Open Research Online

The personal experience of diabetes and its relationship with self-care behaviour

Thesis

oro.open.ac.uk

The personal experience of diabetes and its relationship with self-care behaviour

Katherine Jane Stothard BSc (Hons)

Submitted for the award of Doctor of Philosophy in the discipline of Health and Social Care

Submitted 9th February 2007

Acknowledgements

There are a few people I would like to thank for their help during my PhD:

SE12
(December 2002)

RESEARCH SCHOOL

Research Degrees in Sponsoring Establishments

Library Authorisation

Please return this form to the Research School, The Open University, Walton Hall, Milton Keynes, MK7 6AA with the two bound copies of the thesis to be deposited with the University Library. All candidates should complete parts one and two of the form. Part three only applies to PhD candidates.

Part One: Candidate Details

Name: KATHERINE STOTHARD   PI: C555S119

Degree: PHD   Sponsoring Establishment: OPEN UNIVERSITY

Thesis title: THE EXPERIENCE OF DIABETES AND ITS

RELATIONSHIP WITH SELF-CARE BEHAVIOUR

Part Two: Open University Library Authorisation

I confirm that I am willing for my thesis to be made available to readers by the Open University Library, and that it may be photocopied, subject to the discretion of the Librarian.

Signed: KStothard   Date: 10/07/07

Part Three: British Library Authorisation [PhD candidates only]

If you want a copy of your PhD thesis to be available on loan to the British Library Thesis Service as and when it is requested, you must sign a British Library Doctoral Thesis Agreement Form. Please return it to the Research School with this form. The British Library will publicise the details of your thesis and may request a copy on loan from the University Library. Information on the presentation of the thesis is given in the Agreement Form.

Please note the British Library have requested that theses should be printed on one side only to enable them to produce a clear microfilm. The Open University Library sends the fully bound copy of theses to the British Library.

The University has agreed that your participation in the British Library Thesis Service should be voluntary. Please tick either (a) or (b) to indicate your intentions.

(a) [✓] I am willing for the Open University to loan the British Library a copy of my thesis. A signed Agreement Form is attached.

(b) [ ] I do not wish the Open University to loan the British Library a copy of my thesis.

Signed: KStothard   Date: 10/07/07

An electronic version of this form can be downloaded form http://www3.open.ac.uk/research-school/policy/sponsoring-establishments/ or requested from the Research School by sending an email to research-school@open.ac.uk quoting document reference SE12.

associated with their self-care behaviours. Interview analysis supported the differences found between type of diabetes and gender in the questionnaire analysis. The variance in self-care behaviour explained in the questionnaire analysis was low; however, the interview analysis suggested that aspects of the Commonsense Model of the Self-Regulation of Health and Illness (CSM), such as socio-cultural context and the self-system, which were not measured by the questionnaires, may explain more variation in self-care behaviour.

Contents

List of figures

List of tables

Note: Tables 3-12 refer to differences for illness representations, self-efficacy and self care behaviour

X

List of appendices

Introduction

An introduction to the experience of diabetes and self-care behaviours.

Diabetes mellitus is a long-term condition which requires numerous, continuous and complex self-care behaviours. Diabetes causes an individual's blood sugar level to rise above the level normally found in those without the condition (hyperglycaemia). There are two main types of diabetes mellitus – type 1 and type 2 diabetes. Type 1 diabetes (previously known as insulin dependent diabetes and sometimes referred to as juvenile onset diabetes (DeFronzo et al. 2004; Kahn et al. 2005) is usually diagnosed under the age of 40; whereas type 2 diabetes (previously known as non-insulin dependent diabetes and sometimes referred to as maturity onset diabetes) is usually diagnosed over the age of 40 (Hillson 2002; Pickup and Williams 2003), although there has been an increase in the incidence of type 2 diabetes in younger people in recent years (DeFronzo et al. 2004). Genetic factors are thought to have an impact on the onset of both types of diabetes (Pickup and Williams 2003; DeFronzo et al 2004; Kahn et al. 2005). Type 1 diabetes is thought to be caused by an autoimmune response, possibly to a viral infection (Pickup and Williams 2003; DeFronzo et al 2004; Kahn et al. 2005). In those individuals with type 1 diabetes the pancreas stops producing insulin and so insulin injections are required immediately and for the rest of their life. The development of type 2 diabetes is thought to be influenced by lifestyle factors such as being overweight, dietary habits and leading a sedentary lifestyle (Hillson 2002; Pickup and Williams 2003; DeFronzo et al 2004; Kahn et al.

2005). In type 2 diabetes the pancreas may stop working as efficiently as it should but insulin resistance is also involved in raising blood sugar levels. Insulin resistance means that the person's muscles are unable to effectively use the insulin being produced and so blood sugar levels rise and the pancreas is required to make more insulin than normal. This in turn has an impact on the pancreas and can reduce its ability to produce insulin (Tunbridge and Home 1991; Pickup and Williams 2003; DeFronzo et al 2004; Kahn et al. 2005). Treatment for type 2 diabetes includes dietary self-care, such as the monitoring of carbohydrate intake, exercise, and may involve daily oral hypoglycaemics or insulin injections (Hillson 2002; Pickup and Williams 2003; DeFronzo et al 2004; Kahn et al. 2005).

The management regime prescribed for type 1 and type 2 diabetes, by health professionals, is designed to keep blood sugars within the normal range – or as near as possible to those levels. This is often referred to as glycaemic control. The regime usually includes self-care behaviours such as medication taking, blood glucose monitoring, diet, exercise and foot care (Hillson 2002; Pickup and Williams 2003; DeFronzo et al 2004; Kahn et al. 2005). Self-care is vital for people with diabetes to live healthy and long lives and delay the numerous complications which may develop through the condition such as neuropathy (problems with the nerves leading to loss of feeling and pain in the feet), retinopathy (damage to the blood vessels at the back of the eye potentially leading blindness), circulatory problems and nephropathy (damage to the kidneys) (Pickup and Williams 2003; DeFronzo et al 2004; Kahn et al. 2005). However, research shows that levels of self-care for diabetes mellitus are often much lower than expected (Surwit et al. 1982; Mason et al. 1995; Morris et al. 1997; Paes et al. 1997; Donnan et al. 2002; Rubin 2005). Furthermore different self-care activities are often carried out at different levels,

for example medication is the most frequently maintained activity (Kelleher 1988), and the performance of one part of the diabetes regime does not always relate highly to the performance of another aspect (Glasgow et al. 1987).

Various explanations have been suggested for why individuals may not perform their diabetes self-care behaviours. The diabetes self-care regime is complex, all pervading, and life long with no chance of respite. The varying amounts of successful self-care may be related to the degree to which those activities impact on everyday life and how many alterations need to be made to the person's lifestyle in order to fit in these self-care behaviours. Psychosocial factors may also impact on the extent to which self-care activities are performed. Psychological problems such as affective status and eating disorders are thought to have a dramatic impact on self-care behaviours, and may lead to a lack of motivation to perform dietary self-care behaviours (Thomas et al. 2003, Katon 2003). Social factors are also important when it comes to maintaining self-care behaviours. It has been shown that social support can affect attitudes to self-care in a variety of different ways. Living alone (Toljamo and Hentinen 2001) and type of family structure (Thompson et al. 2001) have been found to influence the performance of self-care behaviours. There may be gender differences in the way that social support affects self-care, for example, Kaplan and Hartwell (1987) found that women satisfied with their social support had better glycaemic control whereas men who were most satisfied with their social support had poorer control. Depending on the diabetes management regime, maintaining blood sugar levels as near as possible to normal when being treated with insulin may result in more frequent hypoglycaemic attacks (DCCT, 1993; Cryer 1999; Cox et al. 2006). Although this is not always the case, when it does occur this not only makes the person with diabetes feel unwell but may produce a fear of hypoglycaemia (for public

embarrassment or illness reasons) and a fear of weight gain due to the additional consumption of carbohydrates (Kelleher 1988).

Although it is well-known that consistent and accurate performance of self-care behaviours is important in the long-term for avoiding serious diabetes complications, in the short-term it is possible to see why attitudes to self-care may not be positive and motivational. Depending on the diabetes management regime, there may be negative re-enforcers such as hypoglycaemic attacks, weight gain due to increased carbohydrate intake, interference in every day life, as well as lack of self-efficacy and different beliefs about diabetes, so it is understandable that the benefits of self-care may be ignored or forgotten.

Beliefs about diabetes, such as its cause and consequences, and beliefs about an individual's ability to perform the self-care activities (self-efficacy) are thought to be associated with self-care behaviour (Siguroardottir 2005). Beliefs about illness severity, vulnerability to negative outcomes and self efficacy have all been shown to be associated with self-care activity. Bond et al. (1992) found that self-care behaviours were 'adhered' to by those people who felt less threatened by their condition and thought that the treatment would benefit them the most. Theories such as the Health Belief Model (Rosenstock et al. 1988) and Leventhal's Commonsense Model for the Self-Regulation of Health and Illness (Leventhal et al. 2003) have been used to model the interaction of beliefs about illness (or illness representations) and self-care behaviours. In this thesis, two theoretical models were chosen as a framework for examining the relationship between self-care behaviour and individuals' beliefs about their diabetes and their ability to look after themselves. These were Leventhal's Commonsense Model for the Self-Regulation of Health and Illness (CSM) and Social Cognitive Theory (Bandura, 1977). The CSM is health specific and so

deals with specific beliefs and emotional experiences which are not explored in more generic models such as Carver and Scheier's self-regulation model (1998). As a self-regulatory model the CSM is dynamic and allows re-evaluation of the success of the self-care behaviours chosen, which reflects the interactive and complex nature of health care decision making. In addition to this the CSM includes both cognitive and emotional processes which occur in parallel but also interact, acknowledging that both may have an impact on the self-care behaviours performed. The decision to also include Social Cognitive Theory in this thesis was made because of the similarities and therefore potential compatibility between it and the CSM. There are common assumptions underlying both theories:

1) Individuals are active in the processes which surround their behaviour, in terms of shaping what happens, rather than being passive and only reacting to events;

2) Self-efficacy beliefs and the illness and emotional representations in the CSM are formed in similar ways – personal experience, vicarious experience and from information given by others – which means that the information can be both abstract and concrete;

3) In both models beliefs or representations are developed from past and present sources.

In addition, self-efficacy has been researched in the past as an example of part of the self-system in the CSM, which has been suggested to moderate the relationship between illness representations and self-care behaviours.

Using both the CSM and Social Cognitive Theory this thesis investigates the differences between the beliefs of individuals with type 1 and type 2 diabetes. The self-care behaviours for type 1 and type 2 diabetes mellitus may be the same or very similar; however, the two conditions differ significantly in a

variety of ways including cause, age of onset, experience at onset, development of diabetes complications, treatment and progression of the condition and societal perceptions of the conditions (in particular causes and severity). Due to all these differences in identity, cause, treatment and consequences it is conceivable that there are also differences in the psychological consequences of the conditions. Emotional and psychological factors have been shown to have an impact on self-care behaviours and metabolic control (Lloyd et al. 2005). Lack of self-care and poor metabolic control can provide numerous problems both for the individual, in terms of long-term complications and everyday ill health, and in terms of the health service which must provide funding to deal with the consequences. If interventions are to be developed to prevent lack of self-care and such consequences occurring then it is important that the psychological impact of these conditions is considered. If, as suggested, type 1 and type 2 diabetes are different in physical and psychological terms then it is important to recognise this in order to find the appropriate interventions for each condition. This would enable appropriate professional help for people with diabetes within a patient centred approach, as recommended by the National Service Framework (Department of Health 2001), and avoid wasted resources within the health service.

