1994).

Establishing the independent predictors of diabetes-related outcomes is an important step towards understanding the initial coping process following the diagnosis of diabetes. It was not until the late 1980s that instruments with better psychometric properties were developed to measure psychological and social outcomes in diabetes specifically (DCCT, 1988; Lewis and Bradley, 1988; Bradley, 1994). However, the psychosocial correlates of scales such as the Diabetes Quality of Life (DQOL) measure and the Diabetes Treatment Satisfaction Questionnaire (DTSQ) are poorly understood. To overcome this problem the EPDS has examined the natural history of diabetes-related quality of life and treatment satisfaction of the patients from the time of diagnosis.

The present investigation supports previous work which found that the DQOL was stable over time (DCCT, 1996). There was also evidence of considerable overlap between the individual dimensions of the DQOL. In particular, diabetes-related life satisfaction, and subjective reports of the impact of diabetes appeared to share common variance ($r = .69$, $p < 0.01$ at four months). Previous literature suggests that these constructs represent what has been referred to as a *'broad gauge of diabetes quality of life'* (DCCT, 1988). The findings of the EPDS support this claim and suggest that the subscoring of the DQOL may not be justified. A sizeable amount of the variance in the DQOL subscale's satisfaction with diabetes quality of life and impact of diabetes was explained by the DTSQ total scores. The association between these measures can be explained in part by the fact that both the DQOL and the DTSQ are diabetes-specific measures. However, in these analyses there was some evidence to suggest that diabetes quality of life may be based on more than a person's satisfaction with their treatment regimen. Psychological factors recorded at diagnosis contributed independent amounts of variance to quality of life. For example, psychiatric distress and happiness were independent predictors of the impact of diabetes at 12 months after diagnosis. This finding suggests that more distal emotional factors recorded shortly after diagnosis can, in part, predict aspects of diabetes-related quality of life, and add additional variance to the model after diabetes-specific measures have been taken into account.

An investigation by Rose, Schirop, Burkert, Danzer, Scholler and Klapp (1998) represents one of the only previous attempts to explore the direct determinants of multidimensional aspects of quality of life. The authors found that people who used active coping strategies had higher scores on all of the dimensions of diabetes quality of life, irrespective of their physical health. In contrast, socially less competent and emotionally more reserved patients coped less well with their diabetes, and reported more negative emotions, greater physical ailments and less social support. Although the scale used by Rose et al. (1998) was multidimensional, it did not assess diabetes-specific quality of life. The EPDS overcomes this methodological problem.

In the present study there was no evidence to support the claim that active (instrumental) coping was associated with better scores on the dimensions of the DQOL, but negative-emotion coping was a consistent predictor of poor scores on all of the dimensions of the DQOL measure. Although these findings provide complementary evidence for an association between emotion-focused coping and poor self-reported quality of life at follow-up, coping did not contribute independent variance in determining self-reported diabetes quality of life outcomes after other psychological (e.g. personality and happiness) and treatment-related variables had been included in the model. The most consistent independent predictors of DQOL satisfaction and DQOL impact of diabetes were diabetes treatment satisfaction recorded at four months after diagnosis, and happiness and psychiatric distress recorded at diagnosis. As reported previously in the DCCT (1996) a patient's overall sense of well-being is likely to compensate for the demands of insulin therapy. Therefore, individuals who are unhappy, less satisfied with their treatment regimen and who have a tendency to experience greater levels of psychiatric distress shortly after diagnosis, are more likely to report having a poorer diabetes-related quality of life in future follow-ups. Furthermore these effects are long lasting and present up to 36 months after diagnosis.

The tendency to worry about the future consequences of diabetes is thought to predict the level of psychological distress perceived by people with diabetes (DCCT, 1988). In the present study, the baseline personality dimension neuroticism, happiness, and negative-emotion coping were consistent predictors of the tendency to worry about the future effects of diabetes at four months, at 12 months and at 24 months after diagnosis. This implies that anxieties about the future consequences of diabetes are substantially predicted by an individual's psychological status shortly after diagnosis, as well as an underlying tendency to report negatively with regard to health. Neuroticism has often been associated with illness reporting (Watson and Pennebaker, 1989; Smith and Williams, 1992) but has few established associations with actual health outcomes. Findings from the EPDS revealed that neuroticism and self-rated happiness contributed independently to an individual's tendency to report worrying about the future effects of their diabetes at 12 months after diagnosis. However, there is no evidence to suggest that neuroticism is associated with poor objective health outcomes (e.g. HbA_{1c}), in fact in the present study the evidence suggests that neuroticism at the time of diagnosis may be associated with better rather than worse glycaemic control at 12 months after diagnosis.

With regard to treatment satisfaction, some existing evidence suggests that a person's self-reported well-being is a good indicator of treatment satisfaction (Petterson, Lee, Hollis, Young, Newton and Dornan, 1998). The present study supplements previous observations by suggesting that individuals who report having a good quality of life shortly after diagnosis are more satisfied with the treatment regimen during the 36 months after diagnosis. A recent study (Deary, Strickland, Frier and Gold, 1998) found that 37.2 % of the variance in self-reported treatment satisfaction could be accounted for by what the authors refer to as *'optimistic control'*, which implies that outgoing people who cope by gathering information and following the advice of health professionals report better treatment satisfaction. The results of the EPDS failed to replicate the relationship between instrumental coping and treatment satisfaction but negative-emotion coping was a highly consistent predictor of treatment satisfaction. This implies that individuals who use an emotion-focused approach to coping with their diabetes have a long-standing tendency to be less satisfied with their diabetes treatment regimen.

To summarise, the findings of the EPDS suggest that, in adults: (i) individual differences in social and educational factors, recorded shortly after diagnosis, are predictive of objective diabetes-related outcomes (glycaemic control and knowledge of diabetes), (ii) the temporal stability of individual differences in psychosocial variables and diabetes-related outcomes remains high during the 36 months following diagnosis of Type 1 diabetes, and (iii) it appears that individual differences in psychosocial variables may be associated with the patient's subjective (e.g. quality of life) as opposed to their objective diabetes treatment-related outcomes (e.g. HbA_{1c}).

In this chapter the relationships between a broad range of psychosocial variables and diabetes-related outcomes have been examined prospectively in a sample of adults following initial diagnosis of Type 1 diabetes. To date there have been very few prospective studies which have attempted to assess the determinants of diabetes-related outcomes longitudinally in a sample of adults following initial diagnosis of diabetes. Longitudinal studies aimed at monitoring the patients' progress from early on in the disease progression are clearly important because in cross-sectional studies it is not possible to determine whether psychological factors have a causal influence on diabetes-related outcomes or vice versa.

In recent years various models have been proposed to link psychosocial factors with objective and subjective indicators of health-related outcomes. In health psychology, coping with illness is often understood in terms of the transactional theory of stress and coping proposed by Lazarus and Folkman (1984, 1987) (see Part I, Chapter 2). This model fits well within the context of the EPDS where the aim is to monitor the coping process in adult patients following initial diagnosis of Type 1 diabetes.

By applying the transactional model of stress and coping to the data obtained in the EPDS, it is possible to provide a conceptual understanding of the longitudinal relationships between psychosocial factors and diabetes-related outcomes in adults from the time of diagnosis of Type 1 diabetes. In the following chapter the present findings will be extended by examining the role of illness-related coping in terms of the theoretical assumptions laid out in the stress and coping model (Lazarus and Folkman, 1984, 1987). This will be followed by a discussion of the methodological problems/limitations of the EPDS and the implications of this research for future investigations and diabetes care (Part II, Chapter 4).

PART II (continued): The Edinburgh Prospective Diabetes Study

CHAPTER 3

The Role of Illness-Related Coping in Adults with Newly Diagnosed Type 1 Diabetes

Introduction

This chapter examines the role of illness-related coping in adults with newly diagnosed Type 1 diabetes. Previous literature on coping suggests that coping strategies play an important mediating role between stress and both health and illness (Lazarus and Folkman, 1984,1987). However, recent research in health psychology relating to the role of coping with specific illnesses is complicated by a general lack of consensus regarding the specific function of different coping strategies in different illnesses and in different situations (Endler and Parker, 1990). Furthermore, many of the coping measures that have been used to assess coping to date have been developed using simplistic techniques, and as such the *'psychometric quality'* of these measures is difficult to determine (Parker and Endler, 1992). In an attempt to overcome this problem the Coping with Health Injuries and Problems (CHIP) scale was developed (Endler, Parker and Summerfeldt, 1998).

In the present study the CHIP scale was used to monitor illness-related coping strategies from the time of initial diagnosis of Type 1 diabetes in a unique sample of adults. The CHIP was chosen because it has good psychometric properties and was developed specifically to measure how people cope with health problems. The CHIP probes the following coping dimensions: Palliative, Instrumental, Distraction, and Emotional Preoccupation (Endler, Parker and Summerfeldt, 1998). This multidimensional approach is advantageous when assessing coping with health problems because it allows a more precise understanding of the relationships between coping ability and individual differences in psychological variables as well as providing the opportunity to investigate the predictive manner in which specific coping strategies may influence a person's illness-related outcomes over time. Validation studies using the CHIP indicate that emotional preoccupation is correlated with the personality trait, neuroticism, while distraction coping was associated with extraversion (Endler et al., 1998). In addition, whereas emotional preoccupation may be linked to maladaptive coping and poor psychological adjustment, the reverse was found with instrumental coping (Endler et al., 1998). The present study aims to extend these findings to a diabetic sample, and to explore the longitudinal relationships between the CHIP's dimensions and a wider range of psychological and social variables.

In general, there have been few attempts to examine coping prospectively in people with diabetes. Those studies that have taken place have produced mixed findings (Cox and Gonder-Frederick, 1992; Felton and Revenson, 1984; Smari and Valtysdottir, 1997) and have often been based on children and adolescents with diabetes (Kovacs and Feinberg, 1982; Hanson Harris, Relyea, Cigrang, Carle and Burghen, 1989). Therefore, the EPDS has attempted to examine the coping process, in adults, from the time of diagnosis of Type 1 diabetes using the CHIP as a psychometrically sound measure of illness-related coping.

A hypothetical framework showing the role of illness-related coping in adults with Type 1 diabetes is displayed in Figure 2.1. The model in Figure 2.1 was specified based on a transactional model of stress and illness (Lazarus and Folkman, 1987). Transactional models rest on the assumption that physical and psychosocial stressors act via mediating variables to produce health-related outcomes. According to Lazarus (1991) stress is experienced when demands are placed on the individual that exceed their ability to adjust. Such demands are defined as physical stressors (e.g. environmental conditions) and psychosocial stressors. Psychosocial stressors are social and psychological factors that may be harmful to the individual and may include: (i) socio-demographic factors such as socio-economic status, or a person's living arrangements; (ii) psychological factors including personality indicators, cognitive ability and psychiatric well-being, and (iii) social factors (e.g. quality of life). In transactional models coping variables are usually seen as important mediators in the link between antecedents to disease and health-related outcomes (Deary, Clyde and Frier, 1997). In the model shown in Figure 2.1 illness-related coping variables are assumed to have an intermediate position between psychosocial variables and diabetes-related outcomes which include: (i) social and psychological consequences such as diabetes-related quality of life and wellbeing, (ii) treatment-related outcomes, (iii) fear of experiencing hypoglycaemia, (iv) self-management outcomes, and (v) objective outcomes (e.g. HbA_{1c} and knowledge of diabetes).

Based on the model of stress and illness-related coping (Figure 2.1), the aims of the analysis were: i) to examine the influence of individual differences in psychological and social variables recorded at the time of diagnosis of Type 1 diabetes on illness-related coping strategies at series of periodic reviews (at 12months, at 24 months and at 36 months after diagnosis), and ii) to investigate the influence of illness-related coping strategies recorded at 12 months after diagnosis on subsequent diabetes-related outcomes at 24 months and at 36 months after diagnosis.

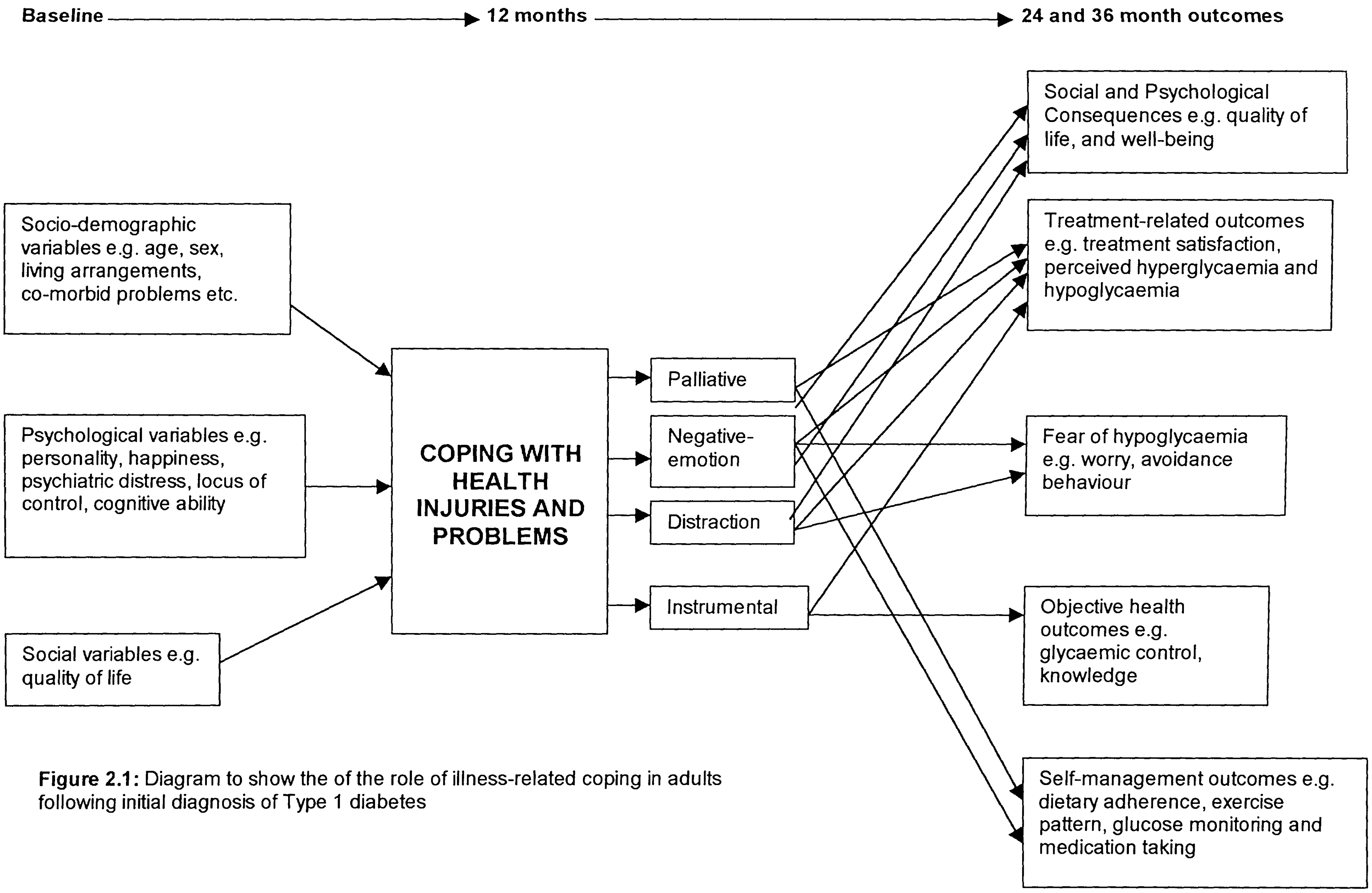


Figure 2.1: Diagram to show the of the role of illness-related coping in adults following initial diagnosis of Type 1 diabetes

The means and standard deviations for each measure recorded at each periodic review are shown in Table 2.15.

Effect of socio-demographic factors on illness-related coping across time

T-tests revealed that those individuals who had additional co-morbid problems (e.g. asthma, allergies, hypertension) at the time of diagnosis reported more negative-emotion focussed coping at 12 months (t [61] = -2.31, $p < 0.05$), at 24 months (t [51] = -2.82, $p < 0.01$) and at 36 months after diagnosis. Single people obtained higher palliative coping scores at 12 months after diagnosis (F [2,61] = 3.49, $p < 0.05$) and reported significantly higher levels of distraction coping at 12 months (F [2, 61] = 6.58, $p < 0.01$) and at 24 months (F [2, 52] = 4.42, $p < 0.05$) after diagnosis than individuals who were married or cohabiting. Females obtained higher scores for distraction coping than males at 12 months after diagnosis (t [62] = 2.17, $p < 0.05$) but there were no sex differences in coping factors at 24 months or at 36 months after diagnosis. None of the remaining social factors including occupational social class, smoking variables, and a family history of diabetes had significant effects on illness-related coping throughout the duration of this study.

Table 2.15: Means (SD) of psychosocial variables, illness-related coping dimensions, and diabetes-related outcomes recorded at each review.

Variable	Scale/Metric	Diagnosis	3-6 weeks	12 months	24 months	36 months
Age	years	30.8 (8.5)				
Education	years	13.0 (2.8)				
NART	1 - 50		30.9 (7.8)			
BMI	kg/m^2	23.6 (4.9)				
Exercise	times/week	1.5 (1.7)				
Alcohol	units/week	11.3 (12.7)				
Personality (EPQ-R)						
Extraversion	1 - 12	8.1 (3.1)				
Neuroticism	1 - 12	5.3 (3.2)				
Psychoticism	1 - 12	4.2 (2.2)				
Conscientiousness		36.0 (6.3)				
Happiness	1 - 10	7.6 (2.5)				
Psychiatric distress	0 - 28		4.7 (5.5)			
Diabetes Locus of Control						
Internal autonomy	6 - 18		14.8 (2.1)			
Internal blame	6 - 18		11.8 (3.0)			
Chance	6 - 36		12.7 (4.4)			
Health prof	6 - 24		12.5 (3.0)			
Non-health prof	6 - 12		6.0 (1.7)			
Diabetes Quality of Life						
Satisfaction	%		69.2 (15.9)		72.4 (15.4)	68.8 (17.2)
Impact	%		71.9 (11.3)		71.4 (11.4)	71.8 (10.7)
Worry	%		72.2 (17.9)		73.5 (15.7)	69.6 (18.3)
General well-being	%		2.4 (0.7)		2.4 (0.7)	2.4 (0.8)
Illness-related Coping						
Palliative	8 - 40			22.0 (4.8)	22.9 (4.8)	24.2 (4.0)
Instrumental	8 - 40			28.3 (4.4)	28.2 (4.5)	28.3 (3.4)
Distraction	8 - 40			23.1 (4.9)	22.8 (5.1)	22.6 (4.1)
Negative-emotion	8 - 40			20.7 (7.3)	20.0 (6.2)	20.5 (6.5)
HbA1c	%				8.2 (1.3)	8.9 (1.7)
Diabetes Knowledge	0 - 24				20.7 (2.5)	20.8 (2.9)
Treatment Satisfaction	0 - 36				27.1 (5.6)	27.1 (6.6)
Perceived hypergleaemia	0 - 6				2.6 (1.5)	3.0 (1.3)
Perceived hypoglycaemia	0 - 6				2.1 (1.4)	2.0 (1.2)
Fear of Hypoglycaemia	0 - 92					33.7 (12.3)
Behaviour	0 -40					17.4 (6.0)
Worry	0 - 52					16.2 (9.2)
Well-being: Total	0 - 66					46.5 (12.7)
Depression	0 - 18					4.4 (3.3)
Anxiety	0 -18					4.5 (3.4)
Energy	0 - 12					7.6 (2.6)
Positive well-being	0 -18					11.5 (4.4)
Self-Care Activities						
Diet	%					64.8 (13.3)
Exercise	%					36.4 (31.8)
Glucose Monitoring	%					81.2 (27.9)
Medication	%					96.1 (9.1)
N Range		84 - 78	66 -54	46 - 66	56 - 36	41 - 31

Psychosocial predictors of illness-related coping across a series of periodic reviews (12 months, 24 months and 36 months) after diagnosis.

To answer the question of who copes well and who does not following initial diagnosis of Type 1 diabetes the relationships between psychosocial variables measured at baseline and three to six weeks after diagnosis, and each dimension of illness-related coping recorded at 12 months, at 24 months and at 36 months after diagnosis were examined. The correlations for each psychosocial measure recorded at baseline and coping outcomes at each review are displayed in Table 2.16. Using multiple (stepwise) regression analyses the independent predictors of the dimensions of coping across time were examined in an attempt to identify longitudinal psychosocial predictors of coping from the time of diagnosis (Table 2.17). The results relating to each dimension of coping will now be discussed in turn.

Palliative Coping: The palliative coping subscale describes various self-help responses used to alleviate the unpleasantness of the illness. Such responses include attempts at feeling better by, for example, getting plenty of rest, or making oneself more comfortable by changing the surroundings (Endler, Parker and Summerfeldt, 1998; Endler, 2000).

The correlations between psychosocial factors recorded at diagnosis and CHIP Palliative recorded at 12 months, at 24 months and at 36 months after diagnosis are displayed in Table 216. In the present study, Diabetes Quality of Life (DQOL) satisfaction and DQOL impact of diabetes were consistent long-term predictors of palliative coping at 12 months ($r = -.37$ and $-.41$, respectively, both $p < 0.01$), at 24 months ($r = -.47$, $p < 0.01$ and $r = -.36$, $p < 0.05$, respectively) and at 36 months ($r = -.45$, $p < 0.01$ and $r = -.37$, $p < 0.05$, respectively) after diagnosis. These results suggest that participants who are less satisfied with their diabetes quality of life and who experience greater perceived burden of the illness shortly after diagnosis are more likely to use palliative coping throughout the three years following diagnosis. None of the remaining psychosocial variables recorded at diagnosis, and 3-6 weeks after diagnosis, were consistent predictors of palliative coping across time. However, participants who reported high chance locus of control at diagnosis reported using more palliative coping at 12 months after diagnosis ($r = .28$, $p < 0.05$). The correlations between chance locus of control and palliative coping were marginal, and similar in magnitude at 24 months ($r = .24$) and at 36 months ($r = .21$) after diagnosis but these values were not significant, perhaps due to the reduction in the number of subjects available for analysis at these follow-ups. Individuals who took more regular exercise at diagnosis were less likely to use palliative coping at 24 months after diagnosis ($r = -.32$, $p < 0.05$). The personality trait, conscientiousness, measured at diagnosis was inversely correlated with palliative coping at 36 months after diagnosis ($r = -.36$, $p < 0.05$).

Using multiple regression (Table 2.17), the perceived impact of diabetes shortly after diagnosis was the only significant predictor of palliative coping at 12 months after diagnosis. DQOL impact accounted for 14% of the variance in palliative coping at 12 months after diagnosis. Satisfaction with diabetes-related quality of life at 3-6 weeks after diagnosis was a significant predictor of palliative coping, in later follow-ups, at 24 months and at 36 months after diagnosis, accounting for 20% and 17% of the variance, respectively. These results indicate that people who experience greater perceived burden of diabetes and those who are least satisfied with their diabetes-related quality of life shortly after diagnosis have a stable tendency to cope using self help responses in an attempt to alleviate the unpleasantness of their illness.

Instrumental Coping: The CHIP Instrumental coping subscale focuses on task-oriented strategies which indicate that the individual is seeking help for the illness or trying to learn more about it (Endler, 2000). This problem-focused approach includes activities such as following the doctor's advice, learning about the most effective treatments available and being prompt about taking medication.

Univariate associations between psychosocial factors recorded at diagnosis and CHIP Instrumental coping recorded at 12 months, at 24 months and at 36 months after diagnosis are displayed in Table 2.16. The results of the EPDS revealed that self-rated happiness at the time of diagnosis of Type 1 diabetes was a consistent, significant predictor of instrumental coping at 12 months ($r = .44$, $p < 0.05$), 24 months ($r = .29$, $p < 0.05$) and at 36 months ($r = .31$, $p < 0.05$) after diagnosis. Happier individuals at diagnosis had a longstanding tendency to take a problem-focussed approach to coping with their diabetes. The personality trait extraversion was significantly correlated with instrumental coping at 12 months after diagnosis ($r = .31$, $p < 0.05$), while participants who reported high levels of psychiatric distress shortly after diagnosis tended to have lower instrumental coping scores at 12 months after diagnosis ($r = -.29$, $p < 0.05$). These relationships were not present in future follow-ups at 24 months or at 36 months after diagnosis. None of the remaining baseline psychosocial variables were significantly correlated with instrumental coping throughout the duration of this study.

In multiple regression analyses (Table 2.17), self-rated happiness at diagnosis and high scores on the personality trait, extraversion, accounted for 17% of the variance in instrumental coping scores at 12 months after diagnosis. Happiness accounted for 12% of the variance in the first step of the analysis and a further 5% of the variance was added by extraversion. Happier individuals who were more extraverted at diagnosis were more likely to cope by following health professionals' advice and trying to learn more about their illness after diagnosis. Happiness was also a significant independent predictor of instrumental coping scores at 24 months and at 36 months after diagnosis, accounting for 7% of the variance at both of these reviews.

Distraction Coping: Distraction coping refers to the extent to which the respondent uses actions or has thoughts aimed at avoiding preoccupation with the illness. This involves thinking about pleasant experiences, being in the company of others and engaging in unrelated activities (Endler, et al., 1998; Endler, 2000).

The associations between the psychosocial factors and CHIP Distraction coping recorded at 12 months, at 24 months and at 36 months after diagnosis are displayed in Table 2.16. The personality trait extraversion was the best predictor of distraction coping across time. Individuals who had high extraversion scores reported significantly greater levels of distraction coping at 12 months ($r = .42$, $p < 0.01$) and at 24 months ($r = .38$, $p < 0.01$) after diagnosis. There was no significant relationship between extraversion scores at diagnosis and distraction coping at 36 months after diagnosis. This is likely to be due to less power to detect a significant correlation caused by a reduction in the number of participants available. Highly sociable individuals appear to have a longstanding tendency to distract their attention from their illness by focusing on pleasant things and enjoying the attention of friends and family. DQOL impact of diabetes recorded shortly after diagnosis was correlated with distraction coping at 12 months after diagnosis ($r = -.27$, $p < 0.05$). This relationship did not persist in future follow-ups. Those respondents who reported experiencing a greater burden of diabetes treatment were less likely to use distraction coping in the early stages of diabetes self-management; however, the impact of diabetes on a person's quality of life was not a long-term predictor of distraction coping in the present study.

There was some evidence to suggest that long-term psychological and social factors recorded at baseline may be predictive of distraction coping beyond the first 24 months following diagnosis. For example, younger participants and those who reported taking more regular exercise at diagnosis reported greater distraction coping at 36 months after diagnosis. In addition, the psychological variables psychoticism, happiness and psychiatric distress at diagnosis were also predictive of distraction at 36 months after diagnosis.

Using multiple regression analyses the independent predictors of distraction coping at each review were examined (Table 2.17). The personality dimension extraversion recorded at diagnosis and DQOL impact of diabetes at three to six weeks after diagnosis accounted for 23% of the variance in distraction coping at 12 months after diagnosis. Extraversion accounted for 15% of the variance and a further 8% of the variance was added by DQOL impact of diabetes. Those participants who were highly extravert and experienced less impact of diabetes shortly after diagnosis used greater distraction coping at 12 months after diagnosis. Extraversion was a consistent independent predictor of distraction coping at the 24 month review, accounting for 12% of the variance. The number of times a person reported exercising per week at diagnosis accounted 24% of the variance in distraction coping at 36 months after diagnosis. Those individuals who took part in regular exercise at diagnosis were more likely to cope by distracting from their illness, perhaps by engaging in other activities such as playing sport.

Negative-emotion Coping: Emotional preoccupation or negative-emotion coping refers to the extent to which an individual focuses on the emotional consequences of their health problem. This type of emotion-oriented coping includes getting frustrated, feeling anxious and worrying, wishing the problem had never happened and fantasizing about being better.

The results of the EPDS revealed that diabetes-related quality of life recorded at three to six weeks after diagnosis was a highly consistent predictor of negative-emotion focussed coping. In particular, DQOL satisfaction (all r's between -.39 and -.50, $p < 0.01$), DQOL impact of diabetes (all r's between -.45 and -.59, $p < 0.01$), and to a lesser extent the individual item that measures general well-being (all r's between .32 and .36, $p < 0.05$) were all consistent predictors of negative-emotion coping across all follow-ups. DQOL worry was a significant predictor of negative-emotion coping at 12 months ($r = -.47$, $p < 0.01$) and at 24 months ($r = -.48$, $p < 0.01$) after diagnosis, but this relationship was not significant at the 36 month review.

Individual differences in baseline psychological variables were also important predictors of negative-emotion coping across successive follow-ups. Participants who were less happy at diagnosis used significantly more negative-emotion focussed coping at 12 months ($r = -.40$, $p < 0.01$), at 24 months ($r = -.39$, $p < 0.01$) and at 36 months ($r = -.32$, $p < 0.01$) after diagnosis. High neuroticism and high levels of psychiatric distress at diagnosis were predictive of greater negative-emotion coping at 12 months ($r = .35$ and .35, respectively, $p < 0.01$) and at 24 months ($r = .37$, $p < 0.01$ and $r = .31$, $p < 0.05$, respectively) after diagnosis whereas high internal autonomy was predictive of less negative-emotion coping across the same period ($r = -.34$, $p < 0.01$ at 12 months, and $r = -.28$, $p < 0.05$ at 24 months). There were no other consistent predictors of negative-emotion coping; however, chance locus of control was positively correlated with negative-emotion coping at 12 months after diagnosis, and high scores on the NART (cognitive ability) were predictive of greater negative-emotion coping at 36 months after diagnosis.

In general, the results of the EPDS show that, in adults, negative-emotion coping during the three years following diagnosis is associated with a broad range of negative self-reported psychosocial variables including quality of life, personality, psychiatric distress and happiness. Multiple regression was used to identify which, if any, of these variables were independent predictors of negative-emotion coping across time. The results showed that DQOL impact of diabetes was a significant predictor of negative-emotion coping at all follow-ups, accounting for 21% of the variance at 12 months after diagnosis, 18% of the variance at 24 months after diagnosis, and 25% of the variance at 36 months after diagnosis. Self-rated happiness was also predictive of negative-emotion coping at 36 months after diagnosis accounting for 13% of the variance. These findings indicate that those participants who experienced greater impact of their diabetes shortly after diagnosis have a stable tendency to cope by being more emotionally preoccupied and worrying about their health.

Table 2.16: Correlations between psychosocial variables recorded shortly after diagnosis (diagnosis and 3-6 weeks) and coping ability at 12 months, 24 months and 36 months after diagnosis

Variable	CHIP: Palliative			CHIP: Instrumental			CHIP: Distraction			CHIP: Negative-emotion		
Months after diagnosis	12	24	36	12	24	36	12	24	36	12	24	36
Baseline												
Age	-.124	-.071	-.098	-.105	-.155	.040	-.232	-.160	**-.353***	-.135	-.196	.054
Education	.169	.063	.104	-.125	-.120	-.015	.153	-.004	.008	.145	.223	.303
NART	.115	.093	.078	.038	-.047	-.009	.000	-.088	-.211	.043	.140	**.389***
Social class	-.020	-.017	.059	.069	-.075	-.099	.042	.040	.182	.058	.061	-.109
BMI	.002	.099	.093	-:040	-.031	-.153	.241	.080	.085	-.005	.096	.012
Exercise	-.066	**-.324***	-.115	-.098	-.238	-.020	.136	.062	**.387***	-.002	.026	-.162
Alcohol	-.122	-.123	.040	-.176	-.231	-.235	.014	.016	-.121	.066	.114	.278
EPQ: E	.128	-.012	-.202	**.315***	.187	.138	**.418****	**.377****	.240	.064	.095	.024
EPQ: N	.215	.188	.254	-.168	-.150	-.052	-.084	-.092	.157	**.346****	**.368****	.302
EPQ: P	.108	.021	.288	.065	-.183	.195	.092	-.001	**.326***	-.198	-.117	-.015
Conscientiousness	-.045	-.006	**-.356***	.098	.150	-.003	.130	.027	-.080	-.169	-.045	-.061
GHQ	.117	.247	.233	**-.286***	-.092	-.046	.020	-.207	**-.350***	**.348****	**.307***	.323
Happiness	-.047	-.101	-.186	**.441***	**.289***	**.314***	.118	.224	**.338***	**-.403****	**-.392****	**-.321***
DLOC: IA	-.082	-.039	-.071	.207	.128	.052	.042	.167	-.022	**-.340****	**-.285***	-.127
DLOC: IB	-.050	.160	.238	-.118	-.144	-.069	.021	.244	.022	.179	-.092	.050
DLOC: C	**.288***	.245	.207	-.214	-.241	-.209	-.013	-.051	-.050	**.429****	.269	.122
DLOC: EHP	.023	.080	.119	.050	-.168	-.188	-.010	.069	.201	-.055	.046	-.112
DLOC: ENHP	**.304***	.257	.235	-.027	.103	.041	-.035	.113	.093	.160	.134	-.054
DQOL: S	**-.366****	**-.469****	**-.449****	.190	-.016	.062	-.102	.095	.299	**-.500****	**-.454****	**-.394****
DQOL: I	**-.409****	**-.356***	**-.373***	.159	.041	.136	**-.266***	-.043	.136	**-.590****	**-.510****	**-.449****
DQOL: W	-.256	-.182	-.209	.040	.026	.218	-.250	-.202	-.080	**-.466****	**-.476****	-.256
DQOL: G	.223	.273	.265	-.224	.020	-.154	.206	-.033	-.253	**.351****	**.358***	**.325***
N Range	49-64	43-56	31-41	49-64	43-55	31-41	49-64	43-55	30-40	49-64	42-54	31-41

Note: * p = < 0.05; ** p = < 0.01. Correlations for social class are based on Spearman's r correlation coefficients.
Abbreviations: NART = National Adult Reading Test; BMI = Body mass index; EPQ = Eysenck's Personality Questionnaire; E= Extraversion; N = Neuroticism; P = Pyschoticism; GHQ = General Health Questionnaire; DLOC = Diabetes Locus of Control; IA = Internal Autonomy; IB = Internal Blame; C = Chance; EHP = External Health Professional; ENHP = External Non-Health Professional; DQOL = Diabetes Quality of Life; S = Satisfaction; I = Impact; W = Worry; G = General well-being

Table 2.17: Multiple regression analyses to identify the independent predictors of illness-related coping at 12 months after diagnosis

Step/Variable	Adjusted R^2	R^2 Increment	*F* Change (*p*)	Part Corr. (*p*)
Palliative coping 12 months (N=57)	.14			
DQOL impact of diabetes			9.87 (.003)	-.39 (.003)
Palliative coping 24 months (N=50)	.20			
DQOL satisfaction			13.80 (.001)	-.47 (.001)
Palliative coping 36 months (N=38)	.17			
DQOL satisfaction			8.36 (.006)	-.43 (.006)
Instrumental coping 12 months (N=56)	.17			
Happiness		.12	8.34 (.01)	.33 (.01)
Extraversion		.05	6.67 (.003)	.26 (.04)
Instrumental coping 24 months (N=55)	.07			
Happiness			4.85 (.03)	.29 (.03)
Instrumental coping 36 months (N=41)	.07			
Happiness			4.26 (.05)	.31 (.05)
Distraction coping 12 months (N=58)	.23			
Extraversion		.15	11.31 (.001)	.43 (.001)
DQOL impact of diabetes		.08	9.48 (.001)	-.30 (.013)
Distraction coping 24 months (N =54)	.12			
Extraversion			8.60 (.005)	.38 (.005)
Distraction coping (N=36)	.24			
Exercise			12.30 (.001)	.51 (.001)
Neg-emotion coping 12 months (N=41)	.21			
DQOL impact of diabetes			11.39 (.002)	-.48 (.002)
Neg-emotion coping 24 months (N=33)	.18			
DQOL impact of diabetes			8.14 (.01)	-.46 (.01)
Neg-emotion coping 36 months (N=28)	.38			
DQOL impact of diabetes		.25	9.79 (.004)	-.40 (.014)
Happiness		.13	9.46 (.001)	-.40 (.014)

The relationships between illness-related coping at 12 months after diagnosis and diabetes-related outcomes at 24 months and at 36 months

The relationships between the dimensions of the Coping with Health Injuries and Problems (CHIP) scale at 12 months after diagnosis and diabetes-related outcomes recorded at 24 months and at 36 months after diagnosis were examined. The diabetes-related outcomes recorded at 24 months and at 36 months after diagnosis were the same as those discussed in Chapter 2 (glycaemic control, diabetes knowledge, treatment satisfaction, and quality of life). At the 36 month review additional outcomes were recorded including the Well-being Questionnaire, the Hypoglycaemia Fear Survey and the Summary of Self-Care Activities Questionnaire. The relationships between illness-related coping and each diabetes-related outcome measure are displayed in Tables 2.18 to 2.20.

Palliative Coping: Greater palliative coping at 12 months after diagnosis of Type 1 diabetes was a consistent predictor of more frequent episodes of perceived hyperglycaemia and greater impact of diabetes at 24 months ($r = .31$ and $-.32$, respectively, both $p < 0.05$) and at 36 months ($r = .34$ and $-.37$, respectively, both $p < 0.05$) after diagnosis. Palliative coping was not significantly correlated with the remaining diabetes-related outcome variables at 24 months after diagnosis. Palliative coping at 12 months after diagnosis was significantly correlated with DTSQ total scores ($r = -.32$, $p < 0.05$) and the perceived frequency of hypoglycaemia ($r = .33$, $p < 0.05$) at 36 months after diagnosis. In addition, the results showed that those participants who reported greater palliative coping at 12 months after diagnosis reported greater anxiety (r

$= .38, p < 0.05$), less energy ($r = -.39, p < 0.05$) and less regular exercise ($r = -.37, p < 0.05$) at 36 months after diagnosis.

In general, adults who coped with their diabetes using self-help responses to alleviate the unpleasantness of the illness at 12 months after diagnosis, were at risk of poor self-reported psychosocial, treatment-related and self-management outcomes in future follow-ups. In particular, high levels of palliative coping were consistently predictive of poor perceived metabolic control and greater perceived burden of the illness.

Instrumental Coping: Instrumental coping recorded at 12 months after diagnosis was not significantly correlated with any of the outcome measures recorded at 24 months after diagnosis, but instrumental coping was a good predictor of glycaemic control ($r = -.45, p < 0.01$) and of more frequent episodes of perceived hypoglycaemia ($r = .33, p < 0.05$) at 36 months after diagnosis. These results indicate that individuals, who coped by actively seeking out information about their illness, and by taking professional advice, were more likely to have good glycaemic control at the 36 months follow-up. The fact that instrumental coping was correlated with greater perceived hypoglcaemia is likely to be a result of a person's ongoing attempts to maintain their blood glucose levels within the normal (non-diabetic) range. Instrumental coping at 12 months after diagnosis was not significantly correlated with self-reported outcomes of diabetes in the present study.

In the present study the number of subjects available for comparison at the 24 months ($n = 56$) and 36 months ($n = 41$) reviews was relatively small. Further investigation using a larger sample is necessary to investigate the nature of any temporal relationships between instrumental coping and psychosocial functioning following diagnosis of diabetes. In general, the results suggest that, in adults, instrumental coping at 12 months may be predictive of good long-term glycaemic control.

Distraction Coping: Distraction coping at 12 months after diagnosis was not significantly associated with diabetes-related outcomes at 24 months after diagnosis but was significantly correlated with diabetes-related outcomes at 36 months after diagnosis. Those participants who reported high levels of distraction coping at 12 months after diagnosis perceived themselves as having more frequent episodes of hypoglcaemia and greater DQOL impact of diabetes at 36 months after diagnosis ($r = .47$, $p < 0.01$ and $-.32$, $p < 0.05$, respectively). In addition, distraction coping was significantly correlated with greater total fear of hypoglycaemia ($r = .42$, $p < 0.01$) at 36 months after diagnosis. This included being more worried about experiencing hypoglycaemia ($r = .35$, $p < 0.05$) and carrying out specific behaviours to avoid episodes of hypoglycaemia ($r = .32$, $p < 0.05$). These results suggest that individuals who distract themselves from their diabetes by carrying out other unrelated activities, or by surrounding themselves with others, are more likely to be fearful of, for example, passing out in public, or losing control during a hypoglycaemic episode. These individuals are also more likely to make attempts to avoid hypoglycaemia by for example, keeping their blood sugars high, or by making sure they are not alone when their blood sugars are low.

Table 2.18: Correlations between the dimensions of the Coping with Health Injuries and Problems scale at 12 months after diagnosis, and diabetes related outcomes at 24 months after diagnosis.

Outcome	HbA_{1c}	DKNQ	DTSQ	Hyper	Hypo	DQOL: S	DQOL: I	DQOL: W	DQOL: G
12 months									
CHIP: P	.013	-.071	-.171	**.315***	.229	-.193	**-.320***	-.275	.052
CHIP: I	-.080	.076	.166	.071	.251	.220	.221	.319	-.122
CHIP: D	.078	.055	-.127	.257	.208	.053	-.218	-.036	.074
CHIP: NE	.136	-.171	**-.541****	**.434****	.170	**-.408****	**-.667****	**-.516****	**.381****

Table 2.19: Correlations between the dimensions of the Coping with Health Injuries and Problems scale at 12 months after diagnosis, and diabetes-related outcomes at 36 months after diagnosis.

Outcome	HbA_{1c}	DKNQ	DTSQ	Hyper	Hypo	DQOL: S	DQOL: I	DQOL: W	DQOL: G
12 months									
CHIP: P	-.268	-.045	**-.319***	**.340***	**.328***	-.294	**-.371***	-.276	.107
CHIP: I	**-.454****	.085	.162	-.078	**.327***	.200	.138	.033	-.111
CHIP: D	-.068	.172	-.271	.164	**.466****	-.124	**-.317***	-.095	.297
CHIP: NE	.162	-.017	**-.589****	**.539****	.033	**-.475****	**-.616****	-.355	**.356***

Table 2.20: Correlations between the dimensions of the Coping with Health Injuries and Problems scale at 12 months after diagnosis, and additional diabetes-related outcomes at 36 months after diagnosis.

	Hypoglycaemia Fear Survey			Well-being Questionnaire					Summary of Diabetes Self-care Activities			
Outcome	Behaviour	Worry	Total	Depress.	Anxiety	Energy	Pos. well	Total	Diet	Exercise	Glucose	Medication
12 months												
CHIP: P	.243	.261	.301	.203	**.378***	**-.392***	-.124	-.231	-.091	**-.368***	.126	-.288
CHIP: I	.103	-.211	-.106	-.271	-.023	.113	.229	.199	-.068	-.329	.162	.095
CHIP: D	**.315***	**.354***	**.409****	-.027	.029	-.104	.142	.033	-.218	-.047	.181	.007
CHIP: NE	**.435****	**.468****	**.563****	.297	**.463****	**-.441****	-.234	**-.346***	-.295	**-.358***	.105	-.118

Negative-emotion Coping: Individuals who reported greater emotional preoccupation at 12 months after diagnosis were less satisfied with their treatment, reported more frequent episodes of hyperglycaemia, and poorer quality of life, including less satisfaction, greater impact of diabetes and poorer general well-being at 24 months (all r's between .38 and -.67, $p < 0.01$) and at 36 months (all r's between .36 and -.62, $p < 0.01$) after diagnosis. These relationships were all highly significant and consistent over time, indicating that individuals who use emotion-oriented coping strategies have a stable tendency to report negatively with regard to their diabetes-related health and well-being.

Furthermore, negative-emotion coping at 12 months after diagnosis was significantly correlated with total scores on the Hypoglycaemia Fear Survey ($r = .56$, $p < 0.01$) at 36 months after diagnosis, which includes the subscales worry about hypoglycaemia ($r = .47$, $p < 0.01$) and avoidance behaviour ($r = .56$, $p < 0.01$). Participants who used emotion-focused coping at 12 months after diagnosis also had lower total scores on the Well-being Questionnaire ($r = -.35$, $p < 0.05$) and reported significantly greater anxiety ($r = .46$, $p < 0.01$), and less energy ($r = -.44$, $p < 0.01$) at 36 months after diagnosis. Negative-emotion coping at 12 months after diagnosis did not significantly predict objective diabetes-related outcomes such as, glycaemic control and diabetes knowledge, but there was a significant inverse relationship between negative-emotion coping at 12 months after diagnosis and amount of exercise a person reported doing at 36 months after diagnosis ($r = -.36$, $p < 0.05$).

In summary, the results of the EPDS revealed that negative-emotion coping is a consistent predictor of poor self-reported outcomes during the period between 12 months and 36 months after diagnosis of diabetes, but negative-emotion coping was not a significant indicator of actual health outcomes. Future follow-ups of longer duration are necessary to investigate the longer-term effects of negative-emotion coping on a person's psychological and physical well-being.

Summary of findings

The aim of the EPDS was to examine the role of illness-related coping in adults following initial diagnosis of Type 1 diabetes. The results provide evidence to suggest that, in adults:

- Longstanding psychological factors (e.g. personality traits and happiness) can, in part, predict illness-related coping outcomes during the 36 months following diagnosis
- People who experienced greater psychiatric distress at diagnosis were significantly more likely to be emotionally preoccupied with their diabetes, and reported using less problem-focused coping in future follow-ups
- The impact of diabetes recorded shortly after diagnosis was a highly consistent predictor of palliative and emotion-focused coping across all follow-ups.
- People that had an additional co-morbid illness (e.g. hypertension, asthma) at diagnosis reported higher levels of emotional preoccupation at 12 months, at 24 months and at 36 months after diagnosis than people who did not have any additional illnesses
- Emotional preoccupation at 12 months after diagnosis was related to poor self-reported outcomes including less treatment satisfaction, poorer quality of life, fear of future complications, poorer well-being and poorer adherence, in future follow-ups
- Interventions to increase active, problem-focused coping may be effective in producing improvements in the quality of glycaemic control that is achieved at

36 months after diagnosis.

- Illness-related coping variables may have an intermediate position between psychosocial factors and diabetes-related outcomes. However, future longitudinal research is necessary to examine the role of coping as a mediating variable between psychosocial variables and diabetes-related outcomes.

Discussion

According to the stress and coping model proposed by Lazarus and Folkman (1984, 1987) coping can be understood in terms of transactional processes whereby antecedents to disease such as psychological indicators (or environmental stressors) act via mediating variables in determining health-related outcomes. In the present study the stress and coping model was applied as a theoretical framework in which to explore the role of illness-related coping in influencing and being subsequently influenced by, psychosocial variables and diabetes-related outcomes. A diagrammatic representation of the role of coping in adults with Type 1 diabetes is displayed in Figure 2.1. The EPDS provides the first longitudinal assessment of the role of illness-related coping in adults with Type 1 diabetes. Referring to the theoretical model presented in Figure 2.1, the results of the EPDS will be discussed with reference to two main areas of interpretation: (i) the influence of psychosocial factors recorded at the time of diagnosis on illness-related coping at follow-up reviews at 12 months, at 24 months and at 36 months after diagnosis, and (ii) the influence of illness-related coping strategies at 12 months after diagnosis on subsequent diabetes-related outcomes at 24 months and at 36 months after diagnosis. This will be followed by a general discussion of the limitations of the EPDS and some implications for future research (Part II, Chapter 4).

The left hand side of the model (Figure 2.1) shows the psychosocial factors that were assumed to influence illness-related coping outcomes during the 12 months following diagnosis of diabetes. These included socio-demographic factors, psychological factors (e.g. personality), and social factors (e.g. quality of life). In order to explore the consistency of the associations, the psychosocial predictors of illness-related outcomes at 24 months and at 36 months after diagnosis were also recorded.

Previous validation studies using the CHIP have provided evidence to suggest that the personality trait neuroticism is associated with negative-emotion coping, while extraversion has been found to correlate with distraction coping (Endler, Parker and Summerfeldt, 1998). The EPDS has replicated these findings and adds additional validation to the CHIP's dimensions. The personality trait neuroticism was found to be consistently associated with negative-emotion coping at 12 months and at 24 months after diagnosis. Extraversion, on the other hand, was a consistent predictor of distraction coping across the duration of the study. Extraversion was also found to correlate with instrumental coping at 12 months after diagnosis. This finding complements those of an investigation by Deary, Strickland, Frier and Gold (1998), which also found evidence of an association between extraversion and instrumental coping. These findings indicate that the personality traits, extraversion and neuroticism may be reliable long-term predictors of illness-related coping strategies during the early stages of diabetes self-management.