Aims of the Study

This research study was designed to look at the relationship between illness representations and self-efficacy and the performance of self-care behaviours by people with type 1 and type 2 diabetes. The relationship between these variables and the metabolic control of the participants was also

investigated. It was hypothesised that due to the social, physical and emotional differences between the experiences of individuals with type 1 and type 2 diabetes, the cognitive representations of the conditions may vary, as might the relationship between these cognitive representations and self-efficacy and self-care behaviour. It was predicted that participants with type 1 and type 2 diabetes would exhibit significant differences in illness representations and self-efficacy and the relationships between these variables and self-care behaviour. It has been suggested in previous research (Anderson et al. 1997; Fitzgerald et al. 2000) that different types of treatment (ie tablets versus insulin) may result in different illness beliefs. Therefore the differences between participants with type 1, tablet treated type 2 and insulin treated type 2 diabetes were investigated to enable the differences between type of diabetes to be examined separately from type of treatment. The following research questions were formulated:

Research questions

1) What differences, if any, are there between individuals with type 1, tablet treated type 2 and insulin treated type 2 diabetes for illness representations, self-efficacy and self-care behaviour?

2) What relationships, if any, are there between illness representations, self-efficacy, self-care behaviour and metabolic control for individuals with type 1, tablet treated type 2 and insulin treated type 2 diabetes?

3) Can the personal experience of diabetes and its relationship to self-care behaviour be described using the Commonsense Model of the Self-Regulation of Health and Illness (CSM) (Leventhal et al. 2003)?

The next chapter introduces the previous research, ideas and theories which have influenced the development of these research questions. The thesis goes on to describe the methods used to investigate the differences between individuals with type 1 and type 2 diabetes and the relationships between personal experience, illness representations, self-efficacy and self-care behaviours. Chapters three, four and five present the findings of the study and the final chapter discusses the answers to the research questions suggested by the findings and the implications for further research.

Chapter One

The diabetes experience: long-term conditions, self-efficacy and illness representations

This chapter describes and discusses the previous literature and research with regard to the experience of long-term conditions, including diabetes, and the theoretical models which underpin this piece of research – the *Commonsense Model for the Self-Regulation of Health and Illness* and *Social Cognitive Theory*.

1.1 The experience of long-term conditions

Health and illness are aspects of life which are universal. At some point during everyone's life they will know how it is to feel ill and how it is to feel healthy. Health is often seen as being the absence of illness (Bury 2005) and is easiest to define in this way – by experiencing illness individuals know what it feels like to be healthy. When looking at the experience of illness it is important to define exactly what is meant by the term. There are three terms which are generally used to describe the absence of health – *disease, illness and sickness* (Radley 1994). *Disease* is concerned with the pathology of what happens to a body during the disease process. It is something which doctors diagnose and treat. *Illness* is "the experience of disease, including the feelings related to changes in bodily states and the consequences of having to bear that ailment; illness, therefore, relates to a way of being for the individual concerned." (Radley 1994, p. 3). *Sickness* refers to the social 'role' which

happens when people are considered to have an *illness* or *disease*. When someone becomes unwell or not healthy the social world around them has an important part to play. For example, in order to receive an official diagnosis (and therefore licence to be sick) or treatment, of necessity other people are involved – usually health practitioners. Added to which people who are ill may require care from significant others and interactions with other people as a result of their *illness*. As Radley (1994) says:

"The relationships in which we live, and the groups to which we belong, have a distinct bearing upon both the maintenance of good health and the care of the sick." (p. 2).

Using these definitions of *disease, illness and sickness*, the experience of *illness* can be seen to encompass not only *illness* but also the experience of *sickness* and how the social world around us reacts.

Long-term conditions are a growing issue in health care today. Due to increasing life expectancy as a result of the advance of modern medical technology such as pharmacology, immunology and bacteriology and raised living standards, the infectious diseases and once terminal conditions of the past have now been replaced by a range of long-term conditions such as diabetes, arthritis, heart disease and so on (Lubkin and Larsen 2002). The traditionally dominant biomedical model looks at illness and disease from the perspective of diagnosing and treating acute illnesses and as a result the increase and dominance of long-term conditions in health care is creating issues about how to cope with these conditions. Defining what a long-term condition or illness is may be problematic. Various definitions have been

suggested, including an early definition by the USA Commission on Chronic Illness (Mayo 1956):

"All impairments or deviations from normal which have one or more of the following characteristics: are permanent, leave residual disability, are caused by non-reversible pathological alteration, require special training of the patient for rehabilitation, and may be expected to require a long period of supervision, observation, or care."
(Mayo (1956) cited in Lubkin and Larsen (2002)).

The difficulty with this definition and many which have followed have been their reliance on biomedicine. Lubkin and Larsen (2002) suggest an alternative definition which appears to be more comprehensive and is written from a nursing perspective:

"Chronic illness is the irreversible presence, accumulation, or latency of disease states or impairments that involve the total human environment for supportive care and self-care, maintenance of function, and prevention of further disability." (Curtin and Lubkin 1995).

Long-term conditions differ from acute illnesses in a variety of ways. Acute illnesses are short lived experiences whereas long-term conditions may last from a long period to a life-time. Acute illnesses are generally treatable by modern medical means or are recovered from using the body's natural defences. Long-term conditions, on the other hand, are distinguishable from these as they are usually incurable and medical intervention is usually aimed at slowing the progress of the illness or relieving symptoms (Radley 1994). This lack of a medical solution is often due to the uncertainty over the cause of the

illness, an uncertainty which becomes characteristic of many long-term conditions, for example diabetes (Kelleher 1988), and is not usually the case with acute illnesses. This lack of certainty over the cause of long-term conditions can also result in delays to diagnosis not usually experienced with acute conditions, for example with rheumatoid arthritis (Bury 1982). The long time-scale for such conditions introduces specific characteristics to the illness experience. The current status of the condition is viewed in the context of a history of past experiences with the condition and what may happen in the future. This means that the long-term condition becomes integrated into the person's biography and gains a deeper significance than acute illness (Radley 1994). The way that people with acute illnesses interact with the world is by moving from being in the realm of 'the healthy' to a 'sick' patient at a doctor's surgery and then returning back to their previous healthy status. In long-term conditions a person moves from being healthy to "having to live with illness in the world of health." (Radley 1994).

1.2 Diabetes mellitus – a long-term condition

Diabetes mellitus results in raised blood sugar levels and the treatment for diabetes may involve taking medication to reduce these levels and performing a range of self-care behaviours, such as diet, exercise, blood testing and foot care, to maintain optimum blood sugar levels and reduce the risk of complications (such as neuropathy, retinopathy, cardio-vascular complications and nephropathy) which may appear as the result of diabetes (Hillson 2002; Pickup and Williams 2003; DeFronzo et al 2004; Kahn et al. 2005). Medication varies depending on whether the diabetes is type 1 or type 2. People with type 1 diabetes do not produce any insulin at all and so have to take regular daily

insulin injections to provide the insulin lacking in their bodies (Pickup and Williams 2003). People with type 2 diabetes may produce some insulin and so may take regular daily tablets to promote insulin production and absorption (Pickup and Williams 2003; DeFronzo et al 2004; Kahn et al. 2005). However, if the blood sugar levels continue to rise and insulin production is further reduced insulin injections may become necessary. Type 1 diabetes is generally diagnosed under the age of 40 whereas type 2 diabetes is more commonly experienced later in life (Hillson 2002; Pickup and Williams 2003; DeFronzo et al 2004; Kahn et al. 2005). In addition to taking these medications, people with diabetes should take regular exercise to maintain fitness levels and a healthy weight (exercise also lowers blood sugar levels). They also need to control the levels of carbohydrate consumed (as well as eating the generally recommended healthy diet) and the timing of when food is eaten to coincide with the injections or tablets. In order to maintain the correct balance between insulin injections or tablets and carbohydrate consumed, regular blood glucose monitoring is required. If the blood sugar level taken is outside the recommended limits the person with diabetes must decide what action to take i.e. more insulin, less food at the next meal or some exercise. Other aspects of diabetes care may include other medications such as those to reduce blood pressure or cholesterol levels (Pickup and Williams 2003; DeFronzo et al 2004; Kahn et al. 2005). It is recommended that people with diabetes should check their feet regularly as decreased sensitivity in the feet is caused by neuropathy and may lead to injuries which are not spotted. Eye screening is also recommended on a regular basis to monitor for any diabetes eye complications which may be developing (Pickup and Williams 2003; DeFronzo et al 2004; Kahn et al. 2005).

The self-care behaviours for type 1 and type 2 diabetes mellitus may be the same or very similar; however, the two conditions vary in several ways including cause, age of onset, experience at onset, development of diabetes complications, treatment and progression of the condition and societal perceptions of the conditions (in particular causes and severity). As mentioned previously, the age of onset for individuals with type 1 diabetes is usually younger than those with type 2 diabetes – under forty years old - whereas the typical age for type 2 diabetes is middle-age or over with the occurrence increasing as age increases (Tunbridge and Home 1991; Warren and Hixenbaugh 1998; Pickup and Williams 2003; DeFronzo et al 2004; Kahn et al. 2005)). The medically recognised causes of the conditions are different. Type 1 diabetes is thought to be caused by an auto-immune response to a virus which kills off pancreatic cells and has a genetic component and type 2 diabetes is thought to be caused by lack of exercise, being overweight, ageing, again with a genetic contribution (Pickup and Williams 2003; DeFronzo et al 2004; Kahn et al. 2005). As a result, the speed of onset may be variable between the two types of diabetes. Type 2 diabetes may develop gradually over a period of time with the symptoms (such as thirst, tiredness, frequency of urination) either building up until they are recognised as diabetes or until a regular test for diabetes is done as part of a medical examination or when investigating another condition (Kahn et al. 2005). This means that at diagnosis twenty percent of people with type 2 diabetes already show signs of diabetes complications (Warren and Hixenbaugh, 1998). It is quite possible for these symptoms to be confused with the experiences of ageing and diabetes is frequently a condition which is added to a list of ailments already acknowledged. People with type 1 diabetes are usually diagnosed before diabetes complications have started to develop and the onset is likely to be rapid and dramatic after a short period of acute illness (Pickup and Williams 2003; DeFronzo et al 2004; Kahn et al.

2005). In addition to this type 1 diabetes usually occurs in a period of life where long-term illness is not expected to the same extent as for individuals with type 2 diabetes.

Another important difference between type 1 and type 2 diabetes is in the course of the illness. Treating both types of diabetes involves lifestyle changes such as healthy eating, monitoring carbohydrate intake and regular exercise; however as the treatment for individuals with type 2 diabetes may focus initially on lifestyle changes, the emphasis is much greater on these aspects of diabetes care than for those with type 1 diabetes where more frequent blood sugar testing and regular insulin injections take priority (Hillson 2002; DeFronzo et al. 2004; Kahn et al. 2005). Those with type 2 diabetes who are not required to take medication are expected to follow guidelines on diet and exercise in order to keep blood glucose levels as close to normal as possible. Those with type 1 diabetes are given dietary and exercise guidelines but since the advent of flexible insulin regimes, such as numerous injections a day and schemes such as DAFNE[1], assuming that the patient can calculate and balance their lifestyle accordingly, then much more flexibility may be achieved. Frequently type 2 diabetes will progress to a point where the individual starts to be treated with tablets and then insulin injections (Hillson 2002; Pickup and Williams 2003; DeFronzo et al 2004; Kahn et al. 2005). This is another difference when compared to type 1 diabetes. The progression from diet to tablets to insulin may be interpreted as the condition becoming more severe; whereas those with type 1 diabetes are treated with insulin injections from the start and so see no progression of diabetes unless diabetes complications develop.

---

[1] Dose Adjustment For Normal Eating – a training scheme for individuals with type 1 diabetes, using group sessions, aimed at enabling a flexible diet by the intensive management of flexible insulin doses (DAFNE Study Group 2002).

Within society there are different perceptions of type 1 and type 2 diabetes. The connection between type 2 diabetes and obesity has been frequently reported in the media over the past few years and this may have effected lay beliefs about type 2 diabetes and its nature as a 'self-caused' condition (Broom and Whittaker 2004). The contrasting treatments for type 1 and type 2 diabetes may also influence the perceived severity of type 1 and type 2 diabetes and combined with misperceptions about the consequences of type 1 and type 2 diabetes lead to different beliefs and cognitive representations of the two conditions.

1.2.1 Diabetes management and care

The traditional[2] approach to diabetes management was developed from the medical model of health and illness. This model of healthcare is based on acute illnesses and focuses on immediate medical problems and symptoms rather than underlying psychological needs, behavioural change and the ongoing physical effects of long-term illness. The health practitioner is responsible for instructing the patient what to do to treat their diabetes and it is up to the patient to 'adhere to' or 'comply with' these instructions and demands. Individuals with diabetes who deviate from these instructions may be seen as 'noncompliant' by their health care practitioners. This model has the potential to create an environment of blame – health practitioners may feel able to blame the patient for not following the regimen they are told to and patients may blame themselves for not achieving the goals set, blame the regimen which may be incompatible with their lifestyle or blame the health practitioner for suggesting a

---

[2] The standard model of diabetes care used in Western medicine which is based on the dominant medical model and is widely accepted in Western culture.

regimen which does not work (Anderson 1985). Patients are often seen as passive and unaware in the process whereas health practitioners are the knowledgeable experts who must "direct the patient's behaviour for the patient's own good." (Anderson 1985). Consultations may be based on question and answer sessions with the practitioner asking most of the questions and are frequently too short to allow time for discussion of issues such as the emotional and psychological impact of the condition (Meetoo 2004). The disadvantage of using this model is that it is designed to deal with brief, acute illnesses and does not take into account the specific issues raised by long-term conditions such as diabetes. Some people with diabetes may see their condition differently from the 'traditional medical model' of the health practitioner. They may consider different things to be important as a result of the reality of experiencing the condition and some people have been shown to consider the treatment regime that must be followed as more distressing than actually being diagnosed with diabetes in the first place (Anderson 1985). Funnell and Anderson (2004) suggest that the self-care regimes that people with diabetes are expected to follow are designed to fit a person's diabetes rather than their life. By ignoring these specific issues and differences of opinion the needs of people with diabetes can go untended and this can result in poor self-care, high blood glucose levels and potential diabetes complications later on. As Glasgow and Anderson (1999) say:

"Modification of the acute-care model will not work because its underlying assumptions are invalid for diabetes care. Diabetes care requires a truly collaborative approach, i.e., patients and health care professionals relating as equals, rather than the hierarchical approach embedded in the acute-care model." (p. 2091).

Over the past twenty years the empowerment model of diabetes care has been suggested as a more appropriate approach to diabetes care than the traditional medical model approach as it.is more representative of how diabetes management decisions actually take place. The empowerment model is based around the idea that the individual is responsible for their own health and that although the health practitioners should be there to give guidance and support in making health related decisions, the final decisions on health matters and the self-care behaviours performed are down to the individual with the condition (Meetoo 2004). Individuals with long-term conditions such as diabetes are seen as active decision makers who have a much greater impact on the arrangements of their self-care regime. Funnell and Anderson (2004) define patient empowerment as "helping patients discover and develop the inherent capacity to be responsible for one's own life.". The aim of an empowerment approach is to create an equal partnership between health practitioner and patient which results in informed decision making. As Bauman et al. (2003) say "Patient-centred care is about sharing the management of an illness between patient and doctor.". They found that this approach led to an "increased adherence to management protocols, reduced morbidity and improved quality of life.". There are certain assumptions and core beliefs to the empowerment approach. These are expressed clearly by Arnold et al. (1995):

"Most of diabetes care is provided by the person with the disease; diabetes affects the emotional, spiritual, social, physical, and cognitive aspects of a person's life; people with diabetes experience both the burdens and benefits of their diabetes and self-care choices; and patients need information about both diabetes and themselves to make informed choices." (p. 308).

From looking at the literature on empowerment in diabetes it can be seen that, from a user's perspective, their empowerment is validated and supported in three ways: first, all involved need to recognise that the individual is responsible for looking after their diabetes and consequently their own self-care behaviours; to maintain this control full and accurate education on all aspects of diabetes is needed in order for the person with diabetes to make the informed choices necessary, and that this form of agency requires the ongoing support and partnership with health practitioners – who may provide continual diabetes education, guidance where necessary and a network where goals for their diabetes care can be discussed.

Accepting responsibility for and recognising that one's diabetes care is solely dependent on one's actions is an essential part of feeling empowered. Glasgow and Anderson (1999) state three reasons why people with diabetes are responsible for their own care. The first is that every day it will be the person with diabetes making important choices about their self-care rather than the health professional. Secondly, people with diabetes can choose to perform self-care behaviours or not and once they leave the diabetes clinic health professionals have no control over this. Finally, all the consequences of performing self-care behaviours, whether the risk of complications or the effects of vigorous control on quality of life, are the person with diabetes' alone. Thorne et al. (2003) used interview, think-aloud and focus group data to research the decision making process in long term conditions. They found that a significant first step was learning to assume control of the condition – "All participants shared a commitment to controlling the disease rather than being controlled by it......and that if they did not assume control, no one else would assume responsibility on their behalf." (p. 1341). This is in contrast to the roles implied by the medical model where the health practitioner takes the position of

responsibility, the position of knowledgeable 'parent' and instructs the patient to comply with their instructions. This gives the person with diabetes two choices – 'comply' with the health practitioners instructions or rebel and be labelled as 'noncompliant'. This creates a 'parent and child' situation where the person with diabetes is being told what to do and therefore retains very little responsibility for their condition. This was explored for individuals with diabetes by Broom et al. (2004) who say:

"Many people's accounts of their management involved a parodic positioning of themselves as children, thus expressing the diminished agency they experience in their management of diabetes......In rhetorically positioning themselves as children they are talking about the power differential implicit in their relationships with health professional......People with diabetes have had their agency as adults diminished both by the health services who admonish them to change their ways....." (p. 2378)

Providing people with diabetes with knowledge about their condition has long been considered to be vital (Bartlett (1986) cited in Norris et al. 2001); however, the results obtained in research looking at the impact of diabetes education seem to vary (Norris et al. 2001, Ellis et al. 2004). For example, McCaul et al. (1987) found no connection between 'adherence to regimen' and level of diabetes knowledge, Rubin et al. (1989) found that increased diabetes education led to increased 'adherence' and lower HbA1c levels and Persell (2004) found diabetes education led to greater 'adherence' and yet had no impact on metabolic levels. Rubin et al. (1989) identified various flaws in their study which may be applicable to much of the research carried out in this area. They mention that the people with diabetes who were interested in taking part in their study were as a result already motivated to improve their knowledge by

the very fact they were willing to take part. The people participating also had a high general education level to start with. The study had no control group and a high staff to patient ratio which brings in issues of practicality in the 'real world' and a possible example of the 'Hawthorne effect' (Roethlisberger and Dickson 1939). Bradley (1995) looked at the importance of diabetes knowledge both of the patient and health practitioner. She makes interesting points about the effectiveness of knowledge measures when comparing with HbA1c levels, for example the fact that knowledge of foot care and hypoglycaemia will have little to no impact on metabolic control. She also suggests that people with diabetes may only learn about a specific aspect of diabetes management when they come across it, for example foot care when confronted with diabetes complications such as a foot ulcer. This results in people with high metabolic levels and complications having greater diabetes knowledge. If this is the case it would suggest that diabetes education needs to be an ongoing feature of diabetes management rather than a one off process at diagnosis when a person is given a large amount of information and instruction.

At this point it is important to make the distinction between diabetes knowledge and diabetes education. Many of the studies purporting to look at diabetes education concentrate solely on knowledge about diabetes. Despite the number of problems with such research it does suggest that diabetes knowledge is essential for maintaining glycaemic control. However, other aspects surrounding diabetes knowledge play an important part in its impact (Norris et al. 2001). A significant factor in how effectively knowledge of diabetes impacts on the performance of self-care behaviours is whether or not people with diabetes feel able to make use of the knowledge they have gained. In order for this diabetes knowledge to be put into practice a person must have sufficient belief in their self-efficacy and a person's self-efficacy is greatly

affected by how they gain knowledge of the situation. This means that how diabetes knowledge is imparted to people with diabetes will have a great impact on how confident people feel to make use of that knowledge. Therefore diabetes education should promote and support 'self-efficacy for diabetes care' in order to make effective use of the diabetes knowledge held (Howells 2002). Self-efficacy will be discussed in greater detail later on in this chapter.

The third aspect of empowerment, after accepting responsibility for self-care and receiving the necessary diabetes education, is support and partnership with the health professionals. The impact of the patient and health professional interaction on performance of diabetes self-care behaviours has been looked at in various studies. For example, Ciechanowski et al. (2003) found that people with diabetes with a 'dismissing' attachment style to their health practitioners were 'less adherent' to various diabetes self-care behaviours and were more likely to view their patient-provider relationship as less satisfying. Price (1989) found that although the health practitioners in her qualitative study were "warm and friendly….and inquired if the patient(s) understood the information" they failed to get any information from the patients about how they experience diabetes management and so why the patients were unwilling or unable to make the changes being suggested. Kyngas (1998) found that health practitioners who were seen to be "routine" or "negligent" were linked to 'poor compliance' in adolescents with type 1 diabetes.

While the benefits of collaborative care for people with diabetes have been recognised, the distinct shift in thinking required to adopt an empowerment approach to diabetes care, as opposed to a medical model approach, for both health care professionals and individuals with diabetes, is not straightforward. Anderson and Funnell (2005) reflected on their experiences

of training health care professionals to adopt an empowerment approach and described five main obstacles: an intellectual adoption of the empowerment approach but still unconsciously using "old techniques"; the fact that such paradigms are powerful but invisible and therefore are held at an unconscious level and so difficult to change; the need to integrate the empowerment approach for long-term conditions at the basic level of medical training; the view that empowerment paradigm is the latest "politically correct" phase; and, the perception that an empowerment approach takes more time to implement than the medical model of diabetes care. Anderson and Funnell (2005) suggest that the difficulties inherent in changing the paradigms behind diabetes care mean that although progress is being made towards a model of care which is more representative of the realities of living with diabetes many individuals with diabetes still experience care for their diabetes which is based on the acute medical model.

1.3 Past research and theoretical approaches

Research into the experience of long-term conditions is important for a variety of reasons. For the health care professional gaining a deeper understanding of the 'insider's perspective' can enable treatment to be focused in a way which best benefits the person with the long-term condition. In long-term illness, where continual self-care behaviour is required but often not maintained, (Surwit et al. 1982; Mason et al. 1995; Morris et al. 1997; Paes et al. 1997; Donnan et al. 2002; Rubin 2005), understanding the practical and psychological issues of living with a long-term condition can enable health care professionals to assist and encourage people to look after themselves to the

best of their abilities. The current movement from the traditional biomedical model to a social model, where the concept of empowerment is important, is also reliant on the understanding of the long-term illness experience. As discussed previously, for individuals with long-term conditions, an empowerment approach means a partnership between health care professionals and 'patients' (Glasgow and Anderson 1999). In order for this collaborative approach to exist the health care professional needs to see the 'patient' as a person rather than just a physical body to treat, (Funnell and Anderson 2004), and as such research into the experience of long-term conditions plays a vital role in helping the health care professional towards this. As well as benefiting from improved understanding and care from health care professionals, research in this area may help people living with long-term conditions by allowing them to see that other people who are in similar positions experience the same things as them, reducing the sense of isolation that is sometimes felt by people who have a long-term condition (Charmaz 1983). From a political point of view the number of people with long-term conditions is increasing dramatically and as a result the welfare, views and experiences of this group is going to becoming increasingly important as time goes on (Lubkin and Larsen 2002). Investigating the experience of long-term conditions does not just expand the knowledge about long-term conditions themselves. Kelly and Millward (2004) suggest that by looking at the way people experience illness we can learn about the way in which people experience the world in general too. Bury (1982) posits that by looking at what happens when 'normal' events and settings are disrupted we can learn much about what usually happens when such disruption does not occur. It has been suggested that to allow us to fully understand the 'human condition' it is vital that we look at human suffering, of which long-term illness is a prime, researchable example (Kelly and Millward 2004). For example, in the area of sociology and identity,

Charmaz (1983) states that long-term illness provides an useful opportunity to look at 'self' because of the high visibility of 'self' and the awareness of people with long-term conditions about 'self' and identity due to the fact that "previously taken-for-granted aspects of self" are "altered or gone", for example in diabetes (Kelleher 1988).