The present investigation extends the results of previous research by providing novel insights into the associations between a broader range of psychosocial factors and illness-related coping outcomes than has been studied in the past. Previous research suggests that in children and adolescents the diagnosis of diabetes is often followed by a 'brief period of psychological and emotional disturbance' (Kovacs, Brent, Steinberg, Paulauskas and Reid, 1986). Such disturbance is likely to facilitate emotion-focused coping styles because people who feel psychologically vulnerable may be more likely to experience greater emotional preoccupation. Support for this claim can been gathered from the present investigation. For example, there was a significant inverse association between self-rated happiness at diagnosis and negative-emotion coping recorded at 12 months and at 24 months after diagnosis, and a positive association between psychiatric distress recorded shortly after diagnosis and negative-emotion coping at 12 months after diagnosis. The direction of these associations was reversed when the associations between psychological factors and instrumental coping were examined; there was a highly consistent positive association between self-rated happiness recorded at diagnosis and instrumental coping, and a negative association between psychiatric distress and instrumental coping. Furthermore, happiness accounted for independent variance in instrumental-focused coping even after the personality trait extraversion had been added to the model at 12 months after diagnosis. These results are similar to those documented in a previous study of Icelandic patients with Type 1 diabetes, which examined the relationships between dispositional coping strategies and psychological distress. In this study task-oriented coping was related to lower levels of anxiety and depression in women, whereas emotion-oriented coping was associated with greater anxiety and depression in both sexes (Smari and Valtysdottir, 1997). The EPDS has replicated these findings using an illness-specific measure of coping. The results imply that emotional factors such as a person's self-reported psychiatric distress and general happiness recorded shortly after diagnosis are important indicators of a person's adjustment following diagnosis and may be used to identify patients who are at risk of greater emotional preoccupation.

To date, there have been no other studies that have attempted to examine the prospective relationships between diabetes-specific aspects of quality of life and illness-related coping in people with diabetes. However a cross-sectional investigation by Rose et al. (1998) examined the relationships between a generic multidimensional measure of quality of life and coping strategies in adults with diabetes. Rose et al. (1998) found that emotionally reserved patients coped less well with their diabetes and reported more negative-emotions. In contrast, active coping strategies were associated with more positive quality of life scores. In the EPDS it has been possible to extend these findings by examining diabetes-specific aspects of quality of life. The results of the present investigation revealed that less satisfaction with diabetes quality of life and an increased sense of burden of diabetes shortly after diagnosis were consistently associated with greater palliative and emotion-focused coping during the 36 months following diagnosis. In multiple regression analyses the perceived burden of diabetes shortly after diagnosis was predictive of palliative coping and negative-emotion coping at 12 months after diagnosis, accounting for 14% and 21% of the variance respectively. Having a positive quality of life shortly after diagnosis, however, was not predictive of greater problem-focused coping at follow-up. The fact that the dimensions of diabetes related quality of life recorded shortly after diagnosis did not predict problem-focused coping in subsequent follow-ups does not mean that no relationship exists between these variables. Instead this may provide important insight into the directional nature of the relationships between illness-related coping variables and diabetes-related quality of life. According to Testa and Simonson (1996), having a positive quality of life is part of a feedback loop in which active coping leads to improved quality of life, which leads to greater adherence, a more positive illness progression, and hence more active coping. By examining the relationships between illness-related coping at 12 months after diagnosis and diabetes related outcomes at 24 months and at 36 months after diagnosis it is possible to shed more light on the causal direction of these relationships.

So far the discussion has focused on examining the influence of psychosocial factors recorded at diagnosis on illness-related coping outcomes. The discussion will now focus on identifying the subsequent relationships between illness-related coping at 12 months after diagnosis and diabetes-related outcomes recorded at 24 months and at 36 months after diagnosis. The findings will then be discussed with regard to the conceptual framework displayed in Figure 2.1. It should be acknowledged that due to the limited number of subjects available for comparison, it has not been possible to draw any firm conclusions with regard to the mediating role of coping. The right hand side of the model displayed in Figure 2.1 shows the relationships between the individual dimensions of the CHIP and the diabetes-related outcomes recorded in the EPDS, which include: glycaemic control, knowledge of diabetes, satisfaction with the treatment for diabetes and diabetes quality of life. Additional outcomes were assessed at the 36 month review. These include, the Summary of Self-Care Activities Questionnaire, the Hypoglycaemia Fear Survey, and the Well-being Questionnaire. By substituting the significant correlates of different coping strategies at follow-up into the stress and coping model (Lazarus and Folkman, 1984, 1987) it is possible to demonstrate the positive and negative effects that different approaches to coping with illness may have on different diabetes-related outcomes. The arrows between the individual dimensions of the CHIP and each outcome category broadly represent the significant associations that were found in the EPDS (Figure 2.1).

The associations between illness-related coping strategies recorded at 12 months after diagnosis and diabetes-related outcomes recorded at 24 months and at 36 months after diagnosis were largely consistent with previous research which found that active coping strategies were associated with positive disease outcomes (Cox and Gonder-Frederick, 1992; Kovacs et al., 1990; Smari and Valtysdottir, 1997), and emotion-oriented coping strategies were associated with negative disease outcomes (Felton and Revenson, 1984).

Some studies suggest that it is only through active coping that patients are able to maintain their adherence to a demanding regimen (Band, 1990; Grey, Cameron and Thurber, 1991; Spirito, Ruggiero, Bowen and McGarvey, 1991). Furthermore there have been suggestions that there may be direct link between problem-focused coping and glycaemic control (Frenzel, McCaul, Glasgow and Schafer, 1988; Hanson, Harris, Relyea, Cigrang, Carle and Burghen, 1989; Lang and Faller, 1992), while others provided evidence to suggest that active coping and resourcefulness may be related to worse metabolic control (Aikens, Wallander, Bell and Cole, 1992; Goetsch, Abel and Pope, 1994). However these findings were obtained in cross-sectional studies where the causal nature of the relationship between active coping and glycaemic control could not be addressed. It may be therefore that active coping was the consequence rather than the cause of deficient glycaemic control in this sample. In the EPDS there was evidence for a positive relationship between problem-focused coping at 12 months after diagnosis and subsequent glycaemic control ($r = .41$, $p < 0.01$) at 36 months after diagnosis. This finding has important implications in the field of diabetes care. In particular, it suggests that interventions aimed at increasing active, problem-focused coping in adults with Type 1 diabetes from the time of diagnosis may be effective in producing improvements in the long-term quality of glycaemic control that is achieved.

In the present investigation high levels of emotional preoccupation recorded at 12 months after diagnosis were associated with poor self-reported outcomes but not to actual health outcomes (i.e. glycaemic control and diabetes knowledge). The findings of the EPDS showed that individuals who reported high levels of negative-emotion focused coping at 12 months after diagnosis were less satisfied with their treatment regimen, experienced more frequent episodes of perceived hyperglycaemia, and had poorer scores on all of the dimensions of the Diabetes Quality of Life measure at 24 months and at 36 months after diagnosis. In addition, there was evidence to suggest that high levels of negative-emotion coping at 12 months after diagnosis were associated with greater fear of hypoglycaemia, poorer well-being and less physical activity at 36 months after diagnosis. The results regarding the negative effects of emotion focused coping in adjustment to diabetes are largely in accordance with previous studies (for example: Felton and Revenson; 1984; Hanson, Harris, Relyea, Cigrang, Carle and Burghen, 1989; Endler and Parker, 1990). In previous cross-sectional studies negative-emotion coping has been linked to higher levels of anxiety and depression (Smari and Valtsdottir, 1997; Endler and Parker, 1990), an increased tendency to worry about hypoglycaemia (Deary, Hunter and Frier, 1997), somatic complaints (Deary, Clyde and Frier, 1997), poorer self-reported quality of life (Rose et al., 1998) and poor psychological adjustment (Felton and Revenson, 1984). The results of the EPDS complement these findings and imply that emotion-focused coping may be a risk factor for maladaptive coping in adults following initial diagnosis of Type 1 diabetes. It is therefore important for health professionals to be aware of this vulnerable group of individuals, and to increase the amount of education and support that is available to them from the time of diagnosis. For example, evidence from an intervention study suggests that for adolescents, coping skills training was effective in producing improvements in both metabolic control and quality of life. In addition, adolescents who received coping skills training found it easier to cope and experienced less negative impact of diabetes (Grey, Boland, Davidson, Chang Yu, Sullivan-Bolyai and Tamborlane, 1998).

According to Endler, Parker and Summerfeldt (1998) distraction coping is closely related to what has been termed as avoidance coping in the general coping literature (Billings and Moos, 1981; Endler and Parker, 1990). Distraction coping measures an individual's attempt to cope with a particular health problem by focusing attention on more pleasant experiences or engaging in other unrelated activities. Palliative coping is also thought to share features with avoidance coping (Endler et al., 1998). In particular, palliative coping assesses a person's attempts to alleviate the unpleasantness of a health problem by, for example, getting plenty of rest, or making one's surroundings more comfortable (Endler et al., 1998). The EPDS revealed that palliative and distraction coping recorded at 12 months after diagnosis were associated with poor self-reported outcomes including more frequently perceived episodes of hyperglycaemia, a tendency to worry about, and to avoid episodes of hypoglycaemia, and greater perceived burden of the illness at 36 months after diagnosis. These findings support those of another study, which found that hypoglycaemic avoidance behaviour was associated with distraction coping (Deary, Hunter and Frier, 1997), and are comparable to other studies that have used general measures of avoidance coping strategies. In these studies avoidance coping strategies were found to be associated with poor adherence (Hanson, Harris, Relyea, Cigrang, Carle and Burghen (1989) and psychological adjustment problems (Felton and Revenson, 1984).

According to Endler and Parker (1990) a major component of the general coping strategy avoidance is seeking social support. Interestingly, in the EPDS women obtained higher scores than men for distraction coping at 12 months after diagnosis. This can be explained by the findings of previous studies which suggest that women are more socially responsive than men (Freedman, 1979, cited in Endler and Parker, 1990), seek more help, and maintain greater proximity to friends than men (Block, 1976, cited in Endler and Parker, 1990).

To summarise, negative-emotion coping appeared to have the strongest and most consistent associations with self-reported diabetes-related outcomes. For example, negative-emotion coping at 12 months after diagnosis was consistently associated with poor self-reported outcomes at follow-up including fear of experiencing episodes of hypoglycaemia, poor self-management, poor self-reported quality of life and less treatment satisfaction. In contrast, instrumental coping was found to be an important indicator of better objective health status (e.g. glycaemic control), but was not associated with self-reported outcomes of diabetes. The absence of a relationship between instrumental coping and self-reported diabetes-related outcomes is in contrast to previous studies which found that active coping was associated with better adherence and quality of life (Rose et al., 1998). In general, the results imply that it is useful to promote task-oriented coping strategies in adults following initial diagnosis of diabetes, and it is especially important to help individuals to reduce emotion-oriented coping. However, based on the present findings it is unclear whether the coping responses observed at 12 months after diagnosis represent real differences in coping or are the result of specific reactions to the diagnosis of diabetes.

The avoidance-related strategies, namely, palliative and distraction coping (Endler, Parker and Summerfeldt, 1998) were more difficult to interpret. This may be partly because diabetes is a controllable illness. Therefore the use of avoidance strategies may be less relevant and potentially destructive if this means not seeking proper treatment or avoiding self-management activities (Felton and Revenson, 1984). There is some evidence to suggest that avoidance coping is the least used strategy among patients with diabetes when compared with patients with less controllable illnesses such as rheumatoid arthritis and osteoathritis (Andersson and Ekdahl, 1992).

In terms of the stress and coping model (Figure 2.1) it appears that psychological factors (e.g. personality traits and psychiatric well-being) and social factors (e.g. the perceived burden of the illness) at diagnosis are associated with individual differences in illness-related coping strategies at 12 months after diagnosis. Specific dimensions of illness-related coping are then, in turn, related to diabetes-related outcomes recorded at subsequent follow-ups at 24 months and at 36 months after diagnosis. In the EPDS there were too few subjects and therefore limited power to use more advanced statistical procedures such as structural equation modeling. It has not therefore been possible to test formally, the potential mediating pathways that are assumed to exist between the different constructs in the model. However, in view of the work of Watson and Pennebaker (1989) an alternative to the dominant stress and coping theory was recently tested using structural equation modelling. The stress and coping model (Lazarus and Folkman, 1984, 1987) presents the causal flow from personality and environmental factors via mediating variables to health-related outcomes. In contrast, the new model was based on construct economy; this was termed the negative affectivity theory (Deary, Clyde and Frier, 1997). The model was hypothesised based on the notion that overlap exists between many health-related constructs that appear to measure a similar latent source of variance. In other words many of the constructs used may be reasonable measures of the same disposition rather than separate independent variables. Using structural equation modelling the authors produced a conceptual model which provides evidence for a general factor related to the reporting of negative affects, but there was also evidence of unique variance, especially in negative emotion coping.

By comparison, the results of the EPDS also provide broad support for substantial overlap between negative self-reported health constructs and negative-emotion coping. In the EPDS it is has not been possible to determine whether psychosocial variables such as neuroticism and psychiatric distress, have a causal influence on diabetes-related outcomes via negative-emotion coping, or whether these variables are simply indicators of a broad latent factor which may represent a person's tendency to report negatively with regard to their health and well-being. Based on the findings of Deary et al. (1997) it is possible to hypothesise that negative-emotion coping has a mediating effect between the personality trait neuroticism and negative self-reported outcomes but it is unclear whether these results can be generalised to other coping constructs. For example, based on the present findings, the personality trait extraversion may have an indirect causal affect on glycaemic control via instrumental coping. In order to test these, and other assumptions, longitudinal studies using a larger sample of adults with diabetes are necessary. In particular, future research should focus on examining whether illness-related coping strategies act as mediators in the link between psychological variables and health constructs. By applying more advanced multivariate analyses (e.g. structural equation modelling) it may be possible to use the results of the present study as the basis for generating hypotheses, and testing different conceptual models competitively. This kind of approach would be advantageous in determining the longitudinal (causal) effects of psychosocial variables on diabetes-related outcomes from the time of diagnosis.

In conclusion, the results of the EPDS presented in this chapter represent the only attempt to examine the role of illness-related coping prospectively in a sample of adults with Type 1 diabetes. The findings have been applied within a conceptual framework based on the stress and coping model (Lazarus and Folkman, 1984, 1987) and provide broad support for the relationships that are assumed to exist within this framework. The results can be summarised as follows: (i) longstanding psychological factors (e.g. personality traits) and social factors (e.g. the impact of diabetes) recorded at the time of diagnosis can in part predict illness-related coping outcomes over time, (ii) emotional preoccupation recorded at 12 months is a consistent predictor of poor self-reported outcomes of diabetes at 24 months and at 36 months after diagnosis and may reflect maladaptive coping, and (iii) instrumental (problem-focussed) coping at 12 months after diagnosis of diabetes may be associated with good glycaemic control at 36 months after diagnosis. These results suggest that interventions aimed at increasing problem-focussed coping and reducing the emotional burden of diabetes shortly after diagnosis may be effective in improving an individual's glycaemic control and well-being in future follow-ups.

PART II (continued): The Edinburgh Prospective Diabetes Study

CHAPTER 4

Limitations of the EPDS and Implications for Future Research

In this chapter the results of the Edinburgh Prospective Diabetes Study (EPDS) discussed in the preceding two chapters (Part II, Chapters 2 and 3) will be discussed with reference to (i) the limitations of the EDPS, (ii) the implications of the EPDS for future research and clinical practice within the field of diabetes care, and finally, (iii) a consideration of the ways in which research into coping in adults with Type 1 diabetes should proceed.

Limitations of the EPDS

The EPDS was originally developed to monitor the psychological status of adults with Type 1 diabetes, prospectively, and to identify the most important determinants of objective and subjective diabetes-related outcomes over a series of periodic reviews after diagnosis. Using a longitudinal design the EPDS has succeeded in providing new and important insights into the most consistent determinants of different outcomes at different time points. In addition, the EPDS has provided considerable evidence to suggest that important psychosocial measures (e.g. diabetes quality of life and treatment satisfaction) remained highly stable over time. However, despite the findings of the EPDS some caution must be taken in their interpretation.

One of the limitations of this study is the non-ideal nature of the time of baseline measurements, which took place at the time of diagnosis and three to six weeks after diagnosis when patients were likely to be experiencing greater levels of anxiety and stress than normal. The objective of employing a baseline assessment is to provide a good estimate of individual differences in the pre-morbid psychological and social responses of the participants. However, it is difficult to assess the extent to which an individual's self-reports of, for example, neuroticism, happiness and psychiatric distress represent true reflections of individual differences in these psychosocial factors, or simply initial reactions to the diagnosis of diabetes. Despite this limitation, early indications suggest that individual differences in baseline personality traits (e.g. neuroticism) can account for variance in diabetes knowledge, and self-reported outcomes including worry about the future effects of diabetes up to 36 months after diagnosis. In order to overcome this problem, the ideal situation would be to measure psychosocial variables prior to the diagnosis of diabetes, however in reality this is not an option. In practice it is possible to either ask the participants to rate their personality traits and psychosocial status retrospectively and use these measures as the baseline responses. Alternatively, in future studies it may be beneficial to take baseline measurements of psychological characteristics after a given time delay when the initial impact of the diagnosis of diabetes has declined. This may be particularly relevant for measures of psychiatric distress which are more prone to change than trait measures of personality that are assumed to remain more stable over time.

The Diabetes Knowledge Questionnaire (DKNQ) was developed specifically for use in the EPDS and as a result this scale has not been validated previously. Therefore some caution must be taken in the interpretation of the associations between psychosocial variables and the DKNQ. Despite this limitation the findings indicate that the test is internally consistent, and has moderate stability over a 12 month duration. The results presented in this thesis provide some evidence for the validity of the DKNQ. In particular, the scale was found to be associated with social class, pre-morbid IQ, and the personality trait neuroticism, and was a significant long-term predictor of glycaemic control. Future studies are necessary to further explore the validity of this measure.

It must be emphasised that the findings of the EPDS presented in this thesis are of an exploratory and preliminary nature and therefore require confirmation. Due to the large number of comparisons made it is acknowledged that some of the associations, particularly in later follow-ups at 24 months and at 36 months after diagnosis where the subject numbers were smaller may be type 1 errors. Similarly, for the same reason, some existing relationships may not have been detected due to type II errors. Caution should therefore be exercised in generalising the results of this study, given the relatively small number of participants, especially in later follow-ups at 24 months and at 36 months after diagnosis. Larger scale studies with sufficient sample sizes to employ more sophisticated analytical procedures, which allow for formal hypothesis testing (e.g. structural equation modelling), are needed to increase current understanding of the causal nature of the relationships between psychosocial factors and diabetes-related outcomes in adults with Type 1 diabetes.

The use of both the Diabetes Quality of Life measure and the Diabetes Treatment Satisfaction which share a significant amount of variance despite the fact that they were designed to measure different concepts, has led to these measures being the best predictors of each other in the multiple regression analysis. The finding that these two measures are highly related is in itself an important finding. However, it may be the case that the covariance between these measures has prevented the emergence of other important predictors in the present analyses. In order to investigate this claim future work should consider the results of the EPDS as the basis for generating hypotheses about other potential predictors that may account for variance in self-reported outcomes, and to look at any potential mediating pathways.

An obvious limitation of the EPDS was the nature of the sample, which was exclusively white with a middle class bias. This population is unlikely to be representative of the diabetic populations as a whole. Furthermore, several patients scheduled to attend the outpatient clinic for follow-up appointments did not attend and/or did not return the questionnaires that were sent to them by post. The difficulties involved in studying patients who do not attend the diabetic outpatient clinic has meant that this special group of patients has often been excluded from research studies. This failure to include non-attendees is a recurring problem in diabetes research and an area that warrants further investigation. Indeed, previous research suggests that non-responders are more likely to have psychological disorders than responders (Van den Akker, Buntinx, Metsemakers and Knottnerus, 1998). The reliance on self-report measures was another weakness of the EPDS and may have added some bias to the data, however the stability and consistency of the relationships across successive follow-ups suggests that the patients were responding fairly honestly.

Implications of the EPDS for future research and practice

The results of this preliminary investigation into determinants of diabetes-related outcomes at a series of periodic reviews after diagnosis goes some way towards elucidating how individuals cope with diabetes following diagnosis. In particular, the findings of the EPDS support the view that self-reported outcomes of diabetes should be considered as independent outcomes of diabetes in their own right. As pointed out by Glasgow et al. (1999) the judgment that someone is 'doing well' is multifactorial. It reflects glycaemic control, but also psychological functioning, treatment satisfaction, knowledge of the illness, and a person's general well-being.

Future follow-ups of longer duration, using a larger sample, are now necessary to replicate these findings of the EPDS, and to investigate the nature of the temporal relationships between psychosocial variables and health-related outcomes after a longer duration of diabetes. For example, it may be that follow-ups that take place after the honeymoon period at, for example, ten years after diagnosis will shed more light on these relationships. In future reports it is important to address these issues, and to attempt to isolate the potential existence of stages in the adjustment process to diabetes.

The EPDS has provided considerable evidence for the reliability and validity of diabetes-specific self-report measures such as the Diabetes Quality of Life measure (DCCT, 1988) and the Diabetes Treatment Satisfaction Questionnaire (Lewis and Bradley, 1988; Bradley, 1994). However, as noted previously there was significant overlap in these constructs and among other self-reported psychosocial variables. Being aware that important variables in health psychology share variance should influence researchers in their decisions to use particular scales. In order to facilitate the generalisability of the results of different studies it is important for researchers to work towards establishing a common set of reliable and valid instruments which can be used to measure different outcomes (Glasgow and Osteen, 1992; Deary, Clyde and Frier, 1997). In reality this rarely happens because as acknowledged by Deary et al. (1997), many researchers either develop their own measures or simply opt for a measure which they feel comfortable with. Future research should focus on refining constructs in health psychology (Deary et al., 1997) and on providing a more coordinated approach whereby constructs with strong validity are retained.

The EPDS found evidence to suggest that those individuals with a good comprehensive knowledge of diabetes at four months after diagnosis were more likely to have good glycaemic control in follow-up reviews at 12 months and at 36 months after diagnosis. This finding has important implications within the field of diabetes care. While diabetes self-management education is already recognised to be an important part of diabetes treatment (Clement, 1995; Rubin, Peyrot and Saudek, 1991) few investigations to date have succeeded in providing evidence for a direct link between diabetes knowledge and objective health outcomes (e.g. HbA_{1c}). The results of the EPDS extend previous research by showing the benefit that a good knowledge of diabetes can have for a person's future glycaemic control, hence potentially reducing the risk of the development of complications of the disorder. Furthermore, the benefit of diabetes knowledge appeared to be long-lasting; present up to 36 months after diagnosis. On the basis of these findings recommendations should be made to target patients who may benefit from additional education to increase their understanding of diabetes at the time of diagnosis. However, further work is necessary to highlight the type of education or intervention that may be most beneficial to the patients.

Moving forward with the assessment of coping in adults with Type 1 diabetes

The results of the EPDS support previous research which suggests that the CHIP is a valid multidimensional measure of coping (Endler, Parker and Summerfeldt, 1998; Endler, 2000). Furthermore there is evidence to suggest that the four subscales are theoretically linked to constructs that are important in the general coping literature (Endler and Parker, 1990; Lazarus and Folkman, 1984). In the EPDS the CHIP scale has been used to examine the relationships between different dispositions of coping and diabetes-related outcomes over time (Part III, Chapter 3). However, as described previously, diabetes is different to other chronic illnesses because it is one of the few diseases that allows the individual to control their own well-being. This means that general measures of illness-related coping such as the CHIP may contain items that are inapplicable to people with diabetes. For example, palliative strategies such as getting comfortable, and making one's surroundings quiet, are likely to have little relevance to people with diabetes who are trying to meet the demands of a complex treatment regimen. The CHIP was originally developed for use with populations experiencing a variety of health problems. Therefore, the scale may fail to capture unique aspects of coping which are relevant to people with diabetes such as the fear of potential complications or the perceived burden of self-management activities.

In future research it would be useful to develop a diabetes-specific measure of coping that is applicable to adults with Type 1 diabetes. This would allow researchers to extend current knowledge of the relationships between psychological and social factors and coping ability, and the influence of coping strategies on objective and subjective outcomes of diabetes. A diabetes-specific coping instrument would also be of considerable benefit as a clinical tool for use within the field of diabetes care. The development of a diabetes-specific measure of coping would allow health professionals to make more informed decisions about the strategies that are most effective in helping patients to overcome the physical, social and psychological 'barriers' to adherence.

Finally, the results of the EPDS (Part II, Chapter 3) have provided broad support for the assumptions laid out by Lazarus and Folkman (1984, 1987) in their stress and coping model. In particular, the results indicate that there are important relationships between psychological and social factors recorded at the time of diagnosis of diabetes and illness-related outcomes, and that different illness-related coping constructs have consistent relationships with different diabetes-related outcome measures. Further work is required to investigate the potential mediating pathways between these variables using more advanced statistical techniques.

With the above considerations in mind, the decision was made to proceed with the assessment of coping in adults with Type 1 diabetes by developing a new diabetes-specific measure of coping. In order to ensure that important issues relevant to coping with diabetes were addressed it was deemed appropriate to adopt a qualitative approach with the goal of identifying particular aspects of coping with diabetes that are perceived to be most relevant to the patients themselves. This approach was adopted initially as a means of identifying categories, subcategories and specific indicators of coping with diabetes.

PART III: Coping with Diabetes: Assessment and Measurement

CHAPTER 1

Qualitative Assessment of Coping in Adults with Type 1 Diabetes

Introduction

The research described in this chapter is concerned with the important question: how do people cope with Type 1 diabetes? One of the many problems facing researchers attempting to measure coping as a construct is that few reliable and validated psychometric instruments exist. Over recent years diabetes-specific instruments with better psychometric characteristics have been developed to measure diabetes-related outcomes such as diabetes treatment satisfaction (Lewis, Bradley, Knight, Boulton and Ward, 1988; Bradley, 1994) and diabetes-related quality of life (DCCT, 1996) but there is still no validated instrument that measures coping in diabetes. This is problematic because diabetes is different from other chronic diseases. Diabetes is one of the rare chronic illnesses which enables individuals to control their own well-being to a large extent (Costa, Sommerfield and McCrae, cited in Zeidner and Endler, 1996). This potentially increases the psychological burden of the illness because diabetes calls upon a process of behavioural self-regulation in an attempt to maintain metabolic processes that are normally performed automatically (Cox and Gonder-Frederick, 1992). Not only do patients have to deal with the daily demands of glucose control and fear of hypoglycaemia (Cox, Irvine, Gonder-Frederick, Nowacek and Butterfield, 1987; Deary, Hunter and Frier, 1997) they are also likely to suffer from at least some of the complications of diabetes as it progresses (Lloyd, Matthews, Wing and Orchard, 1992; Kelleher, 1988).

Endler and colleagues have developed some of the best validated measures of coping available to date. These include the Coping Inventory for Stressful Situations (CISS;

Endler and Parker, 1990a) and the Coping with Health Injuries and Problems scale (CHIP, Endler, Parker and Summerfeldt, 1998; Endler, 2000). The CISS is a general coping measures that was developed to assess the interaction between stressful life events and the ways in which people cope with them (Endler and Parker, 1990a, Endler, 2000). The CISS assess three general styles of coping: (i) Task-oriented coping, which is concerned with purposeful efforts to solve a problem, (ii) Emotion-oriented coping which is concerned with emotional reactions that are self-oriented, and (iii) Avoidance-oriented coping, which discusses activities and cognitive changes which are concerned with avoiding the situation (Endler and Parker, 1990a). In subsequent validation of the CISS depressed people were found to use more emotion-oriented coping than people who were not depressed (Endler and Parker, 1990b). There is also evidence for a negative relationship between depression and task-oriented behaviours (Mitchell and Hodson, 1983, cited in Endler and Parker, 1990). Following the development of the CISS, Endler and colleagues went on to develop the CHIP. The CHIP measures general dispositions of coping with health problems and illness and contains four dimensions: Distraction, Instrumental coping, Palliative coping and Negative-emotion coping (see Table 1.1 in Part 1, Chapter 2). Previous research using this scale suggests that people who use more problem-focused coping styles are more likely to be satisfied with their treatment and have higher self-reported well-being (Deary, Strickalnd, Frier and Gold, 1998). In contrast, those who tend to use more negative-emotional coping styles generally obtained lower well-being scores (Deary, Strickland, Frier and Gold, 1998). In validation studies the CHIP scales were found to be reliable, stable over time and adaptable to different populations including people with acute (e.g. respiratory infections, limb fractures) and chronic health problems (e.g. cancer, diabetes, arthritis) (Endler, Parker and Summerfeldt, 1998). However, the CHIP is a generic coping scale, applicable to all illnesses, and therefore does not acknowledge, or necessarily accommodate, the unique importance of the individual's ability to adhere to a specific, complex regimen, nor is it likely to capture the psychological burden which the daily demands of diabetes place on the individual. With this in mind, the research described here set out to examine what it means to cope with diabetes from the patient's perspective.

Establishing what it means to cope well with diabetes is problematic because coping may have multiple determinants and may refer to multiple outcomes. For the purpose of the present investigation attention was focused on the patients' own subjective accounts and descriptions of their experiences of coping with Type 1 diabetes. This type of qualitative approach was adopted initially as a means of developing core categories, subcategories, and specific indicators of coping with diabetes.

Interviewing can provide important new insights, especially where the research is relevant to changing or improving emotional or behavioural responses (Breakwell, 1990). In the present investigation, interviews are particularly relevant, because they provide an excellent opportunity for the participants to use their own language and experiences to describe their reactions and attitudes towards their diabetes, their ability to cope with the demands of their daily regimen, and to raise other issues they consider to be important. As such this approach lends itself to a deeper analysis of intricate details involved in the coping process such as feelings, thought processes, emotions and descriptions of specific behaviours that may be more difficult to capture using more conventional and non-specific quantitative methods.

The goals of the qualitative approach outlined in this chapter were: i) to conduct a series of semi-structured interviews with patients who attend the diabetic out-patient clinic at the Royal Infirmary of Edinburgh, where the emphasis of the interviews was to identify those aspects of coping that the individuals themselves perceived to be most relevant; ii) to evaluate the participant's responses, and to use these responses to develop an integrated theory of the coping strategies adopted by individuals who have Type 1 diabetes; and iii) to generate items to be used in the development of a structured, quantitative diabetes-specific coping questionnaire.

Research objective

To investigate adults' reports of their psychological adjustment to Type 1 diabetes and to identify the strategies that individuals employ to enable them to cope with the psychological, social and physical burden of diabetes.

Research design and methodology

Subjects and procedure

The participants were 10 patients (5 male, 5 female) with Type 1 diabetes who attended the outpatient clinic at the Royal Infirmary of Edinburgh. All of the participants were currently receiving insulin therapy. Six participants were patients who had completed the 36 month follow-up phase of the Edinburgh Prospective Diabetes Study (see Part II, Chapter 2) and who volunteered to be interviewed as part of this review. The four remaining participants were selected individually in collaboration with health professionals at the diabetes outpatient clinic. These four patients were known to have had difficulty with their diabetes self-management in the past. Clinical characteristics of the participants are shown in Table 3.1.

Table 3.1: Clinical characteristics of the sample (n = 10)

Characteristics	Median (range)	Mean (SD)
Age (years)	32.5 (21 - 48)	34.0 (10.1)
Duration of diabetes (years)	5.0 (2 – 14)	5.3 (3.7)
Body mass index (kg/m^2)	30.5 (25.7 – 36.2)	30.8 (5.3)
Glycated haemoglobin (HbA$_{1c}$)	8.0 (6.4 – 10.3)	8.1 (1.2)

Each participant was contacted by telephone and invited to attend an interview at the outpatient clinic at the Royal Infirmary of Edinburgh. Those individuals who agreed to attend were sent a letter explaining the nature of the interviews and confirming the place, date and time that it would take place. Written informed consent was obtained from all participants. All interviews were carried out in a private consultation room within the Department of Diabetes. The interviews were conducted within the diabetes clinic because this was considered to be a place where the patients could talk openly about their diabetes in a supportive, and to some extent, neutral environment. The interviews were kept relatively informal to ensure that the patient felt comfortable and at ease. Each interview lasted between thirty minutes and one hour and was recorded using an audio-tape recorder. This was useful because it allowed the researcher to respond to the direction of the questions. Following each interview a full transcription was made.

Protocol development: The Edinburgh Diabetes Coping Interview

The Edinburgh Diabetes Coping Interview (EDCI) was developed especially for use in this study. The interview questions were developed using several procedures including: i) consulting commentaries which provided guidelines on asking questions and developing interview schedules (e.g. Breakwell, 1990; Rosenthal and Rosnow, 1991; Banister, Burman, Parker, Taylor and Tindall, 1995); ii) searching the relevant literature and consulting existing diabetes-specific instruments to identify areas of importance; and iii) discussion with diabetes health-care specialists, working within the Department of Diabetes including Dr Brian Frier, a Consultant Physician, Dr Vincent MacAulay, a Diabetes Registrar, and Sister Kay Malloch, a diabetes specialist nurse. This discussion focussed on the relevance, appropriateness, and breadth of the areas addressed in the schedule.

Interviews can vary on a continuum from structured to completely unstructured and there are advantages and disadvantages of both methods. Structured interviews are generally regarded as better when clear cut responses are required from larger samples, because they are easier to compare and quantify (Rosenthal and Rosnow, 1991). The disadvantage of this approach is it provides little space for insights and can miss out on entire areas of concern if these were not considered in the development of the interview. For this reason the present study used a semi-structured interview schedule. The advantages of this approach were that the interviews would all follow a similar structure, and provide broadly comparable responses, but would retain the ability to capture deeper and more personally relevant information, often gained in unstructured interviews, by presenting open ended, flexible questions. Therefore, the resulting interview schedule was regarded as representing a broad structure for the interview, based on a series of open-ended questions. It was decided prior to the interviews that expansion and relevant diversions from this structure were acceptable.

A pilot interview using the Edinburgh Diabetes Coping Interview (EDCI) was carried out following the development of the schedule with the first interviewee. As a consequence, the interview schedule was amended. This involved changing the wording of some of the questions and the order in which they were asked. Prompt questions were added to be used at the interviewer's discretion. These prompts were included to provide the interviewees with some concrete examples to clarify the more general questions. For instance, when presented with the question: "Can you describe any specific things you do to help you to cope with your diabetes?" the interviewer may refer to the kinds of things a person might do such as finding out more about their diabetes, writing things down in a diary, or doing things to take one's mind off his or her diabetes. The revised version of the Edinburgh Diabetes Coping Interview (EDCI) is presented in the appendix.

The qualitative approach: Grounded Theory

Grounded Theory was originally developed by Glaser and Strauss in the 1960's (Glaser and Strauss, 1967) to identify social processes. The overall aim of Grounded Theory analysis is to produce theories which are truly grounded in the data (Willig, 2001, p.47) and it is the researcher's role to use his or her skills as an analyst to identify the concepts and social processes that are present in the data.

Over the years it has become clear that Grounded Theory can be interpreted and applied in different ways depending on the research question, time constraints and the resources available to analysts (Willig, 2001, p .42). Nowadays even the creators of Grounded Theory (Glaser and Strauss, 1967) disagree about the precise nature of the methodology. Glaser (1992) published a new book called *Emergence vs Forcing: Basics of Grounded Theory Analysis* in response to a Strauss and Corbin's (1990) *Basics of Qualitative Research: Grounded Theory Procedures and Techniques.* According to Glaser (1992), Strauss and Corbin's book was too prescriptive and did not represent Grounded Theory as described in the original presentation. Glaser went on to describe Strauss and Corbin's technique as 'fractured, cumbersome and over self-conscious' (Glaser, 1992, p.60) and suggested that they interfere rather than facilitate the process of discovery (Willig, 2001, p.49). However, others have suggested that such disagreements over

Grounded Theory can be traced back to ambiguities in the original text provided by Glaser and Strauss (1967) (Dey, 1999, p. 44). Despite the ongoing debate between Glaser and Strauss, Grounded Theory continues to evolve, and further varieties of Grounded Theory are likely to emerge in the future. Nevertheless, it should be acknowledged that regardless of the approach adopted, Grounded Theory does provide a set of procedures which *'are ways of putting into practice the requirement to actively engage in close and detailed analysis of your research materials, so that they can both stimulate and discipline the theoretical imagination'* (Pidgeon and Henwood, 1997, p.225).

Grounded theory was chosen to analyse the interviews in the present study because using the methodology outlined by Strauss (1987) the theory develops directly from the data, rather than beginning with a preconceived theory in mind. Using grounded theory it is possible to allow the theory to emerge from the data. As Strauss (1987) asserts *'The goal of grounded theory is to generate a theory that accounts for a pattern of behaviour which is relevant and problematic for those involved'*. This approach is distinguished from other approaches to qualitative analyses by its emphasis on 'conceptual density'. This means that the data are 'coded' in terms of dimensions, properties, conditions, and consequences of each code to develop a thorough understanding of the interrelationships between each code, category, subcategory and core category/categories.

In this study the transcriptions of the interviews were analysed using Grounded Theory to derive specific dimensions of coping as described by diabetes sufferers themselves.

This approach generated a taxonomy of categories which acted as a structuring device for the questionnaire and, later, as a means of deriving questionnaire items. The processes involved in this analytic approach are described in detail below.

Concept-Indicator Model: "Grounded theory is based on a *concept-indicator* model" which directs the *conceptual coding* of a set of *empirical indicators*" (Strauss, 1987; p.25). In other words empirical indicators (i.e. interview transcripts) are used as concept indicators. Therefore the data (behavioural actions or emotions as described by the interviewee) are indicators of a concept which the researcher derives from them. The analyst compares a number of transcripts and codes descriptions of an event or action as indicating one or another concept. The aim is for the researcher to constantly compare particular actions or events which are described by the interviewees to other actions or events which appear similar or consistent. This process involves undergoing a rigorous process of constant comparison of indicator to indicator to identify similarities, differences and consistencies within the transcripts. This eventually leads the analyst to appreciate the underlying uniformity between many indicators (i.e. described behaviours or emotions) and so *'code'* them as a category. In other words the researcher decides to name these actions or events as an indicator of a class of actions or events. Adding new indicators to a particular class of actions or events sharpens the code until *saturation* (at which point new samples do not add anything).

Coding: Coding is a general term used for conceptualising data (e.g. raising questions and giving answers about categories and their relations). Coding must go further than simply the discovery and naming of categories; it must also investigate the systematic relationships between them and the phenomena under investigation (Strauss, 1987; p. 27). In grounded theory, coding uses a *coding paradigm*. When using the coding paradigm it is important to code the data for relevance to the category in terms of the following:

> *Causal conditions* are often mentioned by interviewees, and are indicated explicitly in phrases such as "because", "since", "as", or "on account of". These phrases are used to indicate the underlying reason or "cause" behind a person's attitudes, beliefs, behviour or emotions.
>
> *Interactions/Intervening conditions:* Interactions can often occur between or among the actors, (the actors being the people referred to in the dialogue), for example "she said" or "I talked to him". Within the coding paradigm such interactions contribute to strategies and consequences. Intervening conditions are particular situations (e.g. driving a car, attending the diabetes clinic) which are specifically associated with a particular behaviour, emotion, or consequence.
>
> *Strategies/actions/emotions:* describe a person's behaviours, strategies or emotions in response to different causal conditions and/or interactions/intervening conditions.

Consequences of actions are often pointed out in phrases such as "the consequence was", or "as a result" and refer to the specific consequences of a particular action or causal condition.

It is essential when using the coding paradigm that the analyst actively explores the variations in the data, for example, why do consequences differ, strategies differ etc. This forces researchers to go beyond naming of categories and encourages them to think explicitly about the concepts and their relationships. This *"conceptual stepping back"* (Strauss, 1987; p.29) is essential to the development of theoretical understanding. Thus the development of the eventual theory depends heavily on the interplay between the researcher and the data (Strauss and Corbin, 1998).

A diagram showing the different stages involved in the analysis is shown in Figure 3.1. Different types of coding are now described, which are appropriate at different stages of the analyses:

Open coding: This is the initial type of coding and involves unrestricted coding of the data. The process is carried out by scrutinizing the interview closely, line by line, and word by word (Strauss, 1987; p. 28). The goal of open coding is to explore the data and yield initial concepts, or to "open up" the inquiry (Strauss, 1987; p.29). At this stage the aim is to explore possible interpretations of the individuals' descriptions of their behaviour or emotional responses, and to produce concepts which seem to fit the data. These categories should generate provisional questions, answers, ideas, or hypotheses about the data. These interpretations are stored as memos which comprise category labels and an explanation of why the label fits. Codes are either in vivo (the participant's own words) or analyst's constructs.

Axial coding: Axial coding involves intense re-analysis of the interview transcripts in terms of existing codes rather than in an open frame of mind. Axial coding occurs once ongoing codes have begun to emerge. It is an essential part of open coding. At this stage the researcher will have derived several codes each with its own indicators. The next stage involves examining each code in terms of its relationship to other categories and subcategories using the coding paradigm. This is termed axial coding because the analysis revolves around the *'axis'* of one code at a time and attempts to establish relationships between each code. The analysis continues to alternate between loose open coding and axial coding. The purpose of this more directed analysis is to make linkages with the category or categories that eventually become the *"core"*.

Selective coding: The final type of coding begins once the core codes/categories have emerged. At this stage the analyst delimits coding to codes that relate only to the core category. In this way links are drawn between the core category and other subordinate categories. This procedure then guides further sampling and data collection. Selective coding is therefore more systematic and focused than open coding and facilitates the theory's eventual integration.

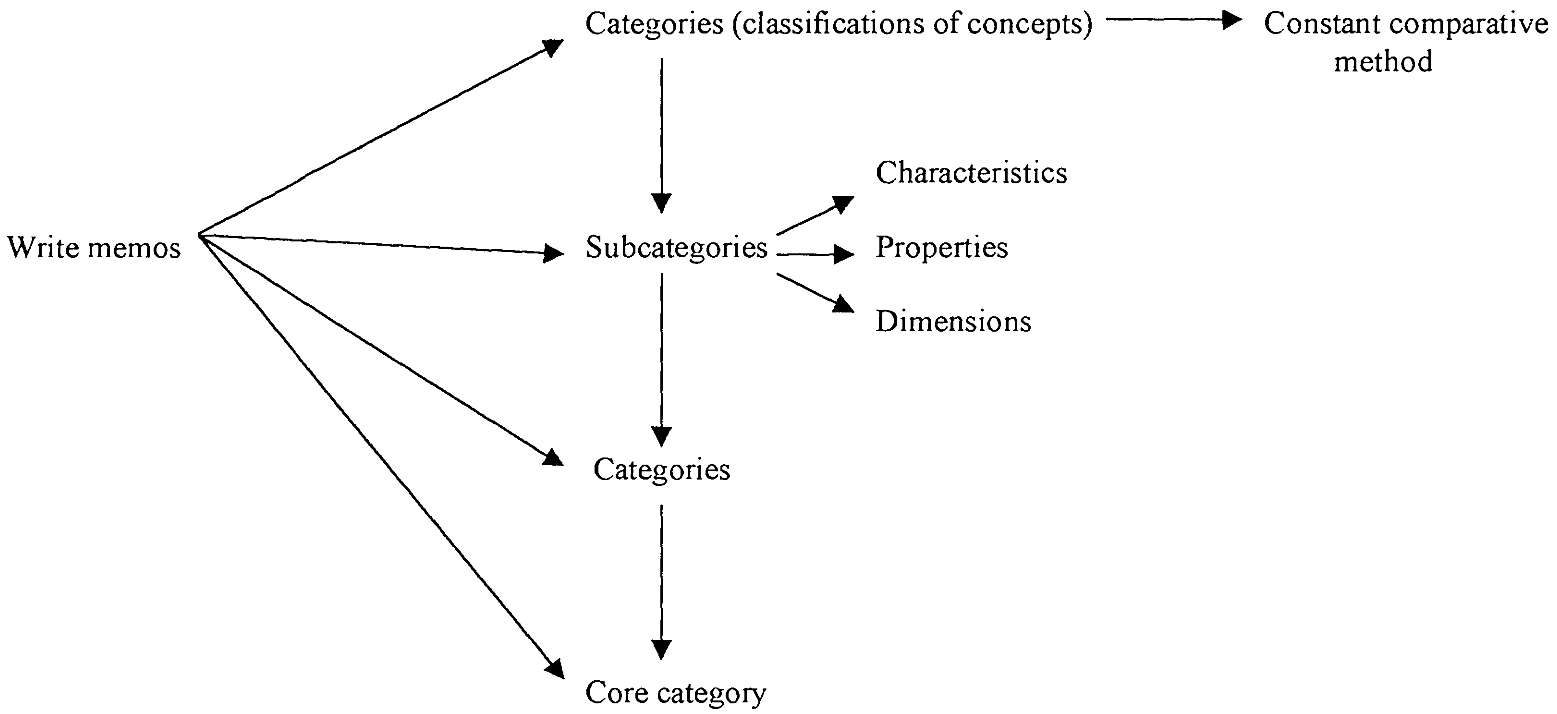


Figure 3.1: Diagrammatic representation of multi-step analytic techniques used to develop Grounded Theory based on Glaser and Strauss (1978).
Adapted from Y.D. Eaves (2001)

Qualitative analysis

The analysis of the interviews followed the analytic steps laid out by Strauss (1987), described earlier in this section and displayed in Figure 3.1. As shown in Figure 3.2, the core category 'Diabetes-related coping in adults with Type 1 diabetes' was explained by three higher order categories: i) task-oriented coping, ii) emotion-oriented coping, and iii) avoidance oriented coping. The coping categories represent the major dimensions of coping discussed in the literature (Endler and Parker, 1990a; Lazarus and Folkman, 1985; 1984). These categories are what Glaser (1978) (p.70) defines as *in vitro* codes, which *'are based on a combination of the analyst's scholarly knowledge and his research knowledge of the substantive field'*. As acknowledged by Glaser the use of *in vitro* codes can add meaning and depth to an analysis by importing relevant prior theory.

Each category consisted of several diabetes-specific subcategories (Figure 3.2). The eight descriptive subcategory labels shown in Figure 3.2 were derived using a method of constant comparison based on the concept-indicator model discussed previously. This process involved using empirical indicators (the participants' own words taken directly from the interview transcript) as concept indicators. Concept indicators are 'coded' (given a descriptive label) by the researcher. The codes are then used as indicators of a particular event or action. After several codes had emerged from the data, different codes were compared to other codes which appeared to be similar or consistent. This process led to the eventual classification of codes into subcategories.

The subcategory labels in Figure 3.2 are what Glaser (1978) terms as *in vivo* codes which are based on the participants' own words or the analysts constructs. The first category termed 'task-oriented coping' was indicated by three subcategories: Information seeking and Adherence, Sources of support, and Acceptance. The second category termed 'Emotion-oriented coping' was indicated by four subcategories: Impact, Diabetes-related distress, Fear of complications, and Isolation/Stigmatisation. The third category termed 'Avoidance-oriented coping' was indicated by the subcategory 'Rebellious decisions'. A diagram showing the relationships (or linkages) between the core category, and each category and subcategory is shown in Figure 3.2. The final model will now be described with reference to Figure 3.2.

In this section, the analysis will focus on unraveling the eight subcategories which relate to each of the three coping categories (Figure 3.2). Examples from the data are used to indicate how the participants' descriptions led to the coding of specific indicators/concepts, and to describe how the comparison of different indicators led to the categorisation of concepts into a particular subcategory. Subcategories with thematic similarity were then grouped together and linked to the higher order categories to form an integrated model (Figure 3.3 – 3.5). The integrated models displayed in Figures 3.3 – 3.5 are provided to show how different subcategories could be drawn together in a conceptual understanding of different approaches to coping in adults with Type 1 diabetes. These models were created based on the work of McVey, Madvill and Fielding (2001). These authors created a similar model based on an investigation of the experiences of patients' who had stoma surgery to treat cancer. In the present study, these models are provided to summarise the causal and intervening conditions, actions and emotions, and subsequent consequences (Strauss and Corbin, 1998) of the different coping styles (task, emotion and avoidance). However, as acknowledged by McVey et al. (2001) in their analysis, because the causal connections are derived based on summaries of the codes which emerged from the interview data, the causal processes are hypothetical at this stage.