There are a variety of approaches which have been used to explore the personal experience of long-term conditions. This thesis makes use of two psychological theories, Leventhal's Commonsense Model of the Self-Regulation of Health and Illness and Bandura's Social Cognitive Theory, which describe the relationships between an individual's beliefs and behaviour. These will be discussed in more detail later in this chapter. However, within these models there are aspects, such as socio-cultural context and environment, which address the importance of the individuals' surroundings, their relationship with other people and the society around them and the context in which their beliefs are developed and relate to their subsequent behaviour. An individual's personal experience of living with a long-term condition, such as diabetes, is integrally linked to the social structures around them and their relationships to other people. Therefore, this literature review incorporates a discussion of sociological theories relating to health and illness which may describe the part that social context plays in influencing behaviour. This literature is important in order to gain a fuller understanding of the ways in which personal experience is thought to relate to beliefs about diabetes and self-care behaviour and is addressed at the outset to underpin the psychological literature.

1.3.1 The 'Sick Role'

One of the first sociological theories about illness to be developed was by Parsons (1951) who developed the *sick role* from role theory to explain what happens to people and how they experience illness. Lubkin and Larsen (2002) state that "society defines every recognised position and assigns roles that contain a set of 'norms', or behavioural rules, that are socially accepted.". During this process 'socialization' takes place and people develop their own identities by watching the people round them who reflect society at large (Mead (1934) cited in Lubkin and Larsen, 2002). People are able to have many different identities which they use at different times and many roles depend on the roles of others around them, for example mother and child roles. Parsons says that the *sick-role* is assumed when certain criteria are fulfilled (Parsons 1951): 1) In this role people are (obliged to be) exempt from normal responsibilities; however, this depends on the nature and severity of the illness and must be legitimised by a health professional in order to "discourage malingerers"; 2) People in the *sick role* have a right to be cared for. They are not expected to get well by just deciding to be well and are not to blame for their condition therefore have the right to have emotional and physical support from others; 3) People in the *sick role* are obliged to want to get better; and 4) People in the *sick role* are obliged to look for and co-operate with appropriate medical help.

There have been subsequent critiques of the *sick-role* both from the perspective of long-term conditions and illness in general. Parsons developed his model when the occurrence of acute illness far outweighed long-term conditions and as a result the assumptions and 'obligations' of the person in the

sick-role clearly apply more to acute illness than to long-term conditions. Charmaz (1999) suggests that the *sick-role* does not take in to account that it is not possible to recover from long-term conditions and that it assumes that illness is not the responsibility of the person who is ill, and so does not take into account any stigma or responsibility frequently attached to certain long-term conditions. The *sick-role* provides automatic exemption from social roles which people with long-term conditions may wish to, or indeed have to keep. In order to be exempt from social roles the *sick-role* must be legitimized by a doctor (Parsons 1951) which may be a difficulty for conditions such as mental illnesses or multiple sclerosis (MS), added to which the exemption from social roles has clear socio-cultural limitations and is based on a Western middle-class view (Lubkin and Larsen 2002). Economics and personal commitments may require people to work when sick and so take on other social roles. It has also been suggested that different illness beliefs and behaviours may be prevalent in different cultures leading to the *sick-role* as described by Parsons being inappropriate (Lubkin and Larsen 2002). It assumes that there is a 'doctor-patient hierarchy' which may be appropriate during brief acute illnesses but given the nature of long-term conditions involving continual self-regulation, self-monitoring and self-care behaviour it is no longer an ideal position when collaborative care and patient empowerment is being strived for (Funnell and Anderson 2004). The involvement of doctors and health care professionals also causes problems for the *sick-role's* need for legitimization. Some long-term conditions may take years to reach the stage of diagnosis by health care professionals, for example MS or type 2 diabetes, and as a result people with these conditions may not feel legitimately 'sick' (Lubkin and Larsen 2002).

Further criticisms of the *sick-role* include the failure to consider that people can and do occupy many different roles at the same time and few have

the opportunity to relinquish them all but the *sick-role*, particularly during a long term illness (Kelly and Millward 2004). There is also no consideration for what happens if people actually wish to take on the *sick-role*. The assumption of Parsons' theory is that people must want to get better however there are secondary gains to be had from remaining sick. For example, Whitehead et al. (1982) found that people who had received 'rewards' or treats when they were ill as children were more likely to move in to the *sick-role* as adults. Taking on the *sick-role* also enables people to have a rest from the pressures of normal life (socio-economics permitting) and psychological factors may also have an impact on the decision to move to or remain in the *sick-role* (Lubkin and Larsen 2002).

These criticisms of the *sick-role*, in particular the lack of suitability for people with long-term conditions, have led to further developments in this area. Gordon (1966) developed the *impairment role* which uses a similar approach to Parsons' *sick role* but allows for the particular characteristics of long-term conditions to be taken in to account. The characteristics of the *impaired role* include: having an impairment which is permanent, not giving up normal responsibilities and being expected to behave as normally as possible as allowed by the long-term condition experienced. There is no requirement to 'want to get well', as required in the *sick-role*, as this is not possible but the person should be encouraged to make the most of their life despite their long-term condition (Lubkin and Larsen 2002). The *impairment role* therefore suggests people should adapt their lives to manage their illness and aim for 'maximization of wellness' (Lubkin and Larsen 2002) whilst maintaining additional roles that are more associated with a 'normal' life. Bury (1982) suggests that people with long-term conditions can do this whilst still being able

to return to the traditional *sick-role* during periods when their symptoms are exacerbated or during specific events such as surgery.

1.3.2 Identity

Both Parsons' (1951) *sick-role* and the *impairment role* have played an important part in suggesting that health and illness are part of the social world and that social aspects of health and illness are vital when considering the experience of people who are ill (Kelly and Millward 2004). However, they are derived from an 'outsider's' perspective and, although they introduced the concept of the separate entities of patient and doctor and the role that authority and place in society plays (Radley 1994), the relatively static 'roles' described may not adequately describe the experiences, beliefs and meanings for people who have long-term conditions. The study of identity and self offers another option for looking at the experience of illness within a societal perspective. The study of identity and self started within psychology but also draws on philosophical ideas and writings by people such as Goffman (1969) and Rosenberg and Turner (1981) and a symbolic interactionist perspective in sociology (Rose (1962) cited in Kelly and Millward (2004)). This research has generally used qualitative research methods to obtain a subjective and phenomenologically based account of the experience of long-term conditions in order to "present the 'authentic' experience of sufferers and give voice to that experience." (Kelly and Millward 2004).

Identity is a complex idea with different facets including visible aspects of identity such as hair colour, height and weight, and abstract aspects such as status, roles within society and membership of groups. There are different types

of identity (Kelly and Millward 2004) – social identity, relating to other people and the assessment of others, and individual identity, relating to 'self' and the assessment of 'self'. Charmaz (1999) says "From a sociological view the self refers to all those qualities, attributes, values and sentiments, including feelings of moral worth, that a person assumes to be his or her own". Kelly and Millward (2004) suggest several propositions for the formation of identity. Firstly, individuals develop in an interactive way from their social environment and gain a sense of self in relation to others around them (Denzin 1992). Secondly, people are able to think about how they are seen by other people using 'sympathetic introspection' (Cooley 1972). Finally, self becomes a 'social object' through the use of abstract and reflexive language whilst at the same time remaining individual (Szacki 1979). In essence, identity and self is developed, in an interactive way, from the society surrounding the person. This means that, although identity may have a 'central core' which retains stable concepts of self, as new information from the person's surroundings is received identity may be reassessed and altered accordingly (Kelly and Millward 2004). The fact that people have the ability to think reflexively about how they are perceived by other people and because social identity relies on 'shared meanings' within society means that in certain circumstances, for example the onset of long-term conditions, there can be disparities between the social identity being conferred on the individual and the concept of self they hold internally. This may result in a 'fracture' in the "previously held conceptions of self" (Kelly and Millward 2004) and provide possible explanations for some of the negative experiences of people who have a long-term condition.

Hernandez (1995) touched on these issues in her discussion of the adaptation process of 'expert patients' with diabetes. She looked at the stages which these 'expert patients' went through to achieve 'good control'. The 'theory

of integration' she suggested had three stages: 1) 'Having' diabetes, which starts at diagnosis and is distinguished by the need to strive for 'normalcy'; 2) 'The turning point', where something happens to upset 'normality' and forces reassessment of the coping strategies being employed, and 3) 'the science of one', where a way is found to live with diabetes with the focus on living without harming diabetes management. Hernandez suggests that to successfully adapt to having diabetes a process of "integration of the diabetic and personal selves" takes place. In other words there is a need for a person with diabetes to integrate their identity as a person (including the identity formed before diagnosis) with their identity as a person with diabetes in order to successfully adapt to living with diabetes. Hernandez also proposes that the tendency of diabetes educators to focus on being able to live with diabetes and yet still maintain 'normalcy' is incongruous with the reality of living with the condition: "The diabetes regimen often is far from the normal, usual way that these individuals lived prior to their diagnoses and is not the way others around them live." (p. 36) and so can delay the integration process and make people with diabetes feel guilty for not feeling 'normal'.

An important aspect of identity which has been shown to be important when considering health and illness and self-care behaviour is gender. Gender is one of many roles that individuals adopt and forms part of their identity and self. As with other aspects of identity, gender is influenced by the social world and interaction with other people. Within society the socially assigned qualities of masculine and feminine identities are different and these differences have an impact on health, illness and self-care behaviours. The general traditional masculine identity is one of being an active problem solver, wage earner, independent and autonomous, having personal power, being dominant, showing bravery in the face of danger and having a strong public persona with

private feelings (Charmaz 1994). This is contrasted with the general traditional feminine identity which is of a care-giver, able to be dependent and subordinate, passive and able to express private feelings to a greater extent. The threat to self which results from having a long-term condition may therefore be more extreme for men as they may become dependent, feel weakened in front of other people, may have to be passive in the face of medical treatments and feeling ill, and feel powerless because of their condition (Charmaz 1994). These experiences contrast with the traditional image of being a man as assigned by society and so may lead to greater discrepancies between an 'ideal self' and the experiences of having a long-term condition impacting on their images of self and therefore their identities. It is important to note that although individuals obviously vary in their adoption of these identities, societal perspectives still influence the roles and identities of men and women to a greater or lesser extent.

Charmaz (1994) investigated identity and men who had a long-term condition using qualitative interviews. She suggested several ways in which male identities may be particularly threatened by long-term conditions: recognising their mortality after a life threatening experience; adjusting to uncertainty; defining their illness and any disability that may come with it; and preserving self whilst coping with loss of their old self. She describes how the men felt betrayed by their bodies after being diagnosed with a long-term condition which "evokes anger, self-pity and envy of the healthy". She found that her interviewees described techniques for coping with the uncertainty brought by long-term conditions by ignoring, minimising or glossing over it. This sometimes resulted in inconsistent changes to lifestyle and self-care behaviour as "Making permanent changes, however, means acknowledging uncertainty and treating its consequences as lasting." (Charmaz 1994). Definitions of their

condition included: an enemy; an ally; an intrusive presence; and an opportunity. She found that at different points in time different definitions were used. In terms of preserving self she found that the men she interviewed had a range of strategies: limiting the effects of their condition on their lives; controlling how their condition and any disabilities were defined; increasing control over their lives in other ways; and trying to minimise how visible and intrusive their condition was on their lives. Koch et al. (2000) investigated the extent to which men with diet and tablet treated type 2 diabetes minimised how intrusive their condition was on their lives using focus groups. They found that the men involved in their research 'normalised' their diabetes and described it as being part of their life rather than an illness. The main focus of the discussions between the men was control of their condition and demonstrating that they were successfully looking after themselves. Koch et al. (2000) described their previous research with women about these issues and how the men and women differed. The researchers found that the women they worked with did not normalise their diabetes but instead were very conscious of the restrictions that diabetes made on their lives. Koch et al. suggested several reasons for this difference: differences in how men and women tell the narratives of their illness experience; techniques for preserving identity; or "the actual constructions of living with diabetes".