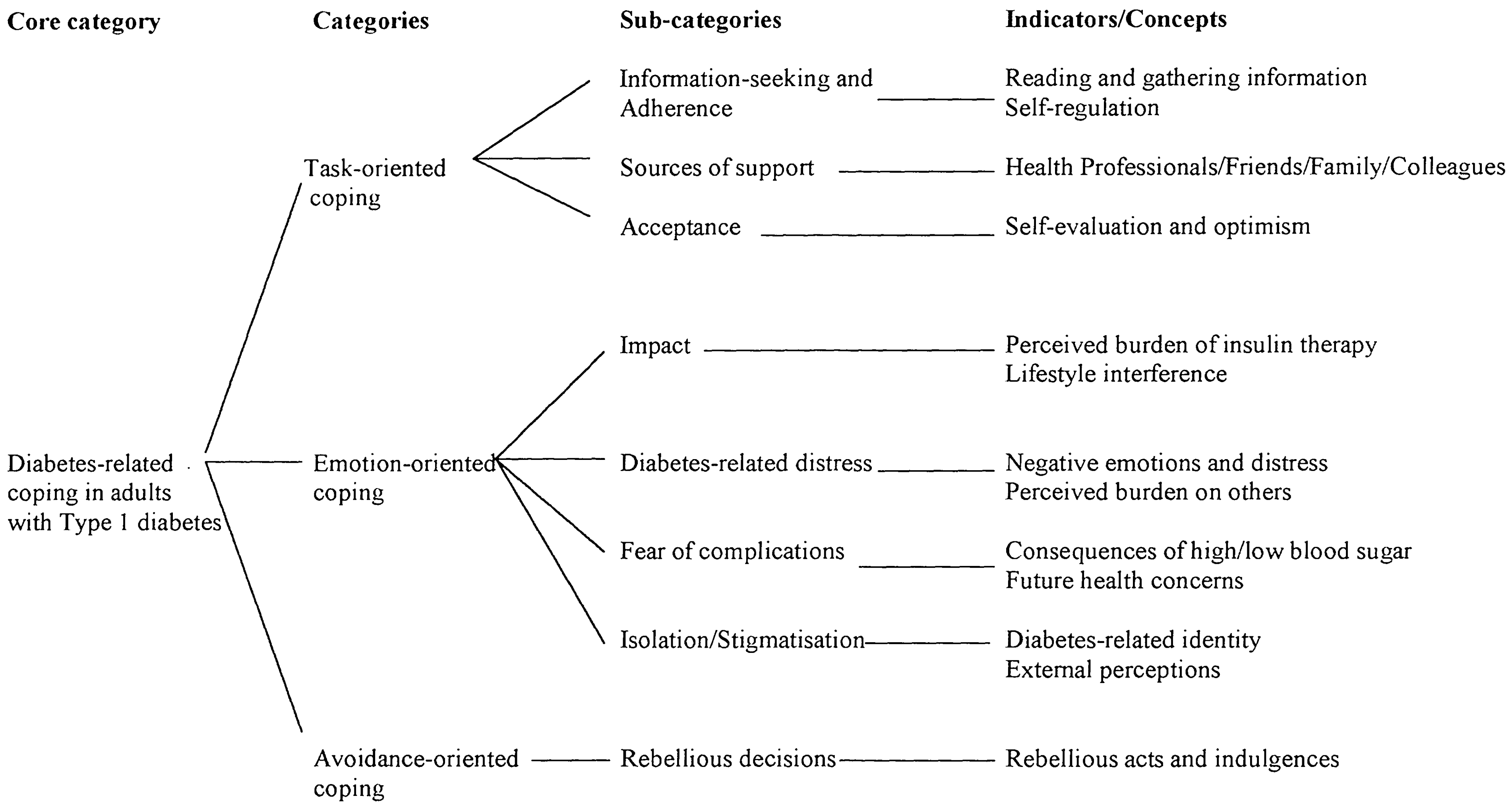


Figure 3.2: Digrammatic representation of diabetes-related coping strategies in adults.

Task-oriented coping

According to previous literature on coping task-oriented coping also known as problem-focused or instrumental coping involves using cognitive or behavioural strategies which are aimed at doing something to change for the better the problem causing distress (Folkman and Lazarus, 1985). In health psychology, problem-focused strategies may include seeking help for the illness or trying to learn more about it (Endler et al., 1998; Endler, 2000). In the present study three subcategories were identified that were associated with task-oriented coping: Information-seeking and adherence, Sources of support, and Acceptance. Each of these subcategories will now be discussed in turn.

Information seeking and adherence

There were two primary indicators of the subcategory termed 'Information seeking and Adherence'. These indicators were coded as follows: (i) reading and gathering information and (ii) self-regulation (Figure 3.2).

All of the patients spoke about the importance of reading and gathering information about diabetes. This was associated with an expectation that having a comprehensive knowledge of diabetes was protective against emotional preoccupation; *"Generally I think knowledge is power and if you've got knowledge about your diabetes then it's not going to bother you so much. I say that to other people as well, because otherwise you do just worry so at least you know how to combat problems as you get them".*

The participants described used several strategies to gather knowledge about their diabetes including using the Internet, reading books and articles about diabetes, watching television documentaries, as well as the education they received at the diabetes clinic. These strategies are evident in the following extract; *"I've looked on the internet a lot. I've got four or five books and the magazine as well [Balance – magazine produced by Diabetes UK]…I've been to lectures as well to try and find out what new stages are coming along, and any information I get I'm really interested to read about it"*. Another person said; *'I get my Balance, you know, the magazine from the BDA [British Diabetic Association] regularly and I always sit and read my way through that and if I find out there's going to be a programme on telly or a bit in the newspaper about diabetes I always find myself sort of homing in on that and reading it, just to try and gather more information and find out about all the so called 'miracle cures' that they're gonna come up with - in the hope that one of these days they might actually find one"*.

As well as empowering the patients the above statements reveal how gathering information particularly *"at the beginning"* helped them to keep up with *"new stages"*, and to find out about so called *"miracle cures"*, and *"different products"*. These strategies and their associated expectations were consequential in increasing the patients' hopes and making them feel more in control of their own self-management. One patient (DL) found learning about diabetes interesting, and described being 'surprised' at the effectiveness of his treatment; *"I was quite surprised how quickly somethings reacted in that you know, I was feeling sort of shaky, sort of the start of a hypo and if I took something you know maybe a drink of fruit juice I was surprised how* *quickly it rectified it. I mean it was quite interesting to just to find out about how the insulin works, sort of catalyst effect of the glucose in the cells and what have you. It was all quite interesting and I think I know enough yeah".*

As shown in the previous statements, information gathering was generally associated with positive outcomes. In particular, it allowed the patients to experiment with their individual prescriptions, to keep up with new developments, and to learn more about how their bodies worked. However, although all the patients reported being 'interested' in finding out about their diabetes, the consequences of this information-seeking behaviour varied amongst different individuals as illustrated in the following example; *"I'm a member of the BDA, and they send me 'Balance' the book once every two months or something like this, they send it out. I sort of keep up to date with what's going on in case there's a major break, you can see things progressing along at the moment, but nothing, there have been programmes on the telly about people having transplants and implantations and all this kind of stuff, but nothing's guaranteed, not in this life anyway".* In this statement the patient (RS) clearly indicates a desire to keep up with what's going on *'in case there's a major break'*. At first, this attitude appears similar to the hopefulness described by other participants in this study, but the statement *"nothing's guaranteed, not in this life anyway"* reflects a more cynical outlook.

Another patient (GP) reveals how being interested in diabetes is not always associated with good self-management; *"I'm very interested in research into cures and new treatments, my mum especially always sends me piles and piles of information of new* *pens that are out, and new blood machines, and new things you can try and do to help your diabetes. I'm really interested in it I just don't actually do it".*

Overall, reading and gathering information was highlighted as a positive coping strategy which allowed the participants to feel empowered, and more in control of their diabetes self-management. There was some distinction between the type of information obtained for example, information about transplantations and implantations were perceived as being *"not guaranteed"*, whereas information which is relevant to the biological, physiological and treatment-related aspects of diabetes was perceived as more helpful, useful and interesting.

The second indicator of the subcategory 'Information-seeking and Adherence' was called 'Self-regulation'. Self-regulation is a concept used to describe the participants' descriptions of their adherence to their diabetes self-care routine. The participants in this study frequently described *"balancing things"*, *"keeping things in check"*, *"adjusting"* and *"controlling levels"*, and *"planning ahead"*. These terms relate specifically to behavioural strategies employed by the participants to help them to cope with their diabetes. The following extracts highlight the four specific activities which the patients described as being important in self-regulating their diabetes.

The first regimen activity referred to was taking regular exercise, for example; *"I go to the gym almost every day and do running and cycling and rowing. I walk everywhere, yeah if I don't do exercise for a while I feel generally pretty rubbish"*. Taking regular exercise was associated with positive psychological outcomes; *"It's really just a case of trying to balance your exercise and everything to try and keep things level, but think I'm coping with it reasonably well"*.

The second regimen activity referred to was glucose monitoring. There was some evidence to suggest that accuracy of measurement, time taken to establish blood glucose levels, and convenience were particularly important determinants of a person's attitudes towards their blood glucose monitoring, as illustrated by the following example; *"I can normally tell how much insulin I've taken and what I've eaten and what exercise I've done. You know if I feel different than I normally would do then I always, I have a testing kit, you know with the 'chuck' in the finger and all that. The accurate one not the tester strips themselves, this gives you the, to the second decimal point of what your blood sugar is, so it only takes about 10 seconds so obviously you just check it before you consume a bottle of cola or something"*.

Taking regular exercise and regular blood glucose monitoring were perceived to be necessary activities in achieving good self-management. Other activities such as adhering to one's diet and achieving good glycaemic control were described as being most important, but also perhaps the most difficult to achieve. Although the majority of the patients described making an effort to follow their recommended diet, some patients spoke about the difficulties they experienced in matching their food intake with their blood glucose readings; *"You can eat the same things two days running and your readings can be totally different one day from the other, and that I can find quite* *difficult to cope with because I don't know why it's doing it, but mainly it's just a case of trying to balance your exercise and everything and to try and keep things level. So coping is really about the ongoing maintenance".*

As one patient pointed out *"diabetes is not an exact science"*, and achieving good control of diabetes was described as a *"balancing act"*. In other words, the regulation of food, insulin and energy expenditure requires considerable effort on the patient's behalf and is sometimes, as a consequence, perceived as difficult to cope with. However, for other participants diabetes self-management was less problematic; *"It's just like brushing my teeth now"*. This reflects the positive perception that diabetes self-management has become integrated into the patient's routine and is almost an automatic process, requiring little conscious thought.

In summary, all of the participants reported making an effort to adhere to their diabetes self-management activities including taking more regular exercise, blood glucose monitoring, having a healthy diet, and taking injections of insulin. Adhering to these self-management activities required considerable effort but on the whole adherence to the demands of insulin therapy was associated with positive outcomes for the person's physical and psychological well-being.

Sources of support

The subcategory termed 'Sources of support' was derived from the participants' references to the support they received from partners, other personal contacts and professionals (Figure 3.2). In particular, this subcategory is concerned with the participants' accounts of the support that they receive from key people in their life, and the consequences of this support for their diabetes-related well-being.

The participants' perceptions of the support which they received from health professionals at the diabetes outpatient clinic were generally positive. The primary role of health professionals was perceived to be reassuring and encouraging, and to provide information and medical advice where necessary. All of the patients who took part in the present study spoke about finding it useful to be able to phone the nurses at the diabetes clinic for advice and to answer general questions abut their diabetes. These interactions between the patients and health professionals at the clinic were illustrated as providing the patients with security, and a sense that help is always available. For example one person stated; *"Everything that I've wanted to know they've told me, and if I did have a problem they are only at the other end of the phone. I think it is really good the information they give out"*.Similarly, another person said; *"I find it useful that the nurses are on call, if you've got a question or a problem you can phone in and you know they'll answer your question over the phone, or you can call in or whatever. I find that very useful"*.

The patients described the support they received from health professionals as *"useful"* and as having positive consequences for their well-being. For example, one patient spoke about *"being treated like a person with different needs and worries"* and felt that is was important to be *"treated like a person and not a number"*. This type of approach on the part of the health professionals involved showing an interest in, and a commitment to the patient's situation. In other cases, a lack of information and understanding, and a reliance on health professionals for advice resulted in a feelings of disempowerment; *"I think I was very careful at the beginning whereas now I'm not so careful. Now I just do it as a routine and there's one or two things I'm not sure about. They tell you to keep your blood sugar at levels between 3 and 7, for example, and how serious is it to be outside that range? They don't tell you about things like this, it's all very approximate, but that's my worry".*

Friends and work colleagues were also mentioned as playing key roles in providing support to the patients. In contrast to health professionals, friends were described as offering a channel through which to share experiences of diabetes; *"I mean, my work they want to know everything. Like 'what happens if this happens?' and 'what happens if this?', so they've been really good".* Another described how his friends made light of the disorder; *"As it happens I play in a chess club and there's three other chess players there who are diabetic as well and we are worried in case we're infecting people and things like this. One player said he's leaving if anyone else becomes diabetic so we make jokes about it".*

Two participants spoke about the role of their family in supporting them with their diabetes. In the following dialogue, the patient (RF) described her family *as "rushing around"* and fussing, in what could be interpreted as a protective or overly concerned manner; *"My family get a bit panicky if I'm gonna hypo and I have to say 'oh, you know*

I need something to eat', and they're like rushing around and I'm like 'just calm down, I'm not gonna collapse in the next few seconds'". In contrast the second patient (GP) described the role of her mother in monitoring her activities; *"When I'm at home my mum's always there looking over my shoulder, and looking after me. She's always going 'Gail do your injection, and test your blood, now write it down'"*.

All of the participants referred to their interactions with people within their social network and to some extent described the kinds of support that they were offered. Overall, three primary sources of support were illustrated, firstly, the help, information and advice offered by health professionals, secondly, the mutual sharing of experiences provided by friends and colleagues, and thirdly, the protective, caring and supervisory role of the family.

Acceptance

The name 'Acceptance' was given to this subcategory because it deals with the way in which the participants internally evaluate their lives following diagnosis of diabetes. These evaluations resulted in a positive and optimistic outlook (Figure 3.2). Such evaluations were common to all of the participants, and reflect their determination to adapt to the changes in lifestyle associated with managing Type 1 diabetes. The participants described taking a problem-focused approach towards their diabetes which included: *"resolving it"*, *"getting on with it"*, *"accepting it"* and *"working with it"*. These strategies are expressed in the following quotes. For example; *"I suppose I just resolved to it, you know, I've just got to get on with it, you know, it's there, it's not going* *to go away"*. Another person commented; *"I've got to live with it and if you let it worry you you'd be slitting your wrists, it's just something I've got to live with and I've accepted that and I just take it from there and work with it.* Similarly another patient said; *"I sort of said well look you know it's not going to go away, you've just got to learn to deal with it. You know once I got past that stage I think I've accepted that I'm just gonna have to put up with it whether I like it or not and that's it basically, you know"*.

These illustrations provide evidence to suggest that by internally evaluating the situation they were able to adopt a more optimistic approach to diabetes and to integrate diabetes into their lifestyle with minimal emotional disruption.

Integrated model of task-oriented coping in adults with Type 1 diabetes

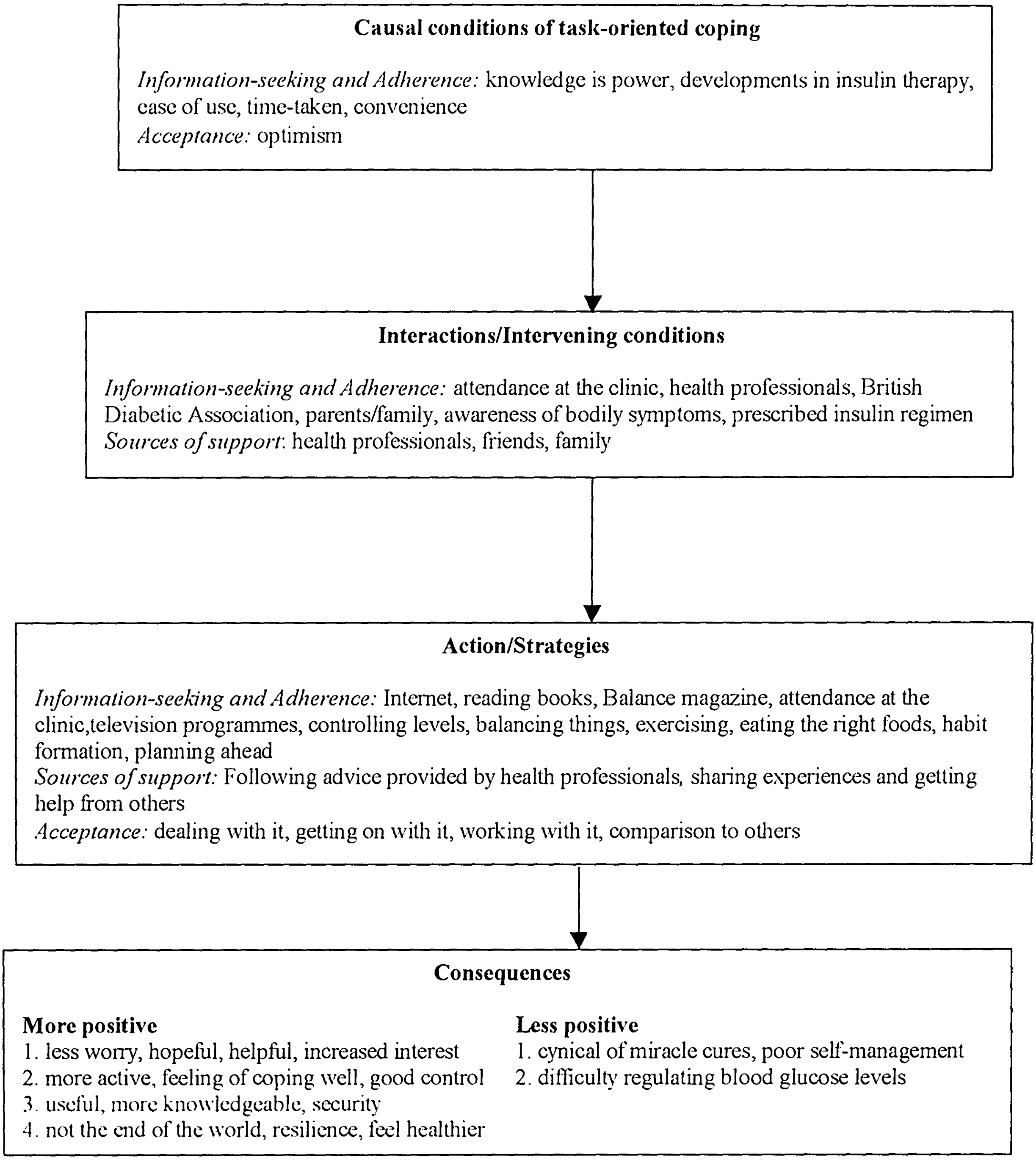
The three subcategories: (i) Information-seeking and Adherence, (ii) Sources of support, and (iii) Acceptance were clustered together to form the higher-order category 'task-oriented coping'. The model displayed in Figure 3.3 was derived using the coding paradigm referred to in the methodology, and provides a conceptual understanding of the preceding analysis relevant to the category task-oriented coping. Based on the work of McVey and colleagues (2001), the purpose of this model is to demonstrate schematically the causal and intervening conditions, actions and emotions and consequences that appear to be associated with task-oriented coping in adults with Type 1 diabetes.

Causal conditions: Several factors appeared to contribute towards a person's tendency to have a task-oriented approach towards their diabetes. A person's perceptions of the importance of having a good knowledge of diabetes, and an interest in recent developments in insulin therapy were associated with more reading and information gathering. Having a positive attitude towards diabetes was associated with greater acceptance of diabetes. Convenience and the time involved in carrying out self-care activities were related to adherence.

Intervening conditions/Interactions: Mitigating factors included attendance at the diabetes clinic and hence contact with health professionals, and membership of the British Diabetic Association (Diabetes UK). These factors acted as tools which helped the participants in their efforts to find out more about their diabetes. Being aware of the symptoms of hypoglycaemia and hyperglycaemia, and being aware of one's own prescribed regimen were important intervening conditions affecting diabetes self-management. Friends, family and health professionals were involved in the provision of encouragement, advice and support.

Action/Strategies: The participants used a number of strategies to help them to cope with their diabetes. These included (i) gathering information from the Internet, books, magazines, and from programmes on television, and (ii) self-management activities such as regular exercise, glucose monitoring, following a recommended diet and injections of insulin. The participants also described developing a routine (habit formation) and planning ahead to anticipate problems. Using various sources of support people described sharing experiences, and following the advice provided by health professionals. Finally, it was felt to be important to “get on with it”, and to “work with” diabetes in achieving optimum control.

Consequences: The consequences of a task-oriented approach to coping with diabetes were mostly positive. The positive influences of good self-management included being more optimistic, feeling more hopeful, healthier, and more active. Having a good knowledge of diabetes was seen to be “useful”, furthermore, by attending the clinic and following the advice of health professionals the patients had a greater sense of security. Less positive consequences included being cynical about the information provided about “miracle cures” for diabetes, and in some cases failure to match food intake to insulin-dose resulted in difficulties regulating blood glucose levels.



Causal conditions of task-oriented coping

Information-seeking and Adherence: knowledge is power, developments in insulin therapy, ease of use, time-taken, convenience
Acceptance: optimism

Interactions/Intervening conditions

Information-seeking and Adherence: attendance at the clinic, health professionals, British Diabetic Association, parents/family, awareness of bodily symptoms, prescribed insulin regimen
Sources of support: health professionals, friends, family

Action/Strategies

Information-seeking and Adherence: Internet, reading books, Balance magazine, attendance at the clinic,television programmes, controlling levels, balancing things, exercising, eating the right foods, habit formation, planning ahead
Sources of support: Following advice provided by health professionals, sharing experiences and getting help from others
Acceptance: dealing with it, getting on with it, working with it, comparison to others

Consequences

More positive	**Less positive**
1. less worry, hopeful, helpful, increased interest	1. cynical of miracle cures, poor self-management
2. more active, feeling of coping well, good control	2. difficulty regulating blood glucose levels
3. useful, more knowledgeable, security	
4. not the end of the world, resilience, feel healthier	

Figure 3.3: Integrated model of task-oriented in adults with Type 1 diabetes.

Emotion-oriented coping

Emotion-oriented coping refers to a person's efforts to regulate distressing emotions (Lazarus and Folkman, 1985). In health psychology, emotion-oriented coping strategies have been found to include self-preoccupation, focusing on the emotional consequences of the illness, and wishful fantasising (e.g. wishing the problem had never happened) (Endler et al., 1998; Endler, 2000). In the present study four subcategories emerged which relate to emotion-oriented coping: Impact, Diabetes-related distress, Fear of complications, and Isolation/Stigmatisation. Each of these subcategories will now be addressed in turn.

Impact

This subcategory termed 'Impact' was derived from the participants' accounts of the social and psychological burden of diabetes self-management, and the impact of diabetes on aspects of their daily life. The descriptions provided by the patients appeared to fall into two broad areas and were coded as follows: (i) Perceived burden of insulin therapy, and (ii) Lifestyle interference (Figure 3.2).

The participants described conditions under which they perceived the treatment for diabetes as being a burden, and the consequences that this had for their quality of life and well-being. Feeling restricted by the treatment for diabetes was a common theme. In the following example, one patient (GP) describes the impact which the treatment for diabetes can have on everyday activities; *"It's like for instance going out this evening, I've got to be careful how much insulin I give myself, and having meal I've got to work* *out how much carbohydrate I'm having in that meal, and then when I'm drinking I've got to be careful I'm not having a hypo which is all extra hassle".* Another person commented on the inconvenience of insulin therapy; *"It's always there and I've got to think about how to fit the diabetes into it, if I was doing anything, I'd be like wait a minute where am I gonna get something to eat or where can I do my injections".*

The above statements are similar in the sense that both participants are describing the strategies they use in their efforts to cope with the burden of insulin therapy. These include being *"careful"*, *"working things out"*, and having to constantly think about how to *"fit"* diabetes into their lifestyle.

The following extracts are provided to demonstrate specific examples of situations when the treatment for diabetes interfered with aspects of the participants' normal routine.

The first emergent theme reflects the impact of diabetes when attending meetings, interviews, and appointments. The participants often spoke about the problems associated with people keeping them waiting, and not knowing whether or not food was going to be available. These problems resulted from their underlying concerns about the threat of experiencing a potential hypoglycaemic attack. In coping with this threat the participants described having to *"be aware"*, *"thinking in advance"* and *"trying to keep things ticking over"* while at the same time not wanting to cause a *"fuss"* as highlighted in the following extract; *"Recently I've found it awkward because I'm taking a lunch time [insulin] dose. I was at a meeting and there was a buffet provided and I wasn't* *sure whether to eat before the meeting or not, and I saw the buffet there and it was just after I started my 4 doses, and I thought do I go to the toilet to take my insulin or do I just leave it till after, and I wish I'd said and gone and taken my insulin. That's the only difficult situation that's a bit annoying, when you meet other important people and you feel that you know you need to eat but do you cause a fuss sort of thing?"*. The threat of experiencing a hypoglycaemic attack in a public place was another common theme; *"If I have an interview or anything like that, I sometimes get a bit worried that I might have a hypo in the middle of it and things like that"*.

Several patients raised their concerns about managing their diabetes when they were traveling or going away from home. The main concerns they expressed were related to the storage of insulin, the availability of appropriate facilities, and adjusting to the disruption in their daily regimen; *"Sometimes traveling can be a problem. As I say it's just thinking in advance you can't just do things like you used to. You always have to be aware of where you're going to be and what's going to be there. Like is there going to be access to food or if there are problems with taking stuff with you, in case you have any problems whilst you are away. Appropriate storage of it if you are going away, because I once went down for a job in Jersey so obviously I had to take a supply with me you see, and I had to see it's properly stored while I'm there and stuff like that, but it's all common sense"*. In consequence, some participants described feeling worried about going on holiday; *"I would be a little bit worried about going abroad on holiday and taking needles and insulin with me and so forth. I think it possibly restricts me in some senses"*.

Driving was also associated with the impact of diabetes. This concern was associated with the perceived risk of hypoglycaemia. The patients described using strategies to reduce the impact of diabetes while driving such as carrying food in the car with them, and stopping regularly to check their blood glucose levels; *"I'm always very conscious as I'm driving. I find I tend to stop a lot more than I normally would just to check, you know whereas, you know a normal person would just drive hundreds of miles and not think about it. I tend to stop more often and check my blood sugar levels, especially if I'm on my own"*. By comparison another person said; *"I'm very cautious driving or anything like that. I always make sure my sugars are okay and I've got food with me before I drive or something like that. My boyfriend says it's great going out with a diabetic because they've always got food in their bags"*.

In summary, all of the participants described feeling restricted by the demands of their diabetes self-management routine and spoke about the strategies they used to reduce the impact of diabetes on aspects of their daily life such as being vigilant, thinking ahead and planning. However, despite their efforts to overcome the obstacles which diabetes self-management presented, in the majority of cases these efforts had negative emotional consequences resulting in more worry and a greater perceived interference.

Diabetes-related distress

The subcategory 'Diabetes-related distress" refers to an individual's tendency to report experiencing negative or distressing emotions which are related to his or her diabetes self-management (Figure 3.2).

Depression was a common theme in the participants' accounts of their psychological adjustment to diabetes, especially following the initial onset of diabetes. Following the diagnosis of diabetes there was a period of coming to terms with diabetes. Shortly after the diagnosis of diabetes the patients described experiencing an initial shock (e.g. *"Then it sort of hit me"*) which was followed by feelings of depression. These emotional reactions were often expressed using a chronological framework as illustrated in the following statements; *"I mean it's very difficult at the beginning, originally it didn't sink in. I just got on with it and I got my control under what I was supposed to do in a matter of months basically, but then it sort of hit me. I thought wait a minute, I've got this for the rest of my life and I sort of got a bit depressed for wee while, but the nurses here were brilliant and I was fine after that"*. Similarly another person described the following; *"The first couple of weeks I was diagnosed I was fine, no problems, and then quite soon after I was diagnosed I had chicken pox and from there I went quite low, and was quite depressed, and put on a lot of weight and just generally trying to cope with the diabetes as well, but it took maybe three months after that and since then I've not really had any problems with diabetes"*. As demonstrated in the above accounts for the majority of the participants there was a notable 'trigger' or series of events that they identified as the cause of their depression. These events were often explicitly expressed in their descriptions, for example, becoming ill, or simply the initial diagnosis of diabetes.

Following the initial period of adjustment after diagnosis, most patients reported feeling an improved sense of well-being, and were able to *"get on"* with their diabetes self-management. However, this was not true of all of the participants. One patient (GP) described how shortly after moving away from home to University she was diagnosed with depression; *"When I was in the first year at Uni. I was diagnosed with depression and put on anti depressants and my diabetes was just absolutely awful and I was in hospital twice and generally felt ill all the time. I think it was like a cycle of I felt ill so that made me feel depressed and then when I was depressed I couldn't be bothered to look after my diabetes, and that way it just went on like a downward spiral".* GP interpreted her depression as being part of an ongoing negative *"cycle"* which appeared to have three phases. In phase 1 the symptoms associated with her diabetes led to depression, then in phase 2 feelings of depression led to a sense of helplessness, which subsequently had a detrimental effect on GP's motivation to adhere to her diabetes self-management routine (phase 3). The longevity of this negative cycle is unclear, but it suggests that, in this particular case, depression is perceived as being the cause rather than consequence of poor self-management.

In addition to episodes of depression, the participants described how failure to maintain optimum blood glucose levels could lead to negative-emotions such as anger and worry. These emotions were usually self-directed and resulted as a consequence of not being able to *"sort out"* the problem. For example one person said; *"When I get high blood sugars I get sort of worried and annoyed at myself for not being able to sort it out but I know that it will go down eventually, or it will sort itself out, or if I adjust my insulin I can work it out".* Other participants felt that having diabetes was unfair; *"You know I* *don't need this and yeah I think that basically it's a case of 'why me'... you know 'why did it have to happen to me, you know couldn't it have happened to somebody else".*

As well as experiencing negative and distressing emotions, one patient said she felt guilty about the impact that her diabetes had on other people. In the following extract the participant reveals how she blames herself for her poor diabetes control and feels guilty when people offer their support; *"I feel guilty about the way that I've coped with it. Especially when my mum's so nice and all my friends are so nice, and I think that it's my fault that I'm in this state and I feel bad that they have to take time out of their lives to come and tend to me and that makes me feel very guilty".*

In summary, the above extracts provide some concrete examples of the direct consequences that diabetes can have on an individual's psychological well-being. The majority of the patients experienced an initial brief emotional response which was characterised by depression and anger following the diagnosis of diabetes. After diagnosis, periods of depression that were directly related to diabetes self-management were less frequent, and appeared to be more related to specific events or changes in the person's surroundings. However, some participants appeared to be more vulnerable to diabetes-related distress than others. The longevity and direct source of these feelings of distress remain unclear.

Fear of complications

Some of the participants in this study reported a feeling of fearful expectancy with regard to the potential consequences of their diabetes. This was labeled as 'Fear of complications' (Figure 3.2). For the majority of the participants the threat of potential complications of diabetes was a consistent source of fear. The patients described *"wondering about it"*, ruminating (e.g. *"It's still at the back of my mind"*), and *"worrying"*. They also expressed uncertainties with regard to their chances of developing complications in later life by asking questions, and recounted the information they had obtained from reading about diabetes and television documentaries. For example one man said; *"On T.V. reports it said that even if you do maintain perfect blood sugar levels with your insulin injections you can still have complications, so I was a bit worried about that. I don't know if these things are true or not"*.

However, in some cases the threat of potential complications of diabetes had positive consequences for the patients' self-management. By increasing their understanding of the risks of future complications the patients felt more in control of their diabetes and empowered to confront the problems associated with the disorder; *"I've still kind of got thoughts or worries about what will happen later on in life. You know will my eyesight go? Limb circulation? But the more I read about it the more I know what I have to do to combat problems, that makes me feel better. It's still at the back of my mind, I still wonder about it, you hear stories about it"*. Similarly, another person commented;

"I don't worry about hypos. I'm more worried about the complications later on. What the chances of going blind are or feet problems or kidney problems. I think they discovered I'd a kidney function a little bit outside the normal range and they were a little bit worried about that... but that sort of thing is worrying. If my kidneys were suddenly deteriorating or some problem arised there".

In summary, fear of complications was seen as a constant stressor, which had both positive and negative influences for the patients' physical and psychological well-being. In coping with the stress associated with the threat of complications the patients reported using two main strategies. The first strategy involved focusing on negative emotions such as ruminating about future health problems, and the second strategy involved gathering information about diabetes in an attempt to build an increased understanding of the risk factors associated with the development of diabetes complications. The consequences of these approaches were two fold. On the one hand, the patients continued to experience negative emotions with regard to their health, but on the other hand, there was some evidence to suggest that fear of complications was associated with an increased effort to avoid hyperglycaemia, and hence reduce the risk of the development of complications.

Isolation/Stigmatisation

The subcategory termed 'Isolation/Stigmatisation' (Figure 3.2) was derived from the participants' accounts of (i) other peoples' reactions to their diabetes, and (ii) their own feelings of isolation as a result of having diabetes.

Isolation was related to an individual's internal feelings of being different from other people and not fitting in with the crowd. The perception of oneself as an outsider was associated with being restricted, and expressed as an internal conflict. In consequence one participant described feeling annoyed and resentful; *"I've just got to take it easy and see that annoys me because I don't like it, because all my friends are going out and if I wasn't diabetic I'd be able to join in. Like it's not good to get absolutely intoxicated anyway but I don't like having this extra thing that I have to worry about"*. Having to make sacrifices was also associated with isolation; *"I love chocolate, that's the problem. I don't know, I always feel why should I go without something just because I've got diabetes, and we all go out and everyone's like wayhey dessert and I'm like 'oh right, I can't have that'"*.

The term 'Stigmatisation' is used here to describe external perceptions and reactions to diabetes. For example one patient said; *"I told one chap I was diabetic and he was like 'oh, dear me, if there's anything to happen that's the worst thing that could happen, you know I would never want diabetes'. You know and he was freaking out about it. You know he seemed really scared of becoming a diabetic, he though it would be a sort of terrible thing to get"*. Another participant described how they *"disliked being referred to as a diabetic"*.

However, despite the above exceptions, the majority of participants felt comfortable with their diabetes-related identity. For example, one person described *"being just like* *any normal person who does not have diabetes"* whiles another person said *"it just becomes part of who you are".*

Integrated model of emotion-oriented coping in adults with Type 1 diabetes

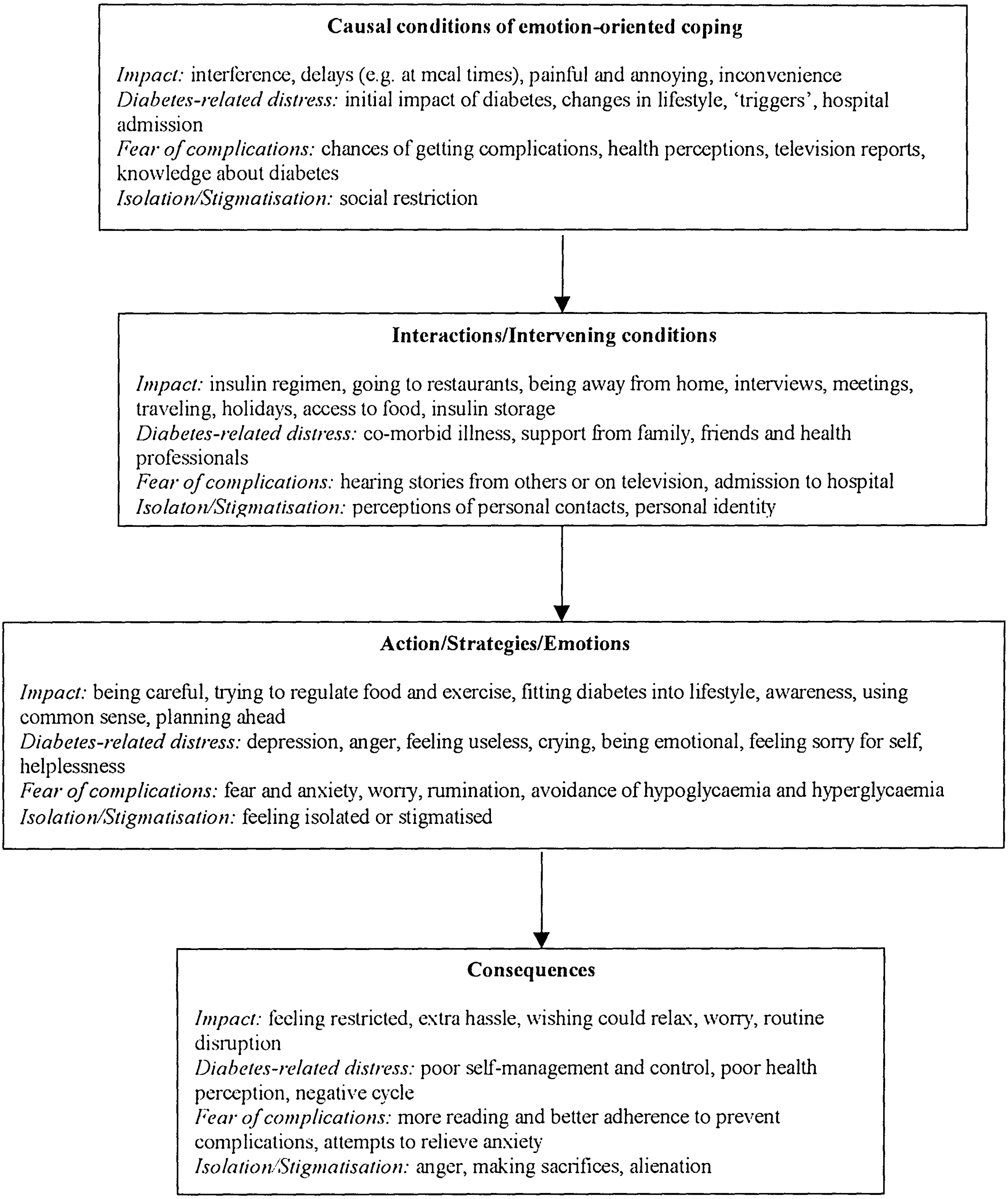
An integrated model of emotion-oriented coping in adults with Type 1 diabetes is displayed in Figure 3.4. The model draws together the four subcategories (i) Impact, (ii) Diabetes-related distress, (iii) Fear of complications, and (iv) Isolation/Stigmatisation, to provide a conceptual understanding of the emotional responses used by the participants in their efforts to cope with diabetes. The model is presented in a structured way to highlight how elements of the preceding analysis were derived using the coding paradigm referred to previously (Strauss, 1987), and to provide a conceptualisation of the most important determinants and consequences of an emotion-oriented approach to coping with diabetes.

Causal conditions: There were several causal risk factors which appeared to contribute to a person's emotional response to diabetes. The interference of self-management activities on aspects of an individual's daily life, and the perceived pain and inconvenience involved in blood glucose monitoring were associated with greater self-reported impact of diabetes. The initial diagnosis of diabetes was associated with a brief period of emotional disturbance, and having to adapt to changes or significant events (e.g. hospital admission) in one's lifestyle was highlighted as a risk factor for increased diabetes-related distress. An individual's perceptions of their present health status and knowledge of diabetes and its complications were associated with a person's emotional reactions to the threat. Internal perceptions of one's self as socially restricted was related to feelings of isolation.

Interactions/Intervening conditions: The factors that mitigated emotion-oriented coping included different settings as well as personal contacts. The impact of diabetes was greatest in particular settings such as when eating out in restaurants, travelling away from home, or attending interviews. People who had co-morbid illnesses were most likely to experience diabetes-related distress, and this was mitigated to some extent by their interactions with health professionals and other personal contacts such as family and friends. Hearing stories about the future effects of diabetes, and previous hospital admissions were associated with an increased fear of complications. Finally, external perceptions of diabetes combined with an individual's own personal identity were related to their experiences of being isolated or stigmatised.

Actions/Strategies: The context of the participants' accounts included a range of emotions and experiences. High impact of diabetes was associated with worrying and feeling disrupted. Diabetes-related distress was characterised by painful emotions such as depression, anger, crying spells and perceived helplessness. Some participants reported being afraid of future complications of diabetes, and tended to ruminate about their future health status, while others reported feeling isolated and stigmatised.

Consequences: In general, negative emotions were associated with poor self-reported outcomes of diabetes. The negative consequences of diabetes-related distress were most notable and included poor self-reported glycaemic control, adherence and perceived health status. However, the majority of participants made attempts to overcome the negative-emotions associated with the impact of diabetes and fear of future complications by finding out more about their diabetes and making attempts to relieve their anxieties. This involved trying to maintain good glycaemic control and accommodating diabetes-self management activities into their lifestyle.



Causal conditions of emotion-oriented coping

Impact: interference, delays (e.g. at meal times), painful and annoying, inconvenience
Diabetes-related distress: initial impact of diabetes, changes in lifestyle, 'triggers', hospital admission
Fear of complications: chances of getting complications, health perceptions, television reports, knowledge about diabetes
Isolation/Stigmatisation: social restriction

Interactions/Intervening conditions

Impact: insulin regimen, going to restaurants, being away from home, interviews, meetings, traveling, holidays, access to food, insulin storage
Diabetes-related distress: co-morbid illness, support from family, friends and health professionals
Fear of complications: hearing stories from others or on television, admission to hospital
Isolaton/Stigmatisation: perceptions of personal contacts, personal identity

Action/Strategies/Emotions

Impact: being careful, trying to regulate food and exercise, fitting diabetes into lifestyle, awareness, using common sense, planning ahead
Diabetes-related distress: depression, anger, feeling useless, crying, being emotional, feeling sorry for self, helplessness
Fear of complications: fear and anxiety, worry, rumination, avoidance of hypoglycaemia and hyperglycaemia
Isolation/Stigmatisation: feeling isolated or stigmatised

Consequences

Impact: feeling restricted, extra hassle, wishing could relax, worry, routine disruption
Diabetes-related distress: poor self-management and control, poor health perception, negative cycle
Fear of complications: more reading and better adherence to prevent complications, attempts to relieve anxiety
Isolation/Stigmatisation: anger, making sacrifices, alienation

Figure 3.4: Integrated model of emotion-oriented coping in adults with Type 1 diabetes.

Avoidance-oriented coping

In the general coping literature avoidance coping has been conceptualised as a strategy which involves avoidance of a particular stressful situation (e.g. seeking the comfort of others or engaging in other activities) (Endler and Parker, 1990). In terms of illness-related coping, avoidance strategies are thought to include distraction from the illness by thinking about other more pleasant experiences or engaging in unrelated activities, and palliative responses which involve using self-help responses to allevitate the unpleasantness of the illness (e.g. making surroundings more comfortable, getting plenty of rest). In the present study the subcategory termed 'Rebellious decisions' was associated with avoidance-oriented coping. This subcategory is described below.

Rebellious decisions

The term 'Rebellious decisions' refers to occasions when an individual deliberately chooses to pursue actions that they believed to be dangerous or detrimental to their health. In some cases these acts appeared to offer some benefit to the patient such as indulgence, comfort, or a feeling of liberation. However in other cases, rebellious acts had negative consequences including poor glycaemic control and the perception of one's self as a "bad diabetic".

The participants in this study spoke about lacking motivation to take care of themselves describing themselves as *"lazy"* and *"not responsible enough"*. In the following example, avoidance of self-care activities was attributed to inadequate support and to the burden of being personally responsible for one's own well-being; *"I'm not responsible* *enough to take care of myself. I think just having no parental control, like I say the responsibility is on yourself, and I can think of much more fun things to do than to think about this so I don't. I just don't do it. I don't quite know how to put it. I don't bother with it. I just can't be bothered. I just think I've got more important things to do and I kind of push it to the side a bit".*

Other people described using diabetes as an excuse to avoid certain activities; *"Someone once tried to teach me how to go surfing and I said 'no way', but then it was just an excuse to get out of it"*. Or to relieve tension at work; *"I have the odd day, when I'm having a bad day at the office and I think, oh, you know, give me a chocolate bar and then you take the reading at tea time and think I don't want to see this, go away".*

The majority of the participants described having occasional lapses in their diet or blood glucose monitoring, and described willingly indulging in foods, smoking or other habits that were either not recommended for people with diabetes or were known to be detrimental to their health, as illustrated in the following example; *"I still have some of my bad habits. I still smoke a little bit and sometimes I have ice-cream which is not recommended, but I quite like that. Originally I was targeted to lose about two stone in weight and I've only lost about 1 stone. So, I haven't, the diet hasn't been going too well. So there have been some minor sort of adjustments that I haven't achieved, but I originally thought that because I became diabetic, I thought my life style and my health might actually improve because I'd be more careful about lots of things like smoking and so forth. It didn't quite work out quite so good as that, but I think possibly in the long* *run it may do"*. Another person spoke about lapses in blood glucose monitoring; *"Well, I know I should be testing my blood sugars and eating properly, at regular times and doing my injections properly and everything, but, I don't really do that. That's what I should be doing, but I don't really do that"*.

Another common theme was avoidance of hypoglycaemia. By maintaining high blood glucose levels the patients were able to avoid hypoglycaemic episodes; *"I used to do a lot of driving and I was worried about having hypo's when I was driving so I always had a constant supply of food next to me, and I used to eat constantly as I was driving along and I'd end up with my blood sugar way too high"*.

In general, rebellious decisions were used as a coping strategy to avoid unpleasant aspects of diabetes self-management including blood glucose monitoring and adherence to a strict diet, as an excuse to avoid taking part in unwanted activities or as a way of easing tension and restoring personal control.

Integrated model of avoidance-oriented coping

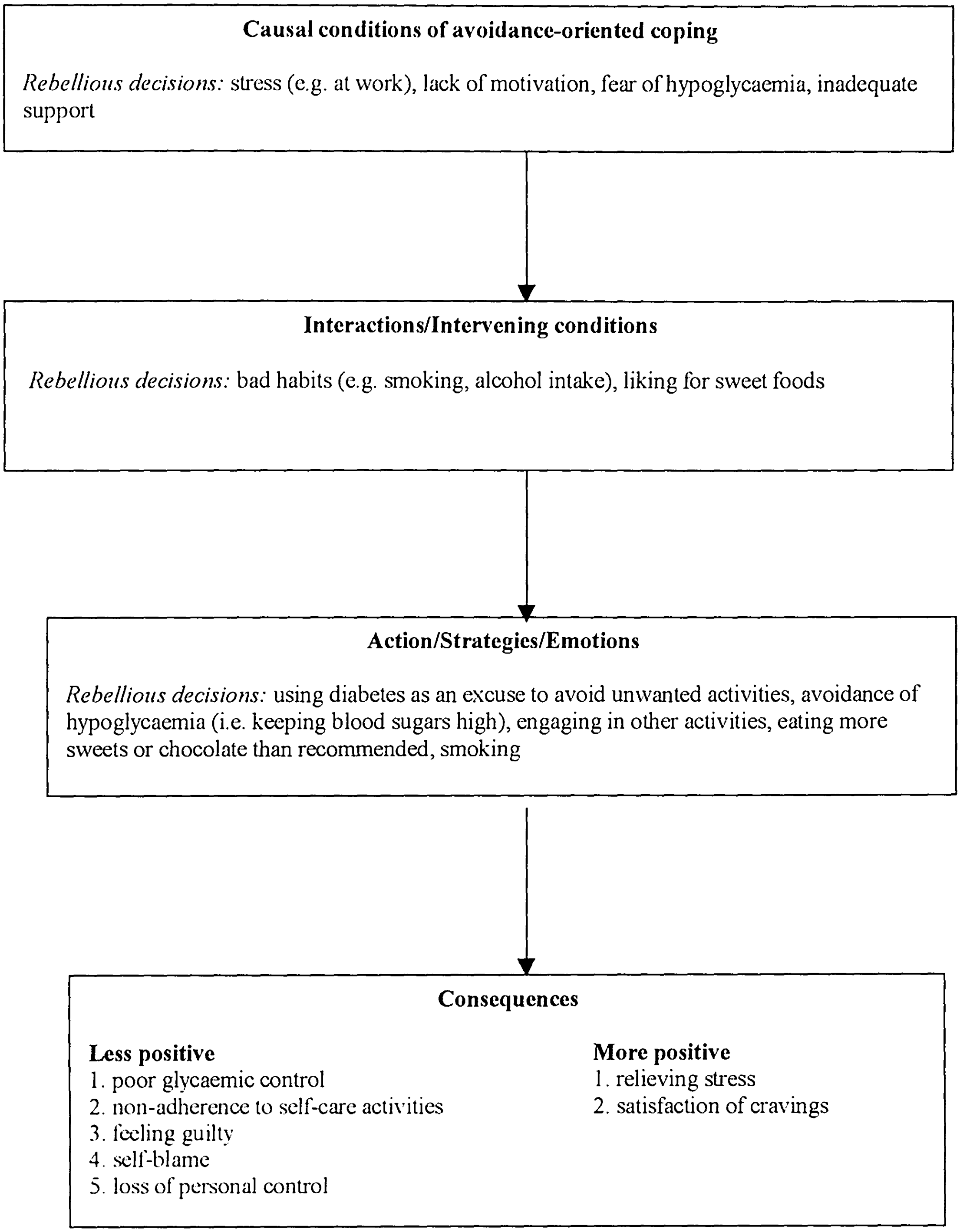
The themes identified within the subcategory 'Rebellious decisions' are now drawn together to provide a conceptual understanding of how they relate to the higher order category 'Avoidance-oriented coping' (Figure 3.5). This model is less integrated than those for Task-oriented coping and Emotion-oriented coping because fewer indicators were identified. However, some interesting themes were identified. The purpose of the model displayed in Figure 3.5 is to demonstrate the proposed links between causal and intervening conditions, actions and emotions, and consequences (Strauss and Corbin, 1998) highlighted in the preceeding analysis, which may be relevant to avoidance-oriented coping in adults with Type 1 diabetes.