Charmaz (1994) observed that age made a difference to the rapidity and way in which men adjusted to the identity issues surrounding long-term conditions. She suggested that the younger and middle-aged men she interviewed took many years to reconcile their new 'long-term illness' identity with the previous self; whereas, older men seemed to be resigned to their condition and "built lines around their illness". She also found socio-economic differences and suggested that those men who were middle class tended to find

positives in their experiences with long-term conditions in a similar way to women. These positives included, for the married men, feeling that their valued identities at home, such as father and husband were confirmed. Her interviewees mentioned the large amount of support they experienced from their wives which affirmed their masculine roles within the household. This was despite the men being at their "most vulnerable" because of their illness – dependent and powerless. Charmaz noted that the situation also allowed the men's partners to confirm their roles as care-givers. This was in contrast to the single men who described coping with their illness mostly on their own. Identity, self and biographical narrative are closely linked and are all effected by the diagnosis and experience of living with a long-term condition. The next section focuses on biographical disruption as a result of long-term conditions.

1.3.3 Biographical Disruption

Bury (1982) looked at the impact of long-term conditions from the perspective of people who had the long-term condition rheumatoid arthritis – an 'insider's' perspective. He found that people with a long-term condition experienced the diagnosis of their condition as "a major kind of disruptive experience". He portrays the occurrence of long-term conditions as 'biographical disruption'. Bury (1982) describes three main aspects of biographical disruption: 1) the disruption of assumptions about everyday life and the behaviours involved in everyday life; 2) the disruption to the person's self, identity and biography; and 3) the mobilisation of resources to cope with the changing situation.

Bury suggests that long-term illness is an event where people come face to face with pain, suffering and mortality which are normally viewed as distant aspects of life or something which happens to other people rather than something which is experienced directly. He also proposes that the disruptive effect of long-term conditions causes the social relationships surrounding the person with long-term illness to become under pressure as they move from the normal situation of "mutual dependency" to a more uneven and dependent relationship. Due to the fundamental and long lasting affects of long-term conditions on life course, identity and social interaction the experience of long-term illness becomes "woven into the person's biography" (Radley 1994).

Many aspects of the experience of diabetes, fit with Bury's theory of biographical disruption. Kelleher (1988) discusses experiences at the diagnosis of diabetes which show it to be a " major kind of disruptive event" (Bury 1982). These include how people with type 2 diabetes may have no symptoms and so experience shock at finding out they have the condition or, in other people with type 1 or type 2 diabetes who have had symptoms for a period of time, relief at having an explanation may be the over-riding emotion felt. Kelleher suggests that the reaction may be dependent on how much information the person has about diabetes prior to diagnosis. Murphy and Kinmonth (1995) explored this in their study looking at a group of individuals with type 2 diabetes. They found that the participants tended to be either symptom or complication focussed and described how some of their participants who were asymptomatic at diagnosis were dismissive of the diagnosis and medical advice as a result. Kelleher (1988) suggests two main aspects of the adjustment to diabetes which reflect Bury's disruption of everyday assumptions about life and behaviour - loss of spontaneity and loss of control. Kelleher describes how when first diagnosed with diabetes a person must learn new, complex treatment regimes and that

taken for granted activities such as eating and exercising must now be planned and organised so taking away "a pleasure of life to be indulged in". This goes against the common assumptions that in 'normal' life people can control most of what goes on around them and have the ability to make choices and act in a spontaneous way if they so wish.

Diagnosis with diabetes challenges other common assumptions about life. As mentioned by Bury (1982) the onset of any long-term condition, including diabetes brings people face to face with their own mortality. Added to which there is the continual possibility of diabetes complications later in life, which even with excellent self-care behaviour are likely due to the progressive nature of diabetes. There is also a disruption of the assumptions about life and behaviour in terms of social relationships. The dynamics of the social relationships of people with a long-term condition often change. Instead of an interdependent relationship with others, the person with the long-term condition may become more dependent than the other party or parties in the relationship. If dependency does not develop immediately then the individual with the long-term condition may face the possibility that as time goes on they will grow more dependent (Charmaz 1994). This means that future plans and dreams may need to be looked at and altered (Bury 1982). Added to which this re-evaluation of social relationships may take place during a "strained situation" during the adaptation process to living with a long-term condition.

Mobilisation of resources is another aspect of 'biographical disruption' suggested by Bury (1982). Social relationships provide an essential resource for people with diabetes. Kelleher (1988) suggests several ways in which social relationships may be useful for a person with diabetes. He proposes that from both a practical and psychological perspective social support can be beneficial

for example helping preparing or administering injections, altering the typical family eating habits to suit the person with diabetes, identifying hypo or hyper symptoms and providing encouragement and emotional support where necessary. Kelleher suggests, however, that social relationships can also be a source of stress and may be damaging to the individual with diabetes. For example, at a physiological level conflict and arguments can cause raised blood sugars. Psychologically significant others may "collude" with the person with diabetes in trying to "normalize" their diabetes by ignoring the requirements and constraints of the condition. The opposite of this can be to become so over-protective and strict about following the regime, for example in terms of eating, that feelings of being ill or 'different' are accentuated. This can be linked back to Parsons' (1951) sick-role where the person with diabetes is 'pushed' into the sick role by the people surrounding them whether they want to or not. The impact of social support on diabetes has been examined in numerous studies, for example Skinner and Hampson (1998) found that family support was a significant predictor of self-care behaviours and Toljamo and Hentinen (2001) found that instrumental and emotional support from family and friends led to better 'adherence' to self-care behaviours.

Charmaz (1983) suggests that the loss of control and lack of spontaneity (as mentioned by Kelleher (1988)) can lead to social isolation. Due to the restrictions of performing a medical regime, the dependency on that regime and the uncertainty connected with having a long-term condition social life can be reduced. For example Kelleher (1988) describes restrictions people with diabetes placed on themselves because of the dietary requirements they perceived as essential to their diabetes care such as not going on holiday, avoiding social situations where they may need to do an injection and so on. By withdrawing from social situations people may lose touch with their friends and

may develop fewer relationships outside of the family network (Charmaz 1983). Due to the changed dynamic in relationships from interdependence or reciprocity to dependence, forming friendships requires much more effort on both sides. Time and energy must be spent on the medical regime (Kelleher 1988) and this can become isolating because it sets the person with the long-term condition apart from everyone else, treatment can be easier to maintain at home and the medical regime focuses the individual's attention on themselves (Charmaz 1983).

The previous sociological theories are important for describing the interaction between social environment and the experience of diabetes; however, they do not address the mechanisms or processes involved in the relationship between personal experience, beliefs about diabetes and behaviour. The following sections of this chapter describe self-efficacy from Social Cognitive Theory (Bandura 1977) and the Commonsense Model of the Self-Regulation of Health and Illness (Leventhal et al. 2003). These are the two psychological theories used in this thesis as a theoretical framework for exploring the relationships between individuals' experiences of their diabetes, their beliefs about their condition and the performance of self-care behaviour.

1.4 Self-efficacy

Self-efficacy has already been mentioned when discussing aspects of the diabetes care regime and an empowerment approach to care. It is one of the central concepts in this research and is thought to be an important aspect of behaviour and in particular self-care.

1.4.1 A definition of self-efficacy

Self-efficacy is the belief that people have about their ability to perform a particular action needed to deal with a particular situation and their ability to regulate the motivation, thought processes, emotional states and environment surrounding that action. This is important in relation to long-term conditions, such as diabetes mellitus, as these conditions often involve a very complex pattern of behaviours which must be carried out every day to maintain good health. People with these conditions need to believe in their own abilities to perform what are very often new and confusing activities, often without any benefit being seen in the short term (Bandura, 1986).

1.4.2 The origins of self-efficacy

Self-efficacy's theoretical foundations lie in Social Cognitive Theory (also known as Social Learning Theory) (Bandura, 1986) which views people as 'active shapers' rather than 'passive reactors' in their environment who self-regulate and self-reflect. It encompasses cognition, action, motivation and emotion. The basic assumptions of Social Cognitive Theory are:

a) People are able to symbolize experiences and create internal models of experience.

b) Behaviour has a goal or purpose and is dependent on symbolizing.

c) People are self-reflective and analyse and evaluate their own thoughts and feelings.

d) People self-regulate by creating their own standards for behaviour, evaluating their behaviour against these standards and then either altering their own behaviour or altering their environment which in turn alters their behaviour.

e) People learn by evaluating others.

f) There is triadic reciprocality which involves environmental events, inner personal factors and behaviour interacting although not necessarily at the same time or at the same strength (see figure 1).

Social Cognitive Theory is mainly concerned with personal cognitive factors, for example, the effect of cognition on affect and behaviour and the effect of behaviour, affect and environment on cognition.
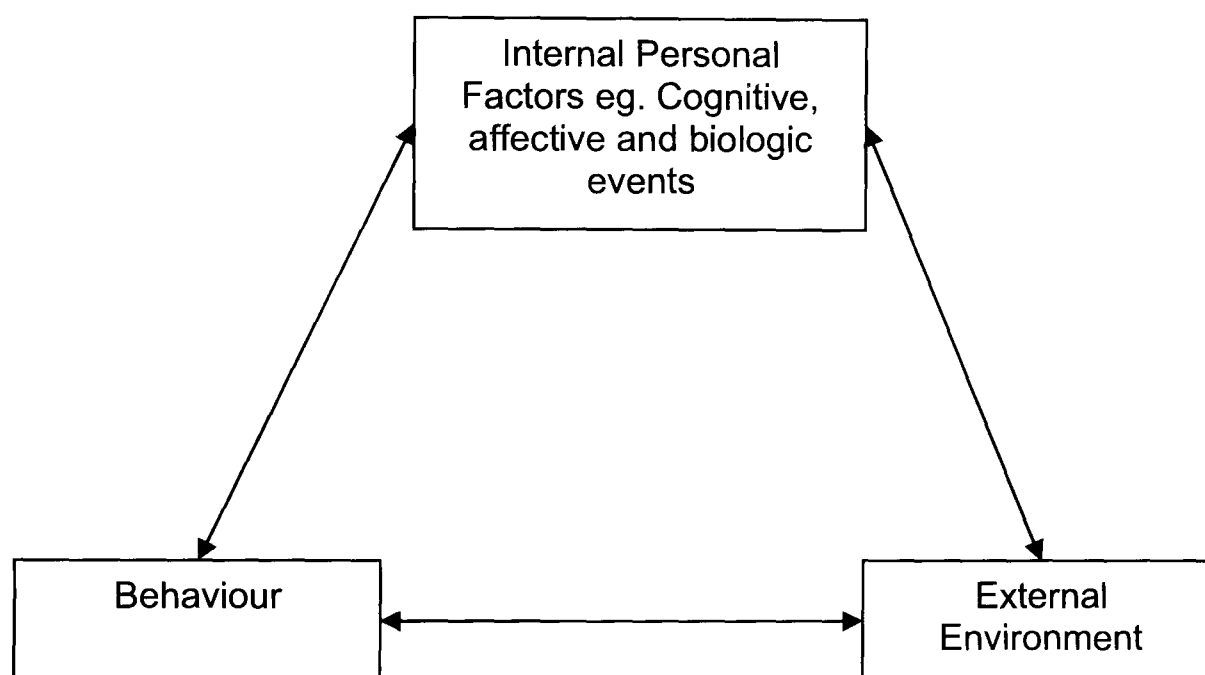
Figure 1 - Triadic reciprocality of personal, environmental and behavioural factors in Social Cognitive Theory (from Bandura 1997)

1.4.3 Self-efficacy beliefs

The self-efficacy beliefs that people hold are developed in a variety of different ways (Bandura 1977). Bandura (1997) suggests four different sources of self-efficacy: performance experience, vicarious experience, verbal or social

persuasion and emotional state. The most powerful source of self-efficacy comes from performance experiences. When attempting to action a particular behaviour if the attempt succeeds then self-efficacy is increased and if it fails then self-efficacy for that task weakens. Bandura (1977) suggests that because in some situations overt performance of a behaviour is not possible then mental rehearsal or imaginal experiences – running through scenarios in one's mind – are also able to affect self-efficacy and develop proficiency. Vicarious experiences, done by another person, have a slightly weaker impact on self-efficacy. The strength of the effect depends on how similar the observer perceives the observed experience to be to their own. It also depends on the number and variety of models of behaviour they observe. Other determinants include verbal (social) persuasion, the strength of which depends on the expertness, trustworthiness and attractiveness of the source. Also physiological states are important because if people associate aversive physiological arousal, for example symptoms of anxiety such as sweating, racing heart etc, with failure to perform a behaviour and perceived incompetence then when they get aversive arousal in the future they are more likely to doubt their abilities to perform a task. This works the other way round too, when positive arousal becomes associated with a behaviour, which produces increased self-efficacy when experienced. Emotional state also impacts on self-efficacy as people are more likely to have a higher self-efficacy about a performance when they are feeling in a positive mood (Maddux 1995).