Causal conditions: Having an inadequate support network and the burden of insulin therapy were associated with a lack of motivation to take adhere to one's self-management routine. Stress (e.g. at work) was associated with temporary lapses in self-care activities, and an underlying fear of the threat of hypoglycaemia was associated with attempts to maintain high blood glucose levels.

Interactions/Intervening conditions: Pre-existing habits such as smoking and alcohol intake were associated with continuation of health damaging behaviours, while a liking for chocolate or other sweet foods was associated with occasional indulgences. These factors appeared to mitigate avoidance-oriented coping

Strategies: The participants described using a number of strategies that were related to the category avoidance-oriented coping. These included a number of rebellious and in some cases detrimental activities such as eating too many sweets or chocolates and smoking. Other common themes include maintaining high blood glucose levels, and the avoidance of essential self-care activities such as blood glucose monitoring.

Consequences: The consequences of rebellious decisions were either more or less positive. The more positive outcomes included relieving tension and satisfaction of cravings. However, when avoidance of self-management activities resulted in poor glycaemic control the psychological consequences were less positive and included feelings of guilt, self-blame, and a loss of personal control.



Causal conditions of avoidance-oriented coping

Rebellious decisions: stress (e.g. at work), lack of motivation, fear of hypoglycaemia, inadequate support

Interactions/Intervening conditions

Rebellious decisions: bad habits (e.g. smoking, alcohol intake), liking for sweet foods

Action/Strategies/Emotions

Rebellious decisions: using diabetes as an excuse to avoid unwanted activities, avoidance of hypoglycaemia (i.e. keeping blood sugars high), engaging in other activities, eating more sweets or chocolate than recommended, smoking

Consequences

Less positive	**More positive**
1. poor glycaemic control	1. relieving stress
2. non-adherence to self-care activities	2. satisfaction of cravings
3. feeling guilty	
4. self-blame	
5. loss of personal control	

Figure 3.5: Integrated model of avoidance-oriented coping in adults with Type 1 diabetes.

Discussion

The aim of this study was to explore the patients' perspectives of what it means to cope well with Type 1 diabetes by asking them to describe their adjustment to diabetes and the impact which diabetes has had on aspects of their daily life. Eight subcategories were identified (Information-seeking and adherence, Sources of support, Acceptance, Impact, Diabetes-related distress, Fear of complications, Isolation/Stigmatisation, and Rebellious decisions). These subcategories were clustered together to form three higher-order categories: Task-oriented coping, Emotion-oriented coping, and Avoidance-oriented coping. A model showing the links between the initial indicators of each subcategory, and the subsequent subcategories, categories, and the core category is displayed in Figure 3.2.

The three major coping categories (task, emotion, and avoidance) identified in this study were defined on the basis of the general coping literature in health psychology (Endler and Parker,1990; Lazarus and Folkman, 1984, 1985, 1987; Endler, Parker and Summerfeldt, 1998; Endler, 2000) and were incorporated in the model (Figure 3.2) to provide the study with a theoretical framework in which to study coping in people with Type 1 diabetes.

Task-oriented coping refers to a person's active efforts to do something to change the problem causing the threat (Lazarus and Folkman, 1987; Billings and Moss, 1981). In research which has focused on illness-related coping specifically an instrumental (or problem-focused) approach has been found to involve specific responses which are aimed at learning more about the illness, following the advice provided by health professionals, and being prompt about taking medication (Endler, Parker and Summerfeldt, 1998; Endler, 2000). These strategies are particularly important in diabetes where the patient is required to control their own well-being to a large extent. In the present study the subcategories termed 'Information-seeking and Adherence', 'Sources of support' and 'Acceptance' appeared to share thematic similarity because they were all associated with active attempts to come to terms with diabetes. As a result they were drawn together to form the higher order category, task-oriented coping. Specific strategies included gathering information about diabetes, adherence to self-care activities, sharing experiences of diabetes with others and seeking support, and acceptance of diabetes leading to a more optimistic and positive outlook. For example, active efforts to learn more about diabetes and good self-management skills had positive consequences for the patients' self-reported well-being and appeared to be associated with a more positive outlook. These findings complement the results of a study by Watkins, Connell, Fitzgerald, Klem, Hickey and Ingersoll-Dayton (2000) which found that individuals who had a greater understanding of their diabetes were more likely to engage in self-care activities and to report less perceived burden of their diabetes. Similar findings were also obtained in previous longitudinal studies of children with diabetes (Kovacs, Brent, Steinberg, Paulaskas and Reid, 1986; Grey, Cameron, Lipman and Thurber, 1995), which found that problem-focused strategies included seeking diabetes-related material, sharing aspects of diabetes with peers (Kovacs et al., 1986) and resiliency (Grey et al., 1995).

Emotion-oriented coping is directed towards the emotional reactions of the individual (Lazarus and Folkman, 1985). According to previous literature emotion-oriented coping involves emotional preoccupation with the negative consequences of a particular health problem (Endler, Parker and Summerfeldt, 1998) and includes specific responses such as feeling frustrated, wishful fantasising, worry about future health status and anger. In the present study the category termed 'Emotion-oriented coping' was indicated by four subcategories: Impact, Diabetes-related distress, Fear of complications and Isolation/Stigmatisation. The integrated model of emotion-oriented coping (Figure 3.4), which was derived by summarising the findings from the interviews, shows that the demands of diabetes-self-management and a person's perceived health status were important determinants of emotion-oriented coping responses. For example, increased rumination, depression and fear of developing complications of diabetes. These responses appeared to be associated with negative consequences for the patient's well-being such as poor perceived glycaemic control, adherence, and subjective health status. These findings complement previous literature which suggests that emotion-oriented coping is associated with poor self-reported outcomes of diabetes (Endler, Parker and Summerfeldt, 1998; Felton and Revenson, 1984; Smari and Valtysdottir, 1997; Cox, Irvine, Gender-Frederick, Nowacek and Butterfield, 1987).

Several of the participants in the present study described feeling depressed about their diabetes shortly after diagnosis. These findings are similar to those of previous longitudinal investigations of children and adolescents with diabetes which have found evidence for an initial period of adjustment following diagnosis which is characterised by depression and withdrawal (Kovacs, Brent, Steinberg, Pauluaskas and Reid, 1986; Kovacs, Iyengar, Goldston, Stewart, Obrosky and Marsh, 1990; Kovacs, Feinberg, Paulauskas, Finkelstein, Pollack and Crouse-Novak, 1985; Grey, Cameron, Lipman and Thurber, 1995). The findings of the present study complement previous research, and have important implications within the field of diabetes care. In particular the results indicate that the period following diagnosis may be a crucial stage in the adjustment process for some adults with Type 1 diabetes. It is therefore important to target those patients who are at risk of depression early in the disease process to reduce the initial impact of diabetes, and to avoid deterioration of their psychological status in the future.

The third category 'Avoidance-oriented coping' was indicated by the single subcategory 'Rebellious decisions'. In health psychology avoidance strategies are thought to include distraction from the illness by thinking about other more pleasant experiences or engaging in unrelated activities, and palliative responses which involve using self-help responses to alleviate the unpleasantness of the illness (e.g. making surroundings more comfortable, getting plenty of rest) (Endler, Parker and Summerfeldt, 1998; Endler, 2000).

The label 'Rebellious decisions' was derived from the participants' descriptions of times when they deliberately chose to pursue actions which are careless, detrimental to their health or dangerous. The majority of the participants in this study talked about being attentive to the self-management activities involved in adhering to their diabetes regimen such as regulating their diet, and taking more physical exercise. However, several participants also talked about times when they avoided these activities. This avoidance behaviour included occasional lapses in their diet or blood glucose monitoring, and indulging in foods, smoking or other habits that were either not recommended for people with diabetes or were known to be detrimental to their health. These behaviours were associated with positive and negative consequences of the person's self-reported well-being. On the one hand, rebellious decisions were associated with relieving tension and satisfaction of cravings and appeared to offer some comfort to the participants. On the other hand, avoidance of self-management activities was associated with less positive outcomes including poor perceived glycaemic control, feeling guilty, self-blame and a loss of personal control. These findings are similar to those obtained in a qualitative study of adults with diabetes which was guided by Parse's theory of human becoming (Mitchell, 1998). According to Mitchell (1998) rebellious behaviours result from a shift in a person's *'vigilant intentions'*. In Parse's theory, a person is said to be both enabled and limited by their values. Mitchell (1998) found that people with diabetes rely on their values to chose their times of rebellion and their times of vigilance. In the present study the participants revealed a similar pattern of describing their choices and decisions to willingly carry out rebellious acts. As a result they felt responsible for the positive and negative consequences of these choices.

Based on the themes generated in this analysis, it is important for health professionals and researchers to recognise the importance of understanding the patient's perceptions of their adjustment. In future, health professionals and researchers should work towards identifying critical periods in the coping process so that interventions can be directed towards changing negative perspectives about diabetes, and increasing more goal-directed behaviour. Educational sessions that proceed from group discussions about the most salient issues to deciding what is most important to learn about may be useful particularly around the time of diagnosis. The findings of a recent randomised control trial of patients with Type 1 diabetes who were either assigned to a standard care group or a monitoring group provided evidence which supports this view. In this study monitoring and discussing psychological well-being had favourable effects on the mood of the patients (Pouwer, Snoek, van der Ploeg, Ader and Heine, 2001). This type of intervention would allow health professionals to design educational programs which are tailored to the needs of the individual.

When using Grounded Theory, the transformation of interview material into a conceptualised model requires a certain amount of interpretation by the researcher (Strauss and Corbin, 1998). With regard to the present analysis, it has been possible to demonstrate by example the ways in which the general coping dimensions (Task, Emotion, and Avoidance), which appear in the coping literature emerged from the participants' accounts of their experiences of their adjustment to diabetes. This means that although these coping dimensions were theorised to be central to coping with diabetes prior to the analysis, they are clearly grounded in the data. The present study, therefore, adds to the validation of these concepts and their usefulness in the study of people with Type 1 diabetes.

In summary, the interview data presented in this chapter have succeeded in identifying those aspects of coping with Type 1 diabetes that the individuals themselves considered to be most relevant, and these concepts have been drawn together to provide a hypothetical conceptualisation of coping in adults with Type 1 diabetes (Figure 3.2). As stated in the introduction to this section, this study was initially driven by the need to enhance current understanding of what it means to cope well with Type 1 diabetes. This qualitative approach was adopted as a means of developing core categories, subcategories and specific indicators of coping in adults with Type 1 diabetes based on the patients' subjective accounts of their experiences of living with diabetes. These accounts could then be used to generate items to be used in the development of a structured, quantitative, diabetes-specific measure of coping. In the following chapter, the process involved in the development and selection of items for a preliminary scale will be described. The goal is to use the information provided by the participants in this study as the basis for the development of specific items which can be used to measure the strategies, emotions and behaviours that were highlighted throughout the preceding analysis.

PART III Coping with Diabetes: Assessment and Measurement

CHAPTER 2

Development of the Pilot Diabetes Impact, Adjustment and Lifestyle Scales

Introduction

In this chapter the processes involved in the selection of items for use in a new questionnaire to assess diabetes-specific coping ability are described. The Diabetes Impact, Adjustment and Lifestyle Scales (DIALS) were developed to measure the strategies used by adults in their efforts to adjust to and control Type 1 diabetes. To date previous measures of coping with illness have fallen into two categories: multiple-situation measures and situation-specific measures. Multiple-situation measures assess how individuals respond to a variety of stressful situations using a number of coping strategies, whereas situation specific measures examine how a person responds to a specific stressful situation or health problem (e.g. cancer, arthritis etc.). There are advantages and disadvantages of both of these approaches.

The Ways of Coping Questionnaire (WCQ; Folkman and Lazarus, 1985, 1988) and the Coping with Health Injuries and Problems scale (CHIP; Endler, Parker and Summerfeldt, 1998) are widely used scales in research on coping with health problems. The main problem with using multiple-situation measures like these in research on coping with illness is that the items used may not be applicable to the sample being studied. This is important because the validity and reliability of a scale can potentially be affected if some of the items contained within the scale are inapplicable. Endler, Parker and Summerfeldt (1998) attempted to get round this problem by ensuring that the items they used in the CHIP would be applicable to coping strategies used by various medical populations. However, this has the drawback of making the items less specific and means that important aspects of dealing with a specific illness may be overlooked or omitted altogether. This criticism is particularly important in the context of coping with diabetes because these individuals are in control of their own well-being to a large extent. Multiple-situation measures may not, therefore, capture unique aspects of coping with diabetes such as the demands of diabetes self-management activities, and the underlying fear associated with the threat of potential complications of the disorder.

In recent years many scales have been developed to assess the coping strategies used by people with specific symptoms and illnesses such as; pain (Butler, Damarin, Beaulieu, Schwebel and Thorn, 1989), cancer (Watson, Greer, Young, Inayat, Burgess and Robertson, 1988), muscular dystrophy (Ahlstrom and Sjodenm 1994) and tinnitus (Wilson, Henry, Bowen and Haralambous, 1991). However, despite the specificity which these scales offer, many of the existing scales have been criticised for their 'psychometric weaknesses' and for the simplistic procedures used in their development (Endler and Parker, 1995; Parker and Endler, 1992). For example, the Mental Adjustment to Cancer questionnaire (MAC; Watson et al., 1988) was developed to assess coping behaviours in cancer patients and consisted of five subscales: Fighting spirit, Helpless, Anxious Preoccupation, Fatalistic and Avoidance. However, the reliability of these scales was quite low, with test retest reliabilities ranging from .38 to .65, and internal reliabilities between .38 and .65, making the psychometric properties of the scale questionable.

One of the central problems in the situation-specific versus multiple situation debate is that when using situation-specific measures it is difficult to compare the results of different studies which have adopted different measures, and to compare coping strategies among different groups. This means that researchers wanting to measure coping strategies are faced with a difficult decision. They can either opt for a situation-specific scale that may have poor psychometric properties or a multiple-situation measure that may not apply to their particular sample. Perhaps the only solution to this problem is to design research studies which incorporate both situation-specific and multiple-situation measures.

To date few standardised tools exist to assess coping and adaptation in adults with Type 1 diabetes. This means that many research studies of coping in people with diabetes have relied on multiple-situation assessments of coping. In an effort to resolve this problem the present research set out to develop a diabetes-specific measure of a person's adjustment to living with diabetes and to assess the impact that aspects of diabetes-self-management may have on their daily life. The goal was to develop a valid and reliable scale, that could be used to identify individual differences in the ways in which people cope with Type 1 diabetes. Diabetes is a lifelong disorder, the severity of which may change depending on how well the individual adapts to and controls the disease. One objective in developing the DIALS was to ensure that the scale could be administered at different stages of the illness to help determine the strategies that may be important at critical times in the progression of the illness.

Development of a preliminary scale

The aim in the development of the preliminary scale was to examine the coherence of items that were developed to fit within the domains/subcategories described in the previous chapter (Part III, Chapter 1). At this early stage in the development of the DIALS each of the eight subcategories: Information seeking and Adherence, Sources of support, Acceptance, Impact, Diabetes-related distress, Fear of complications, and Rebellious decisions were treated as independent scales. The aim of the study that follows was to determine which domains, and items within each domain, provide meaningful measurements of the respondents' self-reported adjustment to diabetes. At this initial stage the combined analysis of multiple scales was not necessary. However, a study using a larger number of participants was planned to take place at a later stage, after the domains and items had been selected (see Part III, Chapter 3). This section describes the initial development, refinement, and selection of items for use in the preliminary scale.

The first stage in developing the DIALS was to generate a list of items representing a wide range of coping-related activities and emotions relevant to diabetes. The domains used to define the most important aspects of diabetes-related adjustment were derived from qualitative one-on-one interviews conducted at the diabetic outpatient clinic of the Royal Infirmary of Edinburgh (Part III, Chapter 1). Based on the results of this study, items and content relating to the patients' self-reported adjustment were identified. At this stage items that covered a broad spectrum of diabetes-related events, behaviours, attitudes and emotions were gathered (120 items). The items were developed specifically to 'fit' within the pre-specified domains which emerged from the interview data (Part III, Chapter 1).

The content of the items was then compared to a variety of diabetes-specific self-report measures including a measure of psychological adjustment to diabetes (ATT39), the Well-being Questionnaire, the Diabetes Quality of Life measure (DQOL), the Diabetes Treatment Satisfaction Questionnaire (DTSQ), and the Diabetes-Specific Health Beliefs measure (all cited in Bradley, 1994). Where appropriate additional items were adapted which appeared to 'fit' within the pre-specified domains. The resulting list contained 170 items and was termed the DIALS-170 (see Appendix).

The item pool was checked, and amended to make sure that all the items were clear and not redundant, though there were related items. Emphasis was placed on using simple, clear and unambiguous wording of items. In particular, each item was carefully worded to ensure that it was directly associated with diabetes. For example, the item 'I follow the advice provided by health professionals' was changed to 'I follow the advice *about diabetes* provided by health professionals', and the item 'I feel frustrated that I can't lead a normal life' was changed to 'I feel frustrated that I can't lead a normal life *because of my diabetes*'. In addition, the items were checked to ensure that at least a few of the items in each domain were reversed. For example, the two items 'I work hard to keep my diabetes under control' and 'I would describe myself as lazy when it comes to managing my diabetes' represent positive and negative items, respectively, contained under the same domain heading 'information-seeking, self-regulation and planning'. This was done to take account of individual differences in people's tendency to agree with statements. A complete list of the items and their respective domains is displayed in the appendix. The responses to each item were based on a five point Likert scale ranging from 'strongly agree' to 'strongly disagree'.

The DIALS-170 was administered to 57 adults with Type 1 diabetes. The instructions for the respondents were as follows: "The list of statements below refer to the way you feel about diabetes, and the effect which it has on your daily life. Please rate each statement on the 1 to 5 scale, from 1 'strongly disagree' to 5 'strongly agree'. Please read each of the statements carefully and circle your first natural response".

Aims of the preliminary study

The aims of the preliminary study were as follows;

(i) To describe the selection of items for use in the pilot version of the DIALS.

(ii) To examine the coherence of items that were developed to measure the strategies, emotions and behaviours that were highlighted as being important in the analysis of interviews presented in the previous chapter (Part III, Chapter 1).

(iii) To determine which domains/subcategories, and items within each domain, provide meaningful measurements of the respondents' self-reported adjustment to diabetes, and hence should be included in the pilot scale.

Research design and methodology

Patient characteristics

All participants were currently receiving insulin therapy and were attendees of the diabetic outpatient clinic at the Royal Infirmary of Edinburgh. The clinical characteristics of the participants are shown in Table 3.2. Each participant was invited to participate by post, or approached in person when they attended the diabetic outpatient clinic for their routine check-up appointment. Of 73 patients approached, 57 agreed to take part – a 78% recruitment rate. The final sample consisted of 27 (47%) men and 30 (53%) women. All of the participants were aged 20 to 57 years with a mean (SD) diabetes duration of 5.6 (6.3) years.

All of the participants were native speakers of English. Occupational details were classified using Goldthorpe's (1987) schema; 14 (25) were defined as working class (skilled and semi-skilled manual workers), 27 (47) as intermediate class (non-manual employees) and 16 (28) as service class (professionals). The majority (n = 28, 49%) of the respondents were single, 23 (40%) were married or cohabiting, 5 (9%) were divorced or separated and one person was widowed (2%). The recent HbA_{1c} values of the participants were between 6.4 and 12.4%, and body mass ranged from 20.3 to 36.5kg/m^2. Fifteen (26%) people reported having additional illnesses or health problems, which included allergies (e.g. hayfever), asthma, Graves's disease, arthritis, thyroid problems, hypertension, and depression. Of the sample 18 (32%) people were current smokers, 11 (19%) were ex-smokers, and 28 (49%) participants had never smoked.

Table 3.2: Clinical characteristics of the study population.

N	57
Sex (Male/Female)	27/30
Age (years)	36.2 ± 10.2 (20 - 57)
Duration of diabetes (years)	5.6 ± 6.3 (0.06 - 29.0)
Education (years)	13.1 ± 3.5 (12.0 - 24.0)
Social class	
- Working	14 (25)
- Intermediate	27 (47)
- Service	16 (28)
Marital status	
- Single	28 (49)
- Married/cohabiting	23 (40)
- Divorced/separated	5 (9)
- Widowed	1 (2)
Body mass index (kg/m^2)	26.0 ± 3.7 (20.3 - 36.5)
Glycated haemoglobin (HbA_{1c})	8.5 ± 1.4 (6.4 - 12.4)
Comorbid problems	15 (26)
Alcohol intake	10.4 ± 10.3 (0 - 40.0)
Smoking	
- Current smoker	18 (32)
- Ex-smoker	11 (19)
- Never smoked	28 (49)

Data are n, means ± SD (range), or n (%).

Procedure

The DIALS-170 was self-administered by each participant either in the diabetes clinic, or at home in their own time, and returned by post (pre-paid envelope provided). Where a questionnaire was not received within four weeks, the individual was contacted by telephone and, if necessary, sent another questionnaire. Body mass index and glycated haemoglobin are recorded at each clinic attendance. These details were obtained from the patient's medical notes.

Statistical analysis

The data were analysed using the Statistical Package for the Social Sciences (SPSS) version 10.0. First the items were screened for poor discrimination properties. To identify those items that did not discriminate, frequency distributions, means and standard deviations were computed for each of the 170 items. Each histogram was examined to identify, and discard, items that had skewed distributions. The criterion used for rejection of an item was set so that items that had a mean of less than 2.0 or more than 4.0 on the 1-5 point scale were removed.

In the second stage of the analysis, item-total correlations were computed to establish the reliability of the items within each pre-defined domain. The purpose of this analysis was to reduce the number of items in each domain by identifying those non-tautologous items that were highly correlated with the other items in the same domain. The criterion used for rejection of a particular item was set so that items that had an item-total correlation of 0.30 or below were identified as being inconsistent with the other items in that domain and were therefore excluded from further analysis.

The third and final stage in the selection of items for inclusion in the DIALS involved using principal components analysis. This process was employed to identify the dimensionality of the items in each of the specified domains. The procedure used to conduct principal components analysis is described in detail below.

Principal components analysis

Principal components analysis is a technique that can be used to reduce a large number of interrelated questions to a smaller number of underlying common components, that are primarily responsible for the covariation in the data (Kline, 1998). This can be achieved by examining the variation in scores on a number of variables, which are then expressed as a smaller number of components. In other words, when a group of variables has a great deal in common one or more components may exist. The resulting components are defined by their correlations (loadings) with the original variables. Components exist when two or more variables are intercorrelated to produce a linear combination of variables. When this happens we can infer that the variables share common variance. The primary aim of principal components analysis is to discover these components.

A standard approach to conducting principal components analysis was adopted. The goal of the analyses was to explore the covariation between the items *within* each of the eight domains: 1) information-seeking and adherence, 2) sources of support, 3) acceptance, 4) impact, 5) diabetes-related distress, 6) fear of complications, 7) isolation/stigmatisation, and 8) rebellious decisions. For each domain an independent analysis was conducted. The objective of the analysis was to fashion domains by examining whether or not the items within each domain shared covariance with other items.

The first step involved deciding upon the number of components to accept. This decision was made based on the percentage of common variance accounted for by a given component and on the results of the Scree test (Cattell, 1966). Using the Scree test the Eigenvalue (i.e. the amount of variance that is accounted for by each component) is plotted against each extracted component. Using this method it is possible to judge where there is a break or discontinuity between the components that have large Eigenvalues and those with smaller Eigenvalues. Components that appear before the break are assumed to be meaningful whereas those that appear on the horizontal line after the break are taken to account for small amounts of variance and are not retained. In addition, the criterion was set so that only components that accounted for more than 20% of the common variance were retained.

Once the number of extracted components had been decided upon, step 2 involved deciding which items to accept as having satisfactory loadings on a given component. For the purpose of this study, the objective was to identify items that had a high degree of covariation within a particular domain. A strict criterion was adopted whereby only those items which had moderate to high loadings (above 0.40) on a retained component were selected for use in the DIALS. This criterion was pre-set after consulting the Burt-Banks formula, with an n of 50, and a maximum of 35 variables, item loadings must reach at least 0.35 or higher in order to satisfy the one percent significance level on the first component.

In the final step the conceptual meaning of the items that loaded on each component was examined. Those items that had high loadings on a particular component were examined and compared to the original interpretation of that domain. Cronbach's α coefficient was computed for each component to measure internal consistency of the items.

Selection of items: examining the coherence of items within each domain

In this section an exploratory approach was used to reduce the initial item pool containing 170 items (see Appendix) by examining the covariance between items within each of the 8 specified domains: 1) information-seeking and adherence, 2) sources of support, 4) acceptance, 5) diabetes-related distress, 6) fear of complications, 7) isolation/stigmatisation, and 8) rebellious decisions. The selection of items for use in a pilot version of the Diabetes Impact, Adjustment and Lifestyle Scales (DIALS) is now described by referring to each domain in turn.

Information seeking and adherence

The domain termed 'Information-seeking and adherence' contained a total of 34 items (Table 3.3). The items in this domain were grouped together to measure the self-regulatory strategies and forward planning involved in diabetes self-management. The items include (i) diabetes information-seeking, such as reading books and articles about diabetes, keeping up with developments in insulin therapy, following the advice provided by health professionals, and sharing experiences of diabetes with other people, and (ii) adhering to a complex regimen, including regulation of diet, taking regular exercise, monitoring blood glucose levels and following a strict self-management routine in an effort to achieve good glycaemic control.

The descriptive statistics for the 34 items in this domain are displayed in Table 3.3. Frequency distributions and mean scores for each individual item were examined. Five items had skewed distributions (items 31, 58, 98, 109 and 115) and were excluded from further analysis. Item-total correlations were computed for the remaining 29 items (Table 3.3). Nine items (items 24, 32, 39, 49, 85, 138, 139, 143, 152 and 153) had item-total correlations of less than .30 and were excluded from further analysis at this stage.

Table 3.3: Descriptive statistics for individual 'Information-seeking and adherence' items

Items	Mean ± SD	Item-total corr.
11. I use the information I have about diabetes to help me to manage it	3.9 ± 0.6	.51
24. It helps to try different diabetes products	2.6 ± 1.1	-.05
31. There is nothing I can do to avoid complications of diabetes	1.8 ± 0.7	
32. High blood sugar can be prevented if I plan ahead	3.7 ± 0.8	.22
38. I try to keep up with developments in insulin therapy	3.4 ± 0.7	.49
39. I eat something as soon as I feel the first sign of low blood sugar	3.9 ± 0.7	.18
43. I try to have a balanced diet because that is important for diabetes	3.8 ± 0.8	.44
48. I am interested in gathering information about diabetes	3.5 ± 0.7	.46
49. I can prevent a severe hypo if I plan ahead	3.7 ± 1.0	.09
56. I am satisfied with my understanding of diabetes	3.8 ± 0.6	.40
58. I almost always keep my appointments at the diabetes clinic	4.4 ± 0.8	
60. I am happy with my current treatment for diabetes	3.7 ± 0.8	.48
62. I am eager to read about diabetes	3.3 ± 0.9	.53
74. I follow the advice about diabetes provided by health professionals	3.8 ± 0.7	.46
85. My blood sugar can be totally different from one day to the next	3.4 ± 1.1	-.25
89. I test my blood sugars regularly	3.5 ± 1.1	.49
94. I work hard to keep my diabetes under control	3.4 ± 0.8	.31
98. Avoiding high blood sugar is important in diabetes	4.3 ± 0.5	
100. I have a very strict self-management routine	2.5 ± 0.8	.34
104. I feel that the more I know about diabetes the less it will bother me	3.2 ± 0.8	.49
109. It is important to know how to combat problems as they arise	4.2 ± 0.5	
115. As a person with diabetes I know what I should eat	4.1 ± 0.5	
127. I believe that I control my diabetes at least as well as most other people with diabetes	3.6 ± 0.9	.31
131. I read magazines and articles about diabetes	3.3 ± 0.9	.60
132. I almost always carry glucose/sweets with me	3.9 ± 1.1	.41
138. I'm hoping for a miracle cure for my diabetes	3.5 ± 1.3	-.17
139. Regular controlled exercise helps me to manage my diabetes	3.5 ± 0.8	.29
140. The more I read the more I know what I have to do to combat problems associated with diabetes	3.4 ± 0.7	.40
143. My current treatment for diabetes is convenient	3.6 ± 0.9	.27
146. I try to share my experiences of diabetes with others who know about it	3.1 ± 1.1	.40
148. Chatting to other people who have diabetes is useful	3.4 ± 0.9	.49
152. It is my own fault if my blood sugar level is too high or low	3.7 ± 0.9	-.26
153. I sometimes think I don't know enough about diabetes	2.9 ± 0.8	-.09
162. The thought of giving myself an injection does not bother me	3.9 ± 0.9	.32

Data are means ± standard deviations (n = 48). A higher item score represents a higher level of agreement with the item.

Items in bold type were entered into principal components analysis.

The remaining 19 items were entered into a principal components analysis to examine whether they shared covariance with the other items resulting in a substantive first unrotated principal component. Five components were extracted with Eigenvalues greater than 1, accounting for 68% of the total variance. The first component accounted for 32.9% of the variance, and subsequent components accounted for progressively lower portions of the variance. The Scree plot (Figure 3.6) shows a break after the first component indicating that the first component represents a general component. The first component satisfied the requirement that at least 20% of the total variance should be explained by a retained component.

The purpose of this analysis was to identify a clear number of items/questions for the 'Information seeking and adherence' domain. Examination of the component matrix revealed that 10 out of the 19 items had loadings of .40 or higher on the first component, ranging from .45 to .75. The loadings for each individual item are displayed in Table 3.4. These items were retained and entered into the pilot version of the DIALS.

The items displayed in Table 3.4 share a common theme in describing a person's active attempts to find out about diabetes and to use the information available to solve problems associated with their diabetes self-management. The internal consistency of the items contained within the component termed 'Information-seeking and adherence' was assessed using Cronbach's α co-efficient. In this analysis Cronbach's alpha was 0.86 indicating good reliability.

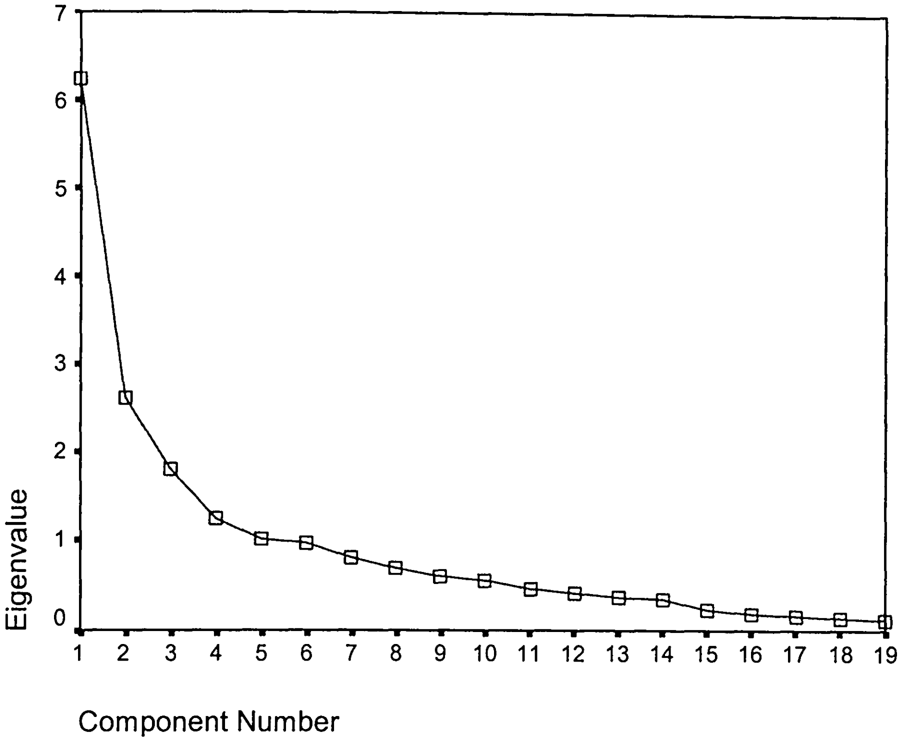


Figure 3.6: Scree plot to show the amount of variance accounted for by the component 'Information-seeking and adherence'.

Table 3.4: Factor loadings for individual 'Information-seeking and adherence' items

Items		Loading
11.	I use the information I have about diabetes to help me to manage it	.63
38.	I try to keep up with developments in insulin therapy	.62
48.	I am interested in gathering information about diabetes	.68
62.	I am eager to read about diabetes	.70
74.	I follow the advice about diabetes provided by health professionals	.66
104.	I feel that the more I know about diabetes the less it will bother me	.59
131.	I read magazines and articles about diabetes	.75
140.	The more I read the more I know what I have to do to combat problems associated with diabetes	.54
146.	I try to share my experiences of diabetes with others who know about it	.45
148.	Chatting to other people who have diabetes is useful	.53

Sources of support

The domain termed 'Sources of support' contained 10 original items. The items within this domain were grouped together because they refer to the individual's perceived source of support, responsibility, control and care for their diabetes. The label 'Sources of support' was applied to indicate the perceived 'source' of responsibility for the respondent's diabetes care. This can include oneself, friends, family, health professionals, and/or colleagues. The descriptive statistics for each individual item are displayed in Table 3.5.

Inspection of the descriptive statistics (Table 3.5) and frequency distributions for the items under the domain heading 'Sources of support' revealed that three items had skewed distributions. Item 1 'I am responsible for taking care of my diabetes', and item 107 'Managing diabetes is my responsibility', had mean scores of above 4 on the 1-5 point scale, indicating that a large proportion of the respondents agreed with these statements. In contrast, item 3 'I rely on others to help me control my diabetes' obtained a mean score of 1.8 (0.8); a large proportion of the respondents tended to disagree with this statement. These items were excluded from further study.

Item-total correlations were calculated for the remaining 7 items (Table 3.5). The item-total correlations ranged from .04 to .28 indicating poor reliability. Cronbach's α co-efficient was also low (0.19). Based on these results the decision was made to exclude these items from the pilot version of the DIALS.

Table 3.5: Descriptive statistics for the individual 'sources of support' items

Items	Mean ± SD	Item-total corr.
1. I am responsible for taking care of my diabetes	4.6 ± 0.6	
15. The nurses at the diabetes clinic have an important role in helping my diabetes	3.6 ± 0.8	.25
33. I rely on others to help me control my diabetes	1.8 ± 0.8	
57. My family/friends/colleagues play a big part in helping to control my diabetes	2.5 ± 1.0	.28
70. There is only so much health professionals can do to help my diabetes	3.7 ± 0.8	-.16
77. People close to me support me in looking after my diabetes	3.7 ± 1.0	.19
88. I don't feel like I need to tell others I'm diabetic	2.9 ± 1.0	.04
92. I don't know what I would do without my family/friends/ colleagues there to support me with my diabetes	2.7 ± 1.0	-.08
107. Managing diabetes is my responsibility	4.4 ± 0.7	
156. I feel capable of looking after my diabetes with minimum outside help	3.7 ± 0.8	.07

Data are means ± standard deviations (n = 55). A higher item score represents a higher level of agreement with the item.

Acceptance

The descriptive statistics for the items grouped under the domain heading 'Acceptance' are displayed in Table 3.6. Five of the fourteen items had skewed distributions. The following five items; 73, 90, 103, 134 and 136 were excluded from further analysis. The remaining 9 items had satisfactory frequency distributions.

Item-total correlations were computed to assess whether the nine remaining items were measuring the same construct (Table 3.6). The item-total correlations ranged from .06 to .38 indicating that the items had poor reliability. Only two items had item-total correlations above 0.30 (items 19 and 165). Cronbach's α was .45, which was below the criteria for acceptable reliability. The items grouped under the domain heading 'Acceptance' were subsequently excluded from the pilot version of the DIALS.

Table 3.6: Descriptive statistics for individual 'Acceptance' items.

Items		Mean ± SD	Item-total corr.
19.	I cope well with my diabetes	3.6 ± 0.8	.38
22.	Diabetes is just something I've got	3.9 ± 0.8	.19
36.	I wouldn't consider diabetes to be a "serious" disease	2.4 ± 0.9	.25
41.	Diabetes is not as bad for your health as smoking/taking drugs	3.3 ± 1.2	.18
73.	The way I see it, if I look after myself properly I should be fine	4.1 ± 0.9	
83.	I have never felt embarrassed about having diabetes	3.4 ± 1.1	.06
90.	I just have to put up with diabetes whether I like it or not	4.0 ± 0.7	
103.	Diabetes is just something I have to live with	4.1 ± 0.7	
116.	I feel well adjusted to life with diabetes	3.3 ± 0.9	.26
134.	I just have to learn to cope with my diabetes	4.0 ± 0.4	
136.	Diabetes is not going to go away so I just have to get on with it	4.2 ± 0.6	
157.	I believe that researchers will find a cure for my diabetes before too long	3.7 ± 0.8	.11
165.	Diabetes is not really a problem for me because it can be controlled	3.4 ± 0.8	.37
170.	I often forget that I even have diabetes	3.9 ± 0.9	.02

Data are means ± standard deviations (n = 53). A higher item score represents a higher level of agreement with the item.

Impact

The domain termed 'Impact' contained at total of 39 items. The items contained within this domain were grouped together to measure the patient's perceived burden of diabetes. The domain 'Impact' includes (i) the burden of the demands of insulin therapy, for example, frequent blood glucose monitoring, sticking to a recommended diet, and taking regular exercise, (ii) the inconvenience associated with adhering to a complex regimen, for example, at meal times, when driving a car or operating machinery, and while travelling away from home (e.g. on holiday), and (iii) the psychological burden which result from the demands of a challenging self-management routine including feeling restricted, getting frustrated and annoyed, making sacrifices and experiencing difficulty in meeting the complex demands of a prescribed regimen.

The mean scores, standard deviations, and item-total correlations for each individual item are displayed in Table 3.7. All of the items were considered to have satisfactory frequency distributions and mean scores were within the acceptable range. Item-total correlations were computed for each item (Table 3.7). Four items: 9, 42, 51 and 66 had item-total correlations of less than 0.30 and were therefore excluded from further study. The 35 remaining items had item-total correlations of between -.30 and .79.

Thirty-five items were entered into a principal components analysis. The initial solution produced seven components with Eigenvalues greater than 1. These components accounted for 70.8% of the total variance. Using the Scree test, a clear break was evident between the first component and the second and remaining components (Figure 3.7). Based on the percentage of variance, items that loaded on the first component made a large contribution to the common variance (38.9%). None of the remaining components accounted for more than 20% of the variance. The purpose of this analysis was to identify a clear set of items/questions for the domain termed ‘Impact’. All of the items entered into this analysis had substantial loadings (above the criteria of 0.40) on the first component ranging from -.42 to .80. The twenty highest loading items were selected. The 20 selected items had factor loadings between .53 and .80, and were extracted for use in the pilot version of the DIALS questionnaire. The retained items are displayed in Table 3.8.

Table 3.7: Descriptive statistics and item-total correlations for individual 'Impact' items

Items		Mean ± SD	Item-total corr.
2.	I feel happy with my life and diabetes hasn't changed that	3.5 ± 1.0	-.48
5.	Taking blood glucose readings is annoying	3.4 ± 1.2	.56
7.	At times trying to manage my diabetes is difficult	3.2 ± 1.1	.56
8.	Diabetes doesn't really bother me at all on a day to day basis	3.4 ± 1.0	-.49
9.	I'd have second thoughts about going abroad by myself because of my diabetes because of my diabetes	2.3 ± 1.1	.18
16.	I feel frustrated that I can't lead a normal life because of my diabetes	2.4 ± 1.0	.62
21.	I wish I could relax without thinking about checking my blood sugars	3.1 ± 1.1	.40
25.	Diabetes has never stopped me doing anything	3.7 ± 1.0	-.30
27.	It is not possible to control my diabetes well and live in a way that is acceptable to me eating out difficult	2.3 ± 1.1	.55
30.	Sticking to my recommended diet makes eating out difficult	2.5 ± 1.2	.61
37.	When I am away from home (e.g. on holiday) I find it more difficult to manage my diabetes	2.8 ± 1.0	.58
42.	I try not to think about diabetes	2.8 ± 0.9	.09
47.	Diabetes interferes with my sex life	2.1 ± 1.1	.51
50.	I enjoy the things I do and diabetes hasn't changed that	3.6 ± 0.9	-.46
51.	I find it difficult to relax when I go out socially because of diabetes	2.1 ± 1.0	.21
53.	I lead a normal life the same as any other person who does not have diabetes	3.4 ± 1.0	-.42
55.	The difficult thing about diabetes is the ongoing self management of the illness	3.2 ± 1.2	.57
63.	It is difficult to regulate when I'm going to do things like eat and have exercise	2.8 ± 1.0	.63
79.	Checking my blood sugars is so routine it is not any bother	3.1 ± 1.2	-.50
84.	It's annoying to have to watch what you eat	3.5 ± 1.0	.52
87.	I've not really had any problems with diabetes	3.1 ± 1.1	-.34
93.	I find it difficult to get a good nights rest because of my diabetes	2.2 ± 1.1	.50
96.	My blood sugar level tends to go up and down a lot	3.2 ± 1.0	.40
97.	Managing diabetes is a balancing act	3.7 ± 0.7	.32
99.	My lifestyle is too controlled because I have diabetes	2.7 ± 0.9	.53
106.	My diabetes means others have to wait for me at meal times	2.3 ± 0.9	.49
110.	Diabetes isn't a problem for me (R)	3.0 ± 1.1	-.41
112.	Having diabetes causes some inconvenience	3.7 ± 0.8	.50
117.	Diabetes causes inconvenience when driving a car/operating machinery (e.g. a computer)	2.5 ± 1.1	.43
118.	Diabetes interferes with my social life	2.3 ± 1.1	.48
124.	I feel restricted in what I can do because of my diabetes	2.7 ± 1.1	.65
130.	Diabetes interferes with me taking exercise when I want to	2.4 ± 0.9	.52
135.	Diabetes interferes with me eating when I want to	2.9 ± 1.1	.60
141.	Diabetes interferes with my work	2.3 ± 0.9	.52
145.	Controlling my diabetes well imposes restrictions on my whole lifestyle	2.6 ± 1.1	.79
158.	There is little hope of leading a normal life with diabetes	2.1 ± 0.8	.41
160.	The proper control of diabetes involves a lot of sacrifice	2.7 ± 1.1	.74

Data are means ± standard deviations (n = 52). A higher item score represents a higher level of agreement with the item. Items in bold type were entered into principal components analysis.

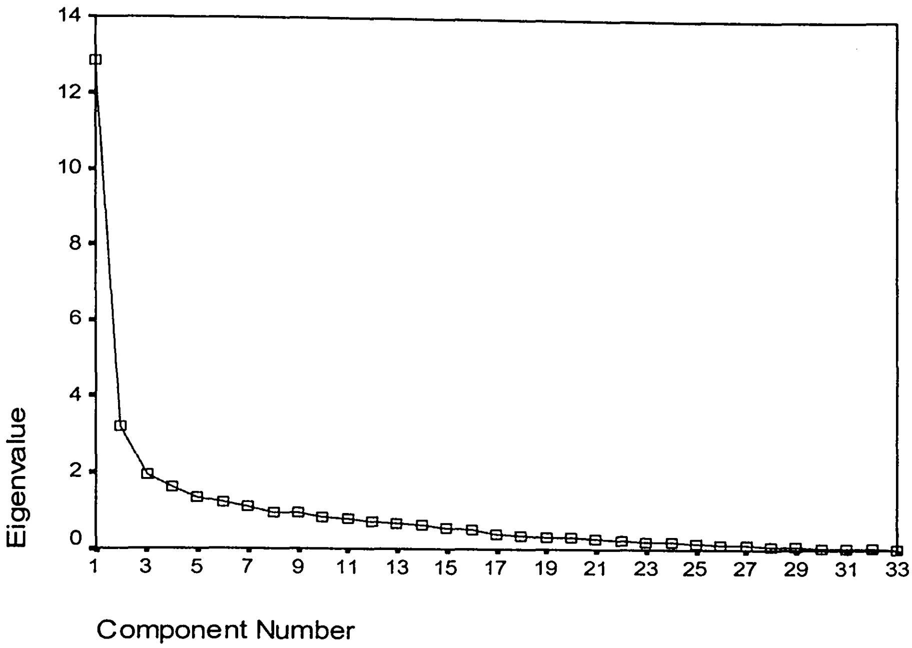


Figure 3.7: Scree plot to show the amount of common variance accounted for by Factor 2 'Impact'.

Table 3.8: Factor loadings for the 'Impact' items

Items	Loading
2. I feel happy with my life and diabetes hasn't changed that (R)	-.63
5. Taking blood glucose readings is annoying	.64
8. Diabetes doesn't really bother me at all on a day to day basis (R)	-.71
16. I feel frustrated that I can't lead a normal life because of my diabetes	.80
30. Sticking to my recommended diet makes eating out difficult	.60
37. When I am away from home (e.g. on holiday) I find it more difficult to manage my diabetes	.62
50. I enjoy the things I do and diabetes hasn't changed that (R)	-.70
53. I lead a normal life the same as any other person who does not have diabetes (R)	-.68
93. I find it difficult to get a good nights rest because of my diabetes	.53
99. My lifestyle is too controlled because I have diabetes	.74
106. My diabetes means others have to wait for me at meal times	.67
110. Diabetes isn't a problem for me (R)	-.65
112. Having diabetes causes some inconvenience	.57
118. Diabetes interferes with my social life	.73
124. I feel restricted in what I can do because of my diabetes	.71
130. Diabetes interferes with me taking exercise when I want to	.61
135. Diabetes interferes with me eating when I want to	.70
141. Diabetes interferes with my work	.62
145. Controlling my diabetes well imposes restrictions on my whole lifestyle	.80
160. The proper control of diabetes involves a lot of sacrifice	.74

(R) = Item should be reverse scored.

The items that had high loadings on this component were associated with lifestyle restrictions and the psychological burden of diabetes resulting from the specific demands of diabetes self-management and the personal responsibility for treatment.

The internal consistency of the 20 selected items was examined using Cronbach's α co-efficient. Cronbach's α was 0.72, which is acceptable. The items appear to be reasonably strong in demonstrating reliability and supporting that the items are measuring the same construct.