All these determinants of self-efficacy operate from two different sources – distal (past experiences) and proximal (current sources). According to Bandura (1989), an important aspect of self-efficacy beliefs is that they do not need to be accurate in order to be effective. In fact "positive illusion" or exaggerated opinions of our own abilities actually leads to healthier adaptation

and a better psychological state, as long as the beliefs are not too exaggerated and may therefore lead to failure.

Social Cognitive Theory, as developed by Bandura, suggests numerous ways in which self-efficacy beliefs or expectations determine people's choice of goals and choice of goal directed actions. According to Social Cognitive Theory, people tend to take part in activities and perform behaviours which they have positive self-efficacy beliefs for. They also choose to perform behaviours which will confirm existing beliefs and avoid behaviours which they have low self-efficacy beliefs for. People pick environments which allow their skills to show. They listen selectively and in particular listen and attend to information that reinforces their existing self-efficacy beliefs whether that is high or low. In this way self-efficacy beliefs are self-confirming, self-perpetuating and can create self-fulfilling prophecies. The expected rate of improvement for a behaviour is also important. Social Cognitive Theory suggests that people are more likely to perform a behaviour that they expect to improve quickly at. Consequently, self-efficacy beliefs dictate the amount of effort expended to achieve a goal and the amount of persistence in the face of barriers to performance (Bandura 1986). Weak self-efficacy results in doubts which means people may cease their efforts more quickly whereas strong self-efficacy results in increased efforts, success and this in turn reinforces self-efficacy beliefs again creating self-perpetuating beliefs. There is a circular effect.

Self-efficacy beliefs also operate via thought patterns and emotional reactions. Thought patterns are affected by self-efficacy beliefs and so can enhance or undermine performance due to the effect on goals and aspirations, the visualisation of positive and negative scenarios and the quality of inferential thinking – the use of analytical thought processes (Maibach and Murphy, 1995).

As noted above, emotional states are closely linked to self-efficacy. Maddux (1995) suggests that low self-efficacy for preventing harmful events can lead to anxiety and low self-efficacy for attaining goals can lead to depression. The more important the goal to be attained, the stronger the negative affective and physiological reaction if people believe they lack the abilities necessary to achieve it. For example Kuijer and deRidder (2003) examined the differences between how their participants with a long-term condition ranked a goal's importance and how they ranked how attainable they thought this goal was for them personally. They found that these differences were significantly associated with lower self-efficacy, lower levels of quality of life and psychological well-being.

According to Bandura (1977), there are three dimensions to self-efficacy - magnitude, strength and generality. *Magnitude* refers to the number of 'steps' of difficulty or threat that a person feels they are able to cope with (Maddux 1995). *Strength* refers to how strongly and resolutely a person holds their self-efficacy belief and has been frequently related to persistence when faced with barriers to performance such as pain (Bandura 1986). Self-efficacy beliefs are very task specific. Beliefs are directly related to the type of behaviour and the context in which the behaviour is performed. However, depending on how similar the context and how similar the task is, there may be a degree of transfer of self-efficacy belief to different behaviours and generalisability. *Generality* is the extent to which success or failure effects specific self-efficacy beliefs or generalises to similar behaviours and situations.

1.4.4 Self-efficacy and diabetes

Research on self-efficacy in relation to diabetes includes that which focuses on how individual behaviour distinguishes certain types of self-efficacy, and also how certain social factors may influence behaviour. For example, self-efficacy has been shown to be significantly correlated with self-care behaviour and blood glucose levels in individuals with type 1 and type 2 diabetes (Grossman et al. 1987; Hurley and Shea 1992; Kavanaugh et al. 1993; Griva et al. 2000; Aljasem et al. 2001; Johnston-Brooks et al. 2002; Ikeda et al. 2003). Grossman et al. (1987) and Griva et al. (2000) found that diabetes specific self-efficacy was significantly correlated with metabolic (ie blood glucose) control and self-care behaviour. Due to the task specificity of self-efficacy many of the studies have broken it down into different types of self-efficacy. Aljasem et al. (2001) broke self-efficacy down into *planning efficacy* (significantly associated with more blood glucose testing, better diet and less binge eating), *insulin efficacy* (significantly associated with ability to adjust insulin to avoid hypos), *reliance efficacy* (getting diabetes related help from others - significantly associated with better diet) and *assertiveness efficacy* (significantly associated with less medication skipping and less blood glucose testing). In terms of social factors, Bernal et al. (2000) carried out a study with Hispanic adults with diabetes in Connecticut (USA), and found that language ability and education level were both significantly associated with general self-efficacy for diabetes. Another demographic, gender, was found to be significantly associated with diabetes self-efficacy by Padgett (1991) who studied people with diabetes in Yugoslavia. Padgett found that self-efficacy was moderately associated with male gender, a younger age and a higher education level. This contrasts with Grossman et al. (1987) who found no gender differences in self-efficacy beliefs.

Padgett hypothesises that this is due to 'gender role socialisation' being greater in Yugoslavia than in the USA where many of the other studies have been carried out. The emotional association with self-efficacy can also be seen in the studies looking at diabetes and self-efficacy. Padgett (1991) found that self-efficacy was significantly associated with the performance of diabetes self-care behaviours and depressive symptoms.

As discussed earlier diabetes education has been traditionally given in a lesson format where a health professional 'tells' the person with diabetes how to perform self-care behaviours. This would be classed as *verbal persuasion* in terms of developing self-efficacy beliefs and as such is one of the weaker methods for encouraging self-efficacy to perform the behaviours being described, according to Bandura (1977). According to Broom and Whittaker (2004) this is particularly relevant when considering that people with diabetes may view the health practitioner, 'telling' them how to perform these behaviours, not being in their position and not having experienced diabetes directly, and therefore perceiving themselves as in a 'them and us' situation. As mentioned previously, according to Social Cognitive Theory (Bandura 1977) the strongest source of self-efficacy comes from performance experience. This can be achieved in a diabetes education setting by encouraging patients to make small step by step changes which they can succeed at and therefore develop self-efficacy before moving on to larger changes (Funnell and Anderson 2004). Bandura (1977) suggests that people tend to take part in activities and perform behaviours which they have positive self-efficacy beliefs for. They also choose to perform behaviours which will confirm existing beliefs and avoid behaviours which they have low self-efficacy beliefs for. So by succeeding at small changes in behaviour this may develop self-efficacy and encourage people to attempt and succeed at making larger changes. Another reason why this step

by step approach may be appropriate is the suggestion that determinants of self-efficacy operate from two different sources – distal (past experiences) and proximal (current sources) (Maddux 1995). If a person with diabetes has had negative past experiences with their diabetes and the performance of self-care behaviours this does not encourage self-efficacy to develop. After the initial diagnosis of diabetes people are required to master a large number of often complex self-care behaviours, such as injections, blood tests, carbohydrate monitoring and so on. This may be extremely difficult and when, in type 1 diabetes, combined with fluctuating residual insulin production due to the 'honeymoon period', may result in very negative experiences and so it is understandable that some people with diabetes may have low self-efficacy for the necessary self-care behaviours. By introducing gradual changes that encourage positive feedback in a proximal source self-efficacy may be increased.

Vicarious experience also encourages self-efficacy and the use of group sessions with other patients are examples of this. By sharing knowledge and the implementation of this knowledge from a person in the same position the effect may be strengthened (Maddux 1995). The impact of emotional state on self-efficacy should not be dismissed. It has been suggested by past research that stress has a major impact on metabolic control through both physiological and psychosocial pathways (Lloyd et al. 1999). Research has shown that stress, anxiety and depression have a negative impact on the performance of self-care behaviours (Lin et al. 2004). A potential mechanism for this relationship is suggested by Social Cognitive Theory - if negative emotional states become connected to particular behaviours the self-efficacy for that behaviour may reduce and therefore the self-care behaviour will be performed to a lesser extent.

The perceived importance of self-efficacy in the performance of self-care behaviour is reflected in the various interventions which have been designed to increase self-efficacy in people with diabetes, and therefore improve glycaemic control. However, these interventions have had mixed results. Howells et al. (2002) found that their telephone support for young people with type 1 diabetes intervention produced significant improvements in self-efficacy; however, there was no significant improvement in glycaemic control. Adolfsson et al. (2007) found no significant differences in self-efficacy as a result of their intervention which was based on a group education and empowerment approach. They also found no significant improvements in glycaemic control. Anderson et al. (1995) used a patient empowerment programme and demonstrated a significant improvement in self-efficacy in the intervention group compared to the controls for four out of eight of their self-efficacy subscales. In contrast to the other studies they found an improvement in glycaemic control at 12 weeks when compared with their baseline measurements.

There are several reasons why these intervention studies may have failed to observe an impact on glycaemic control or even self-efficacy. Anderson et al. (1995) suggest that the measurement of self-efficacy prior to the interventions may be over-estimated due to the participants not fully understanding the skill or concept they are being asked about. They suggest that this may result in an underestimation of the effect of the intervention on self-efficacy. Another possibility is that the measurement techniques used to assess self-efficacy may not be particularly effective. As mentioned earlier Bandura suggests that self-efficacy has three dimensions: magnitude, strength and generality. The questionnaires used by Adolfsson et al. (2007), Howells et al. (2002) and other researchers in this area do not reflect the three dimensional nature of self-efficacy. For example, Adolfsson's measurement of self-efficacy involved

participants completing a set of questions on how confident they were about various aspects of their diabetes on a likert scale. This is similar to the research conducted by Howells et al. (2002) as well as by other researchers. Clark et al. (2004) found no significant differences in self-efficacy between their intervention and control groups in an intervention study designed to look at dietary and physical activity behaviour. However, Clark et al. only used two questions to assess self-efficacy, again based on a 10 point likert scale asking how confident they were that they could take part in exercise or cut down their intake of high fat food. Bandura (1997) suggests that measurement of self-efficacy should involve all three dimensions. Self-efficacy beliefs differ depending on the perceived difficulty of the task. For example, an individual may have high self-efficacy when confronted with a task with a low level of difficulty but when faced with the same task at a more difficult level may have a different self-efficacy belief. Self-efficacy beliefs also vary in terms of strength. Individuals may have a weak sense of high self-efficacy which when faced with adversity may be quickly reduced or a strong sense of low self-efficacy which may be hard to increase. An individual with strong high self-efficacy beliefs for a certain task will persevere with that task in difficult circumstances (Bandura 1997). Bandura suggests that measurement of self-efficacy should include questions referring to if a person thinks they can do something and then to rate the strength of that belief. He also states that the measures should include questions asking about different levels of the task. Few of the studies described previously employ this type of measurement. It is possible that the interventions may not be improving self-efficacy and therefore this may account for the lack of relationships with glycaemic control or lack of improvement in self-efficacy beliefs. However, this is difficult to determine given the issues with measurement of self-efficacy as described above.