Diabetes-related distress

The domain termed 'diabetes-related distress' contained 19 items. The descriptive statistics for each item are displayed in Table 3.9. Three of the items in this domain were negatively skewed, these items had a mean score of less than 1 on the 1 - 5 point scale. Items 3, 4, and 154 were subsequently excluded from further analysis. Item-total correlations were computed for the remaining 16 items (Table 3.9). Item 26 'I don't see any point in getting angry about my diabetes' had an item-total correlation of -.28, which was below the requirement of .30. The remaining 15 items had moderate to high item-total correlations of between .36 and .77.

Table 3.9: Descriptive statistics for individual 'Diabetes-related distress' items

Items	Mean ± SD	Item-total corr.
3. I feel pretty useless much of the time because of my diabetes	1.8 ± 0.9	
4. I find that I can't think clearly because of my diabetes	1.9 ± 0.9	
6. I worry about making a mistake or having an accident because of my diabetes	2.3 ± 1.1	.49
10. I feel anxious because of my diabetes	2.3 ± 1.1	.62
14. I have crying spells or feel like it because of my diabetes	2.1 ± 1.1	.68
17. I often feel sorry for myself because I have diabetes	2.1 ± 1.0	.57
20. I feel like I am falling apart because of my diabetes	2.0 ± 0.8	.77
26. I don't see any point in getting angry about my diabetes	3.9 ± 0.9	-.28
61. In general I try not to let diabetes worry me	3.9 ± 0.7	-.55
64. I get upset easily and feel panicky because of diabetes	2.1 ± 0.9	.61
68. It is hard to concentrate because of my diabetes	2.3 ± 0.8	.61
71. I sometimes feel depressed about my diabetes	2.7 ± 1.2	.63
76. I'm not a worrier and diabetes hasn't changed that	3.3 ± 1.0	-.41
119. I feel angry that I have diabetes	2.6 ± 1.1	.69
126. I feel a burden to other people because of my diabetes	2.2 ± 1.1	.71
142. I worry about losing control because of my diabetes	2.6 ± 1.2	.64
150. Diabetes is the worst thing that ever happened to me	2.9 ± 1.3	.36
151. I feel bad when other people help me because of my diabetes	2.6 ± 0.9	.53
154. I worry that my body looks different because I have diabetes	1.9 ± 0.9	

Data are means ± standard deviations (n = 54). A higher item score represents a higher level of agreement with the item. Items shown in bold type were entered into principal components analysis.

The remaining 15 items contained under the domain heading 'Diabetes-related distress' were entered into a principal components analysis. The initial solution produced three components with Eigenvalues above the cut off point of 1. These three components accounted for 64% of the total variance. The items that loaded on the first component made a large contribution to the total variance (47%). The Scree plot (Figure 3.8) shows a clear break after the first component, which suggests that only the first component was meaningful. Those items that had loadings of above .40 on the first component were therefore, selected for use in the pilot version of the DIALS (Table 3.10). The loadings for these items ranged from .65 to .86.

The extracted items were retained for use in the DIALS and kept the original label 'Diabetes-related distress'. The items that loaded on this component referred specifically to negative diabetes-related emotions and may reflect maladaptive coping. The internal consistency of the items in this component was examined by computing Cronbach's α coefficient. Cronbach's α was high (0.86) indicating that the items had good internal reliability.

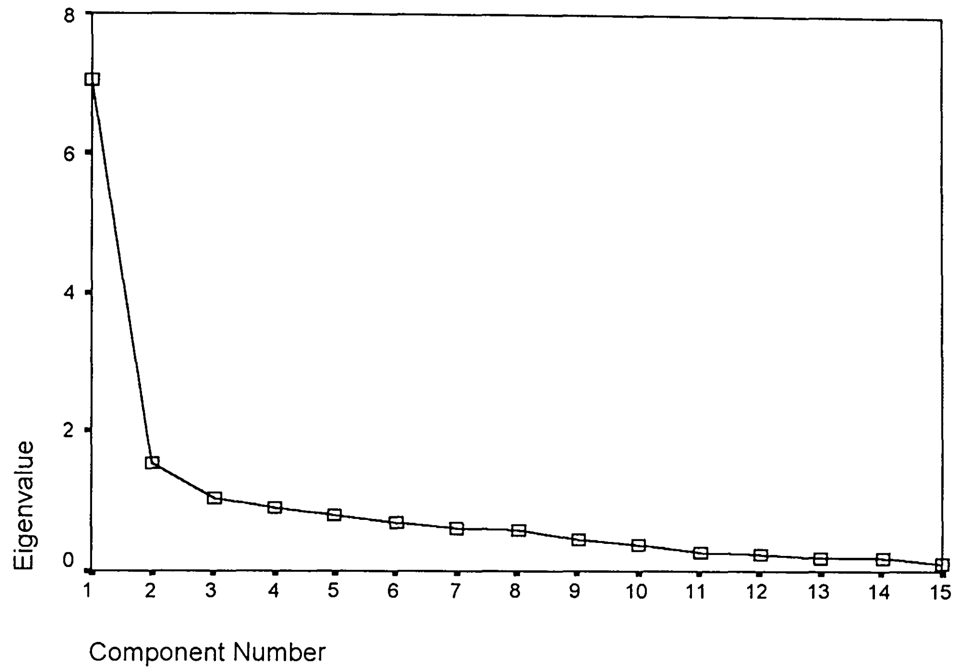


Figure 3.8: Scree plot showing the amount of variance accounted for by the component 'Diabetes-related distress'.

Table 3.10: Factor loadings for retained 'Diabetes-related distress' items

Item		Loading
10.	I feel anxious because of my diabetes	.72
14.	I have crying spells or feel like it because of my diabetes	.76
17.	I often feel sorry for myself because I have diabetes	.72
20.	I feel like I am falling apart because of my diabetes	.86
61.	In general I try not to let diabetes worry me (R)	-.65
64.	I get upset easily and feel panicky because of diabetes	.74
68.	It is hard to concentrate because of my diabetes	.65
71.	I sometimes feel depressed about my diabetes	.75
119.	I feel angry that I have diabetes	.73
126.	I feel a burden to other people because of my diabetes	.80

(R) = Item should be reverse scored.

Fear of Complications

The domain named 'Fear of complications' contained 20 items. The items contained in this domain measure the individual's fear of the threat of potential complications of diabetes resulting from hyperglycaemia and hypoglycaemia. The means and standard deviations for each individual item are shown in Table 3.11. Frequency distributions and mean scores were examined for each item to identify items that had poor discrimination properties. All of the items had satisfactory distributions and mean scores within the acceptable range (between 2.0 and 4.0). Item total correlations were computed (Table 3.11) to identify whether or not the items appeared to be measuring the same construct. Four items; 12, 54, 65 and 163 had item-total correlations of less than .30 and were removed from further analyses at this stage. The remaining items had item-total correlations between .34 and .70.

Sixteen items were entered into principal components analysis to examine the coherence of items within this domain and to identify a clear number of questions to include in the pilot version of the DIALS. The first component accounted for 37.8% of the total variance. The Scree plot (Figure 3.9) shows a large break between the first component and subsequent components. The first component was extracted based on the Scree test and the requirement that at least 20% of the variance be explained by a retained factor.

Table 3.11: Descriptive statistics for individual 'Fear of complications' items

Items	Mean ± SD	Item-total corr.
12. I avoid exercise when my blood sugar is low	3.5 ± 1.0	.29
18. I avoid being alone when my blood sugar is low	2.4 ± 1.0	.34
21. I wish I could relax without thinking about checking my blood sugars	3.3 ± 1.1	.52
29. I get annoyed with myself when my blood sugar is high	3.5 ± 0.9	.42
54. My health is not as good as other people my age because I have diabetes	2.6 ± 1.1	.25
65. I keep my blood sugars high when I plan to be in a long meeting or at a party	2.9 ± 1.0	.29
82. I am afraid of being admitted to hospital because of my diabetes	2.8 ± 1.1	.51
95. I am afraid of experiencing a severe hypoglycaemic attack	3.3 ± 1.0	.45
105. It is probably best not to think about the future consequences of diabetes	2.7 ± 1.0	.55
114. I worry about not realising that I am having low blood sugar	3.0 ± 1.2	.55
121. I worry about getting long term complications of diabetes	3.6 ± 0.9	.50
122. I don't worry about hypos	2.6 ± 0.9	
123. I worry about my health because of my diabetes	3.4 ± 0.9	.65
125. I worry about having high blood sugar	3.5 ± 0.8	.58
128. I often worry that my health will deteriorate as a result of diabetes	3.4 ± 1.0	.70
129. I worry about no one being around to help me during a reaction caused by diabetes	2.9 ± 1.2	.59
133. I have thoughts or worries about what will happen later in life because of diabetes	3.6 ± 0.9	.62
149. My blood sugar level is too high	3.1 ± 1.0	.39
161. Being told you have diabetes is like being sentenced to a life time of illness	2.9 ± 1.2	.65
163. Hypos are not as frightening as people think	3.0 ± 1.0	-.24

Data are means ± standard deviations (n = 49). A higher item score represents a higher level of agreement with the item. Items in bold type were entered into principal components analysis.

The component matrix revealed that 10 items had loadings of above 0.40 on the first component ranging from .54 to .80 (Table 3.12). These items were extracted for inclusion in the pilot version of the DIALS.

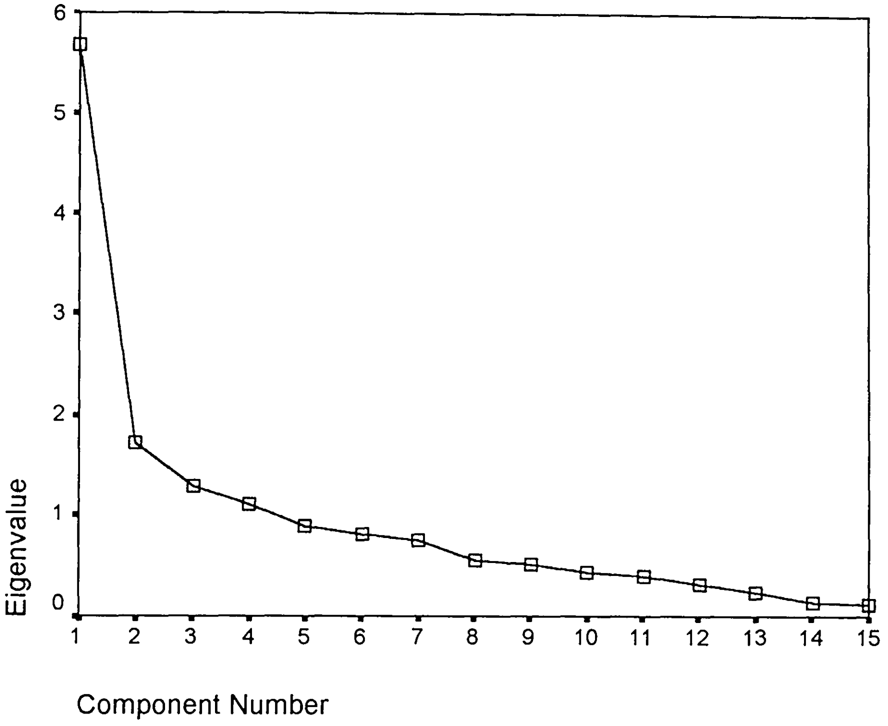


Figure 3.9: Scree plot to show the amount of variance accounted for by the component 'Fear of complications'.

Table 3.12: Factor loadings for selected 'Fear of complications' items

Items		Loading
21.	I wish I could relax without thinking about checking my blood sugars	.64
82.	I am afraid of being admitted to hospital because of my diabetes	.62
105.	It is probably best not to think about the future consequences of diabetes	.54
121.	I worry about getting long term complications of diabetes	.66
123.	I worry about my health because of my diabetes	.80
125.	I worry about having high blood sugar	.71
128.	I often worry that my health will deteriorate as a result of diabetes	.79
129.	I worry about no one being around to help me during a reaction caused by diabetes	.68
133.	I have thoughts or worries about what will happen later in life because of diabetes	.72
161.	Having diabetes is like being sentenced to a life time of illness	.64

The items that loaded on this component were interpreted as relating to a person's health-related worries about diabetes and the threat of long-term complications of the disorder. Cronbach's α reliability coefficient was high (0.87) indicating that the items that loaded on this component had good internal reliability.

Isolation/Stigmatisation

The category termed 'Isolation/stigmatisation' contained 14 original items. These items represented a person's perceived isolation and their sense of being stigmatised because of their diabetes. The descriptive statistics and item-total correlations for the items in this domain are displayed in Table 3.13.

Table 3.13: Descriptive statistics for individual 'isolation/stigmatisation items

Items		Mean ± SD	Item-total corr.
28.	I don't like to tell other people I have diabetes	2.3 ± 1.0	.51
34.	I worry that people treat me differently because I have diabetes	2.4 ± 1.0	.57
35.	Sometimes I wonder if I did something to cause my diabetes	2.3 ± 1.2	.34
45.	I worry about being criticised because of my diabetes	2.1 ± 1.0	.36
59.	I sometimes hide the fact that I am having a diabetes reaction from others	2.5 ± 1.1	.36
69.	Diabetes sometimes causes me embarrassment	2.2 ± 1.1	.58
80.	I don't like to think of myself as a person with diabetes	2.9 ± 1.0	.44
81.	I think it is unfair that I have got diabetes	2.8 ± 1.0	.42
147.	Sometimes I think I shouldn't have to go without something just because I'm diabetic	3.2 ± 1.0	.24
155.	I dislike being referred to as 'a diabetic'	2.8 ± 1.1	.48
159.	Most people would find it hard to adjust to having diabetes	3.1 ± 1.0	.45
167.	It is unfair that I have diabetes when other people are so healthy	2.1 ± 0.9	.48
168.	There is no one I can talk to openly about my diabetes	2.9 ± 1.0	-.14
170.	Most people don't really understand the problems associated with diabetes	3.8 ± 1.0	.40

Data are means ± standard deviations (n = 56). Items in bold were entered into principal components analysis.

Two items had item-total of less that 0.30 and were removed from further analysis (items 147 and 168). The remaining 12 items had moderate item-total correlations of between .34 and .57.

Principal components analysis was used to examine the covariation between the items in the domain 'Isolation/stigmatisation'. Five components with Eigenvalues above 1 were extracted. The first component accounted for 26.7% of the variance and the second and third components accounted for 14.8% and 10.7% of the variance respectively. Based on the percentage of variance, the first component satisfied the requirement that 20% of the variance should be accounted for by a retained factor. However, none of the components contained more than 6 items with loadings above 0.40. Based on the small number of items that loaded on this factor, the decision was made to exclude 'Isolation/stigmatisation' items from the pilot version of the DIALS.

Rebellious decisions

The term ‘Rebellious decisions’ has been used here to describe a person’s tendency to knowingly carry out activities which may be counterproductive to their diabetes-related well-being. The items grouped under this heading include indulgences (e.g. eating too many sweets/chocolates), laziness, and a lack of motivation to adhere to the demands of a diabetes regimen (e.g. skipping injections). The descriptive statistics of the original 20 items included in this domain are displayed in Table 3.14. The mean scores and frequency distributions for each individual item were examined. At this stage item 72 was excluded from further study because it had a negatively skewed distribution indicating that the majority of respondents disagreed with this statement. Item total correlations were computed (Table 3.14). Three items; 75, 120 and 137 had item total correlations of below .30 and were subsequently discarded. The remaining sixteen items had item-total correlations between .34 and .76 (Table 3.14).

Sixteen items were entered into a principal components analysis. Three components were extracted with Eigenvalues above 1. Collectively these three components accounted for 64.6% of the variance. The first component accounted for the largest amount of the variance (46.3%). Based on the percentage of variance and the Scree plot (Figure 3.10), items that had high loadings on the first component were extracted for use in the pilot version of the DIALS.

Table 3.14: Descriptive statistics for the individual 'Rebellious decisions' items

Items	Mean ± SD	Item total corr.
13. I feel guilty about the way I manage my diabetes	2.5 ± 1.1	.73
23. I think my control of diabetes is quite good	3.7 ± 0.9	-.63
40. I feel guilty if I eat foods which I know are bad for me	3.1 ± 1.0	.45
44. I tend to eat what I feel like at the time rather than what is good for my diabetes	2.7 ± 0.9	.64
46. Sometimes I think I am a "bad" diabetic	2.9 ± 1.2	.58
52. I am not very good at following the diabetes advice I am given	2.5 ± 1.0	.34
67. As a diabetic person, I eat a diet which keeps me healthy	3.6 ± 0.8	-.52
72. I sometimes do my injections in public to shock people	1.8 ± 1.0	.29
75. When I do my injections, if others don't like it it's their problem	3.2 ± 1.2	.22
78. I eat a lot of food that I know is not recommended for people who have diabetes	2.8 ± 1.0	.58
86. Sometimes I can't be bothered to check my blood sugar level	3.1 ± 1.2	.58
91. I eat too many sweets/chocolates for a person with diabetes	2.9 ± 1.1	.61
101. Sometimes I skip injections	2.0 ± 1.1	.36
108. Sometimes I eat more sweets or chocolate than a person with diabetes should	3.2 ± 1.1	.57
111. I don't have the motivation to take care of my diabetes	2.1 ± 0.9	.54
113. I would describe myself as lazy when it comes to managing my diabetes	2.3 ± 1.1	.78
120. I often do things to take my mind off diabetes	2.3 ± 1.0	.08
137. I deliberately put diabetes out of my mind	2.6 ± 0.8	.03
144. I think that I am eating properly for a person with diabetes	3.4 ± 1.0	-.70
164. Sometimes I have used my diabetes as an excuse to get my own way	2.1 ± 1.0	.40

Data are means ± standard deviations (n = 51). A higher item score represents a higher level of agreement with the item. Items shown in bold were entered into principal components analysis.

The component matrix showed that 14 items had loadings of above 0.40 on the first component. These fourteen items were extracted for inclusion in the pilot version of the DIALS (Table 3.15). Item loadings ranged from .47 to -.87.

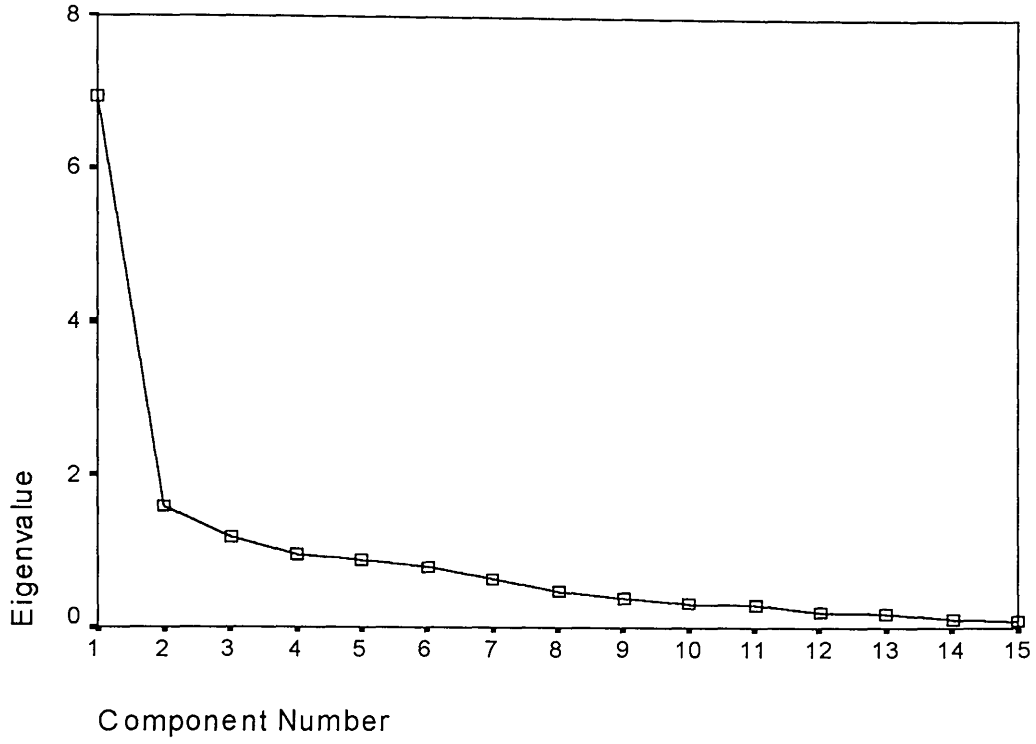


Figure 3.10: Scree plot to show the amount of variance accounted for by Component 5 'Rebellious decisions'

Table 3.15: Loadings for individual 'Rebellious decisions' items

Items		Loading
13.	I feel guilty about the way I manage my diabetes	.77
23.	I think my control of diabetes is quite good (R)	.44
40.	I feel guilty if I eat foods which I know are bad for me	.60
44.	I tend to eat what I feel like at the time rather than what is good for my diabetes	.85
46.	Sometimes I think I am a "bad" diabetic	.48
67.	As a diabetic person, I eat a diet which keeps me healthy (R)	-.72
78.	I eat a lot of food that I know is not recommended for people who have diabetes	.75
86.	Sometimes I can't be bothered to check my blood sugar level	.68
91.	I eat too many sweets/chocolates for a person with diabetes	.80
101.	Sometimes I skip injections	.47
108.	Sometimes I eat more sweets or chocolate than a person with diabetes should	.66
111.	I don't have the motivation to take care of my diabetes	.73
113.	I would describe myself as lazy when it comes to managing my diabetes	.81
144.	I think that I am eating properly for a person with diabetes (R)	-.87

(R) = Item should be reverse scored.

Close inspection of the items which loaded on this component suggested that high scores indicate a person's tendency to avoid unpleasant aspects of diabetes self-management by indulging in rebellious acts which are counterproductive for their diabetes-related well-being. The internal consistency of the 14 items that loaded on the component termed 'Rebellious decisions' was examined using Cronbach's α coefficient. The internal consistency of the items was acceptable, Cronbach's α was 0.75.

Discussion

In this chapter the procedures and analyses involved in the development and selection of items for use in the pilot version of the DIALS questionnaire have been described. The aims of the study were to (i) describe the selection of items for use in the pilot version of the DIALS, (ii) examine the coherence of items that were developed to measure the strategies, emotions and behaviours that were highlighted as being important in the analysis of the interviews presented in the previous chapter (Part III, Chapter 1), and (iii) determine which domains/subcategories, and items within each domain, provide meaningful measurements of the respondents' self-reported reactions to diabetes, and hence should be included in the pilot version of the DIALS.

In the present study the initial development and selection of items for use in the pilot version of the DIALS questionnaire has been described. The items that were generated were adapted and developed directly from patients' descriptions of their experiences and efforts to cope with Type 1 diabetes. One hundred and seventy items were entered into the initial item pool (see Appendix). These items were developed and organised to fit within the eight pre-defined subcategories/domains which emerged from the interview data (Part III, Chapter, 1). This particular approach has the advantage of taking into account specific aspects of coping which are perceived to be important to the patients themselves. In doing so it has been possible to capture unique aspects of coping with diabetes that may be overlooked or missed out completely in general measures of coping with illness.

Responses to the original items in the DIALS-170 (n = 57) were examined. The aim of the analysis was to establish the coherence of items *within* each domain and to identify a clear set of items that could be used in the pilot version of the DIALS. This process was necessary to reduce the initial item pool (170 items) to a smaller number of items. By identifying those items that shared covariance within each domain it has been possible to retain items with the most coherence within each domain, and to omit items that fit least well in these domains. Provisional components were extracted using principal components analyses. This exploratory process led to the eventual selection of a total of 64 individual items. The analysis suggests that these items had coherence within the following five domains: Information-seeking and adherence (10 items), Impact (20 items), Diabetes-related distress (10 items), Fear of complications (10 items), and Rebellious decisions (14 items).

One limitation of the present study lies in the exclusion of the items within some of the pre-specified domains. The process of selecting items on the basis of domain coherence inevitably led to the exclusion of some items, but also to the exclusion of three of the original domains. The decision to include items within a particular domain in the pilot version of the DIALS questionnaire was made on the basis of strict criteria specified prior to the analysis. The criteria included (i) rejecting items that had a mean of less than 2.0 or more than 4.0 on the 1-5 point Likert scale, (ii) rejecting items that had an item-total correlation of 0.30 or below, and (iii) a minimum of eight items were required to have moderate to high loadings (above 0.40) on an unrotated component in order to be selected for use in the pilot version of the DIALS. The items contained within three domains: Sources of support, Acceptance and Isolation/stigmatisation, failed to meet one or more of these criteria and were therefore excluded from the pilot questionnaire.

The omission of these domains means that potentially important areas that may be relevant to coping with Type 1 diabetes have been omitted from the DIALS questionnaire. However, in the present analyses the items that were developed to measure these domains did not produce a clear number of items that showed coherence within the respective domain. It may be the case that the items contained within the excluded domains are relevant to other domains which have been incorporated into the pilot version of the DIALS. These suggestions warrant further investigation. In addition, further research is needed to explore the domains that were excluded from the pilot questionnaire in more detail and to potentially develop new items that are capable of measuring these concepts.

Despite these limitations the present study has succeeded in developing and selecting specific items that are directly relevant to the patients' perspectives of issues that they perceive to be most important in coping with Type 1 diabetes. Furthermore, as discussed in the previous chapter (Part III, Chapter 1) the pre-specified domains/subcategories that resulted from the analysis of the interview data were hypothesised to be theoretically relevant to the major dimensions of coping commonly referred to in the health-related coping literature (Endler, Parker and Summerfeldt, 1998; Lazarus and Folkman, 1984). In the present analysis, items within domains that are assumed to be broadly relevant to each of the major coping dimensions: task, emotion, and avoidance, have been incorporated in the pilot version of the DIALS.

Following the results presented in this preliminary study, a larger study was considered necessary to extend the present findings, and to understand the possible interpretations and potential use of the DIALS as a tool in the assessment of adults with Type 1 diabetes. In Part III, Chapter 3 the pilot testing and subsequent partial validation of the DIALS questionnaire is described. The study presented in Part III, Chapter 3 was carried out to achieve the following objectives: (i) to explore the internal structure of the DIALS in a larger sample of adults with Type 1 diabetes, and to provide further evidence for the dimensionality of coping, (ii) to examine the reliability, stability, and partial validity of the DIALS, and (iii) to provide a model of the relationships between illness-related coping constructs and the dimensions of the DIALS.

PART III Coping with Diabetes: Assessment and Measurement

CHAPTER 3

Establishing the Structure, Reliability, and Partial Validity of the Diabetes Impact, Adjustment and Lifestyle Scales

Introduction

The Diabetes Impact, Adjustment and Lifestyle Scales (DIALS) were developed to measure more precisely how individuals cope with Type 1 diabetes and the impact that the treatment of diabetes has on aspects of a person's daily life. The purpose of this chapter is to (i) establish the underlying structure of the DIALS by identifying the number of dimensions contained within the test and their conceptual meaning, and (ii) to provide evidence for the scales reliability, partial validity and stability.

The goal of the study was to identify a set of constructs that were capable of measuring some important aspects of the impact of diabetes and the effects that the demands of diabetes self-management have on a person's daily life. In addition, the aim was to develop a measure that could be administered on multiple occasions, in order to examine changes in coping over the course of a person's adjustment to diabetes. Although it is acknowledged that the validation of any psychometric instrument is an ongoing process, the overall purpose of this chapter is to provide sufficient evidence to warrant recommendation of the DIALS use as a potential research tool in future investigations.

Ethical permission

Ethical permission for the study was obtained from the Lothian Research Ethical Committee of Lothian Health and approved by the chairman of the Medical and Oncology subcommittee. Management approval was obtained from the NHS Trust.

Research design and methodology

Patient characteristics

Five hundred patients with Type 1 diabetes were asked to take part in the study. Of these 182 people were approached directly, and invited to participate when they attended the diabetic outpatient clinic at the Royal Infirmary of Edinburgh for their routine check-up appointment. This first stage of the recruitment process yielded a total of 128 responses – a 70% response rate. The remaining 318 people were selected at random from the diabetic registration database held within the diabetic outpatient clinic. These individuals were sent an invitation letter, and the study questionnaire by post (pre-paid envelope provided). This second phase of the recruitment process yielded a much lower response rate. A total of 118 (37%) complete responses were obtained. The final sample consisted of 246 adults with Type 1 diabetes – overall this was a 49% recruitment rate. One hundred and eighteen (48%) respondents were men and 228 (52%) were women.

Each participant provided details of their social and educational background (Table 3.16). The median (range) age of the participants was 42 (17 - 77) years, and the median (range) duration of diabetes was 18 (0.7 – 53) years. Occupational details were classified according to Goldthorpe's (1987) scheme. Of the sample, 96 people (39%) were professionals, 57 (23.2%) were non-manual employees, 31 (12.6%) were manual workers, 13 (5.3%) were unemployed, 18 (7.3%) were in full-time higher education, and 8 (3.3%) people were retired.

Table 3.16: Characteristics of the sample

Patient Characteristics	N	%	Median (range)	Mean (SD)
Age (years)	246		42 (17 –77)	41.1 (11.5)
Duration (years)	223		18 (0.7 – 53)	19.3 (12.0)
Occupational details:				
Professionals	96	39.0		
Non-manual employees	57	23.2		
Manual employees	31	12.6		
Unemployed	13	5.3		
Full-time education	18	7.3		
Retired	8	3.3		
Marital status:				
Single	68	27.6		
Married/cohabiting	151	61.4		
Divorced/separated	24	9.8		
Widowed	1	0.4		
Body mass index (kg/m^2)	150		25.5 (18.7 – 48.6)	26.4 (4.2)
Males	80		25.8 (18.8 – 38.2)	26.4 (3.4)
Females	70		25.3 (18.7 – 48.6)	26.4 (5.0)
Glycated haemaglobin (HbA$_{1c}$)	186		8.5 (5.5 – 15.8)	8.7 (1.5)
Males	97		8.4 (5.5 – 11.2)	8.5 (1.1)
Females	89		8.7 (6.0 – 15.8)	8.9 (1.7)
Alcohol (units/week)	241		6.0 (0 – 70)	9.0 (9.8)
Smoking:				
Never smoked	115	46.7		
Ex-smoker	64	26.0		
Current smoker	63	25.6		
Admission at diagnosis:				
Yes	179	72.8		
No	67	27.2		
Comorbidity:				
Yes	121	49.2		
No	122	49.6		

Note: For the whole sample n = 246, for males n = 118, for females n = 128

The majority of the sample were married or cohabiting (n = 151, 61.4%), 68 (27.6%) people were single, 24 (9.8%) people were divorced or separated and 1 (0.4%) person was widowed. Information on tobacco and alcohol consumption was recorded. One hundred and fifteen (46.7%) participants reported never having smoked, 64 (26%) were ex smokers, and 63 (25.6%) people were current smokers. The mean (SD) number of units of alcohol consumed per week was 9.4 (9.8). A large proportion of the respondents were admitted to hospital at the time of diagnosis (n = 179, 72.8%) and the remaining 67 (27.2%) were treated as outpatients. The department policy is generally not to admit patients unless there is evidence of significant metabolic decompensation or ketoacidosis. One hundred and twenty one (49.2%) people reported having comorbid problems in addition to their diabetes.

Procedure

Patients were invited to participate either when they attended the diabetes clinic for their routine appointment or by post. All of the respondents completed the questionnaire at home in their own time. A stamped addressed envelope was provided. If a questionnaire was not returned, the individual was contacted by telephone and/or sent a second questionnaire. The patients were given a subject information sheet explaining the nature of the study and written informed consent was obtained if they agreed to participate. Once written consent was received a letter was sent to each respondent's General Practitioner informing them of their patient's participation in the study. Only patients over the age of 16 were included in the study. Demographic data and information on the participant's social and educational background was collected. This information was completed by the participant. Each respondent was required to complete a series of self-administered questionnaires. The time involved in completing the questionnaires was not expected to exceed one hour. All of the questionnaires have been administered to other adults who have Type 1 diabetes previously in the Edinburgh Prospective Diabetes Study (see Part II, Chapter 2), with the exception of the Diabetes Impact, Adjustment and Lifestyle Scales (DIALS). All of the measures used in the EPDS were found to be acceptable and stable across time. The DIALS was re-sent to each participant (by post) after a one-month interval so that reliability could be estimated. Relevant biochemical information (HbA_{1c} and Body Mass Index) was obtained from participants by referring to their medical notes. Permission for access to the patients notes was granted by the Lothian Research Ethical Committee.

Each respondent completed a patient information form and a battery of relevant psychosocial measures. The measures included the pilot version of the Diabetes Impact, Adjustment and Lifestyle Scales (DIALS), individual difference measures to assess personality traits and coping styles, and a series of diabetes-related outcome measures including diabetes knowledge, self-management activities, quality of life, and well-being.

Diabetes Impact, Adjustment and Lifestyle Scales

This DIALS was designed to measure individual differences in adjustment to type 1 diabetes and the impact which the disorder has on aspects of a person's daily life.

Patients' descriptions of their experiences of coping with diabetes were derived from a qualitative research study that consisted of one-to-one interviews with outpatients attending the diabetes outpatient clinic at the Royal Infirmary of Edinburgh (Part III, Chapter 1). Based on this study, items and content relating to the impact of diabetes, self-reported adjustment, and other lifestyle-related issues were identified. The resulting list consisted of 170 items. Responses to each item were based on a five point Likert scale ranging from 1 'strongly disagree' to 5 'strongly agree'. The initial pool of items was administered to a sample of adults with Type 1 diabetes (n = 57). The responses obtained from this study were used to reduce the initial pools of items (see Part III, Chapter 2). The pilot version of the Diabetes Impact, Adjustment and Lifestyle Scales (DIALS) used in the present study contained 64 items relevant to five domains: Information-seeking (10 items), Impact (20 items), Diabetes-related distress (10 items), Fear of complications (10 items), and Rebellious decisions (14 items).

Individual difference measures

Eysenck's Personality Questionnaire-Revised, Short Form (EPQ-R; Eysenck and Eysenck, 1975; Eysenck, Eysenck and Barrett, 1985)

The EPQ-R short form consists of 48 items and measures three personality dimensions; Extraversion (E) (sociability and optimism), Neuroticism (N) (negative emotions, anxiety and moodiness) and Psychoticism (P) (solitary, hostile and lacking empathy). In addition there is a Lie scale (L), which detects socially desirable responding patterns. Participants answer yes or no to each question. The scores are then summed for each dimension.

Coping with Health Injuries and Problems (CHIP; Endler, Parker and Summerfeldt, 1998; Endler, 2000)

The CHIP was designed to measure the different methods used by individuals to cope with health problems. The scale contains 32 items which measure four dimensions of coping: Palliative (P) (self-help responses used to alleviate unpleasantness), Instrumental (I) (task-orientated responses such as obtaining information and following advice), Distraction (D) (thinking about other activities) and Negative-Emotion (NE) (preoccupation with emotional consequences). The statements are rated by the participants on a 1 – 5 scale, 1 indicates that the statement applies 'not at all', 3 indicates that the statement applies 'moderately' and, 5 indicates that the statement applies 'very much'. Each subscale contains eight items which are summed to give individual scores for each dimension.

Diabetes-related outcome measures

Diabetes Knowledge Questionnaire (DKNQ; Gold et al. 1995)

The DKNQ was developed specifically for use in the Edinburgh Prospective Diabetes Study (EPDS). It measures patients' knowledge in four areas of diabetes i) diet (6 items), ii) insulin therapy (7 items), iii) general knowledge (7 items), and iv) dealing with intercurrent illness (4 items). The questions are presented in a multiple-choice format with a total of 24 items. A mark is scored for each correct response and a total score derived for analyses.

Summary of Self-Care Activities Questionnaire (SSCAQ; Toobert and Glasgow, 1994)

The SSCAQ is a self-report measure of the frequency with which individuals have completed different regimen activities over the preceding seven days. The SSCAQ was constructed to assess absolute levels of self-care behaviour as well as an individual's perceived adherence to their individual prescriptions. The scale consists of twelve items, the first five items relate to levels of diet self-care and adherence. The first two items are referred to as diet amount items (adherence). The following three items are referred to as diet type items (absolute). Items 6 to 8 assess how often and the amount of time individuals spent exercising in the past week (absolute activity levels) and how much the individual adhered to their prescribed exercise regimen (adherence). The final two sections of the questionnaire relate to glucose testing and medication taking to control diabetes. Scores for each regimen behaviour are calculated by giving items with differing scales equal weighting, the scores are then transformed into percentage scores for analysis.

Diabetes Quality of Life (DQOL; The Diabetes Control and Complications Research Group, 1988)

The DQOL was developed for use in the Diabetes Control and Complications Trial (DCCT, 1988). It measures the patient's personal experience of diabetes care and treatment using Likert scales. The scale addresses four areas: Satisfaction with Treatment (15 items), Impact of Treatment (20 items), Worry about the Future Effects of Diabetes and Social Issues (11 items). A formula is used to convert raw scores to a 100-point scale. In addition, an individual item of general (health-related) well-being is included where participants rate their health on a four point scale: 1 'excellent, 2 'good', 3 'fair' or 4 'poor'.

The Well-being Questionnaire (WHO; Bradley, 1994)

The Well-being Questionnaire contains twenty-two items which address four subscales labeled as Depression (6), Anxiety (6), Positive well-being (6) and Energy (4). Each item is scored on a 0 to 3 Likert scale ranging from 0 which indicates that the respondent felt that the item applied to them "not at all" over the past few weeks and 3 indicating that it applied "all the time". Complete ratings for each subscale are summed after reverse scoring where necessary. A high score on each subscale indicates more of the mood described. A general well-being total score can be obtained by summing the scores from each subscale after reversing the scores of the Anxiety and Depression subscales.

Physiological and biochemical measurement

These measures include Body Mass Index (kg/m^2) and glycated haemoglobin (HbA_{1c}), a measure of long term glycaemic control. The assay for HbA_{1c} used high performance liquid chromatography based on ion-exchange reverse-phase partition method and the local non-diabetic range is 5.0 - 6.5%.

Statistical analyses

The data were analysed using the Statistical Package for the Social Sciences (SPSS) version 10.0 for Windows. Structural equation modelling was conducted using the EQS Structural Modelling Program (Bentler, 1995).

Establishing the internal structure of the DIALS. Means, Standard deviations and frequency distributions were computed and examined for each of the 64 items in the pilot version of the DIALS. The individual responses to each item were then entered into a principal components analysis. With an n of 229 (listwise) the study is sufficient to allow principal components analysis of the DIALS questionnaire with a ratio of 3.6 patients to each item (Kline, 1993). Three major sequential steps were undertaken in this analysis.

Step 1 involved identifying the number of meaningful components to retain based on the Scree test (Cattell, 1966) and the percentage of variance accounted for by a given component. Using the Scree test, eigenvalues (i.e. the amount of variance that is accounted for by a given component) associated with each component were plotted. The Scree plot was then examined to identify a break between components with relatively large and those with smaller eigenvalues. Components that appeared before the break were assumed to be meaningful and were retained for rotation. Components that appeared on the horizontal line after the break were thought to account for only trivial amounts of variance and were not retained.

Step 2 involved conducting an oblique rotation on the retained components. An oblique rotation was applied because it was hypothesised that the components would be correlated with each other. Pattern matrix loadings above .35 on more than one component, or items that did not load above .35 on any one factor were eliminated (Endler, Parker and Summerfeldt, 1998). The principal components analytic procedure was repeated using an oblique rotation until all of the items loaded uniquely on one component. In order to be accepted each rotated component was required to contain at least five items with pattern matrix loadings above .35.

Step 3 involved interpreting the rotated solution by identifying which items load on each retained component, and the conceptual meaning of items that load on the same component. Items with the highest pattern matrix loadings were used to interpret the results.

Reliability of the DIALS. Cronbach's α reliability coefficient was computed for each component to measure internal consistency. The mean inter-item correlation for each component was also calculated to further assess reliability. The test-retest reliability (stability) of each component was assessed over a one month period.

Criterion-related validity of the DIALS. The effects of socio-demographic variables on the DIALS scores were examined using independent samples t-tests and analysis of variance. The Scheffe test, a conservative post hoc test was used to identify between groups differences. Pearson's product moment correlation coefficients were used to examine the relationships between the DIALS scores, and psychosocial variables and diabetes-related outcome variables.

Structural equation modelling. The technique of structural equation modeling (SEM) was employed to provide information about the possible causal relationships between psychological variables (personality and coping constructs) and the DIALS. SEM is a sophisticated statistical technique which combines the techniques of multiple linear regression, factor analysis, and path analysis (Musil, Jones and Warner, 1998). This allows the experimenter to take a hypothesis testing approach to providing a conceptual model based on existing theoretical and empirical research. Once a hypothesised model has been posed it can be tested using SEM to determine the extent to which it is consistent with the data. In other words it is tested for its 'goodness of fit'. SEM has an added advantage over other former methods of multivariate analysis because it allows the investigator to incorporate both observed and unobserved (latent) variables in the analysis (Musil et al., 1998) and to explore the determinants of multiple outcomes (dependent variables) in the same analyses. The term structural equation modelling conveys two aspects of the procedure. Firstly, the causal processes are represented by a series of structural equations (i.e. regression equations) which are used to describe the associations among the measured variables (Deary, Clyde and Frier, 1997; Bentler, 1995; Musil et al. 1998). Secondly, the structural equations can then be modelled pictorially to enable a clearer conceptualisation of the theory under investigation. Following the stipulation of a SEM model, the EQS programme provides a number of assessments of the adequacy of the model which include the following. The overall fit of the model is determined by the Bentler Bonnet normed and non-normed fit indices and the comparative fit index. These tests take values between 0 and 1 values of .90 and preferably higher are evidence of an acceptable fit of the hypothesised model to the sample data (Bentler, 1995; Musil et al. 1998). The average of the standardised off-diagonal residuals is used to indicate the covariance which is unexplained in the model (Deary et al., 1997). A chi square of less than twice the degrees of freedom in the model is also used as an indicator of acceptable fit.

Results

Means, standard deviations and frequency distributions were calculated for each of the 64 items. All of the items were considered to have satisfactory response distributions and were retained for further analysis.

Principal Components Analysis of the DIALS

The responses to the 64 items contained in the pilot version DIALS were analysed using principal components analysis. The Scree plot in Figure 3.11 shows an abrupt break before the fourth component, then a smaller break after the fifth component suggesting that the first five factors were meaningful. A five-component solution was chosen based on the percentage of variance accounted for by each component and the Scree plot. The five extracted components accounted for 52.2% of the cumulative variance.

The five extracted components were rotated using oblique rotation. Items that loaded above .35 or more on more than one component and items that did not load above .35 on any component were removed. The oblique rotation was repeated until the remaining 51 items loaded uniquely above .35 on one component. By examining the pattern loadings from the oblique rotation of each of the five components the items that loaded uniquely on each component were identified.

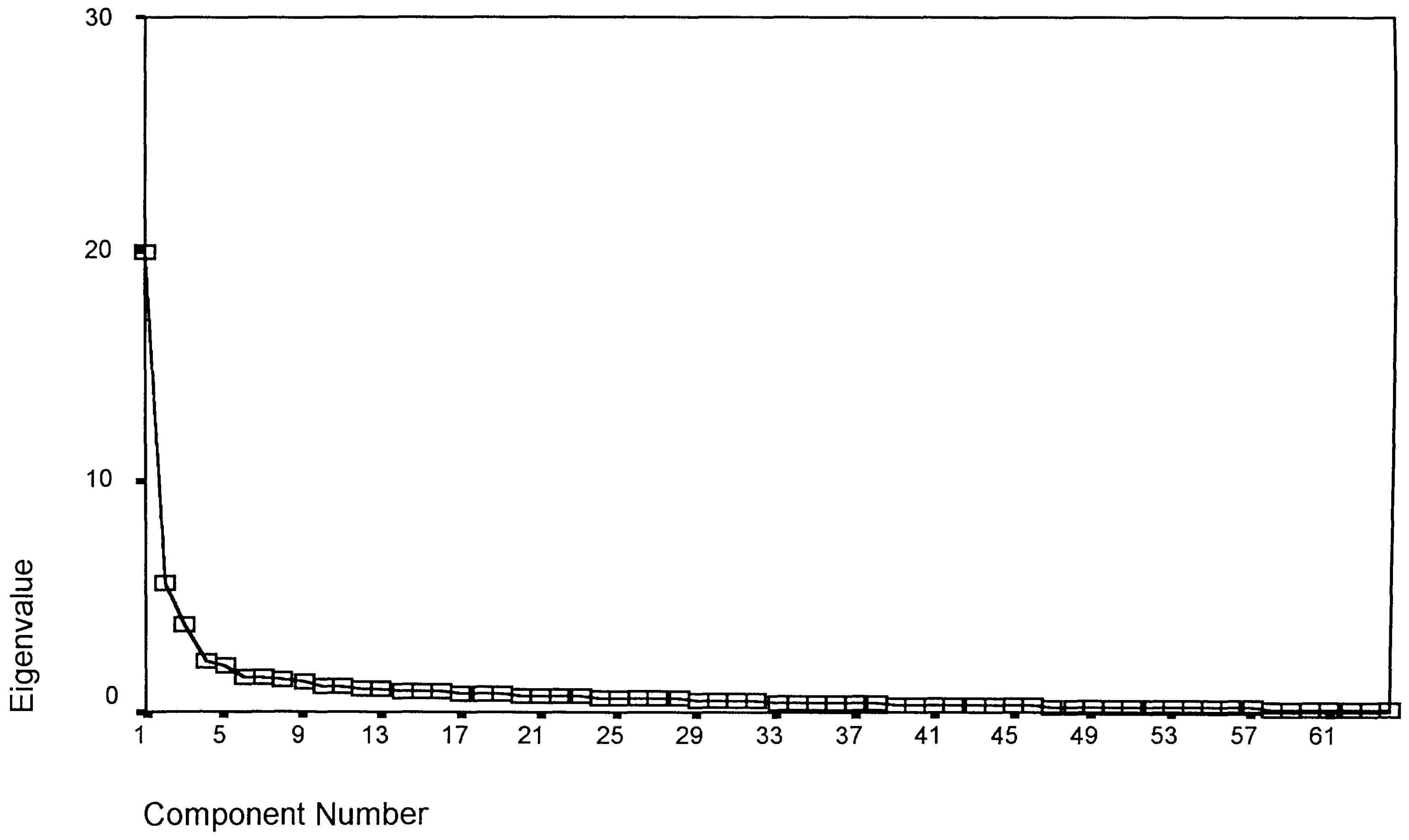


Figure 3.11: Scree plot to show the amount of variance accounted for by each component in the 64 items of the DIALS (n =229).

At this stage one item (i.e. Sometimes I eat more sweets or chocolate than a person with diabetes should) was eliminated from the scale because it was considered to be too similar to another item that loaded on that particular component (i.e. I eat too many sweets/chocolate for a person with diabetes). An oblique rotation of the 50 remaining items was conducted.

Table 3.17 shows the pattern loadings, eigenvalues and percentage of variance accounted for by the five components. The first rotated component accounted for 10.8% of the variance, the second rotated component accounted for 9.1% of the variance, the third rotated component accounted for an additional 4.3% of the variance, and the fourth and fifth rotated components accounted for 6.7% and 9.5% of the variance respectively. The pattern loadings in this matrix show the regression weights associated with each factor in prediction of the item score. These values are essentially standardised regression weights similar to those obtained in multiple regression analyses (Kline, 1998). This matrix was used to determine which groups of items were measuring a given component, and later to interpret the meaning of each component. The five extracted components accounted for 54.8% of the cumulative variance.

Component 1 (14 items; 10.8% of the variance) was labelled 'Impact'. The highest loading items on component 1 seem to assess a person's tendency to feel that they are restricted and controlled by their diabetes.

I feel restricted in what I can do because of my diabetes (.78)

My lifestyle is too controlled because I have diabetes (.74)

Diabetes interferes with me eating when I want to (.70)

People who obtain high scores on this dimension perceive diabetes as involving sacrifice (i.e. item14), and as interfering with aspects of their lifestyle such as eating out, taking exercising and social activities (i.e. items 34, 36 and 38). Low (negative) scores indicate that the person has accommodated diabetes into their lifestyle with minimal disruption. This is reflected by positive perceptions such as 'I lead a normal life the same as any other person who does not have diabetes' and 'Diabetes isn't a problem for me'.

Component 2 (13 items; 9.1% of the variance) was labelled 'Adherence'. High loading items on this component include:

I would describe myself as lazy when it comes to managing my diabetes (-.77)

I think I am eating properly for a person with diabetes (.70)

I eat too many sweets/chocolates for a person with diabetes (-.73)

The person who obtains high positive scores on this dimension follows the advice provided by health professionals (i.e. item 31) and feels that they are adhering to the demands of their diabetes self-management routine (i.e. item 10, 41 and 62). Low scores on this dimension are interpreted as indicating some kind of resistance to the treatment for diabetes, and may be associated with feelings of guilt (i.e. item 24) and the perception of oneself as a "bad" diabetic (i.e. item 22). This particular component appears similar to the original domain 'Rebellious decisions' (Part III, Chapters 1 and 2), but has been renamed due to the positive loadings of the items which measure a person's tendency to follow advice and adhere to their self-management activities (e.g. regulation of diet).

Component 3 (8 items; 4.3% of the variance) was labelled 'Information-seeking'. Examples of high loading items include:

'I am eager to read about diabetes'	(.78)
'I am interested in gathering information about my diabetes	(.75)

Positive scores on this component would indicate that the person is interested in finding out about diabetes, and that they feel more equipped to manage their diabetes by making good use of the information (i.e. items 25, 64) and support (i.e. item 3) available to them.

Component 4 (6 items; 6.7% of the variance) was labelled 'Fear of complications'. Items that had high loadings on this component include:

'I often worry that my health will deteriorate as a result of my diabetes'	(-.73)
'I worry about getting complications of my diabetes'	(-.82)

A person who obtains high scores on this dimension has a high tendency to worry about the future especially with regard to their future health status, and the threat of potential complications of diabetes.

Component 5 (9 items; 9.5% of the variance) was labelled 'Diabetes-related distress'. Items that loaded highly on this component included:

'I have crying spells or feel like it because of my diabetes'	(-.82)

'I get upset easily and feel panicky because of my diabetes' (-.70)

High scores on this factor indicate that the individual has a tendency to experience greater levels of diabetes-related distress. This may include a broad range of negative-emotions including anger, depression, and poor concentration (i.e. items 20, 27 and 39). Low score on this dimension indicates a more positive view, for example, item 45: 'In general I try not to let diabetes worry me'. This item reflects a more optimistic approach towards diabetes.

Table 3.17: Results of principal components analysis of the DIALS: rotated pattern matrix (5 rotated components)

Items	Components 1	2	3	4	5
Impact					
1 I lead a normal life the same as any other person who does not have diabetes	**-.55**	-.12	.10	.12	.22
6 My diabetes means others have to wait for me at meal times	**.48**	-.06	.24	.21	-.29
14 The proper control of diabetes involves a lot of sacrifice	**.51**	-.20	-.03	-.06	-.09
15 I feel frustrated that I can't lead a normal life because of my diabetes	**.61**	-.11	-.05	-.15	-.15
18 Diabetes isn't a problem for me	**-.44**	.02	.09	.20	.26
33 My lifestyle is too controlled because I have diabetes	**.74**	.06	-.10	-.05	-.03
34 Diabetes interferes with me taking exercise when I want to	**.65**	-.04	.10	.09	.04
36 Sticking to my recommended diet makes eating out difficult	**.61**	-.21	.02	.10	-.10
37 Diabetes interferes with me eating when I want to	**.70**	-.04	.10	-.12	.02
38 Diabetes interferes with my social life	**.67**	-.03	-.13	-.07	-.22
52 I feel restricted in what I can do because of my diabetes	**.78**	.05	-.05	-.05	-.09
54 Controlling my diabetes well imposes restrictions on my whole lifestyle	**.61**	-.04	-.06	-.18	-.09
59 Diabetes doesn't really bother me at all on a day to day basis	**-.45**	.04	.13	.14	.25
61 When I am away from home (e.g. on holiday) I find it more difficult to manage my diabetes	**.60**	-.01	-.02	-.01	.13
Adherence					
9 I would describe myself as lazy when it comes to managing my diabetes	.06	**-.77**	-.06	-.02	.07
10 As a diabetic person, I eat a diet which keeps me healthy	-.08	**.70**	.10	-.05	.07
13 I eat too many sweets/chocolate for a person with diabetes	.03	**-.73**	.13	-.02	.08
22 Sometimes I think I am a "bad" diabetic	-.04	**-.69**	.09	-.19	-.17
24 I feel guilty about the way I manage my diabetes	.06	**-.71**	.11	-.21	-.10
31 I follow the advice about diabetes provided by health professionals	-.09	**.60**	.15	-.19	.02
32 I don't have the motivation to take care of my diabetes	.17	**-.70**	-.02	.17	-.13
40 Sometimes I can't be bothered to check my blood sugar level	-.09	**-.56**	-.08	-.11	-.08
41 I think my control of diabetes is quite good	.07	**.65**	-.08	.11	.08
42 I eat a lot of food that I know is not recommended for people who have diabetes	.06	**-.74**	.05	.10	.06
55 I use the information I have about diabetes to help me to manage it	.12	**.48**	.29	-.03	.09
62 I think I am eating properly for a person with diabetes	-.06	**.70**	-.03	.10	.08
63 I tend to eat what I feel like at the time rather than what is good for my diabetes	-.06	**-.76**	-.08	.05	.01
Information seeking					
3 Chatting to other people who have diabetes is useful	-.26	-.06	**.59**	-.12	-.18
11 I try to share my experiences of diabetes with others who know about it	-.08	.06	**.51**	-.03	-.17
16 I try to keep up with developments in insulin therapy	.05	.31	**.48**	.16	-.24
23 I am eager to read about diabetes	.08	.04	**.78**	-.06	.17
25 The more I read the more I know what I have to do to combat problems associated with my diabetes	.10	-.05	**.64**	-.18	.22

46	I am interested in gathering information about my diabetes	-.03	-.04	**.75**	-.07	.16
51	I read magazines and articles about diabetes	-.01	.04	**.75**	.02	.09
64	I feel that the more I know about diabetes the less it will bother me	-.10	-.03	**.52**	.25	.05
Fear of complications						
7	I worry about my health because of my diabetes	.21	-.07	-.03	**-.61**	-.11
26	I worry about having high blood sugar	.06	.03	.11	**-.62**	-.02
35	I feel guilty if I eat foods which I know are bad for me	.12	-.24	.26	**-.42**	.03
43	I often worry that my health will deteriorate as a result of my diabetes	.10	-.03	-.04	**-.73**	-.17
44	I have thoughts or worries about what will happen later in life because of diabetes	.08	.08	-.02	**-.80**	-.10
49	I worry about getting complications of my diabetes	.04	.03	-.01	**-.82**	-.06
Diabetes-related distress						
17	I have crying spells or feel like it because of my diabetes	-.14	-.08	-.02	-.04	**-.82**
19	I get upset easily and feel panicky because of diabetes	.10	.09	-.06	-.15	**-.70**
20	It is hard to concentrate because of my diabetes	.18	-.08	.02	.05	**-.66**
21	I feel like I am falling apart because of my diabetes	.23	-.15	-.03	-.03	**-.64**
27	I feel angry that I have diabetes	.25	-.05	-.12	-.14	**-.51**
30	I find it difficult to get a good nights rest because of my diabetes	.14	-.07	.06	-.04	**-.60**
39	I sometimes feel depressed about my diabetes	.23	-.07	-.06	-.23	**-.51**
45	In general I try not to let my diabetes worry me	-.02	.12	.05	.24	**.53**
58	I often feel sorry for myself because I have diabetes	.19	-.10	-.04	-.10	**-.61**
Eigenvalues		15.3	5.0	3.4	2.0	1.7
% of variance		10.8	9.1	4.3	6.7	9.5

40.4 % of the variance (n = 229)

Note: Figures represent standardised regression coefficients. Pattern loadings of above .35 are shown in bold.

Reliability of the DIALS

Three types of reliability information are presented here: internal consistency reliability, mean inter-item correlations, and test retest reliability (stability). Table 3.18 shows the results of the various measures of reliability for the whole sample and separated by gender. Overall, the reliability of the scales was high.

Internal consistency: Internal reliability refers to the degree to which all items on a particular scale measure the same construct (Kline, 1993). The internal consistency of a particular scale is a function of both the qualities of the scale's items as well as the respondent's answers (Endler, 2000). Cronbach's α coefficients were highly satisfactory for all of the components of the DIALS for the whole sample: 0.92 for component 1 'Impact', 0.91 for component 2 'Adherence', 0.81 for component 3 'Information-seeking', 0.85 for component 4 'Fear of complications, and 0.91 for component 5 'Diabetes-related distress' (Table 3.18).

Table 3.18: Reliability (internal consistency, mean inter-item correlations, and test retest reliability across a 1 month interval) of the DIALS for the whole sample and separated by gender

	Internal consistency			Mean inter-item corr.			Test retest reliability		
DIALS	Total	Male	Female	Total	Male	Female	Total	Male	Female
Impact	.92	.91	.93	.46	.43	.49	.85	.84	.86
Adherence	.91	.89	.92	.46	.42	.49	.89	.90	.88
Information-seeking	.81	.83	.77	.35	.38	.30	.72	.76	.71
Fear of complications	.85	.84	.86	.49	.46	.52	.80	.77	.84
Diabetes-related distress	.91	.91	.92	.55	.53	.58	.90	.89	.91
N	241	114	125	241	114	125	116	62	54

Mean inter-item correlations: The mean inter-item correlation co-efficient provides an indication of the degree to which a particular scale is consistently measuring the same construct. The higher the inter-item correlation the more likely it is that the scale is unidimensional (Endler, 2000). The magnitude of the mean inter-item correlations for the whole sample and separated by gender, provide additional support for the internal stability of the DIALS (Table 3.18). For the whole sample the mean inter-item correlations were as follows: 0.46 for component 1 'Impact', 0.46 for component 2 'Adherence', 0.35 for component 3 'Information-seeking', 0.49 for component 4 'Fear of complications, and 0.55 for component 5 'Diabetes-related distress.

Test retest reliability: The test-retest reliability assesses the temporal stability of the responses to the items on each dimension. In this study the participants were administered the DIALS twice, at baseline and then approximately one month later. The test retest reliabilities for the sample ranged from .72 to .90. In general the test retest reliabilities were excellent (Table 3.18), indicating that the individual scales have good within subjects stability over a one month interval.

Validity of the DIALS

Following the development of a test it is important to establish the scale's validity. A test is said to be valid if it measures what it claims to measure. Unlike reliability, which can be measured using a single coefficient, there is no way of being certain that a test is valid because perfect measurement of a construct can never be achieved (Kline, 1998). The ultimate validity of a particular test therefore, rests on the accumulation of evidence from a number of studies using different methodologies. The information presented in this section will focus on establishing support for the criterion-related validity of the DIALS.

Means, standard deviations, minimum and maximum scores, and the range of available scores for each subscale (and for men and women separately) are displayed in Table 3.19.

Table 3.19: Descriptive statistics of the DIALS for the total sample (and separated by gender).

DIAL Scales	Number of items	Mean	SD	Min found	Max found	Range
Impact	14					14 - 70
Total		35.1	11.0	14	69	
Male		36.5	10.7	17	69	
Female		33.9	11.2	14	46	
Adherence	13					13 - 65
Total		44.5	10.0	15	64	
Male		44.5	9.1	16	64	
Female		44.5	10.7	15	63	
Information-seeking	8					8 - 40
Total		27.0	4.7	10	38	
Male		25.9	4.9	15	38	
Female		28.0	4.4	10	38	
Fear of complications	6					6 - 30
Total		21.0	4.8	7	30	
Male		20.5	4.6	8	30	
Female		21.5	4.8	7	30	
Diabetes-related distress	9					9 - 45
Total		19.5	7.6	9	43	
Male		19.3	7.5	9	41	
Female		19.6	7.7	9	43	

Note: For total n = 230, for males n = 110, for females n = 120

Intercorrelations of the DIALS

The intercorrelations of the individual DIALS scales are presented in Table 3.20. As expected, the DIALS Fear of complications, Diabetes-related distress and Impact subscales were moderately correlated (r's between .56 and .74, all $p < 0.01$) indicating some substantial covariance between the measures. There were inverse associations between the DIALS Adherence, and the DIALS Impact, Diabetes-related distress, and Fear of complications scales (r's between .45 and .57, all $p < 0.01$). The DIALS Information-seeking scale was not significantly correlated with the any of the other four subscales. Overall, the magnitude of the correlations suggests that the DIALS subscales are measuring related but not identical constructs.

Table 3.20: Intercorrelations among the DIALS

	Impact	Adherence	Information seeking	Fear of complications
Impact				
Adherence	**-.482****			
Information-seeking	-.101	.124		
Fear of complications	**.563****	**-.446****	.171	
Diabetes-related distress	**.744****	**-.570****	-.017	**.564****

Note: ** $p < 0.01$ (n = 116)

Socio-demographic characteristics and the DIALS

The socio-demographic characteristics of the sample are displayed in Table 3.16. Females obtained higher scores on the DIALS Information-seeking scale than males ($t(228) = -3.29$, $p < 0.001$). There were no other significant gender differences in scores on the DIALS. Occupational social class had a significant effect on the DIALS Impact

(F (188, 4) = 5.01, $p < 0.01$), Adherence (F (4, 188) = 5.71, $p < 0.01$) and Diabetes-related distress scores (F 188, 4) = 5.72, $p < 0.01$). Post hoc (Scheffe test) analysis revealed that people who were unemployed had significantly higher DIALS Impact scores than people who were classified as professionals. Those respondents that had non-manual occupations had higher DIALS Adherence scores than people who had manual occupations and people who were unemployed. People who were unemployed obtained significantly greater DIALS Diabetes-related distress scores than people who had professional occupations and non-manual occupations. Occupational social class had no significant effect on DIALS Information seeking and DIALS Fear of complications scores. People who were single reported greater DIALS Impact (F (225, 2) = 3.71, $p < 0.05$) and less DIALS Adherence than people who were married or cohabiting (F (225, 2) = 6.43, $p < 0.01$).

The DIALS Adherence scale was positively correlated with increasing age ($r = .26$, $p < 0.01$) and duration of diabetes ($r = .20$, $p < 0.01$). Body mass index was inversely correlated with the DIALS Impact scale ($r = -.18$, $p < 0.05$). The magnitude of these associations was small. Current smokers had lower DIALS Adherence scores (F (2, 223) = 13.0, $p < 0.001$) and greater DIALS Impact scores (F (2, 223) = 4.86, $p < 0.01$) than participants who had never smoked. Current smokers and ex-smokers had higher DIALS Diabetes-related distress scores than people who had never smoked (F (2, 223) = 10.46, $p < 0.001$). There were no other significant relationships between the DIALS and socio-demographic factors.

DIALS and personality

In this section the relationships between the DIALS and basic personality traits assessed by the Eysenck Personality Questionnaire – Revised short form (EPQ-R; Eysenck and Eysenck, 1975), specifically the Neuroticism, Extraversion and Psychoticism scales, will be examined. In previous research the Neuroticism scale has been defined as 'a broad dimension of individual differences in the tendency to experience negative or distressing emotions and to possess associated behavioural and cognitive traits' (Costa and McCrae, 1987). Research on the relationships between personality traits and coping in people with diabetes has shown that people who score highly on the personality trait neuroticism are more likely to be pre-occupied with the emotional consequences of their illness, in contrast people who reported high extraversion were found to report more instrumental or problem-focussed coping and more distraction coping (Strickland, Deary, Frier and Gold, 1998). In the present study it was predicted that the Neuroticism scale would correlate with the DIALS Diabetes-related distress, Fear of complications and Impact scales. A negative association was predicted between the Psychoticism scale and the DIALS Adherence scale because part of the Psychoticism construct involves a tendency to disregard rules and social norms.

Table 3.21 presents the correlations between the DIALS and the EPQ-R. As expected the EPQ-R Neuroticism scale was moderately correlated with the DIALS Impact, Fear of complications and Diabetes-related distress scales (r's between .38 and .56, $p < 0.01$).

The EPQ-R Neuroticism scale was negatively correlated with the DIALS Adherence and Information-seeking scales (r = -.36 and -.14, respectively, p < 0.01).

Table 3.21: Correlations between the DIALS and Eysenck's Personality Questionnaire – revised short form

	EPQ-R Extraversion	 Neuroticism	 Psychoticism
DIALS:			
Impact	**-.212****	**.395****	**.289****
Adherence	.073	**-.364****	**-.293****
Information seeking	**.185****	**-.137****	-.092
Fear of complications	-.086	**.382****	-.003
Diabetes-related distress	-.075	**.561****	**.158***

Note: * p < 0.05, ** p < 0.01 (n = 229)

The EPQ-R Extraversion scale was positively correlated with the DIALS Information seeking scale (r = .18, p < 0.01), and negatively correlated with the DIALS Impact scale (r = -.21, p < 0.01). The EPQ-R Psychoticism scale was found to be negatively associated with the DIALS Adherence scale (r = -.29, p < 0.01) and positively correlated with the DIALS Impact and Diabetes-related distress scales (r = .29, p < 0.01 and r = .16, p < 0.05, respectively).

DIALS and illness-related coping

The relationships between the DIALS and illness-related coping ability assessed by the Coping with Health Injuries and Problems scale (CHIP; Endler, Parker and Summerfeldt, 1998) were examined. Previous research has established support for the construct validity of the CHIP in adults with both chronic (e.g. diabetes, arthritis and cancer) and acute illnesses (e.g. fractures, respiratory infections) by examining the relationships between basic coping styles assessed by the Coping Inventory for Stressful Situations (CISS; Endler and Parker, 1990a, 1994) and illness-related coping assessed by the CHIP (Endler, Parker and Summerfeldt, 1998). The preliminary findings reported by Endler, et al. (1998) suggested that basic coping styles such as task-oriented and emotion-oriented coping were good indicators of the type of illness-related coping strategy used in a stressful situation. The results are summarised below.

The CHIP contains four dimensions. The CHIP Instrumental scale was designed to assess task-oriented approaches to a health problem (e.g. actively seeking information and following medical advice) and was found to have a positive association with the CISS Task-oriented coping style. The CHIP Palliative scale was developed to assess a person's attempts to alleviate the unpleasantness of their health problem (e.g. getting plenty of rest, conserving energy). This scale correlated with the CISS Avoidance coping scale. The CHIP Distraction scale was developed to assess a person's tendency to focus on more pleasant experiences (e.g. engaging in other unrelated activities, being with friends). This dimension was also found to have moderate correlations with the CISS Avoidance scale. The CHIP Negative-emotion scale measures a person's tendency to become preoccupied with the emotional consequences of their health problem (e.g. rumination about the future, frustration and helplessness). This dimension was found to correlate with the CISS Emotion-oriented coping style. Based on the findings of Endler et al. (1998) it was predicted that (i) the DIALS Information-seeking and Adherence scales would be positively correlated with the CHIP Instrumental coping scale, and (ii) the DIALS Impact, Fear of complications and Diabetes-related distress scales would be correlated with the CHIP Negative-emotion scale.

Table 3.22: Correlations between the DIALS and the Coping with Health Injuries and Problems scales

	CHIP			
	Palliative	Instrumental	Distraction	Negative-emotion
DIALS:				
Impact	.124	**-.263****	**-.160***	**.446****
Adherence	**-.148***	**.447****	**.132***	**-.268****
Information seeking	.051	**.326****	**.338****	**-.138***
Fear of complications	.066	.003	.052	**.508****
Diabetes-related distress	.102	**-.269****	.017	**.560****

Note: * $p < 0.05$, ** $p < 0.01$ ($n = 224$)

The relationships between the DIALS and the CHIP are displayed in Table 3.22. Consistent with expectations the DIALS Adherence and Information seeking scales were positively correlated with the CHIP Instrumental coping scale ($r = .45$ and .33, respectively, $p < 0.01$). The DIALS Impact and Diabetes-related distress scales were negatively correlated with the CHIP Instrumental coping scale ($r = -.26$ and -.27, respectively, $p < 0.01$). Also consistent with predictions the DIALS Impact, Fear of complications and Diabetes-related distress scales had moderate positive associations with the CHIP Negative-emotion coping scale (r's between .45 and .56, $p < 0.01$). The DIALS Adherence and Information seeking scales were negatively correlated with the CHIP Negative-emotion coping scale ($r = -.27$, $p < 0.01$ and $r = -.14$, $p < 0.05$, respectively). Other associations were also present: the DIALS Information-seeking and

Adherence scales were positively correlated with the CHIP Distraction scale ($r = .13$, $p < 0.05$ and $r = .34$, $p < 0.01$, respectively), and the DIALS Impact scale had a small but significant negative correlation with the CHIP Distraction scale ($r = -.16$, $p < 0.05$). The DIALS Adherence scale was inversely correlated with the CHIP Palliative coping scale ($r = -.16$, $p < 0.05$).

DIALS and diabetes-related outcomes

The criterion-related validity of the DIALS was assessed by identifying the relationships between the DIALS and both subjective and objective indicators of diabetes-related outcomes including (i) glycaemic control, (ii) diabetes knowledge, (iii) adherence to self-care activities, (iv) diabetes quality of life, and (v) well-being. In the following section the relationships between the DIALS and each of these outcomes will be addressed in turn.

The correlations between the DIALS and diabetes-related outcomes are displayed in Table 3.23.

Glycaemic control.

In this study it was predicted that there would be an inverse relationship between the DIALS Adherence scale and HbA_{1c}; people who obtained higher scores on the DIALS Adherence scale were expected to have better glycaemic control. It was also predicted that people who obtained high scores on the DIALS Diabetes-related distress scale would have poorer glycaemic control. The correlations between the DIALS and HbA_{1c}

are displayed in Table 3.23. As expected there was a significant inverse correlation between the DIALS Adherence scale and HbA_{1c} ($r = -.36$, $p < 0.01$) and a positive correlation between the DIALS Diabetes-related distress scale and HbA_{1c} ($r = .20$, $p < 0.01$). In addition, the DIALS Fear of complications scale was significantly correlated with HbA_{1c} ($r = .16$, $p < 0.05$). These findings suggest that people who follow a strict self-management routine are likely to have better glycaemic control. In contrast people who report more diabetes-related distress and greater fear of complications are more likely to have poor glycaemic control. However, despite these findings, the cross-sectional nature of this study makes it impossible to determine the causal direction of these associations. It may be that individuals who have know they good glycaemic control then report better adherence or vice versa, and individuals who have poorer glycaemic control report more diabetes-related distress.

Diabetes knowledge.

The Diabetes Knowledge Questionnaire (DKNQ) used in the present study was developed specifically for the Edinburgh Prospective Diabetes Study (see Part II). The findings of the EPDS suggest that the DKNQ is negatively correlated with the CHIP Negative-emotion coping scale and the EPQ-R Neuroticism scale, and positively correlated with EPQ-R Psychoticism. Other studies of the relationships between the psychosocial variables and diabetes knowledge have shown that a person's level of understanding of their diabetes may be linked to an increase in diabetes-health specific behaviours and a decreased sense of burden of the illness (Watkins, Connell, Fitzgerald, Klem, Hickey and Ingersoll-Dayton, 2000), reading more diabetes literature, and motivation to exercise frequently (Beeney, Stewart, Dunn and Welch, 1994). Following the results of these studies the relationships between the DIALS and diabetes knowledge were examined. It was predicted that (i) the DIALS Adherence and Information seeking scales would correlate positively with DKNQ scores, and (ii) the DIALS Impact scale would correlate negatively with DKNQ scores. The correlations between the DIALS and the DKNQ are displayed in Table 3.23. In line with the predictions the DIALS Adherence scale was moderately correlated with total scores on the DKNQ (r = .22, p < 0.01), and the DIALS Diabetes-related distress scale was negatively correlated with DKNQ total scores (r = -.13, p < 0.05). Contrary to expectations there was no significant association between the DIALS Information-seeking scale and the DKNQ.

Table 3.23: Correlations between the DIALS and diabetes-related outcome measures

	DIALS					
	Impact	Adherence	Information seeking	Fear of complications	Diabetes-related distress	N
Diabetes outcomes						
HbA$_{1c}$	.087	**-.363****	-.030	**.162***	**.200****	172
Diabetes Knowledge	-.122	**.216****	.088	.008	**-.135***	224
Self-care activities (SDSCA)						
Diet	**-.214****	**.600****	**.202****	-.107	**-.228****	211
Exercise	-.119	**.215****	.028	-.015	**-.185****	211
Glucose monitoring	-.104	**.420****	**.180****	-.082	**-.162***	211
Medication	**-.142***	**.212****	.031	**-.179****	**-.186****	211
Diabetes Quality of Life						
Satisfaction	**-.627****	**.473****	**.194****	**-.444****	**-.570****	227
Impact of diabetes	**-.721**	**.532****	**.155****	**-.528****	**-.663****	229
Worry	**-.495****	**.249****	.048	**-.564****	**-.599****	152
General well-being	**.419****	**-.440****	-.090	**.311****	**.441****	216
Well-being Questionnaire						
Total score	**-.518****	**.486****	**.172****	**-.375****	**-.627****	224
Depression	**.411****	**-.456****	**-.145***	**.218****	**.512****	224
Anxiety	**.409****	**-.324****	-.061	**.352****	**.567****	224
Energy	**-.437****	**.406****	.128	**-.306****	**-.503****	224
Positive well-being	**-.567****	**.499****	**.213****	**-.314****	**-.604****	224

Note: * $p < 0.05$, ** $p < 0.01$

Adherence to self-care activities.

It has been suggested that the adoption of a healthy lifestyle will produce better glycaemic control in people with diabetes (Toobert and Glasgow, 1994). However previous investigations have often found it difficult to demonstrate any relationships between adherence and levels of glycaemic control (Cox, Taylor, Nowacek, Holley-Wilcox, Phol and Guthrow, 1984). This is likely to be due, in part, to the difficulties involved in evaluating a person's actual compliance to various regimen activities. Such problems may include difficulty comparing regimen behaviours to a known standard, errors on the patient's behalf versus non adherence, differences in individual prescriptions, and perhaps most problematic, the fact that measures of adherence are inevitably based on self-reports. The Summary of Diabetes Self-care Activities questionnaire (SDSCA; Toobert and Glasgow, 1994) was developed in an attempt to overcome some of these problems by assessing both absolute levels of self-care behaviour and adherence to individual prescriptions.

The SDSCA was incorporated in the present study to identify the relationships between the DIALS and adherence to a prescribed regimen. It was predicted that the DIALS Adherence scale would be moderately correlated with all four regimen activities assessed by the SDSCA (Diet, Exercise, Glucose monitoring and Medication taking). It was also hypothesised that people who scored highly on the DIALS Information seeking scale would report greater levels of self-care. Finally, an inverse correlation was expected between the DIALS Impact scale and the SDSCA Diet scale because part of the DIALS Impact scale involves feeling restricted by one's diet.

The correlations between the DIALS and the SDSCA are displayed in Table 3.23. As expected there was a significant correlation between the DIALS Adherence scale and outcomes in terms of actual self-care activities. The DIALS Adherence scale was moderately correlated with all four regimen activities; Diet ($r = .60$, $p < 0.01$), Exercise ($r = .21$, $p < 0.01$), Glucose monitoring ($r = .42$, $p < 0.01$), and Medication taking ($r = .21$, $p < 0.01$). The DIALS Information seeking scale was associated with SDSCA Diet and Glucose monitoring ($r = .20$ and $.18$, respectively, $p < 0.01$), but the DIALS Information seeking scale was not significantly correlated with the SDSCA Exercise or Medication taking scales. The DIALS Diabetes-related distress scale was inversely correlated with all four regimen activities (r's between -.16 and -.23, all $p < 0.05$) indicating that greater levels of distress are associated with poorer self-management of diabetes. As expected the DIALS impact scale was negatively correlated with the SDSCA Diet scale ($r = -.21$, $p < 0.01$) and had a smaller but significant correlation with the SDSCA Medication taking scale ($r = -.14$, $p < 0.05$). The DIALS Fear of complications scale was negatively correlated with the SDSCA Medication scale ($r = -.18$, $p < 0.01$).

Quality of life.

In previous studies the Diabetes Quality of Life (DQOL) measure has been found to be highly reliable (DCCT, 1988), sensitive to the effects of treatment (Selam, Micossi, Dunn and Nathan, 1992) and improvements in quality of life following pancreatic transplantation (Nathan, Fogel, Noran, Russell, Tolkoff-Rubin, Delmonico, Auchinloss, Camuso and Cosimi, 1991). Further testing has indicated that increasing severity of diabetes was associated with lower satisfaction and greater impact of diabetes (Jacobson, de Groot and Samson, 1994). In general the DQOL Impact and Satisfaction subscales are thought to represent "broad aspects of global diabetes quality of life", whereas the DQOL Worry subscale appears to be more relevant to specific aspects of an individual's diabetes-related distress (DCCT, 1988).

In the present study the DIALS were compared with the DQOL to identify whether the individual constructs measured by the DIALS are related to specific dimensions of the DQOL measure. It was predicted that the DIALS Impact scale would correlate highly with the DQOL Impact and Satisfaction scales. It was also predicted that the DIALS Fear of complications and Diabetes-related distress scales would be related to the DQOL worry subscale.

The relationships between the DIALS and the DQOL measures are displayed in Table 3.23. There was high degree of overlap between the dimensions of the DIALS and the DQOL. Despite the overlap, the magnitude of the correlations suggested that the DIALS Impact, Adherence and Diabetes-related distress and Fear of complications scales were all moderately related to the DQOL Satisfaction and Impact of diabetes scales (r's between .44 and -.72, all $p < 0.01$). The DIALS Fear of complications and Diabetes-related distress scales had the strongest correlations with the DQOL Worry scale ($r = -.56$ and $-.59$, respectively, $p < 0.01$). The DIALS Information seeking scale had small but significant correlations with the DQOL Satisfaction and DQOL Impact of diabetes scales ($r = .19$ and $.15$, respectively, both $p < 0.01$).

Well-being.

The Well-being Questionnaire was designed to provide a measure of depressed mood, anxiety and aspects of positive well-being in a study evaluating new treatments for people with diabetes (World Health Organisation, 1982). Studies that have used the well-being questionnaire suggest that the scale is a useful measure of psychological outcomes of diabetes, and that the depression and anxiety scales may be useful to detect individuals who are having psychological problems (Bradley, 1994). The Well-being Questionnaire, although designed for use with people who have diabetes, does not contain items that refer directly to diabetes. The purpose of the scales inclusion in this present study was to examine the relationships between subscales of the Well-being Questionnaire and the DIALS, and to establish support for the concurrent validity of the DIALS. The relationships between the DIALS and the Well-being Questionnaire (total score and subscales) are displayed in Table 3.23.

There was a high degree of overlap between the DIALS and the Well-being Questionnaire. The strongest correlation were observed between the DIALS Diabetes-related distress scale and the Well-being Questionnaire total score ($r = -.63$, $p < 0.01$). However, The DIALS Impact, Adherence, Diabetes-related distress and Fear of complications scales were moderately correlated with all of the dimensions of the Well-being Questionnaire (r's between .22 and -.63, all $p < 0.01$). The DIALS information seeking scale was positively correlated with Well-being total scores and Positive well-being scores ($r = .17$ and .21, respectively, both $p < 0.01$), and negatively correlated with the Well-being Depression scale ($r -.14$, $p < 0.05$). Overall, these results suggest that the

DIALS, and in particular the Diabetes-related distress scale, is capable of detecting people who may be having problems psychologically adjusting to diabetes self-management.

Coping with diabetes: a model of the relationships between the psychological variables and the DIALS.

In this section some possible causal relationships between psychological variables (i.e. personality traits and coping styles), and the DIALS will be examined. Previous research on coping in general suggests that there are two major dimensions of coping termed emotion-oriented and task-oriented coping. This distinction is widely documented in the literature (Lazarus and Folkman, 1987; Billings and Moos, 1981, 1984; Pearlin and Schooler, 1978). Emotion-oriented coping refers to a person's emotional reactions to a particular event (e.g. regulating distressing emotions), whereas task-oriented coping involves coping directly with an external threat (Lazarus and Folkman, 1987).

For many years coping has been understood in terms of the stress and coping model (Lazarus and Folkman, 1984, 1987) discussed previously in the Introduction (see Part I, Chapter 2). The model assumes that antecedent variables (e.g. personality or environmental stressors) act via mediating variables (e.g. coping strategies) to influence stress-related outcomes (Lazarus and Folkman, 1987). One of the limitations of the stress and coping model is that it fails to account for individual differences in coping responses in different situations, and across different illness groups. The Coping with

Health Injuries and Problems (CHIP) scale used in the present study was designed to overcome this problem (CHIP; Endler, Parker and Summerfeldt, 1992,1993) by assessing specific coping responses in the setting of illness. In particular, the negative-emotion coping scale has been found to correlate with neuroticism (Endler, Parker and Summerfeldt, 1998) and there is some evidence to suggest that negative-emotion coping may act as a mediating variable in the link between neuroticism and illness self-reports (Deary, Clyde and Frier, 1997). The CHIP Instrumental coping scale reflects a more problem focussed approach to coping with illness and may be expected to correlate with positive disease outcomes. The present study set out to test these assumptions by examining the relationships between the personality trait neuroticism, the two major coping constructs, negative-emotion coping and instrumental coping, and the DIALS.

The aim of the following set of analyses was to formulate a hypothetical model of the relationships between the aforementioned variables based on the stress and coping model, and to test the goodness of fit of the model to the sample data using structural equation modelling. It was hypothesised that the two major coping dimensions assessed by the CHIP, namely negative-emotion coping and instrumental coping, would share significant covariance with specific dimensions of the DIALS. The ideas driving the formulation of the stipulated model are described in full throughout the following sections.

The intercorrelations, means and standard deviations between the variables of interest are displayed later in Table 3.25.

Principal components analysis of psychological constructs and the DIALS

Prior to a formal model-testing exercise a principal components analysis was conducted to explore the intercorrelations between the personality dimension of neuroticism, the two coping styles of negative-emotion coping and instrumental coping, and all five of the DIALS subscales (Impact, Adherence, Information seeking, Fear of complications and Diabetes-related distress). The Scree test (Figure 3.12) showed a break after the second component suggesting that only the first two components were meaningful. Closer examination revealed in addition that only the first two components had eigenvalues greater than 1 and were therefore extracted for rotation.

The first unrotated component accounted for 44.9% of the variance, and the second unrotated component accounted for 13.4% of the variance – a total of 63.3% of the total variance in the eight scales included in the analysis (n = 225). The two components were then rotated using an oblique rotation. The rotated pattern matrix showing the standardised regression weights for each variable on the two rotated components is displayed in Table 3.24.

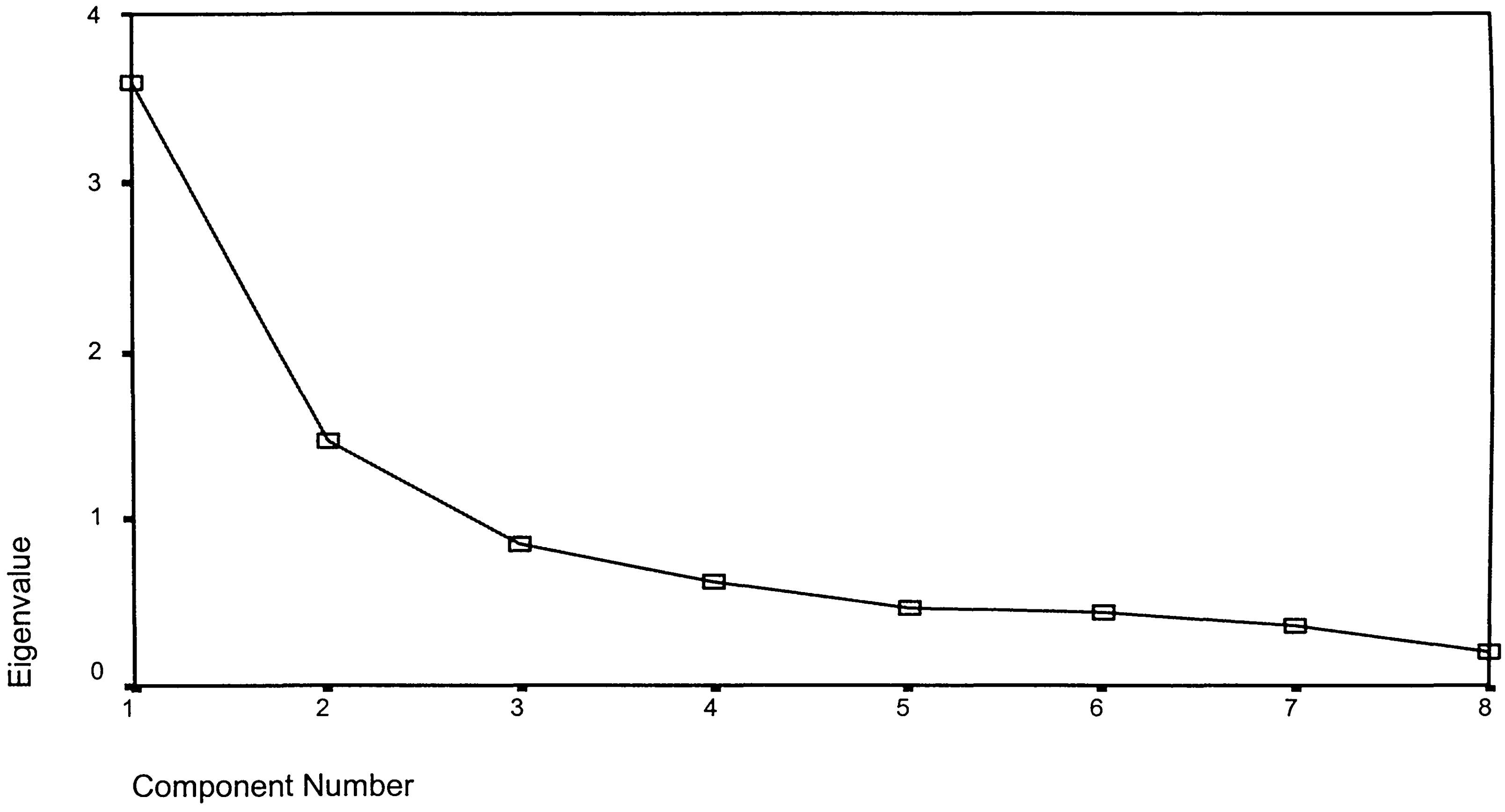


Figure 3.12: Scree plot to show the amount of variance accounted for by the two extracted components (n = 225).

Table 3.24: Rotated pattern matrix: standardised regression coefficients

	Component 1	Component 2
EPQ-R: Neuroticism	**.67**	-.04
CHIP: Negative-emotion	**.79**	.18
CHIP: Instrumental	.08	**.86**
DIALS: Impact	**.75**	-.24
DIALS: Adherence	**-.44**	**.59**
DIALS: Information seeking	.03	**.70**
DIALS: Fear of complications	**.84**	.17
DIALS: Diabetes-related distress	**.84**	-.19

Figures above .40 indicate moderate to high loadings and are shown in bold type (n = 225)

Variables that had pattern loadings of 0.40 or higher were assumed to be characteristic of a particular component. The variables that had positive loadings on the first component were as follows: EPQ-R Neuroticism (.67), CHIP Negative-emotion coping (.79), DIALS Impact (.75), DIALS Fear of complications (.84) and DIALS Diabetes-related distress (.84). The DIALS Adherences subscale had a negative loading on the first component (-.44). The results indicate that these variables have considerable overlap and appear to reflect an 'emotion-oriented approach' to coping with diabetes. In previous literature such overlap between health-related constructs has often been referred to as 'a broad dimension of negative-affectivity' or 'symptomatic distress' (Watson and Pennebaker, 1989; Deary, Clyde and Frier, 1997). Variables that had moderate to high pattern loadings on the second component were as follows: CHIP Instrumental coping (.86), DIALS Adherence (.59) and DIALS Information-seeking (.70). The second component seemed to reflect a 'task-oriented approach' to coping with diabetes.

Structural equation modelling

The findings so far suggest that key psychological variables share common variance with the dimensions of the DIALS. In particular there appear to be two overlapping diabetes-specific coping components that reflect what have been termed here as an 'emotion-oriented approach' and a 'task-oriented approach' to coping with diabetes. In this final set of analyses the possible causal links between the psychological constructs, neuroticism, negative-emotion coping and instrumental coping, and the DIALS will be tested formally. The model to be tested is based on the stress and coping model proposed by Lazarus and Folkman (1984, 1987) (see Part I,Chapter 2 [Figure 1.1]). The model was first specified on the basis of the prior theoretical and empirical results discussed at the beginning of this section, as well as *apriori* assumptions about the associations among the key variables to be used in the model. The descriptive statistics and intercorrelations between the variables are shown in Table 3.25. A diagrammatic representation of the proposed hypothetical model is displayed in Figure 3.13.

Table 3.25: Mean, standard deviations and correlations among the variables used in structural equation modeling (n = 225)

	EPQ-R: N	CHIP: NE	CHIP: I	Impact	Adherence	Information seeking	Fear of complications	Mean (SD)
EPQ-R: Neuroticism	–							5.0 (3.3)
CHIP: Negative-emotion	.460**	–						22.0 (7.2)
CHIP: Instrumental	-.072	.064	–					29.5 (4.9)
Impact	.386**	.446**	-.262**	–				35.1 (11.0)
Adherence	-.357**	-.269**	.444**	-.511**	–			44.5 (10.0)
Information seeking	-.160*	-.140*	.324**	-.194**	.306**	–		27.0 (4.7)
Fear of complications	.374**	.509**	.004	.581**	-.371**	.032	–	21.0 (4.8)
Diabetes-related distress	.550**	.560**	-.267**	.754**	-.529**	-.156*	.602**	19.5 (7.6)

Note: * $p < 0.05$, ** $p < 0.001$

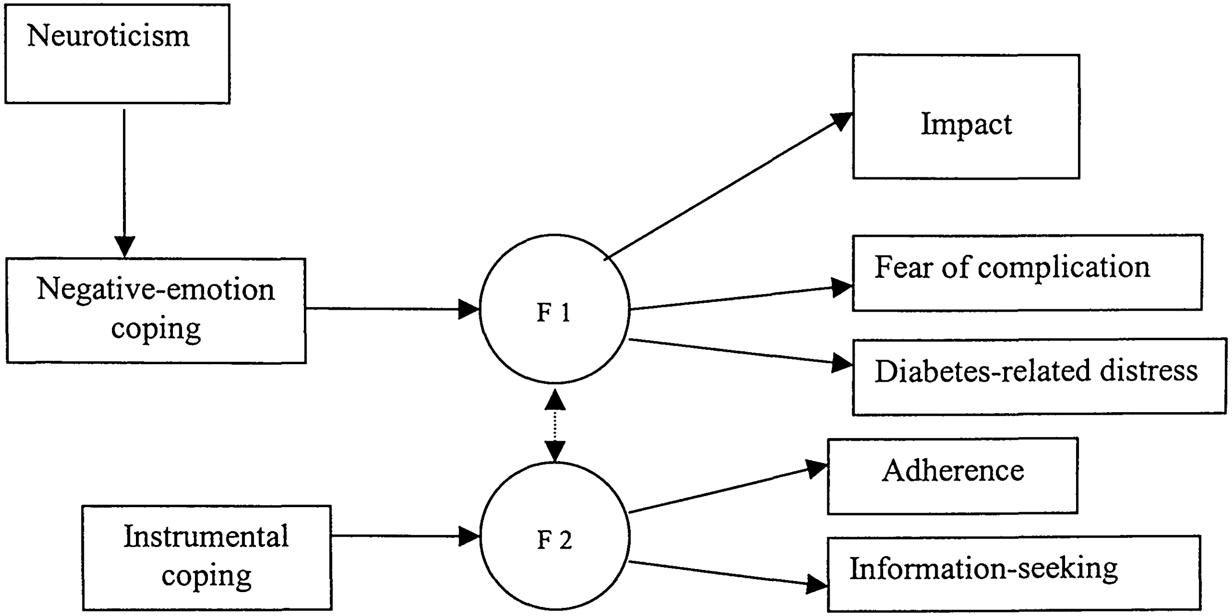


Figure 3.13: Diagrammatic representation of the relationships between psychological variables (personality and illness-related coping constructs) and the DIALS.

The two major coping dimensions of the CHIP, namely, Negative-emotion coping and Instrumental coping, are assumed to be predictors of two latent constructs F1 and F2, broadly defined as a diabetes-specific 'emotion-oriented approach' and a 'task-oriented approach' respectively. The DIALS Impact, Fear of complications and Diabetes-related distress scales have been shown to be highly interelated and appear to represent a diabetes-specific 'emotion-oriented approach' to coping with diabetes. Therefore an association was entered between F1 and these three dimensions.

As shown in Table 3.25, EPQ-R Neuroticism and CHIP Negative-emotion coping are moderately correlated ($r = .46$, $p < 0.01$). The association between EPQ-R Neuroticism and CHIP Negative-emotion coping has been well documented in previous literature (Deary, Clyde and Frier, 1997; Endler et al., 1992, 1998). Based on the stress and coping model (Lazarus and Folkman 1984, 1987), one would expect that the coping construct, negative-emotion coping, will have a mediating effect between self-reported outcomes of diabetes and the antecedent personality trait, neuroticism. In line with these assumptions a direct association was entered between the EPQ-R Neuroticism and CHIP Negative-emotion coping, and then between CHIP Negative-emotion coping and the DIALS latent variable F1. A further path was entered between the CHIP Instumental coping construct and the DIALS latent variable F2. In principal components analysis the DIALS Adherence and Information-seeking scales were found to have moderate loadings on the second extracted component. Based on these results an association was hypothesised between F2 and the DIALS Adherence and Information seeking scales. The DIALS Adherence subscale was also found to have a negative loading on the first component, therefore a further association was hypothesised between F1 and the DIALS Adherence scale. In Table 3.25, the CHIP Instrumental coping and the CHIP Negative-emotion coping scales were not significantly correlated. Therefore no relationship was entered between these constructs. However, using prinicpal components analysis the two latent variables F1 and F2 were found to have a small inverse correlation, indicating that people who are more 'emotion-oriented' have a tendency to be less 'task-oriented'.

The model displayed in Figure 3.12 was tested using the EQS Structural Equation Modelling Program (Bentler, 1995). The Lagrange multiplier suggested that the addition of four new paths would improve the overall fit of the model. The Lagrange multiplier suggested adding a direct path between the the EPQ-R Neuroticism scale and F1, a second path was added between Neuroticism and the DIALS Impact scale, and a third parameter was added between Neuroticism and the DIALS Information seeking scale. The fourth parameter was added between CHIP Instrumental coping and the DIALS Fear of complications scale. The resulting model is displayed in Figure 3.14. The goodness of fit of the model will be described first, and then its meaning.

Assessment of the overall fit of a model is important to establish the extent to which the sample data are consistent with the model that is hypothesised (Musil, Jones and Warner, 1998). The average of the absolute standardised residuals was .02, and the average off-diagonal absolute rediuals was .03, indicating that the model was able to account for most of the covariance in the variable matrix. The largest standardised residual was fairly small (.09) which indicates that the covariances among the variables were explained well by the model. The fit statisitics for the model are good. The comparative fit index (CFI) is based on a chi-square (χ^2) estimate using a maximum-likelihood solution. Typically values of at least .90 are considered evidence for an acceptable fit of the model to the data (Musil et al., 1998; Bentler, 1995; Byrne, 1994). In the case of the present analysis the CFI was .98 suggesting an acceptable fit. Although the χ^2 value obtained in this analysis was significant (χ^2 (14) = 27.72, $p < 0.015$), the general rule of thumb that the value of chi square should be less than double the number of degrees of freedom was satisfied.