1.4.5 Self-efficacy and similar constructs

One construct which is entwined with self-efficacy and is important in Social Cognitive Theory is *outcome expectancy*. Social Cognitive Theory suggests that behaviour is affected by three different types of expectancy (Schwarzer 1992): 1) situation-outcome expectancies, which are beliefs that certain consequences will happen if a behaviour is not performed; 2) outcome expectancies, which are beliefs about what will happen if a behaviour is performed or "the assumed normal consequences of action"; and 3) self-efficacy expectancies or beliefs which, as described earlier, refer to whether an individual believes they are capable of performing a particular behaviour. For example, with regards to an individual with diabetes and their performance of dietary self-care behaviours: 1) situation-outcome expectancies refers to the belief that if the recommended dietary self-care behaviour is not performed then blood sugars will be more erratic; 2) outcome expectancies refers to the belief that if the recommended dietary self-care behaviour is performed then blood sugars will be more stable, and; 3) self-efficacy beliefs refers to the belief in the ability to eat the recommended diet.

Bandura (1997) describes the relationship between self-efficacy beliefs and outcome expectancies as being a causally related process with performance occurring before outcomes (see figure 2). Outcomes derive from the performance of a behaviour. Therefore, how an individual behaves generally determines the outcomes that are experienced. For example, in terms of performing exercise self-care behaviour for a person with diabetes, an individual is unlikely to think that the outcome of exercising will be a debilitating hypo and then feeling unwell unless they also have low self-efficacy for

adapting their insulin requirements or intake of carbohydrate to compensate for the exercise. The low self-efficacy beliefs about adapting diet and insulin intake come first which leads to the outcome expectancy of a hypo resulting from exercise.

```
┌──────────┐        ┌──────────────┐        ┌──────────┐
│  PERSON  │───────▶│  BEHAVIOUR   │───────▶│ OUTCOME  │
└──────────┘        └──────────────┘        └──────────┘
        \                    \
         \                    \
    ┌──────────────┐    ┌──────────────┐
    │  EFFICACY    │    │   OUTCOME    │
    │  BELIEFS     │    │ EXPECTANCIES │
    │  Level       │    │  Physical    │
    │  Strength    │    │  Social      │
    │  Generality  │    │  Self-evaluative │
    └──────────────┘    └──────────────┘
```
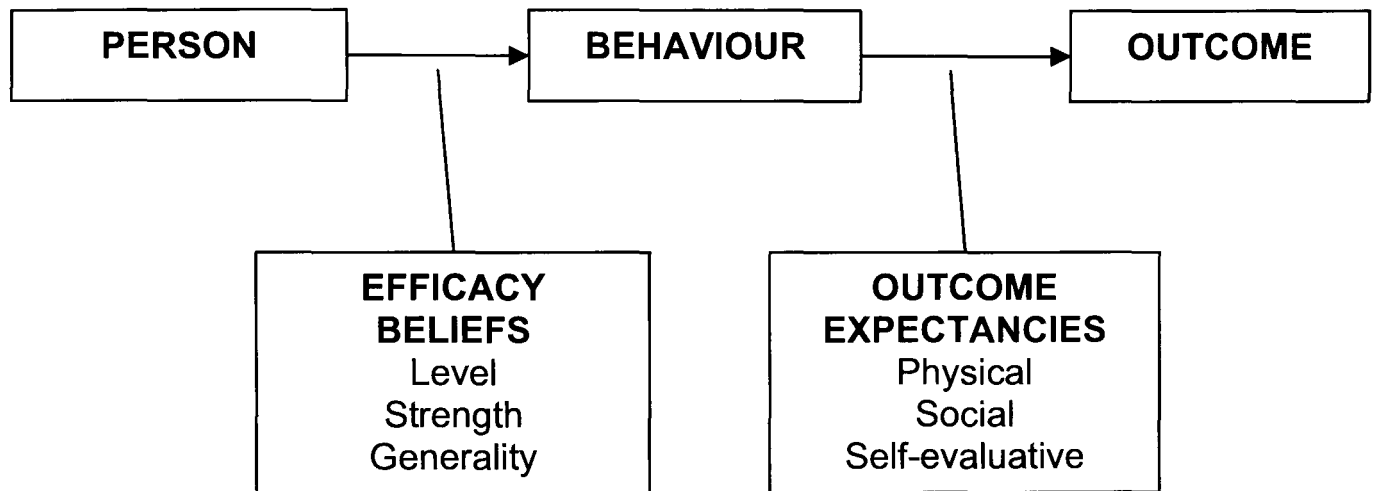
Figure 2 - The conditional relationships between efficacy beliefs and outcome expectancies from Bandura (1997)

Bandura (1997) suggests that there are three different classes of outcome expectancy – physical, social and self-evaluative. Bandura suggests that the relationship between self-efficacy and outcome expectancy depends on the type of activity and situation. For example, for outcomes which are highly dependent on how well the behaviour is performed then the outcome expectancies of an individual will depend to a great extent on how well the individual believes they can perform the necessary behaviour. For outcomes which are less reliant on the quality of the performance of a particular behaviour, for example where external factors may have an influence, self-efficacy beliefs are less influential in predicting performance (Bandura 1997).

One study looking at self-efficacy and outcome expectancies in the context of diabetes was carried out by McCaul et al. (1987). They looked at people with type 1 diabetes and found that self-efficacy beliefs and outcome expectancies were significantly correlated with 'adherence' (the performance of self-care behaviours): "Adherence is better when the person expected that 1) they could execute the regimen behaviour [self-efficacy] and 2) the behaviour would produce a strong ratio of positive versus negative outcomes [outcome expectancy]." (McCaul et al. 1987). However as this was a correlational study it is not possible to establish a causal link and it may be that better adherence led to greater self-efficacy and more positive outcome expectancies. Kingery and Glasgow (1989) carried out a similar study looking at people with type 2 diabetes. They found that self-efficacy and outcome expectancies were moderately strong predictors of self-care in exercise regimes but weaker predictors for dietary self-care and blood glucose testing. Self-efficacy and outcome expectancies were modestly correlated, but outcome expectancies were 'found to add little if anything to self-efficacy in predicting dietary and glucose testing self-care'.

Self-efficacy is a concept which is very similar to other concepts surrounding human agency, motivation and behaviour. There are, however, important distinctions between them. Other constructs similar to self-efficacy include self-esteem and locus of control, which have been studied by researchers such as Epstein (1991), Havermans and Eiser (1991) and Deci and Ryan (1995). Skinner (1996) suggests that self-efficacy is one of many constructs of control which have been developed from sociological and psychological research. She describes a framework for distinguishing these similar constructs of control in terms of *objective control, subjective control* and *experiences of control*, and between *agents, means* and *ends of control*. Self-

efficacy refers to beliefs about whether an individual feels they are able to perform a certain behaviour therefore it is perceived control (how much control an individual perceives they have over a certain situation) and so would be classed as subjective control. The interaction of agents, means and ends is important for describing behaviour and the beliefs about behaviour. An *agent* usually refers to the self, *means* refers to the actions needed to reach a particular outcome and *ends* are the outcomes. Skinner suggests that *means-ends relations* include constructs such as locus of control (eg. Lefcourt 1981) and universal helplessness (eg. Abramson et al. 1978). Means-ends relations refer to the association between causes and outcomes. For example, locus of control looks at how people have an internal or external locus of control which relates to beliefs about whether they or an external force, such as 'powerful others', have the means to affect the desired or undesired outcomes. *Agent-ends relations* include constructs such as control beliefs (eg. Skinner et al. 1988) and personal control (eg. Gurin et al. 1978) which describe beliefs about if an outcome is available to a particular agent, usually the self. Skinner classifies self-efficacy as an *agent-means relation*. Other constructs in this category include action-outcome expectations (eg. Heckhausen 1977) and perceived competence (Harter 1978). Agent-means relations are constructs which look at whether a particular means is "available to a particular agent" (Skinner 1996). So for self-efficacy beliefs this is whether an individual feels they have the necessary ability to perform a certain behaviour or make a specific response.

Bandura (1997) argues that this conceptual framework of control is flawed in several ways. He suggests that only three of the four elements of the concept of control are mentioned and that the issue lies with how *ends* are defined and conceptualised. He states that "if positive or negative events represent the

rewarding or punishing outcomes that flow from performance attainments, then performance is missing from the tripartite scheme." (p. 27). *Means* do not directly relate to an *outcome* or *end*. In between means and ends, performance is needed. In other words an individual may believe they have the means to achieve a specific outcome and an end or outcome in mind however, without the performance of a behaviour the end or outcome will not be met and means refers to the ability to perform a behaviour rather than the actual performance of that behaviour. However, Bandura states that "if positive and negative ends represent variations in performance attainments, then the tripartite scheme is missing outcome" (p. 27). Therefore depending on the interpretation of *ends* either performance or outcome is missing from Skinner's framework. Additionally, Bandura suggests that the definition of *means* by Skinner (1996) is slightly problematic as in her categorisation means refers to "things people can do (effort)", "things they presumably have (abilities)" or external forces such as powerful others, luck and so on. Bandura (1997) proposes that *means* should refer to something which is *done by* the person rather than something *done to* the person and that therefore this classification of means is problematised by the inclusion of luck, chance, powerful others and so on in this category.

Another set of beliefs which are related to self-efficacy and to outcome expectancies are *strategy beliefs* and *capacity beliefs*. Strategy beliefs refer to the beliefs about the way in which an individual's diabetes is treated, whether these strategies work and their effect on short-term management of their diabetes and the longer term possibility of consequences. Capacity beliefs refer to beliefs that an individual has about whether they have or have access to a certain ability or means (Skinner et al. 2000).

Self-efficacy is an important concept for explaining behaviour such as self-care and is therefore a central part of this research into the experience of diabetes. Self-efficacy is a concept which is significant in numerous models of health behaviour including the Self-Regulation Model (Cameron and Leventhal 2003) and can be linked to many other ideas surrounding current diabetes care such as patient empowerment (Funnell and Anderson 2004) as discussed earlier. The part that self-efficacy plays in the Commonsense Model of the Self-Regulation of Health and Illness (Cameron and Leventhal 2003) is discussed in the next section of this chapter.

1.5 The Commonsense Model of the Self-Regulation of Health and Illness (CSM)

Self-regulation is a term used to describe the way in which individuals manage their thoughts and behaviour and adapt to the world around them. Zimmerman (2000) states that "Self-regulation refers to self-generated thoughts, feelings, and actions that are planned and cyclically adapted to the attainment of personal goals." (p. 14). It is suggested that self-regulation is a triadic interaction between personal, behavioural and environmental factors (Bandura 1986). Personal self-regulation involves aspects such as self-efficacy and processes such as assessing cognitive and affective states. Behavioural self-regulation is where the behaviours performed are evaluated and adapted where necessary to obtain personal goals. Environmental self-regulation involves the monitoring and adaptation of environmental factors (Zimmerman 2000). Self-regulation is an important concept for describing and explaining

behaviour such as self-care behaviour in the context of long-term conditions, for example diabetes. It is a flexible, dynamic and interactive approach which combines personal, behavioural and environmental factors, all of which are thought to have an influence on self-care.

1.5.1 Self-regulation models

Self-regulation models were developed as a consequence of a perceived need to explain the complex and dynamic interaction of thoughts, emotions and behaviour. There are models specific to health and illness, such as the Commonsense Model (Leventhal et al. 1980), as well as more general human behaviour models, such as Carver and Scheier's self-regulation model (1998). The term 'self-regulation' refers to two different aspects within the regulation of the self. Firstly, the way in which these models self-regulate using a feedback loop within the model and secondly, what is actually being regulated – the self (Leventhal et al. 2003).