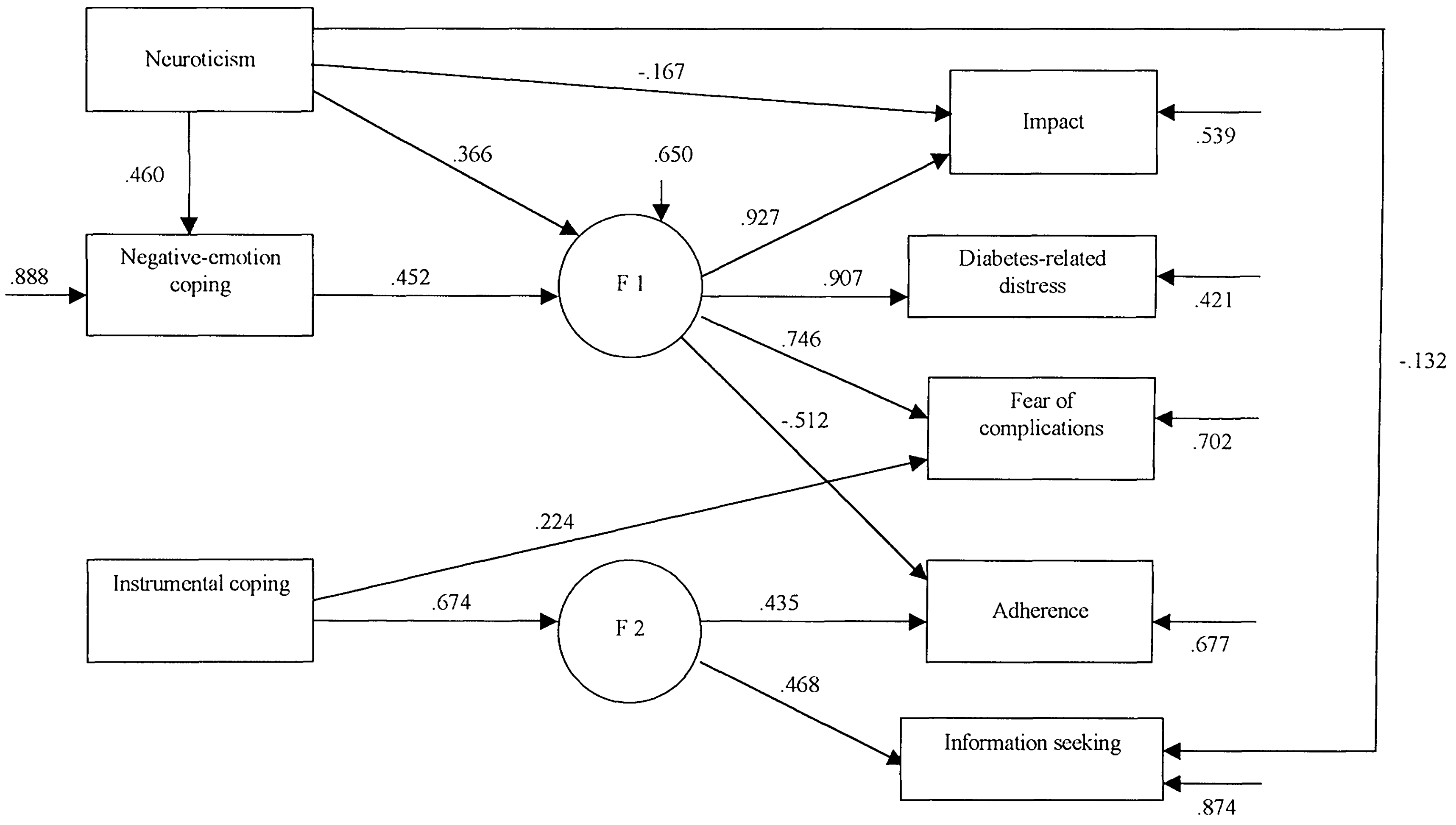


Figure 3.14: Structural equation model (with corresponding beta weights) to show the relationships between psychological variables (personality and coping constructs) and the DIALS. All parameters shown are significant.

The remaining two fit indices were highly acceptable: the Bentler-Bonnett normed fit index = .96 and the Bentler-Bonnett non-normed fit index = .96. These take values between 0 and 1, and models with values above .90 are deemed acceptable (Bentler, 1995). Additional statistical tests, namely the Wald and the Lagrange Multiplier test, showed that none of the pathways in the model should be dropped, and that no further new pathways could be added to improve the fit of the model, respectively.

The model shown in Figure 3.14 provides a highly acceptable account of the relationships between the variables studied in this analysis, and provides broad support for two latent overlapping diabetes-specific coping constructs, tentatively referred to as diabetes-specific emotion and task oriented coping dimensions. The two DIALS latent variables can be seen in part to be a result of variance in personalty traits and coping styles. Latent variable F1 in Figure 3.14 loads substantially on the DIALS Impact, Fear of complications, Diabetes-related distress and Adherence scales and appears similar to the general coping dimension 'emotion-oriented coping'. This is supported by the significant pathway between the CHIP Negative-emotion coping scale and F1. The latent variable F2 loaded significantly on the DIALS Adherence and Information seeking scales, and appears similar to the 'task-oriented coping' style discussed earlier. This is supported by the causal path between the CHIP Instrumental coping scale and F2.

Discussion

The DIALS questionnaire discussed in this chapter was developed using a novel approach which combined the use of (i) existing coping theory, to give the scale an empirical basis, and (ii) patient's perceptions of the most important issues involved in coping with diabetes. By investigating those aspects of coping which are perceived to be most relevant to the patients themselves it has been possible to derive items that capture aspects of coping which are specific to people with diabetes. In the following discussion the results will be addressed as three areas of interpretation:

1) The structure of the DIALS
2) Establishing the reliability and partial validity of the DIALS
3) Evaluation of a conceptual model of the relationships between psychological constructs and the DIALS

The discussion will be followed by a consideration of the limitations of the study and the implications and potential use of the DIALS in future research.

The structure of the DIALS

Prinicipal components analysis of the 64 item pilot version of the DIALS revealed five components: Impact, Diabetes-related distress, Fear of complications, Information-seeking, and Adherence. Reanalysis of the DIALS using the 50 items that loaded above 0.35 on one of the five components yielded five components each of which contained items which loaded uniquely on a single component. The criteria used to judge the interpretability and the overall structure of the DIALS questionnaire were met. First, at least five items loaded on each of the retained components. Second, the items on a given component shared some conceptual meaning. Third, the rotated pattern matrix revealed that all of the retained items had moderate to high pattern loadings (> 0.35) on one component and low loadings (< 0.35) on the other components. The structure of the DIALS provides preliminary evidence for the multidimensionality of the measure and suggests that the DIALS assesses five aspects of coping which are specific to people with Type 1 diabetes.

Establishing the reliability and partial validity of the DIALS

The results of the present study provide support for the reliability and partial validity of the DIALS. The internal consistency (.81 - .92) and test re-test reliability (.72 - .90) of the five subscales was high (Table 3.18). The validity of any psychometric instrument is an ongoing process. However, the present study provides some preliminary evidence towards the validation of the DIALS. Preliminary evidence for the criterion-related validity of the the DIALS was obtained by examining the links between personality traits and coping styles, and the DIALS.

The five dimensions of the DIALS have some conceptual overlap with illness-related coping constructs assessed by the Coping with Health Injuries and Problems scale (Endler, Parker and Summerfeldt, 1998; Endler, 2000). The CHIP Instrumental coping scale was developed to assess a task-oriented approach to health problems (e.g. actively seeking out information and medical advice, and following this advice) (Endler et al., 1998). In the present study positive assocations were found between the CHIP

Instrumental coping scale, and the DIALS Adherence ($r = .45$, $p < 0.01$) and Information seeking ($r = .33$, $p < 0.01$) scales. These moderate relationships were not surprising because these scales include items about taking an active appoach towards coping.

The CHIP Negative-emotion scale was developed to assess an emotion-oriented approach to coping with health problems (Endler et al., 1998). The DIALS Impact and Fear of complications scales had substantial overlap with the CHIP Negative-emotion coping scale ($r = .45$ and $.51$, respectively, $p < 0.01$), which implies that these dimensions may be diabetes-specific measures of an emotion-oriented approach to coping with diabetes. The positive association between the DIALS Diabetes-related distress scale and the CHIP Negative-emotion scale ($r = .56$, $p < 0.01$} also complements previous research which has found a positive correlation between emotion-focussed coping and depression (Billings and Moos, 1985, Barnett and Gotlib, 1988), and between emotion-focussed coping and state anxiety (Dusenburg and Albee, 1988; Endler, 1983, cited in Endler and Parker, 1992). The CHIP's Distraction coping scale was moderately correlated with the DIALS Information-seeking scale.

The CHIP Distraction coping scale was developed to assess an individual's attempt to cope with a health problem by focusing on more pleasant activities, engaging in unrelated activities, or by seeking the company of others (Endler et al., 1998) and has been found to share important features with general avoidance coping (Billings and Moos, 1981; Endler and Parker, 1990). The DIALS Information-seeking scale contains items which relate to sharing experiences of diabetes, reading books and gathering information about diabetes (e.g. reading books and articles about diabetes, chatting to other people about diabetes), which could explain the moderate association between these measures.

In previous literature the personality traits neuroticism and extraversion have been found to be associated with negative-emotion coping and instrumental coping, respectively (Deary, Strickland, Gold and Frier, 1998; Endler, Parker and Summerfeldt, 1998; Endler, 2000). On the basis of previous research it was anticpated that neuroticism would be associated with the DIALS Impact, Fear of complications and Diabetes-related distress scales. The results supported these predictions. Neuroticism and the DIALS Diabetes-related distress scale were particularly highly related ($r = .56$, $p < 0.01$), while the DIALS Adherence and Information-seeking scales were inversely associated with neuroticism ($r = -.36$ and $-.14$, respectively, $p < 0.01$). These results are consistent with evidence that individuals who score highly on neuroticism are more likely to experience negative or distressing emotions (Costa and McCrae, 1987) and have been postulated to have a low threshold for activiation of the autonomic nervous system, which makes them more prone to anxiety and fear responses (Eysenck and Eysenck, 1985). Extraversion on the other hand, had a small but significant association with the DIALS Information seeking scale ($r = .18$, $p < 0.01$). This relationship provides some evidence to suggest that extraverts are more likely to share their experiences of diabetes with other people and to actively seek information about their diabetes than introverts.

Further assessment of the validity of the DIALS was carried out by comparing it with various diabetes-related outcome measures which included: glycaemic control, diabetes knowledge, adherence to self-care activites, diabetes-related quality of life, and well-being. In the present study the expectation was met that people who obtained higher scores on the DIALS Adherence scale had better glycaemic control than people who had lower scores on the DIALS Adherence scale ($r = -.35$, $p < 0.01$). The DIALS Adherence scale measures a person's efforts to adhere to their diabetes treatment regimen and to follow the advice provided by health professionals. The findings of the present study are comparable to those of previous studies which have found a link between adherence and glycaemic control using measures of adherence to specific regimen activites (Hanson, Henggeler and Burghen, 1987; Skinner and Hampson, 2001). However, in other studies there was no evidence for a link between adherence and glycaemic control (Toobert and Glasgow, 1994). The relationship between the DIALS Adherence subscale and glycaemic control therefore warrants further investigation. It should be acknowledged that the patients in this investigation were already aware of their blood glucose levels (HbA_{1c}). This prior knowledge may have introduced some bias in their responses to the adherence items.

In the present investigation, people who reported high levels of DIALS Diabetes-related distress had poorer glycaemic control ($r = .20$, $p < 0.01$). Until recently the relationship between psychiatric distress and glycaemic control has been unclear, however, a recent meta-analysis performed to assess the reliability and strength of the association between depression and glycaemic control found conclusive evidence for an association between depression and hyperglycaemia (Lustman, Anderson, Freedland, de Groot, Carney and Clouse, 2000). The relationship between the DIALS Diabetes-related distress scale and glycaemic control provides further support for the association between psychiatric distress and glycaemic control. Furthermore, the DIALS Diabetes-related distress scale is one of the few existing scales which has been developed to assess diabetes-specific aspects of distress.

It was anticipated that total scores on the Diabetes Knowledge Questionnaire (DKNQ) would correlate significantly with the DIALS Adherence and Information-seeking scales. The results revealed an association between the DKNQ and the DIALS Adherence scale ($r = .22$, $p < 0.01$). This finding is consistent with previous research which has suggested that a person's level of understanding of diabetes is related to an increase in diabetes-specific health behaviours (Watkins, Connell, Fitzgerald, Klem, Hickey and Ingersoll-Dayton, 2000). However, contrary to the findings of Watkins et al. (2000), the present study did not find evidence to suggest that an increased understanding of diabetes was related to a decreased sense of burden of the illness. A study by Beeney et al. (1994) found that having a comprehensive knowledge of diabetes was associated with reading more diabetes literature. However, in the present study there was no evidence for a relationship between a person's knowledge of diabetes and the DIALS Information-seeking scale.

It was predicted that there would be a different pattern of relationships between the DIALS scales and other conceptually relevant measures of diabetes-related outcomes including the Diabetes Quality of Life (DQOL) measure, the Summary of Diabetes Self-Care Activites Questionnaire (SDSCA), and the Well-being Questionnaire (Table 3.23). There was evidence for strong positive associations between these measures and the DIALS. The predictions made were partially supported. For example, the DQOL Worry scale was most strongly linked to the DIALS Diabetes-related distress scale ($r = -.60$, $p < 0.01$) and the DIALS Fear of Complications scale ($r = -.56$, $p < 0.01$). The DQOL Worry scale measures a person's tendency to worry about future complications of diabetes and has been found to be specifically related to patient-perceived psychological distress (DCCT, 1988). These findings provide support for the critierion-related validity of the DIALS Fear of complications and Diabetes-related distress scales. There was evidence for substantial content overlap between the DIALS Impact and Diabetes-related distress scales and the DQOL Satisfaction and Impact scales which suggests that these measure are closely related but not identical to measures of diabetes-related quality of life. One of the limitations of the DQOL is that it was developed for use with adolescents with diabetes rather than adults. As a result the DQOL worry scale, in particular, contains some items that may be inapplicable to adults with Type 1 diabetes who are more settled in their lifestyle. The DIALS overcomes this problem because this new measure was developed specifically for use with adults with Type 1 diabetes.

The use of the SDSCA helped to identify specific regimen activities that were most closely tied to the patients' perceptions of the impact of diabetes, adjustment and lifestyle issues assessed by the DIALS. The Diet and Glucose monitoring scales had stronger associations with the DIALS Adherence scale ($r = .60$ and .42, respectively, $p < 0.01$) than Exercise and Medication ($r = .21$ and .21, respectively, $p < 0.01$). This can be explained by the content overlap between these measures, particularly with the Diet scale. According to previous research patients' regulation of their diet is frequently reported as the most difficult part of the diabetes treatment regimen (Bradley, Todd, Gordon, Symonds, Martin and Plowright,1999), and a recent study of adolescents found that better dietary self-care was associated with better glycaemic control (Hampson and Skinner, 2001). The findings of the present study suggest that the DIALS Adherence scale may be a useful indicator of people who are having difficulty regulating their diet, and who may be at risk of poor glycaemic control.

In previous studies the Well-being questionnaire has been used to identify individuals who may be having psychological problems adjusting to their diabetes (Bradley, 1994). However, the Well-being Questionnaire is a measure of general psychological well-being and so does not contain items that refer directly to people with diabetes. Therefore, the Well-being Questionnaire may be less capable of detecting diabetes-related emotional problems, such as a person's worries about complications (Snoek, Pouwer, Welch and Polonsky, 2000; Pouwer, Snoek, van der Ploeg, Ader and Heine, 2001).

In the present analysis, the Well-being questionnaire had strong and consistent associations with the dimensions of the DIALS (Table 3.23), in particular the Diabetes-related distress scale (r's between .51 and -.63, $p < 0.01$). These findings indicate that the DIALS may be capable of detecting individuals who are having problems adjusting psychologically to their diabetes. Futher work is needed to determine whether the DIALS adds any additional information in the identification of these patients.

Evaluation of a conceptual model of the relationships between psychological constructs and the DIALS

The results of the present study suggest that there is substantial construct overlap between psychological variables (i.e. personality traits and coping styles) and the DIALS. The possible causal links between between the psychological constructs, neuroticism, negative-emotion coping and instrumental coping, and the DIALS were, therefore, tested formally by specifying a conceptual model which was based on the theoretical assumptions laid out by Lazarus and Folkman (1984, 1987) in their stress and coping model. The hypothetical model (Figure 3.13) was fitted to the data to establish whether the two major coping dimensions of the CHIP, namely, negative-emotion coping and instrumental coping, were predictors of the two latent constructs F1 and F2, which were termed as diabetes-specific 'emotion-oriented' and 'task-oriented' approaches to coping with Type 1 diabetes, respectively. In addition, the personality trait neuroticism was assumed to act via negative-emotion coping in predicting the latent variable F1. After the addition of four new pathways the model fitted in this study had an acceptable fit to the data, providing broad support for two latent overlapping diabetes-specific coping constructs (Figure 3.14).

By modelling the relationships between existing illness-related coping constructs and the dimensions of DIALS it has been possible to confirm the prediction that the the two major illness-related coping constructs, negative-emotion coping and instrumental coping share significant overlap with the dimensions of the DIALS. In the model (Figure 3.14), the two DIALS latent factors were in part a result of variance in personality traits and generic illness-related coping styles. The latent variable F1 loaded substantially on the DIALS Impact, Fear of complications, Diabetes-related distress and Adherence scales. This factor is similar to the general coping dimension 'emotion-oriented coping' (Endler and Parker, 1992). The latent variable F2 loaded significantly on the DIALS Adherence and Information seeking scales and appears similar to 'task-oriented coping'. In summary the results of the present study have in part replicated the two major illness-related coping dimensions assessed by the CHIP using a scale which measures diabetes-specific aspects coping with diabetes.

Based on the results of this study some immediate support for the stress and coping model (Lazarus and Folkman, 1987) can be seen. Consistent with expectations, neuroticism was shown to influence negative-emotion coping, which in turn was related to the latent factor F1. Similarly, instrumental coping was found to have a positive relationship with the latent factor F2. This suggests that illness-related coping constructs may act as mediators in the link between psychological antecedents (e.g. neuroticism), and self-reported aspects of the impact of diabetes, psychological adjustment and lifestyle-related issues assessed by the DIALS. Contrary to predictions the two latent variables, F1 and F2, were not significantly correlated. However, the addition of several unpredicted pathways (suggested by the Lagrange multiplier) to improve the overall fit of the model provided evidence for construct overlap between neuroticism and negative-emotion coping. In particular, neuroticism had a direct influence on several variables in the model including the DIALS Information seeking scale and the DIALS impact scale. Neuroticism was also directly related to the latent variable F1. This implies that the link between neuroticism and self-reported outcomes is only partly mediated by negative-emotion coping and that neuroticism has some direct influence on the self-reported outcomes assessed by the DIALS. Previous research using structural equation modelling has provided evidence to suggest that neuroticism is a central contributor to the variance of self-reported outcomes of diabetes self-management including worries about hypoglycaema, and impaired symtpomatic awareness of hypoglycaemia (Hepburn, Deary, MacLeod and Frier, 1994). The only other significant path in the model is an association between CHIP Instrumental coping and the DIALS Fear of complications scale, but the causal direction of this relationship is unclear. It may be that the threat of developing complications associated with diabetes leads to a more problem-focussed approach rather than vice versa.

In summary, the results presented in this study are similar to previous research which suggests that the illness-related coping constructs may be mediators in the link between personality and self-reported outcomes of diabetes (Deary, Clyde and Frier, 1997), and therefore offer broad support to process models of illness-reporting in diabetes. It should also be acknowledged that there was significant overlap between the psychological constructs and the DIALS. In particular, neuroticism was found to contribute independently to the latent factor F1, and there were direct paths between neuroticism and the DIALS impact and information-seeking scales. These results suggest that neuroticism and negative-emotion coping share common variance. According to work by Watson and Pennebaker (1989), negative self-reports share a common source of variance in what has been termed as a 'broad dimension of negative affectivity'. Deary et al. (1997) tested this view using an alternative to the stress and coping model termed 'negative affectivity theory'. In this study Deary et al. (1997) tested negative affectivity theory and transactional theory competitively to establish their goodness of fit. The results suggested that an integrated model which combined aspects of both models had the best fit to the data. The findings of the present study support this view.

In conclusion, the present investigation has focused on the development of a reliable and valid multidimensional assessment of the how people cope with the impact of diabetes, and other diabetes-related adjustment and lifestyle issues, namely, the DIALS. Unlike many existing diabetes-specific measures the DIALS has been developed using a novel approach which has combined existing empirical theory, with the patients' self-reports of the most important issues invloved in coping with Type 1 diabetes. The resulting dimensions of the DIALS (Impact, Fear of complications, Diabetes-related distress, Adherence and Information seeking) have been shown to be related to personality and illness-related coping constructs that are considered to be important in general models of stress and coping. Although only preliminary validity data has been provided here for the DIALS, it is suggested that the DIALS contains sufficient psychometric properties and correlations with other important health-related variables to allow its use for future research purposes and within clinical settings.

Limitations of the DIALS

The issue of construct overlap is a potential problem for self-report scales such as the DIALS. In the present study there was considerable overlap between the dimensions of the DIALS and existing diabetes-related outcome measures including the Diabetes Quality of Life measure, the Well-being Questionnaire, and the Summary of Self-Care Activities Questionnaire. The associations between these existing self-report measures and the dimension of the DIALS means that the constructs contained within the DIALS share variance with these constructs. Due to the large number of constructs that exist within health psychology, and to the increasing number of self-report measures being developed to assess diabetes-specific outcomes, it is necessary to study the overlaps between the DIALS and other self-report measures in more detail to identify whether or not the DIALS contains unique variance within its constructs. However, with reference to this limitation, it should be acknowledge that the DIALS was developed using a novel approach which combined the theroretical assumptions about coping processes (Lazarus and Folkman, 1984, 1987) with a consideration of the patients' views of the most important issues involved in coping with the impact of diabetes self-management, as well as other adjustment and lifestyle-related issues. The DIALS therefore, has the advantage over existing diabetes-specific measures which have often been developed on the basis of the clinical experience of health professionals who are knowledgeable about the treatment of diabetes. By incorporating a relevant theoretical perspective of coping it has also been possible to make comparisons between diabetes-specific aspects of coping and more general coping dispositions which appear in the health psychology literature (Lazarus and Folkman, 1984; Endler and Parker, 1990a; Endler, Parker and Summerfeldt, 1998).

A second potential problem for self-report measures of coping, such as the DIALS is that they may miss important constructs that are relevant to coping with diabetes. For example, while the dimensions of the DIALS questionnaire were found to correlate highly with the two major coping dimensions, instrumental coping and negative-emotion coping (Endler, Parker and Summerfeldt, 1998; Endler, 2000), the relationships between the dimensions of the DIALS and distraction and palliative coping styles were less clear. These illness-related coping dimensions are thought to be linked to measures of general avoidance coping referred to in the literature (Endler, Parker and Summerfeldt, 1998).

By restricting the number of items that could be included in the pilot version of the DIALS questionnaire, some of the original domains were, inevitably, omitted from the final version of the scale. The decision to excluded the items within these domains was made on the basis of pre-specified criteria that were used in an effort to retain those items that had the highest degree of domain coherence (Part III, Chapter 2). The problem of omitting relevant items and/or constructs from self-report measures is a general criticism that can be applied to all self-report measures and there is no simple solution to resolve this issue. The development and refinement of self-report measures such as the DIALS should therefore be considered as an ongoing process. Further work is necessary to explore the domains that were omitted from the present analysis and to identify whether or not they add anything further to the study of coping in adults with Type 1 diabetes.

Several other general limitations of this study should be considered. As no data were available for the non-responders of this study, it is impossible to rule out selection bias. The present study was conducted using a sample of patients who attend the diabetic outpatient clinic at the Royal Infirmary of Edinburgh. All of these participants volunteered to participate in the study. These patients are not likely to be representative of the general population of adults with diabetes. The fact that the patients were all regular attenders at the diabetes clinic suggests that they may be more actively involved in their treatment and psychologically more healthy than other patient groups not represented in this study.

The present study only had a moderate response rate (49%). This may have been the result of the size of the battery of the questionnaires. There was no added incentive to encourage the participants to take part in the study. This should perhaps be a consideration in future studies in an attempt to involve more particpants. Another reason for the moderate response rate may have been the fact that a large proportion of the respondents were recruited by post. In this study there was evidence to suggest that the particpants who were recruited in person, when they attended the clinic for their six monthly review appointment (70% response rate) were more likely to respond than individuals that were invited to participate by post (37% response rate), even though both groups of particpants completed the questionnaire at home in their own time. These findings indicate that it is more beneficial and perhaps ethically more appropriate to recruit particpants when they attend the clinic.

Implications of the DIALS for future research and clinical practice

Despite the above limitations, the evidence from the present study indicates that the DIALS has adaquate reliability and validity to recommend its use as a potential clinical and research tool. The final version of the DIALS is presented at the end of this chapter (Figure 3.14).

In future research the DIALS should be considered as part of a package of questionnaires that are selected to capture the range of possible impacts which diabetes can have on a person's life. The DIALS may also be useful as a tool that can be used to evaluate different treatments and the effectiveness of intervention studies. Further work is also necessary to develop an understanding of whether or not particular conditions and treatments are determinants of changes in the DIALS over time. This can be assessed longitudinally and may provide an understanding of the scale's sensitivity to change.

The DIALS was developed from the descriptions provided by adult patients with Type 1 diabetes, however there is no reason why the DIALS should not have wider applications for use with other patient groups such as adolescents with diabetes and the elderly, or to compare people using different treatment regimens. Although the scales are assumed to be equally appropriate for use within these samples, further work is required to check the psychometric properties of the scale within such samples.

Future validation studies using the DIALS are recommended and should attempt to replicate the findings reported here. In particular, it may be possible to test the different models of the relationships between personality traits and illness-related coping constructs and the DIALS competitively. In the present study some evidence has been provided to show that the DIALS can be applied within a coping framework. However, it would be useful to investigate possible causal relationships between the DIALS and a wider range of constructs including demographic and other social factors which may influence a person's ability to cope with diabetes. The findings from the present investigation may be used as a means of generating hypotheses for the development of future models.

The DIALS may also be a useful clinical tool with the field of diabetes care. Diabetes-specific self-report measures, along with more traditional physiological measures of a person's health status, are becoming increasingly recognised as valuable end-points for evaluating medical treatment outcomes (Bradley, 1994, DCCT, 1988, Cox and Gonder-Frederick, 1992). The relationships between the dimensions of the DIALS and other psychosocial measures assessed in the present study suggest that the DIALS may be capable of assessing valuable end-points related to the pyschological and social functioning of the individual. By examining the relationships between the DIALS and these psychosocial measures longitudinally it may be possible to determine the predictive value of the scales.

The associations between the dimensions of the DIALS and specific illness-related coping constructs implies that using the DIALS in a clinical setting may be a valuable way of identifying individuals who are having problems coping with their diabetes. The ease of administration and the use of items that are directly relevant to people with diabetes also makes the DIALS applicable to patients with a broader range of clinical characteristics. In addition, responses to specific items could provide a stimulus for further discussions between patients and health professionals about their experiences of diabetes and treatment-related issues.

Diabetes Impact, Adjustment and Lifestyle Scales

Instructions: This questionnaire asks how you feel about diabetes, how much of an impact diabetes has on your daily life, and your typical reactions to diabetes. Please rate each statement on the 1 to 5 scale, from 1 'strongly disagree' to 5 'strongly agree'. Please read each of the statements carefully and circle your first natural response

		Strongly Disagree				Strongly Agree
1.	I lead a normal life the same as any other person who does not have diabetes	1	2	3	4	5
2.	Chatting to other people who have diabetes is useful	1	2	3	4	5
3.	My diabetes means others have to wait for me at meal times	1	2	3	4	5
4.	I worry about my health because of my diabetes	1	2	3	4	5
5.	I would describe myself as lazy when it comes to managing my diabetes	1	2	3	4	5
6.	As a diabetic person, I eat a diet which keeps me healthy	1	2	3	4	5
7.	I feel like I am falling apart because of my diabetes	1	2	3	4	5
8.	I try to share my experiences of diabetes with others who know about it	1	2	3	4	5
9.	I eat too many sweets/chocolates for a person with diabetes	1	2	3	4	5
10.	The proper control of diabetes involves a lot of sacrifice	1	2	3	4	5
11.	I feel frustrated that I can't lead a normal life because of because of my diabetes	1	2	3	4	5
12.	I try to keep up with developments in insulin therapy	1	2	3	4	5
13.	Diabetes isn't a problem for me	1	2	3	4	5
14.	I get upset easily and feel panicky because of diabetes	1	2	3	4	5
15.	It is hard to concentrate because of my diabetes	1	2	3	4	5
16.	Sometimes I think I am a "bad" diabetic	1	2	3	4	5
17.	I am eager to read about diabetes	1	2	3	4	5
18.	I feel guilty about the way I manage my diabetes	1	2	3	4	5
19.	The more I read the more I know what I have to do to combat problems associated with diabetes	1	2	3	4	5
20.	I worry about having high blood sugar	1	2	3	4	5
21.	I feel angry that I have diabetes	1	2	3	4	5
22.	I find it difficult to get a good nights rest because of my diabetes	1	2	3	4	5
23.	I follow the advice about diabetes provided by health professionals	1	2	3	4	5
24.	I have crying spells or feel like it because of my diabetes	1	2	3	4	5
25.	I don't have the motivation to take care of my diabetes	1	2	3	4	5

		Strongly Disagree				**Strongly Agree**
26.	My lifestyle is too controlled because I have diabetes	1	2	3	4	5
27.	Diabetes interferes with me taking exercise when I want to	1	2	3	4	5
28.	I feel guilty if I eat foods which I know are bad for me	1	2	3	4	5
29.	In general I try not to let diabetes worry me	1	2	3	4	5
30.	Sticking to my recommended diet makes eating out difficult	1	2	3	4	5
31.	I often worry that my health will deteriorate as a result of my diabetes	1	2	3	4	5
32.	Diabetes interferes with me eating when I want to	1	2	3	4	5
33.	I sometimes feel depressed about my diabetes	1	2	3	4	5
34.	Sometimes I can't be bothered to check my blood sugar level	1	2	3	4	5
35.	I think my control of diabetes is quite good	1	2	3	4	5
36.	I eat a lot of food that I know is not recommended for people who have diabetes	1	2	3	4	5
37.	I am interested in gathering information about diabetes	1	2	3	4	5
38.	I worry about getting long term complications of diabetes	1	2	3	4	5
39.	I read magazines and articles about diabetes	1	2	3	4	5
40.	I feel restricted in what I can do because of my diabetes	1	2	3	4	5
41.	I use the information I have about diabetes to help me to manage it	1	2	3	4	5
42.	I often feel sorry for myself because I have diabetes	1	2	3	4	5
43.	Diabetes doesn't really bother me at all on a day to day basis	1	2	3	4	5
44.	When I am away from home (e.g. on holiday) I find it more difficult to manage my diabetes	1	2	3	4	5
45.	I have thoughts or worries about what will happen later in life because of diabetes	1	2	3	4	5
46.	I think that I am eating properly for a person with diabetes	1	2	3	4	5
47.	Controlling my diabetes well imposes restrictions on my whole lifestyle	1	2	3	4	5
48.	I tend to eat what I feel like at the time rather than what is good for my diabetes	1	2	3	4	5
49.	Diabetes interferes with my social life	1	2	3	4	5
50.	I feel that the more I know about diabetes the less it will bother me	1	2	3	4	5

Thank you for taking the time to complete this questionnaire. Your responses are greatly appreciated.
All responses will be strictly confidential.

PART IV:

Conclusions

The research described in the present thesis was conducted to provide an assessment of coping in adults with Type 1 diabetes. The specific aims of the thesis were as follows. First, to examine, prospectively, the relationships between psychosocial factors recorded shortly after diagnosis and diabetes-related outcomes including (i) glycaemic control, (ii) diabetes knowledge, (iii) treatment satisfaction, and (iv) quality of life in adults following initial diagnosis of Type 1 diabetes. Second, to identify which psychological and social factors at the time of diagnosis determine those patients who are most likely to respond well to diabetes education, and to identify patients who appear vulnerable to being poorly controlled. A third objective was to assess the role of illness-related coping styles in adults with newly diagnosed Type 1 diabetes, and to examine the ways in which particular strategies relate to objective and subjective indicators of physical and psychological well-being in Type 1 diabetes across time. Finally, the fourth aim was to provide an evaluation of coping from the patients' perspectives in order to derive aspects of coping which are specific to the individuals themselves. The goal of this approach was to work towards providing a more sensitive, diabetes-specific measure of coping designed to assess the psychological impact of diabetes, as well as other important adjustment and lifestyle-related issues in adults with Type 1 diabetes. The studies presented in the present thesis have attempted to address these aims.

The Edinburgh Prospective Diabetes Study

The Edinburgh Prospective Diabetes Study (EPDS) (see Part II) was designed to monitor the progress of adults with Type 1 diabetes following initial diagnosis of the disorder.

The EPDS adds to past research by demonstrating that individual differences in social and educational factors (i.e. socio-economic status and diabetes knowledge) are the most consistent long-term predictors of glycaemic control. In particular, people who had a more comprehensive knowledge of their diabetes at four months after diagnosis were more likely to have good glycaemic control in future follow-ups at 12 months and at 36 months after diagnosis. These important findings imply that by increasing the patients' knowledge of diabetes shortly after diagnosis, it may be possible to produce subsequent improvements in the quality of glycaemic control achieved up to 36 months after diagnosis. Furthermore, it appears that people who have a lower socio-economic status are at increased risk of poor glycaemic control. This vulnerable group of individuals may be most likely to benefit from such an intervention.

From the results of the EPDS there was little evidence for any consistent relationships between individual differences in self-reported psychosocial variables recorded shortly after diagnosis and subsequent glycaemic control during the 36 months following initial diagnosis of Type 1 diabetes. This suggests that, in adults, self-reported psychological variables (e.g. personality and psychiatric distress) recorded shortly after diagnosis, and social factors (e.g. quality of life) are not reliable predictors of glycaemic control during the early stages of diabetes self-management, but may be important long-term predictors of glycaemic control. In the future, longitudinal studies of longer duration are required to replicate these findings and to further examine the temporal relationships between psychological factors and glycaemic control in adults with Type 1 diabetes.

The findings of the EPDS have provided broad support for the Intelligence-as-Process, Personality, Interests and Intelligence-as-Knowledge (PPIK) theory (Ackerman, 2000; Ackerman and Rolfhus, 1999) (discussed in Part I, Chapter 2) and suggest that the PPIK model provides a theoretical framework which can be used to direct future research into the determinants of diabetes-related knowledge. In addition to premorbid IQ, a person's socio-economic status, personality traits, and coping styles were important determinants of diabetes knowledge. These early risk factors can be used to identify those patients who may benefit from educational interventions at the time of diagnosis of Type 1 diabetes.

The results presented in this thesis add to previous studies which have found evidence for the reliability and validity of Diabetes Quality of Life (DQOL) measure and the Diabetes Treatment Satisfaction Questionnaire (DTSQ). These scales had excellent within subjects stability across follow-ups reviews. However, the EPDS also revealed that the dimensions of the DQOL shared significant overlap with the DTSQ. This is not surprising because both of these measures are diabetes-specific scales. As acknowledged by Deary and colleagues (1997), being aware that important constructs in health psychology have significant overlaps should direct future research to identify portions of variance that particular constructs can account for that are not captured by other variables. This would allow those constructs that have strong validity to be retained (Deary, Clyde and Frier, 1997).

There was a consistent pattern of associations between psychological factors (e.g. neuroticism and psychiatric distress) recorded shortly after diagnosis, and negative self-reported diabetes-related outcomes including low levels of satisfaction, greater impact of diabetes, the tendency to worry about the future complications of diabetes and social issues, and poor treatment satisfaction, which provides evidence for a group of overlapping health constructs that relate to the reporting of negative effects shortly after diagnosis. This apparent overlap in self-report measures suggests that these variables are measuring a common source of latent variance and may reflect what has been termed as 'a broad dimension of negative affectivity' (Watson and Pennebaker, 1989; Alder and Matthews, 1994).

Prior to the EPDS, few studies had attempted to investigate the indcpendent predictors of multidimensional aspects of diabetes-related quality of life, prospectively, in adults with Type 1 diabetes. The results of the EPDS have demonstrated that long-standing psychological factors (e.g. neuroticism, psychiatric distress and self-rated happiness) recorded shortly after diagnosis, and a person's satisfaction with their treatment regimen recorded at four months after diagnosis were the most consistent predictors of individual differences in self-reported aspects of diabetes quality of life up to 36 months after diagnosis. Therefore, individuals who report more neuroticism, greater unhappiness, less satisfaction with their treatment regimen, and individuals who have a tendency to experience greater psychiatric distress shortly after diagnosis are more likely to report having a poorer quality of life in future follow-ups. Furthermore, these effects appear to be long-lasting and may represent a general risk factor for poor psychological adjustment.

The role of illness-related coping in adults with Type 1 diabetes

One of the aims of the present thesis was to explore the role of illness-related coping in adults with Type 1 diabetes. In addressing this aim the theoretical framework laid out by Lazarus and Folkman (1984, 1987) in the stress and coping model was used to (i) examine the influence of psychological factors recorded at diagnosis on illness-related coping over time, and (ii) to examine the subsequent influence of illness-related coping constructs at 12 months after diagnosis on diabetes-related outcomes (Part II, Chapter 3). According to Lazarus and Folkman (1984, 1987) antecedents to disease such as psychological indicators act via mediating variables in determining health-related outcomes. Using this unique approach, the EPDS has provided the first longitudinal assessment of the role of illness-related coping in adults with Type 1 diabetes and extends past research by focusing on a broader range of psychosocial factors and illness-related coping outcomes than has been studied in the past.

The results presented in this thesis indicate that in adults, individual differences in long-standing psychological factors (e.g. personality traits) and social factors (e.g. the perceived impact of diabetes) recorded shortly after diagnosis are reliable indicators of illness-related coping strategies over time. For example, negative psychosocial factors including less happiness, neuroticism, greater psychiatric distress, and poor self-reported quality of life recorded shortly after diagnosis were consistent predictors of negative-emotion coping during the three years following diagnosis. In contrast, extraversion, less psychiatric distress and happiness were predictive of more instrumental (problem-focused) coping. These results indicate that psychosocial factors such as personality traits, and a person's self-reported well-being recorded shortly after diagnosis may be used to identify patients who are at risk of greater emotional preoccupation in later follow-ups.

As expected, people who reported greater emotional preoccupation at 12 months after diagnosis were consistently more likely to report negatively with regard to their health and well-being at 24 months and at 36 months after diagnosis including greater fear of hypoglycaemia, poor self-management, poor self-reported quality of life, and less treatment satisfaction. In contrast, instrumental coping was found to be associated with better objective health status (e.g. glycaemic control) but was not associated with self-reported outcomes of diabetes. The findings of the EPDS complement the results of previous cross-sectional studies, and suggest that emotion-focused coping is a maladaptive coping strategy in adults following initial diagnosis of Type 1 diabetes. It is therefore important for health professionals to identify individuals at the time of diagnosis who may be at risk of maladaptive coping responses, and to increase the amount of education and support that is available to them.

Coping with diabetes: assessment and measurement

Evaluating the patients' perspective

In evaluation of the patients' perspectives of coping with diabetes eight diabetes-specific domains were identified which appeared to reflect adaptive and maladaptive responses to diabetes self-management (Part III, Chapter I).

All of the patients spoke about the burden of diabetes and the impact which diabetes has on aspects of their daily life. Some people also described experiencing negative-emotions including depression and anxiety, and a fear of the threat of potential complications of the disorder. From the results it appears that these emotion-oriented responses are linked to negative self-reported outcomes of diabetes including poor perceived control, poor self-management and feelings of alienation.

Often in health psychology researchers have focused on maladaptive coping responses, however, in the present thesis several adaptive responses emerged from the participants' accounts of their experiences of adjusting to diabetes. These included active efforts to gather information about diabetes, adherence to diabetes self-management activities, and acceptance of diabetes as a problem leading to a more positive outlook, and finally, a willingness to make use of the support and guidance provided by health professionals, and to share their experiences of diabetes with other personal contacts (e.g. friends and family members). More importantly, these factors were often described as having positive consequences for the patients' self-reported well-being.

These findings have a number of implications for future research. Firstly, they suggest that it is important for researchers and health professionals to facilitate goal-directed/problem-focused responses to coping with diabetes, and to attempt to reduce the emotional burden of diabetes, particularly during the period following diagnosis. Secondly, the results highlight the fact that adjustment to diabetes is an individual process. It is therefore important for health professionals to work towards the implementation of interventions and treatments that are tailored to the needs of the individual. If such interventions are to be effective then it is likely that more prolonged education and psychological support will be necessary for some patients.

The Diabetes Impact, Adjustment and Lifestyle Scales

The Diabetes Impact, Adjustment and Lifestyle Scales were developed by building on the aforementioned patient's perspectives of their adjustment to Type 1 diabetes and by combining this approach with existing, empirically based, coping theory (Lazarus and Folkman, 1984, 1987). The development of a preliminary scale, pilot testing, and subsequent reliability and validity testing of the DIALS have been described (Part III, Chapters 2 and 3).

Preliminary findings presented in the present thesis indicate that the dimensions of the DIALS (Impact, Fear of complications, Diabetes-related distress, Adherence and Information-seeking) (i) provide support for the multidimensional assessment of coping in adults with Type diabetes, (ii) appear to be associated with basic personality traits and illness-related coping constructs that are considered important in general models of coping, and (iii) contains sufficient psychometric properties to recommend its use for future research purposes and within clinical settings. In particular, it has been possible to replicate, in part, the two major illness-related coping constructs, negative-emotion coping and instrumental coping, assessed by the CHIP using a scale that was developed specifically to measure diabetes-specific aspects of coping in adults with Type 1 diabetes. Further investigations are necessary to extend these findings by exploring the causal relationships between the DIALS and a broader range of demographic and social constructs.

Using structural equation modelling, it has been possible to support previous research which has found evidence to suggest that illness-related coping constructs act as mediators in the link between personality (e.g. neuroticism) and self-reported outcomes of diabetes (Deary, Clyde and Frier, 1997) and therefore offer broad support for process models of illness-reporting in diabetes. However, neuroticism and negative-emotion coping also shared common variance, and neuroticism did have some direct influence on diabetes-related outcomes. Based on these findings, it would be useful to test alternative models (e.g. negative affectivity theory) competitively to establish their goodness of fit.

The validation of any instrument is an ongoing process, therefore, future longitudinal studies are recommended to replicate these findings and to further investigate the reliability and validity of the DIALS, as well as the scales sensitivity to change. Particular recommendations are made to apply the DIALS in different settings and with different groups of patients such as children or adolescents with diabetes. The results of the present study may also be used to generate hypotheses which can be tested in future investigations. Finally, it is hoped that the DIALS will be used in the future to bring about improvements in the assessment of coping in people with diabetes.

In conclusion, the present thesis has both theoretical and practical implications within health psychology, and more specifically within the field of diabetes care. The general focus of the present thesis has been to provide an assessment of coping in adults with Type 1 diabetes. In doing so it has been possible to draw on the use of dominant theories of coping which are frequently discussed in the health psychology literature (Lararus and Folkman, 1984, 1987), and hence to enhance current understanding of the relevance and potential applications of process models of coping in adults with Type 1 diabetes. The theoretical basis for the present thesis has followed, primarily, the assumptions laid out by Lazarus and Folkman (1984, 1987) in their stress and coping model. In previous research, process models of coping have often been applied to assess how people cope with stressful situations, but rarely, to assess how people cope with specific health problems such as diabetes. The present thesis has taken a novel approach to the prospective analysis of the multiple determinants, and outcomes of particular coping styles in adults with Type 1 diabetes and has made several contributions to this field of research.

On the basis of the research presented in this thesis several recommendations can be made. In terms of future research, the findings of the EPDS should now be used to generate hypotheses about the direct links between psychosocial variables and diabetes-related outcomes which can then be tested using formal hypothesis testing techniques (e.g. structural equation modelling). In doing so, it may be possible to test different models competitively to establish their goodness of fit. The results of the present research suggest that the development of future models may benefit from the inclusion of coping constructs as mediators of the effects of personality dimensions on behavioural outcomes.

Following the results of the DCCT (1993) it is particularly important to examine the influence of psychosocial factors on regimen adherence and glycaemic control in people with Type 1 diabetes. Such studies should incorporate larger patient samples and use longitudinal designs that are capable of monitoring the patients' progress over a longer duration. Longitudinal studies like the EPDS are particularly important because they allow researchers to determine how psychosocial factors and other health-related variables, affect a person's objective and subjective health status over time. Furthermore the results of prospective studies such as the EPDS can help to inform the development of intervention studies, as well as identifying vulnerable groups of patients.

The results of the present thesis also have practical implications within the field of diabetes care. In particular, the findings suggest that intervention studies that incorporate specific coping skills training aimed at increasing problem-focussed coping and reducing the emotional burden of Type 1 diabetes may be effective in improving an individual's glycaemic control and self-reported well-being in future follow-ups. So far, the results of intervention studies that have attempted to evaluate the effectiveness of coping skills training in adolescents with Type 1 diabetes have produced promising results (Grey, Boland, Davidson, Chang Yu, Sullivan-Bolyai and Tamborlane, 1998). Future research is now necessary to evaluate the effectiveness of coping skills training in adults with Type 1 diabetes.

The DIALS may also be a useful tool in clinical settings to identify individuals who may be having problems coping with their diabetes. The ease of administration of this measure, the use of items that are directly relevant to people with diabetes, and the associations that have been found between the DIALS and valuable end-points related to the psychological and social functioning of the individual, makes the DIALS a particularly attractive measure for both future research and medical interventions.

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APPENDIX

(i) QUESTIONNAIRES AND MEASURES USED IN THE STUDIES

Background Information Form
National Adult Reading Test (NART)
Eysenck Personality Questionnaire (EPQ-Revised short form)
Goldberg's Conscientiousness scale
Coping with Health Injuries and Problems Scale (CHIP)
General Health Questionnaire (GHQ)
Diabetes Locus of Control (DLOC)
Diabetes Knowledge Questionnaire (DKNQ)
Diabetes Quality of Life Measure (DQOL)
Diabetes Treatment Satisfaction Questionnaire (DTSQ)
Well-being Questionnaire
Hypoglycaemia Fear Survey (HFS)
Summary of Diabetes Self-Care Activities Questionnaire (SDSCA)

NAME...

1. Age in years: ....

2. Gender: Male Female (please circle)

3. Marital Status: (please circle)

   single married/co-habiting divorced/separated widowed

4. What is your current occupation?: ....

   ....

5. Please indicate below the number of alcohol units you normally consume per week:

   one unit = half a pint of beer/a glass of wine

   .... units/week

6. Smoking: (please circle)

   never smoked

   ex-smoker (how long is it since you last smoked? ....)

   current smoker (no. of cigarettes per day.........................)

7. Do you have any additional health problems/illnesses aside from diabetes? (please give details below)

   ....

   ....

   ....

8. Were you admitted to hospital when you were first diagnosed with diabetes?

   YES NO (please circle)

   If yes;

   How long were you in hospital for? ....

9. How many times have you been admitted to hospital for diabetes-related problems during the past twelve months?

   ....

10. How happy are you with your present life at home? (please circle a number on this line)

    Very unhappy 0---1---2---3---4---5---6---7---8---9---10 Very happy

NART

chord
ache
depot
aisle
bouquet
psalm
capon
deny
nausea
debt
courteous
rarefy
equivocal
naive
catacomb
gaoled
thyme
heir
radix
assignate
hiatus
subtle
procreate
gist
gouge
superfluous
simile
banal
quadruped
cellist
facade
zealot
drachm
aeon
placebo
abstemious
detente
idyll
puerperal
aver
gauche
topiary
leviathan
beatify
prelate
sidereal
demesne
syncope
labile
campanile

Name: ....

EPQ-R (Short Form)

Please answer **ALL** of the questions, *CIRCLING* the answer you feel best describes you. Answer the questions honestly and do not spend too much time thinking about them.

1.	Does your mood often go up and down?	YES	NO
2.	Do you take much notice of what people think?	YES	NO
3.	Are you a talkative person?	YES	NO
4.	If you say you will do something, do you keep your promise no matter how inconvenient it might be?	YES	NO
5.	Do you ever feel 'just miserable' for no reason?	YES	NO
6.	Would being in debt worry you?	YES	NO
7.	Are you rather lively?	YES	NO
8.	Were you ever greedy by helping yourself to more than your share of anything?	YES	NO
9.	Are you an irritable person?	YES	NO
10.	Would you take drugs which may have strange or dangerous effects?	YES	NO
11.	Do you enjoy meeting new people?	YES	NO
12.	Have you ever blamed someone for doing something you knew was really your fault?	YES	NO
13.	Are your feelings easily hurt?	YES	NO
14.	Do you prefer to go your own way rather than act by the rules?	YES	NO
15.	Can you usually let yourself go and enjoy yourself at a lively party?	YES	NO
16.	Are *all* your habits good and desirable ones?	YES	NO
17.	Do you often feel 'fed-up'?	YES	NO
18.	Do good manners and cleanliness matter much to you?	YES	NO
19.	Do you usually take initiative in making new friends?	YES	NO
20.	Have you ever taken anything (even a pin or button) that belonged to someone else	YES	NO
21.	Would you call yourself a nervous person?	YES	NO
22.	Do you think marriage is old-fashioned and should be done away with?	YES	NO
23.	Can you easily get some life into a rather dull party?	YES	NO
24.	Have you ever broken or lost something belonging to someone else?	YES	NO
25.	Are you a worrier?	YES	NO
26.	Do you enjoy co-operating with others?	YES	NO
27.	Do you tend to keep in the background on social occasions?	YES	NO
28.	Does it worry you if you know there are mistakes in your work?	YES	NO
29.	Have you ever said anything bad or nasty about anyone?	YES	NO
30.	Would you call yourself tense or 'highly-strung'?	YES	NO
31.	Do you think people spend too much time safeguarding their future with savings and insurances?	YES	NO
32.	Do you like mixing with people?	YES	NO
33.	As a child were you ever cheeky to your parents?	YES	NO
34.	Do you worry too long after an embarrassing experience?	YES	NO
35.	Do you try not to be rude to people?	YES	NO
36.	Do you like plenty of bustle and excitement around you?	YES	NO
37.	Have you ever cheated at a game?	YES	NO
38.	Do you suffer from 'nerves'?	YES	NO
39.	Would you like other people to be afraid of you?	YES	NO
40.	Have you ever taken advantage of someone?	YES	NO
41.	Are you mostly quiet when you are with other people?	YES	NO
42.	Do you often feel lonely?	YES	NO
43.	It is better to follow society's rules than go your own way?	YES	NO
44.	Do other people think of you as being very lively?	YES	NO
45.	Do you always practice what you preach?	YES	NO
46.	Are you often troubled about feelings of guilt?	YES	NO
47.	Do you sometimes put off until tomorrow what you ought to do today?	YES	NO
48.	Can you get a party going?	YES	NO

Ref: Eysenck et al (1985) Personality and Individual Differences, 6, 21-29.

Name: ....

Goldberg's C Self-Assessment

Please circle the number which you think tells us what you are really like, on a scale of 1 to 7:

organised	1	2	3	4	5	6	7	disorganised
irresponsible	1	2	3	4	5	6	7	responsible
negligent	1	2	3	4	5	6	7	conscientious
impractical	1	2	3	4	5	6	7	practical
thorough	1	2	3	4	5	6	7	careless
hardworking	1	2	3	4	5	6	7	lazy
extravagant	1	2	3	4	5	6	7	thrifty

Name: ....

The following are ways of reacting to HEALTH PROBLEMS, such as ILLNESSES, SICKNESSES, and INJURIES. These are typically difficult, stressful, or upsetting situations. We are interested in your typical reactions to illness in general, not just your current problem. Please circle a number from 1 to 5 for each of the following items. Indicate how much you have engaged in these types of activities when you have encountered health problems. Please be sure to respond to each item.

1 = Not at all **3 = Moderately** **5 = Very Much**

1.	Think about the good times I've had.	1	2	3	4	5
2.	Stay in bed.	1	2	3	4	5
3.	Find out more information about the illness.	1	2	3	4	5
4.	Wonder why it happened to me.	1	2	3	4	5
5.	Be with other people.	1	2	3	4	5
6.	Lie down when I feel tired.	1	2	3	4	5
7.	Seek medical treatment as soon as possible.	1	2	3	4	5
8.	Become angry because it happened to me.	1	2	3	4	5
9.	Daydream about pleasant things.	1	2	3	4	5
10.	Get plenty of sleep.	1	2	3	4	5
11.	Concentrate on the goal of getting better.	1	2	3	4	5
12.	Get frustrated.	1	2	3	4	5
13.	Enjoy the attention of friends and family.	1	2	3	4	5
14.	Try to use as little energy as possible.	1	2	3	4	5
15.	Learn more about how my body works.	1	2	3	4	5
16.	Feel anxious about the things I can't do.	1	2	3	4	5
17.	Make plans for the future.	1	2	3	4	5
18.	make sure I am warmly dressed or covered.	1	2	3	4	5
19.	Do what my doctors tell me.	1	2	3	4	5
20.	Fantasise about all the things I could do if I was better.	1	2	3	4	5
21.	Listen to music.	1	2	3	4	5
22.	Make my surroundings as quiet as possible.	1	2	3	4	5
23.	Try my best to follow my doctor's advice.	1	2	3	4	5
24.	Wish that the problem had never happened.	1	2	3	4	5
25.	Invite people to visit me.	1	2	3	4	5
26.	Be as quiet and still as I can.	1	2	3	4	5
27.	Be prompt about taking medications.	1	2	3	4	5
28.	Feel anxious about being weak and vulnerable.	1	2	3	4	5
29.	Surround myself with nice things (e.g. flowers).	1	2	3	4	5
30.	Make sure I am comfortable.	1	2	3	4	5
31.	Learn more about the most effective treatments available.	1	2	3	4	5
32.	Worry that my health might get worse.	1	2	3	4	5

1 = Not at all **3 = Moderately** **5 = Very Much**

THE GENERAL HEALTH QUESTIONNAIRE

GHQ 28

David Goldberg

Please read this carefully.

We should like to know if you have had any medical complaints and how your health has been in general, *over the past few weeks*. Please answer ALL the questions on the following pages simply by underlining the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those that you had in the past.

It is important that you try to answer ALL the questions.

Thank you very much for your co-operation.

Have you recently

A1 – been feeling perfectly well and in good health?	Better than usual	Same as usual	Worse than usual	Much worse than usual
A2 – been feeling in need of a good tonic?	Not at all	No more than usual	Rather more than usual	Much more than usual
A3 – been feeling run down and out of sorts?	Not at all	No more than usual	Rather more than usual	Much more than usual
A4 – felt that you are ill?	Not at all	No more than usual	Rather more than usual	Much more than usual
A5 – been getting any pains in your head?	Not at all	No more than usual	Rather more than usual	Much more than usual
A6 – been getting a feeling of tightness or pressure in your head?	Not at all	No more than usual	Rather more than usual	Much more than usual
A7 – been having hot or cold spells?	Not at all	No more than usual	Rather more than usual	Much more than usual

---

B1 – lost much sleep over worry?	Not at all	No more than usual	Rather more than usual	Much more than usual
B2 – had difficulty in staying asleep once you are off?	Not at all	No more than usual	Rather more than usual	Much more than usual
B3 – felt constantly under strain?	Not at all	No more than usual	Rather more than usual	Much more than usual
B4 – been getting edgy and bad-tempered?	Not at all	No more than usual	Rather more than usual	Much more than usual
B5 – been getting scared or panicky for no good reason?	Not at all	No more than usual	Rather more than usual	Much more than usual
B6 – found everything getting on top of you?	Not at all	No more than usual	Rather more than usual	Much more than usual
B7 – been feeling nervous and strung-up all the time?	Not at all	No more than usual	Rather more than usual	Much more than usual

Have you recently

C1 –	**been managing to keep yourself busy and occupied?**	More so than usual	Same as usual	Rather less than usual	Much less than usual
C2 –	**been taking longer over the things you do?**	Quicker than usual	Same as usual	Longer than usual	Much longer than usual
C3 –	**felt on the whole you were doing things well?**	Better than usual	About the same	Less well than usual	Much less well
C4 –	**been satisfied with the way you've carried out your task?**	More satisfied	About same as usual	Less satisfied than usual	Much less satisfied
C5 –	**felt that you are playing a useful part in things?**	More so than usual	Same as usual	Less useful than usual	Much less useful
C6 –	**felt capable of making decisions about things?**	More so than usual	Same as usual	Less so than usual	Much less capable
C7 –	**been able to enjoy your normal day-to-day activities?**	More so than usual	Same as usual	Less so than usual	Much less than usual

D1 –	**been thinking of yourself as a worthless person?**	Not at all	No more than usual	Rather more than usual	Much more than usual
D2 –	**felt that life is entirely hopeless?**	Not at all	No more than usual	Rather more than usual	Much more than usual
D3 –	**felt that life isn't worth living?**	Not at all	No more than usual	Rather more than usual	Much more than usual
D4 –	**thought of the possibility that you might make away with yourself?**	Definitely not	I don't think so	Has crossed my mind	Definitely have
D5 –	**found at times you couldn't do anything because your nerves were too bad?**	Not at all	No more than usual	Rather more than usual	Much more than usual
D6 –	**found yourself wishing you were dead and away from it all?**	Not at all	No more than usual	Rather more than usual	Much more than usual
D7 –	**found that the idea of taking your own life kept coming into your mind?**	Definitely not	I don't think so	Has crossed my mind	Definitely has

A ☐ B ☐ C ☐ D ☐ **TOTAL** ☐

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Name: ....

CONTROL OF DIABETES QUESTIONNAIRE

Please answer each question by circling the number that corresponds to the answers the way you feel:

	Strongly Disagree	Disagree	Mildly Disagree	Mildly Agree	Agree	Strongly Agree
1 I can avoid complications of diabetes.	1	2	3	4	5	6
2 When my sugar is too high it is because of something *I've* done.	1	2	3	4	5	6
3 Good health is a matter of good fortune	1	2	3	4	5	6
4 Regular doctor's visits avoid problems	1	2	3	4	5	6
5 What *I* do is the main influence on my health.	1	2	3	4	5	6
6 If it's meant to be I will avoid complications of diabetes.	1	2	3	4	5	6
7 I should call my doctor whenever I feel bad.	1	2	3	4	5	6
8 My blood sugars will be what they will be.	1	2	3	4	5	6
9 Blood sugars are controlled by accident	1	2	3	4	5	6
10 I can only do what my doctor tells me.	1	2	3	4	5	6
11 I never know why my diabetes is out of control.	1	2	3	4	5	6
12 Health professionals keep me healthy	1	2	3	4	5	6
13 My family is a big help in controlling my diabetes.	1	2	3	4	5	6
14 When my blood sugar is high it's because *I've* made a mistake.	1	2	3	4	5	6
15 Good control is a matter of luck.	1	2	3	4	5	6
16 Complications are the result of carelessness.	1	2	3	4	5	6
17 *I* am responsible for my health.	1	2	3	4	5	6
18 Other people (not doctors or nurses) have a big responsibility for my diabetes.	1	2	3	4	5	6

Name: ....

DIABETES KNOWLEDGE QUESTIONNAIRE

Please circle the letter beside the answer which you think is correct. There is only one correct answer for each question.

DIET QUESTIONS

1 Potatoes are mainly:

a Carbohydrate

b Fat

c Vitamins/minerals

d Protein

2 Butter is mainly:

a Carbohydrate

b Protein

c Vitamins/minerals

d Fat

3 Special "DIABETIC" foods are:

a Less fattening than the non-diabetic equivalent

b Essential in a diabetic diet

c Usually more expensive than the non-diabetic equivalent

d Better to take than other "low-sugar" foods

4 Food containing alot of sugar:

a Is forbidden in a diabetic diet

b Will lower your blood sugar

c Will have no effect on your blood sugar

d Will make your blood sugar rise

5 If you miss a meal :

- a You may have a 'hypo'
- b Your blood sugar will go up
- c You will then have to take double your usual insulin dose for the next meal
- d You must eat double at the next meal

6 People eating a diabetic diet:

- a Should never eat chocolate
- b Must eat every two hours
- c Have a healthy diet that everyone should be eating
- d Should avoid going out for meals

QUESTIONS ABOUT INSULIN MANAGEMENT

1 You should inject your insulin:

- a About half an hour before meals
- b Immediately before you eat
- c As soon as you finish eating
- d Once you have started eating

2 If you accidently inject too much insulin you should:

- a Take some extra insulin
- b Eat extra carbohydrate and check your blood sugar frequently
- c Do nothing
- d Do some excercise to 'work it off'

3 You should aim to keep your blood tests:

- a Less than 4 mmol/l
- b 4 to 9mmol/l
- c 7 to 11 mmol/l
- d Over 11 mmol/l

4 If your blood test is high before lunch 3 days running :

a You should eat less at breakfast time

b Increase your morning dose of short-acting insulin

c Stop doing any exercise in the morning

d Take a extra insulin at teatime

5 When you inject your insulin :

a You should try and use the same place every day

b You should try to inject into muscle rather than fat

c If you inject into the same place, this may eventually make your blood sugar difficult to control

d If you get a bruise you should give the same dose again as the insulin may not have been absorbed

6 If you are travelling by car on a hot day, you should store your insulin:

a On the back window ledge of the car

b In the glove compartment of the car

c In the boot

d Inside the car out of direct sunlight

7 If you are going to do alot of exercise you should:

a Take extra insulin and check your sugar frequently

b Reduce your insulin and eat less beforehand

c Have a smaller meal than usual afterwards

d Take extra carbohydrate and check you sugar after exercise

GENERAL DIABETES

1 The type of diabetes you have :

a Occurs because you have an unhealthy diet

b Occurs because your body produces too little insulin

c May disappear after a few years

d Occurs because you have too much insulin in your blood

2 Haemoglobin A1C tests show how well your blood sugar has been controlled:

a Over the last year
b Over the last 6 to 8 weeks
c Over the last week
d Over the last 6 months

3 Which of the following may put your blood sugar up:

a Stress, such as difficulties at work or home
b Taking too much insulin
c Cold weather
d Extra activity

4 Insulin :

a Makes the blood sugar go up
b Makes the blood sugar go down
c Makes the blood sugar stay the same
d Is usually made by the stomach

5 You should avoid being overweight with diabetes because:

a Insulin is absorbed from fat more rapidly
b Insulin may not work as efficiently
c 'Hypos' are more frequent in overweight people
d People with diabetes should not go on a weight-reducing diet

6 If you are going out for the evening with friends :

a You should avoid alcohol if possible
b If you have a drink you should eat less as it will make your blood sugar run high
c Drinking Pils low sugar lager is better than ordinary lager
d If you have alcohol, you should check your blood sugar before going to bed

7 If you are going on holiday and may have to go by plane:

- a You should avoid flying if you have diabetes
- b You should always pack your insulin in the hold as it is cooler there
- c You should only take one bottle/cartridge of insulin or the customs officer may detain you
- d It is a good idea to let a friend take spare supplies for you

SICK DAYS and HYPOS

1 Testing your urine for ketones is :

- a Important if you think you are going hypo
- b Important if you feel unwell for any reason
- c Important if you have been doing alot of exercise
- d A good alternative to doing blood tests

2 If you are feeling unwell:

- a You can miss out doing blood tests as long as you are not thirsty
- b Your insulin dose is likely to go down
- c You may need to increase your insulin
- d You do not need to check for ketones unless you are vomiting

3 If you have been sick and do not feel like eating:

- a You should miss out your insulin
- b You should never take sweet drinks such as lucozade as these will put your blood sugar to high
- c You should call your doctor if you keep being sick
- d Blood tests are not helpful as they are inaccurate if you have ketones around

4 If you are going 'hypo' which of the following would be the best food to eat:

- a Chips
- b Chocolate
- c Burgers
- d Diet Coke

DQOL

Name: ....

Please read each statement carefully. Please indicate how satisfied or dissatisfied you currently are with the aspect of your life described in the statement. Circle the number that best describes how you feel. There are no right or wrong answers to these questions. We are interested in your opinion.

	Very satisfied	Moderately satisfied	Neither	Moderately dissatisfied	Very dissatisfied
Satisfaction - core items:					
1. How satisfied are you with the amount of time it takes to manage your diabetes?	1	2	3	4	5
2. How satisfied are you with the amount of time you spend getting checkups?	1	2	3	4	5
3. How satisfied are you with the time it takes to determine your sugar level?	1	2	3	4	5
4. How satisfied are you with your current treatment?	1	2	3	4	5
5. How satisfied are you with the flexibility you have in your diet?	1	2	3	4	5
6. How satisfied are you with the burden your diabetes is placing on your family?	1	2	3	4	5
7. How satisfied are you with your knowledge about your diabetes?	1	2	3	4	5
8. How satisfied are you with your sleep?	1	2	3	4	5
9. How satisfied are you with your social relationships and friendships?	1	2	3	4	5
10. How satisfied are you with your sex life?	1	2	3	4	5
11. How satisfied are you with your work, school, and household activities?	1	2	3	4	5
12. How satisfied are you with the appearance of your body?	1	2	3	4	5
13. How satisfied are you with the time you spend exercising?	1	2	3	4	5
14. How satisfied are you with your leisure time?	1	2	3	4	5
15. How satisfied are you with life in general?	1	2	3	4	5

	Never	Very seldom	Sometimes	Often	All the time
Impact - core items:					
1. How often do you feel pain associated with the treatment for your diabetes?	1	2	3	4	5
2. How often are you embarrassed by having to deal with your diabetes in public?	1	2	3	4	5
3. How often do you have low blood sugar?	1	2	3	4	5
4. How often do you feel physically ill?	1	2	3	4	5
5. How often does your diabetes interfere with your family life?	1	2	3	4	5
6. How often do you have a bad night's sleep?	1	2	3	4	5
7. How often to you find your diabetes limiting your social relationships and friendships?	1	2	3	4	5
8. How often do you feel good about yourself?	1	2	3	4	5
9. How often do you feel restricted by your diet?	1	2	3	4	5
10. How often does your diabetes interfere with your sex life?	1	2	3	4	5
11. How often does your diabetes keep you from driving a car or using a machine (e.g. a typewriter)?	1	2	3	4	5
12. How often does your diabetes interfere with your exercising?	1	2	3	4	5
13. How often do you miss work, school, or household duties because of your diabetes?	1	2	3	4	5
14. How often do you find yourself explaining what it means to have diabetes?	1	2	3	4	5
15. How often do you find that your diabetes interrupts your leisure-time activities?	1	2	3	4	5
16. How often do you tell others about your diabetes?	1	2	3	4	5
17. How often are you teased because you have diabetes?	1	2	3	4	5
18. How often do you feel that because of your diabetes you go to the bathroom more than others?	1	2	3	4	5
19. How often do you find that you eat something you shouldn't rather than tell someone that you have diabetes?	1	2	3	4	5
20. How often do you hide from others the fact that you are having "hypo"?	1	2	3	4	5

Please indicate how often the following events happen to you. Please circle the number that best describes your feeling. If the question is not relevant to you, circle non-applicable.

	Never	Very seldom	Sometimes	Often	All the time	Does not apply
Social Worry & Diabetes - core items:						
1. How often do you worry about whether you will get married?	1	2	3	4	5	0
2. How often do you worry about whether you will have children?	1	2	3	4	5	0
3. How often do you worry about whether you will not get a job you want?	1	2	3	4	5	0
4. How often do you worry about whether you will be denied insurance?	1	2	3	4	5	0
5. How often do you worry about whether you will be able to complete your education?	1	2	3	4	5	0
6. How often do you worry about whether you will miss work?	1	2	3	4	5	0
7. How often do you worry about whether you will be able to take a vacation or a trip?	1	2	3	4	5	0
8. How often do you worry about whether you will pass out?	1	2	3	4	5	0
9. How often do you worry that your body looks differently because you have diabetes?	1	2	3	4	5	0
10. How often do you worry that you will get complications from your diabetes?	1	2	3	4	5	0
11. How often do you worry about whether someone will not go out with you because you have diabetes?	1	2	3	4	5	0

Individual general item:

Compared to other people for your age, would you say your health is : (circle one)

1. Excellent
2. Good
3. Fair
4. Poor

Name: . . . .

DTSQ

The following questions are concerned with the treatment for your diabetes (including insulin, tablets and/or diet) and your experience over the past few weeks. Please answer each question by circling a number on each of the scales.

1. How satisfied are you with your current treatment?

very satisfied 6 5 4 3 2 1 0 very dissatisfied

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

most of the time 6 5 4 3 2 1 0 none of the time

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

most of the time 6 5 4 3 2 1 0 none of the time

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

very convenient 6 5 4 3 2 1 0 very inconvenient

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

very flexible 6 5 4 3 2 1 0 very inflexible

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

very satisfied 6 5 4 3 2 1 0 very dissatisfied

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

Yes, I would definitely recommend the treatment 6 5 4 3 2 1 0 No, I would definitely not recommend the treatment

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

very satisfied 6 5 4 3 2 1 0 very dissatisfied

Please make sure that you have circled one number on each of the scales.

WELL-BEING QUESTIONNAIRE

Please circle a number on each of the following scales to indicate how often you feel each phrase has applied to you in the past few weeks:

	all the time			not at all
1. I feel that I am useful and needed	3	2	1	0
2. I have crying spells or feel like it	3	2	1	0
3. I find I can think quite clearly	3	2	1	0
4. My life is pretty full	3	2	1	0
5. I feel downhearted and blue	3	2	1	0
6. I enjoy the things I do	3	2	1	0
7. I feel nervous and anxious	3	2	1	0
8. I feel afraid for no reason at all	3	2	1	0
9. I get upset easily or feel panicky	3	2	1	0
10. I feel like I'm falling apart and going to pieces	3	2	1	0
11. I feel calm and can sit still easily	3	2	1	0
12. I fall asleep easily and get a good night's rest	3	2	1	0
13. I feel energetic, active or vigorous	3	2	1	0
14. I feel dull or sluggish	3	2	1	0
15. I feel tired, worn out, used up, or exhausted	3	2	1	0
16. I have been waking up feeling fresh and rested	3	2	1	0
17. I have been happy, satisfied, or pleased with my personal life	3	2	1	0
18. I have felt well adjusted to my life situation	3	2	1	0
19. I have lived the kind of life I wanted to	3	2	1	0
20. I have felt eager to tackle my daily tasks or make new decisions	3	2	1	0
21. I have felt I could easily handle or cope with any serious problem or major change in my life	3	2	1	0
22. My daily life has been full of things that were interesting to me	3	2	1	0

Please make sure that you have considered each of the 22 statements and have circled a number on each of the 22 scales.

Name : ....

Hypoglycaemic Fear Survey

Low Blood Sugar Survey

I. Behaviour: Below is a list of things people with diabetes do in order to avoid low blood sugar. Read each item carefully. Circle one of the numbers to the right that best describes what you do during your daily routine to AVOID low blood sugar.

	Never	Rarely	Sometimes	Often	Always
1. Eat large snacks at bedtime	0	1	2	3	4
2. Avoid being alone when my sugar is likely to be low	0	1	2	3	4
3. If test blood glucose, run a little high to be on the safe side	0	1	2	3	4
4. Keep my sugar high when I will be alone for a while	0	1	2	3	4
5. Eat something as soon as I feel the first sign of low blood sugar	0	1	2	3	4
6. Reduce my insulin when I think my sugar is low	0	1	2	3	4
7. Keep my sugar high when I plan to be in a long meeting or at a party	0	1	2	3	4
8. Carry fast-acting sugar with me	0	1	2	3	4
9. Avoid exercise when I think my sugar is low	0	1	2	3	4
10. Check my sugar often when I plan to be in a long meeting or out at a party	0	1	2	3	4

II. Worry: Below is a list of concerns people with diabetes sometimes have. Please read each item carefully (do not skip any). Circle one of the numbers to the right that best describes how often you WORRY about each item because of low blood sugar.

I worry about....	Never	Rarely	Sometimes	Often	Always
11. Not recognising/realising I am having low blood sugar	0	1	2	3	4
12. Not having food, fruit or juice with me	0	1	2	3	4
13. Passing out in public	0	1	2	3	4
14. Embarrassing myself or my friends in a social situation	0	1	2	3	4
15. Having a reaction while alone	0	1	2	3	4
16. Appearing stupid or drunk	0	1	2	3	4
17. Losing control	0	1	2	3	4
18. No one being around to help me during a reaction	0	1	2	3	4
19. Having a reaction while driving	0	1	2	3	4
20. Making a mistake or having an accident	0	1	2	3	4
21. Difficulty thinking clearly when responsible for others	0	1	2	3	4
22. Feeling lightheaded or dizzy	0	1	2	3	4

SUMMARY OF DIABETES SELF-CARE ACTIVITIES

Instructions: Thankyou for taking the time to fill this out. The questions below ask you about your diabetes self-care activities *during the past 7 days.* If you were sick during the past 7 days, please think back to the last 7 days that you were not sick. Please answer the questions as honestly and accurately as you can. Your responses will be confidential.

DIET

The first few questions ask about your eating habits aver the last 7 days. If you have not been given a <u>specific</u> diet by your doctor or dietician, answer Question 1 according to the general guidelines you have received.

1. How often did you follow your recommended diet over the last 7 days?
__ 1. Always __ 2. Usually __ 3. Sometimes __ 4. Rarely __ 5. Never

2. What percentage of the time did you successfully limit your calories as recommended in healthy eating for diabetes control?
__0% (none) __25% (1/4) __50% (1/2) __75% (3/4) __100% (all)

3. During the past week, what percentage of your meals included high fibre foods, such as fresh fruits, fresh vegetables, whole grain breads, dried beans and peas, bran?
__0% (none) __25% (1/4) __50% (1/2) __75% 93/4) __100% (all)

4. During the past week, what percentage of your meals included high fat foods such as butter, ice cream, oil, nuts and seeds, mayonnaise, avacado, deep-fried food, salad dressing, bacon, other meat with fat or skin?
__0% (none) __25% (1/4) __50% (1/2) __75% 93/4) __100% (all)

5. During the past week what percentage of your meals included sweets and desserts such as pie, cake, jelly, soft drinks (regular, not diet drinks), cookies?
__0% (none) __25% (1/4) __50% (1/2) __75% 93/4) __100% (all)

EXERCISE

6. On how many of the last 7 days did you participate in at least 20 minutes of physical exercise?
0 1 2 3 4 5 6 7

7. What percentage of the time did you exercise the amount suggested by your doctor? (For example, if your doctor recommended 30 minutes of activity.)
__0% (none) __25% (1/4) __50% (1/2) __75% 93/4) __100% (all)

8. On how many of the last 7 days did you participate in a specific exercise session other than what you do around the house or as part of your work?
0 1 2 3 4 5 6 7

GLUCOSE TESTING

9. On how many of the last 7 days (that you were not sick) did you test your glucose (blood suger) level?
   __ 1. Every day __ 2. Most days __ 3. Some days __ 4. None of the days

10. Over the last 7 days (that you were not sick) what percentage of the glucose (blood sugar or urine) tests recommended by your doctor did you actually perform?
   __ 0% (none) __ 25% (1/4) __ 50% (1/2) __ 75% (3/4) __ 100% (all)

DIABETES MEDICATION

11. How many of your recommended insulin injections did you take in the last 7 days that you were supposed to?
   __ 1. All of them __ 2. Most of them __ 3. Some of them __ 4. None of them
   __ 5. I do not take insulin

12. How many of your recommended number of pills to control diabetes did you take that you were supposed to?
   __ 1. All of them __ 2. Most of them __ 3. Some of them __ 4. None of them
   __ 5. I do not take pills to control my diabetes

(ii) PATIENT INFORMATION SHEET FOR THE EDINBURGH PROSPECTIVE DIABETES STUDY

THE EDINBURGH PROSPECTIVE DIABETES STUDY

Patient Information Sheet

You have recently been diagnosed as having diabetes which requires treatment with insulin. One of the aims in the management of diabetes is to allow you to be able to pursue an active lifestyle with as few restrictions as possible but still maintaining good control of blood glucose. Everybody is different and has a different ability to cope with changes in lifestyle. We are trying to identify which patients with diabetes may need extra help to achieve these goals. This will allow us in the future to tailor diabetes education to the needs of individuals.

In order to help us with this, we would be grateful if you could complete a few questionnaires which are designed to assess your personality, coping abilities, quality of life and how diabetes affects daily living. We will ask you to complete some of these questionnaires every few months.

Although this study will not benefit you directly, the information which it will provide, should help us to improve the design of our education package in the future. We will keep you informed about any important results which arise from the study.

Any information or questions answered by you during the study will be treated in strict confidence.

MANY THANKS FOR YOUR HELP.

(iii) THE EDINBURGH DIABETES COPING INTERVIEW (EDCI)

Edinburgh Diabetes Coping Interview

Introduction

- I'm going to be asking you about how you have been coping with your diabetes and how well you feel you have adjusted to it.
- Some of the questions will relate to the questionnaires you completed but the main purpose of the interview is to gather information about what you consider to be the most important aspects of involved in coping with diabetes.
- **Check Tape** - then start it.

Coping

1) What does it mean to you to cope well with diabetes?

   (what is coping?)

   - does it mean being able to control blood sugar
   - being satisfied with your quality of life
   - having a comprehensive knowledge of diabetes
   - adhering to a complex regimen
   - adjusting emotionally and accepting diabetes as a part of life

2) How do you cope with your diabetes on a day to day basis?

   prompts:
   - control of emotions
   - physical maintenance

3) Can you describe any specific things you do (i.e. Specific mental or behavioural procedures), to help you to cope?

   prompts:
   - actively finding out about your diabetes
   - writing things down, e.g.. a diary
   - doing things to take your mind off it
   - things you do automatically

4) How did you feel when you were first told that you had diabetes?

5) How would you describe your emotional reaction to diabetes?

e.g. did you ever think why did this have to happen to me?

6) How do you feel now in comparison?

7) Do you feel that you went through a series of stages of adjustment to diabetes?

Lifestyle adjustments

8) How satisfied are you with your diabetes control?

prompts; - with the amount of time it takes to determine your sugar level

- the time it takes you to manage your diabetes

9) Do you have any problems injecting or maintaining your diabetes?

- do you feel pain as a result of the treatment
- do you often have high or low blood sugar
- do you ever feel embarrassed about having to deal with your diabetes in public

10) How satisfied are you with the flexibility which you have in your diet?

- do you find it difficult to stick to a strict diet regimen
- do you feel restricted in what you can eat

11) Are you happy with the amount of time you spend exercising?

- do you exercise more now than you did prior to diagnosis?
- does your diabetes interfere with your exercise pattern

12) Do you ever worry that you will experience complications from your diabetes?

prompts: - eye problems/feet problems

- circulatory/kidney problems

13) Are their any other day to day things associated with your diabetes which cause you to worry?

e.g. - being denied insurance

- passing out in public
- going away on a trip/holiday
- driving

14) Has diabetes ever prevented you from doing anything which you did before you were diagnosed?

e.g. have any changes occurred in your life as a result of being diagnosed with diabetes?

15) Are you happy with your general health at the moment?

Treatment and Clinic Satisfaction

16) Are you happy with your current treatment?

- Is it convenient?
- would you recommend it to others?
- would you be happy to continue with your present treatment?

17) How satisfied are you with the service you receive at the diabetes clinic?

prompts:
- at diagnosis: training
- now, at check-ups: updating treatment, etc.

18) What are your perceptions of the role of the diabetes clinic? (In what ways is it most useful to you?)

prompts:
- advice/support
- training
- information
- general check-up

19) Does the clinic offer enough training/advice to help you cope?

20) How satisfied are you with your knowledge and understanding of your diabetes?

Hypoglycaemia

21) How often have you felt that your blood sugars have been unacceptably high/low recently?

22) Have you ever experienced a severe hypo?

find out: - how often

- severe/mild
- warning signs/symptoms

23) Do you worry about experiencing hypos?

prompts: - what are your main concerns

- in what circumstances e.g. In bed, while driving,
- do you worry about being unconscious

24) Do you take any precautions to avoid having a hypo?

prompts: - carry sweets

- keep glucose levels high
- mental/behavioural strategies

25) Does the threat of experiencing a hypo ever interfere with your day to day life?

e.g. - at work

- in a public place

26) When your blood sugar is too high/low do you ever think it is because of something you have done?

Social Issues

27) Do you think that other people in your life play a part in helping you to maintain/cope with your diabetes?

e.g. family, friends, health professionals, colleagues?

28) How have other people in you life reacted to you having diabetes?

29) Have you ever felt embarrassed about being diabetic?

30) In general, what have you found is the most difficult thing about having diabetes?

Feedback

31) Would you like to receive feedback on the results of this study?

32) What sort of information would you like to see included in the feedback?

33) Are there any questions you would like to ask about the study and/the questionnaires?

34) How much had you thought about your adjustment to diabetes before this interview?

END OF INTERVIEW

(iv) ORIGINAL ITEMS DEVELOPED FOR USE IN THE DIABETES IMPACT, ADJUSTMENT AND LIFESTYLE SCALES (DIALS-170)

Information seeking and adherence

I use the information I have about diabetes to help me to manage it
I avoid exercise when my blood sugar is low
It helps to try different diabetes products
There is nothing I can do to avoid complications of diabetes
High blood sugar can be prevented if I plan ahead
I try to keep up with developments in insulin therapy
I eat something as soon as I feel the first sign of low blood sugar
I am interested in gathering information about diabetes
I can prevent a severe hypo if I plan ahead
I am not very good at following the diabetes advice I am given
I am satisfied with my understanding of diabetes
I almost always keep my appointments at the diabetes clinic
I am eager to read about diabetes
I follow the advice about diabetes provided by health professionals
I test my blood sugars regularly
I work hard to keep my diabetes under control
Avoiding high blood sugar is important in diabetes
I have a very strict self-management routine
I feel that the more I know about diabetes the less it will bother me
It is important to know how to combat problems as they arise
As a person with diabetes I know what should eat
I read magazines and articles about diabetes
I almost always carry glucose/sweets with me
Regular, controlled exercise helps me to manage my diabetes
The more I read the more I know what I have to do to combat problems associated with diabetes
I try to share my experiences of diabetes with others who know about it
Chatting to other people who have diabetes is useful
I sometimes think I don't know enough about diabetes
My blood sugar level can be totally different from one day to the next
My blood sugar level tends to go up and down a lot
I feel capable of looking after my diabetes with minimum outside help
Managing my diabetes is a balancing act

Sources of support

I am responsible for taking care of my diabetes
Managing diabetes is my responsibility
The nurses at the diabetes clinic have an important role in helping my diabetes
I rely on others to help me control my diabetes
My family/friends/colleagues play a big part in helping to control my diabetes
There is only so much health professionals can do to help my diabetes
People close to me support me in looking after my diabetes
I don't know what I would do without my family/friends/colleagues there to support me with my diabetes

Acceptance

I wouldn't consider diabetes to be a "serious" disease
I just have to put up with diabetes whether I like it or not
Diabetes is just something I have to live with
The way I see it, if I look after my self properly I should be fine
I'm hoping for a miracle cure for my diabetes
I just have to learn to cope with my diabetes
Diabetes is not going to go away so I just have to get on with it
Diabetes is just something I've got
Diabetes is not as bad for your health as smoking/taking drugs etc.
I don't see any point in getting angry about my diabetes

I believe that researchers will discover a cure for diabetes before too long
Most people would find it hard to adjust to having diabetes

Impact
Diabetes causes inconvenience when driving a car/operating machinery (e.g. a computer)
Diabetes interferes with me taking exercise when I want to
My current treatment for diabetes is convenient
The thought of giving myself an injection does not bother me
I feel happy with my life and diabetes hasn't changed that
I find that I can't think clearly because of my diabetes
My diabetes means others have to wait for me at meal times
Having diabetes causes some inconvenience
Diabetes doesn't really bother me at all on a day to day basis
I'd have second thoughts about going abroad by myself because of my diabetes
I feel frustrated that I can't lead a normal life because of my diabetes
I wish I could just relax without thinking about checking my blood sugars
Sticking to my diet causes inconvenience to others
Diabetes has never stopped me doing anything
It is not possible to control my diabetes well and live in a way that is acceptable to me
I try not to think about diabetes
Diabetes interferes with my sex life
I enjoy the things I do and diabetes hasn't changed that
I find it difficult to relax when I go out socially because of my diabetes
I lead a normal life the same as any other person who does not have diabetes
I've not really had any problems with diabetes
I find it difficult to get a good nights rest because of my diabetes
My lifestyle is too controlled because I have diabetes
Diabetes isn't a problem for me
Diabetes interferes with my social life
I feel restricted in what I can do because of my diabetes
Diabetes interferes with me eating when I want to
Diabetes interferes with my work
Controlling my diabetes well imposes restrictions on my whole lifestyle
There is little hope of leading a normal life with diabetes
I believe I control my diabetes at least as well as most other people with diabetes
At times trying to manage my diabetes is difficult
Sticking to my recommended diet makes eating out difficult
The difficult thing about diabetes is the ongoing self-management of the illness
I am happy with my current treatment for diabetes
It is difficult to regulate when I'm going to do things like eat and have exercise
When I go out I avoid drinking alcohol because of my diabetes
Checking my blood sugar is so routine, it is not any bother
It's annoying to have to watch what you eat
The proper control of diabetes involves a lot of sacrifice
Being told you have diabetes is like being sentenced to a lifetime of illness
Diabetes is not really a problem because it can be controlled
I often forget that I even have diabetes
When I am away from home (e.g. on holiday) I find it more difficult to manage my diabetes

Diabetes-related distress
I feel pretty useless much of the time because of my diabetes
I feel anxious because of my diabetes
I have crying spells or feel like it because of my diabetes
I often feel sorry for myself because I have diabetes
I feel like I am falling apart because of my diabetes
I worry that people treat me differently because I have diabetes
In general I try not to let diabetes worry me
I get upset easily and feel panicky because of diabetes

It is hard to concentrate because of my diabetes
I sometimes feel depressed about my diabetes
I'm not a 'worrier' and diabetes hasn't changed that
I feel angry that I have diabetes
I feel a burden to other people because of my diabetes
Sometimes I wonder if I did something to cause my diabetes
I worry about losing control because of my diabetes
Diabetes is the worst thing that ever happened to me
It's my own fault if my blood sugar is too high/low

Fear of Complications

I worry about making a mistake or having an accident because of my diabetes
I avoid being alone when my blood sugar is low
My health is not as good as other people my age because I have diabetes
I keep my blood sugar high when I plan to be in a long meeting or at a party
I am afraid of being admitted to hospital because of diabetes
I am afraid of experiencing a severe hypoglycaemic episode
It is probably best not to think about the future consequences of diabetes
I worry about not realising that I am having low blood sugar
I worry about getting long term complications of diabetes
I don't worry about hypo's
I worry about my health because of my diabetes
I worry about having high blood sugar
I get annoyed with myself when my blood sugar is high
I often worry that my health will deteriorate as a result of diabetes
I worry about no one being around to help me during a reaction caused by diabetes
I have thoughts or worries about what will happen later in life because of diabetes
I worry that my body looks different because I have diabetes
Hypo's are not as frightening as people think
My blood sugar level is often too high
Having diabetes is like being sentenced to a lifetime of illness

Isolation/Stigmatisation

I worry about being criticised because of my diabetes
I sometimes hide the fact that I am having a diabetes reaction from others
Diabetes sometimes causes me embarrassment
I have never felt embarrassed about having diabetes
I don't feel like I need to tell others I'm diabetic
I don't like to tell other people I have diabetes
I feel bad when other people help me because of my diabetes
I dislike being referred to as 'a diabetic'
It is unfair that I have diabetes when other people are so healthy
There is no one I can talk to openly about my diabetes
Most people don't really understand the problems associated with diabetes
Most people would find it hard to adjust to having diabetes
Sometimes I think I shouldn't have to go without something just because I'm diabetic

Rebellious Decisions

I feel guilty about the way I manage my diabetes
I think my control of diabetes is quite good
I feel guilty if I eat foods which I know are bad for me
I try to have a balanced diet because that is important for diabetes
I tend to eat what I feel like at the time rather than what is good for my diabetes
Sometimes I think I am a "bad" diabetic
As a diabetic person, I eat a diet which keeps me healthy
I sometimes do my injections in public to shock people
When I do my injections, if others don't like it, it's their problem
I eat a lot of food that I know is not recommended for people who have diabetes

Sometimes I can't be bothered to check my blood sugar level
I eat too many sweets/chocolate for a person with diabetes
Sometimes I skip injections
Sometimes I eat more sweets or chocolate than a person with diabetes should
I don't have the motivation to take care of my diabetes
I would describe myself as lazy when it comes to managing my diabetes
I think that I am eating properly for a person with diabetes
Sometimes I have used my diabetes as an excuse to get my own way
I often do things to take my mind off my diabetes
I don't like to think of myself as a person with diabetes
I try not to think about diabetes
I deliberately put diabetes out of my mind

(v) PILOT VERSION OF THE DIABETES IMPACT, ADJUSTMENT AND LIFESTYLE SCALES – DIALS-64 (PART III, Chapter 2)

DIALS-64

Instructions: The list of statements below refer to the way you feel about diabetes, and the effect it has on aspects of your daily life. Please rate each statement on the 1 to 5 scale, from 1 'strongly disagree' to 5 'strongly agree'. Please read each of the statements carefully and circle your first natural response

		Strongly Disagree				**Strongly Agree**
1.	I lead a normal life the same as any other person who does not have diabetes	1	2	3	4	5
2.	I worry about no one being around to help me during a reaction caused by diabetes	1	2	3	4	5
3.	Chatting to other people who have diabetes is useful	1	2	3	4	5
4.	Having diabetes causes some inconvenience	1	2	3	4	5
5.	Taking blood glucose readings is annoying	1	2	3	4	5
6.	My diabetes means others have to wait for me at meal times	1	2	3	4	5
7.	I worry about my health because of my diabetes	1	2	3	4	5
8.	It is probably best not to think about the future consequences of diabetes	1	2	3	4	5
9.	I would describe myself as lazy when it comes to managing my diabetes	1	2	3	4	5
10.	As a diabetic person, I eat a diet which keeps me healthy	1	2	3	4	5
11.	I try to share my experiences of diabetes with others who know about it	1	2	3	4	5
12.	I feel a burden to other people because of my diabetes	1	2	3	4	5
13.	I eat too many sweets/chocolates for a person with diabetes	1	2	3	4	5
14.	The proper control of diabetes involves a lot of sacrifice	1	2	3	4	5
15.	I feel frustrated that I can't lead a normal life because of my diabetes	1	2	3	4	5
16.	I try to keep up with developments in insulin therapy	1	2	3	4	5
17.	I have crying spells or feel like it because of my diabetes	1	2	3	4	5
18.	Diabetes isn't a problem for me	1	2	3	4	5
19.	I get upset easily and feel panicky because of diabetes	1	2	3	4	5
20.	It is hard to concentrate because of my diabetes	1	2	3	4	5

		Strongly Disagree				**Strongly Agree**
21.	I feel like I am falling apart because of my diabetes	1	2	3	4	5
22.	Sometimes I think I am a "bad" diabetic	1	2	3	4	5
23.	I am eager to read about diabetes	1	2	3	4	5
24.	I feel guilty about the way I manage my diabetes	1	2	3	4	5
25.	The more I read the more I know what I have to do to combat problems associated with diabetes	1	2	3	4	5
26.	I worry about having high blood sugar	1	2	3	4	5
27.	I feel angry that I have diabetes	1	2	3	4	5
28.	Having diabetes is like being sentenced to a lifetime of illness	1	2	3	4	5
29.	I feel anxious because of my diabetes	1	2	3	4	5
30.	I find it difficult to get a good nights rest because of my diabetes	1	2	3	4	5
31.	I follow the advice about diabetes provided by health professionals	1	2	3	4	5
32.	I don't have the motivation to take care of my diabetes	1	2	3	4	5
33.	My lifestyle is too controlled because I have diabetes	1	2	3	4	5
34.	Diabetes interferes with me taking exercise when I want to	1	2	3	4	5
35.	I feel guilty if I eat foods which I know are bad for me	1	2	3	4	5
36.	Sticking to my recommended diet makes eating out difficult	1	2	3	4	5
37.	Diabetes interferes with me eating when I want to	1	2	3	4	5
38.	Diabetes interferes with my social life	1	2	3	4	5
39.	I sometimes feel depressed about my diabetes	1	2	3	4	5
40.	Sometimes I can't be bothered to check my blood sugar level	1	2	3	4	5
41.	I think my control of diabetes is quite good	1	2	3	4	5
42.	I eat a lot of food that I know is not recommended for people who have diabetes	1	2	3	4	5
43.	I often worry that my health will deteriorate as a result of diabetes	1	2	3	4	5

		Strongly Disagree				**Strongly Agree**
44.	I have thoughts or worries about what will happen later in life because of diabetes	1	2	3	4	5
45.	In general I try not to let diabetes worry me	1	2	3	4	5
46.	I am interested in gathering information about diabetes	1	2	3	4	5
47.	I am afraid of being admitted to hospital because of my diabetes	1	2	3	4	5
48.	I feel happy with my life and diabetes hasn't changed that	1	2	3	4	5
49.	I worry about getting long term complications of diabetes	1	2	3	4	5
50.	I enjoy the things I do and diabetes hasn't changed that	1	2	3	4	5
51.	I read magazines and articles about diabetes	1	2	3	4	5
52.	I feel restricted in what I can do because of my diabetes	1	2	3	4	5
53.	Sometimes I skip injections	1	2	3	4	5
54.	Controlling my diabetes well imposes restrictions on my whole lifestyle	1	2	3	4	5
55.	I use the information I have about diabetes to help me to manage it	1	2	3	4	5
56.	Sometimes I eat more sweets or chocolate than a person with diabetes should	1	2	3	4	5
57.	I wish I could relax without thinking about checking my blood sugars	1	2	3	4	5
58.	I often feel sorry for myself because I have diabetes	1	2	3	4	5
59.	Diabetes doesn't really bother me at all on a day to day basis	1	2	3	4	5
60.	Diabetes interferes with my work	1	2	3	4	5
61.	When I am away from home (e.g. on holiday) I find it more difficult to manage my diabetes	1	2	3	4	5
62.	I think that I am eating properly for a person with diabetes	1	2	3	4	5
63.	I tend to eat what I feel like at the time rather than what is good for my diabetes	1	2	3	4	5
64.	I feel that the more I know about diabetes the less it will bother me	1	2	3	4	5

Thank you for taking the time to complete this questionnaire. All responses will be strictly confidential.

(vi) SUBJECT INFORMATION FORM FOR THE DIALS VALIDATION STUDY (PART III, Chapter 3)

SUBJECT INFORMATION SHEET

Coping with diabetes: How can this be measured in people with insulin-dependent diabetes?

Introduction:

We would like to invite you to take part in a study which aims to measure how people cope with insulin-dependent diabetes. One of the aims in the treatment of diabetes is to allow you to be able to lead a normal life with as few restrictions as possible but still keeping good control of blood glucose. Everybody is different and has a different ability to cope with changes in lifestyle. This study aims to identify how people with diabetes view their treatment, what problems they meet and how diabetes affects their daily life. This may allow health care workers such as doctors and nurses, to adjust education about diabetes to the needs of the individual.

Study Plan:

In this study you will be asked to answer a number of simple questions about how you cope with your diabetes and the impact which it has had on your daily life. The time taken to complete the questions is not expected to exceed one hour. The questionnaire can be completed at home in your own time and returned by post (a stamped addressed envelope is provided), or completed at the outpatient clinic when you attend for your next appointment. We will use your answers to the questions to devise a method of measuring coping by individuals. Once we have received your completed questionnaire we will consult your notes to obtain information about your recent body mass index (BMI) and glycated haemoglobin (HbA_{1c}).

While the study will not benefit you directly it may help to improve the education and support which we are able to provide to people with type 1 diabetes.

Taking Part:

If you agree to take part in this study you are free to withdraw at any time without having to give a reason. You will be given adequate time to consider whether you wish to take part and if you do decide to take part you will be asked to sign a consent form.

All information provided by yourself and your identity will be kept strictly confidential. No names will be entered onto the computer. Any records would be disclosed only to authorised persons from the Royal Infirmary of Edinburgh or the Ethical Committee. The data from the study will be held on file and analysed with a computer. The results of the study are likely to be published in a scientific journal.

Further Information:

If you have any questions regarding the study or the procedures involved, please do not hesitate to contact me at the Department of Psychology, University of Edinburgh by telephone on 0131 650 3339. Alternatively, if you wish to speak to a doctor who is not involved in the study please contact Dr Matthew Young on 0131 536 2072 who will be able to provide you with independent advice on the overall value of the study.

MANY THANKS FOR YOUR HELP

Michelle Taylor