The basic principle of a self-regulation model is that within the self-regulation system: a) goals are set; b) action or behaviour to reach these goals takes place; c) progress towards these goals is appraised and; d) as a consequence of this appraisal, the goals and strategies for reaching the goals are revised. This process is aided by the feedback loop mentioned above with the goals that were set being used as reference values in order to measure the success of strategies of action as can be seen in figure 3 (Scheier and Carver 2003).
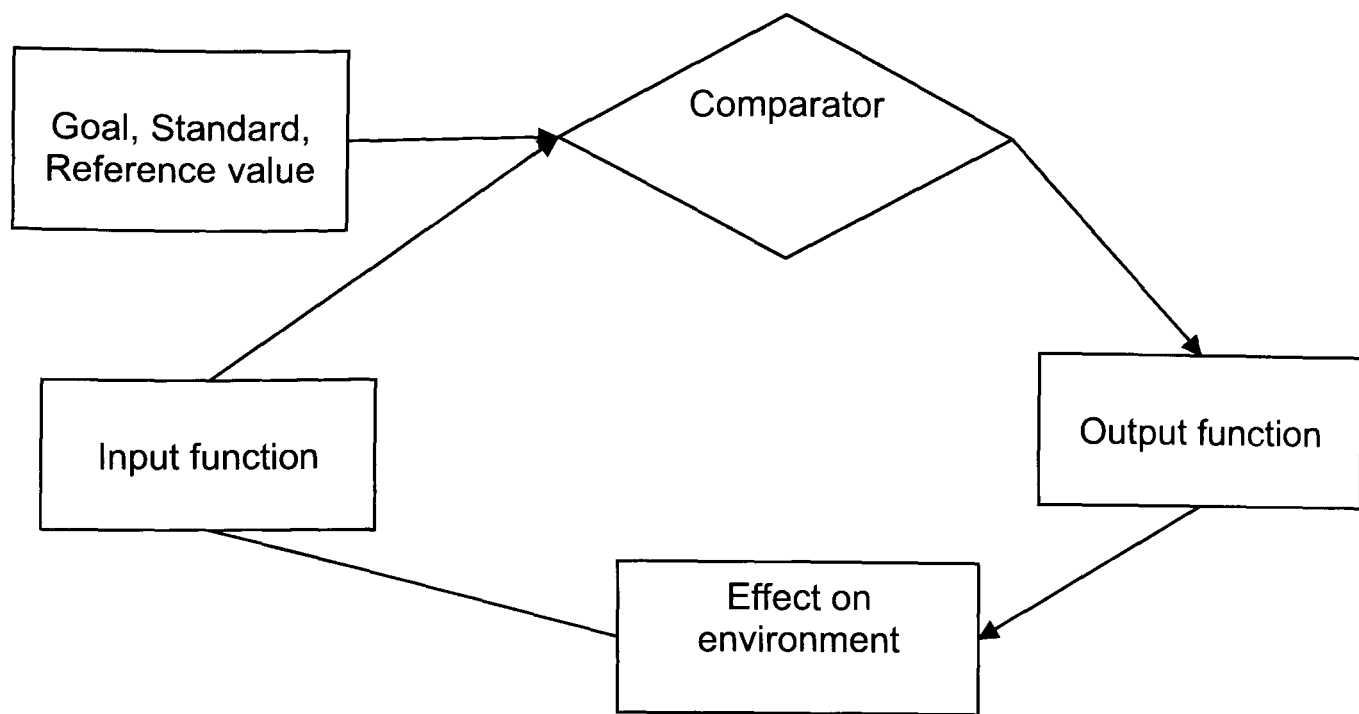
Figure 3 - A schematic depiction of a feedback loop (Scheier and Carver, 2003)

Scheier and Carver (2003) suggest that there are two types of feedback loop –
discrepancy enlarging and discrepancy reducing loops. Discrepancy enlarging
loops are concerned with avoiding the reference value or goal. For example, if
an individual with diabetes knows a friend who has diabetes and has
experienced severe diabetes complications such as a leg amputation due to
poor metabolic control the individual may use his or her friend's behaviour as a
reference value and seek to avoid the same consequences by adapting his or
her behaviour (see figure 4).
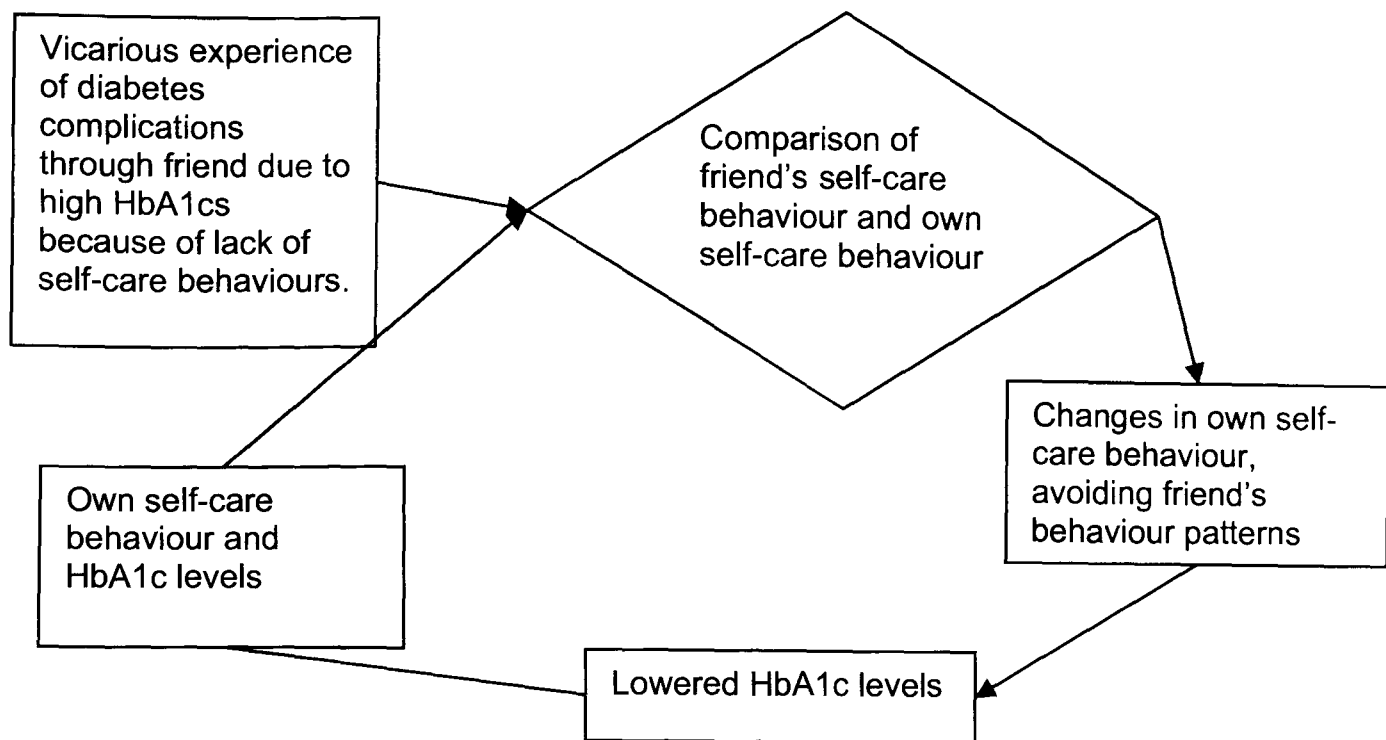
Figure 4 - A discrepancy enlarging feedback loop for an individual with diabetes.

Discrepancy reducing loops involve having a reference value or goal that the individual wishes to attain and regulating behaviour to reduce the difference between the present situation and the reference value. For example, if the individual with diabetes also has another friend who has reached old age with no diabetes complications due to good metabolic control the individual may attempt to change his or her behaviour to reduce the difference between their behaviour and the friend's behaviour in order to produce the same result of no complications (see figure 5).
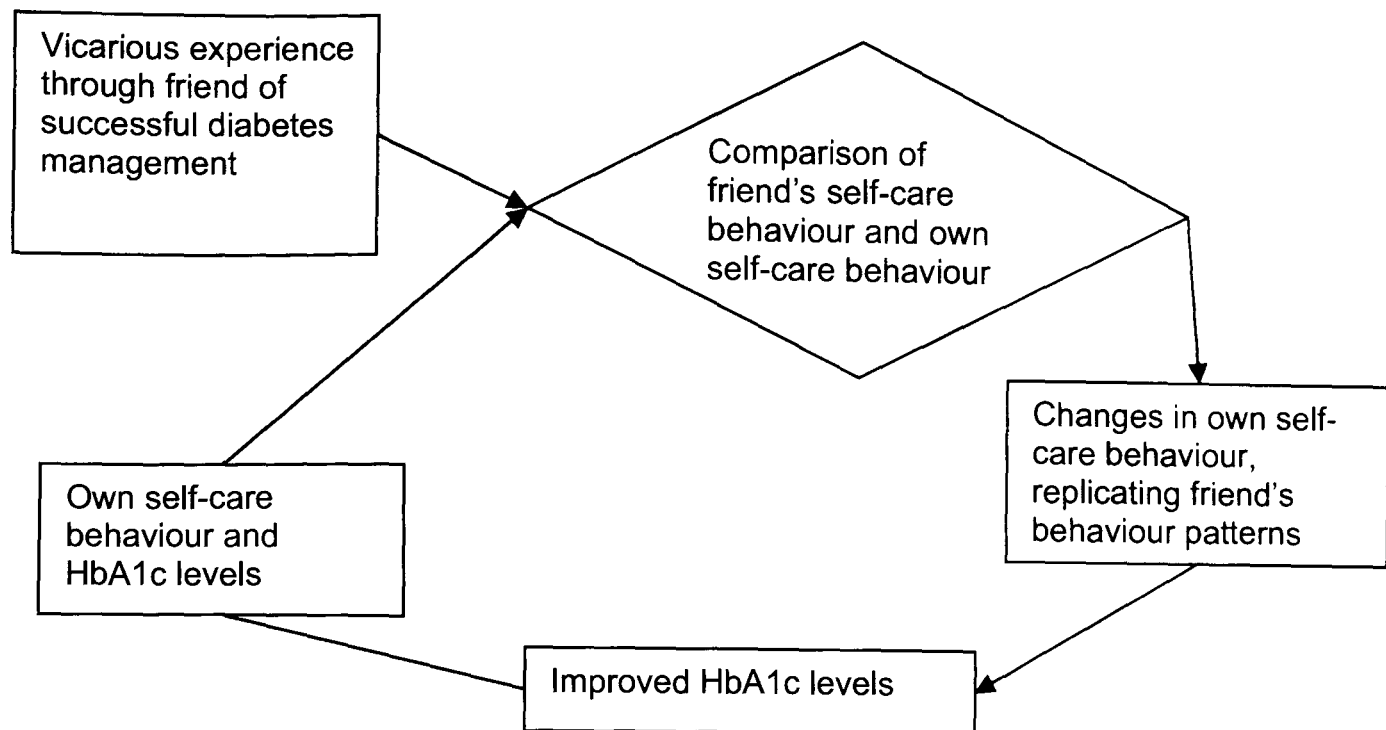
Figure 5 - A discrepancy reducing feedback loop for an individual with diabetes.

Within the self-regulation system, thoughts or cognitions and emotions are processed simultaneously. Emotional processes can be experiences due to a health threat or specific situation or a consequence of the appraisal system evaluating the success of strategies to reach the goals. In addition they can have a direct or indirect affect on cognitions or behaviours (Leventhal et al. 2003).

There are several other important aspects to be found in self-regulation models. Within some models, in particular Carver and Scheier's (1998) model for general self-regulation of behaviour, there is a hierarchical goal structure (see figure 6). This means that goals are arranged in a "linked hierarchy" where more abstract goals such as 'stay healthy' are placed at the top of the hierarchy. As the hierarchy descends the goals become more and more concrete and detailed such as 'do regular exercise'. The lower level goals are

linked to the higher level more abstract goals and are more concrete ways of attaining those higher level goals.
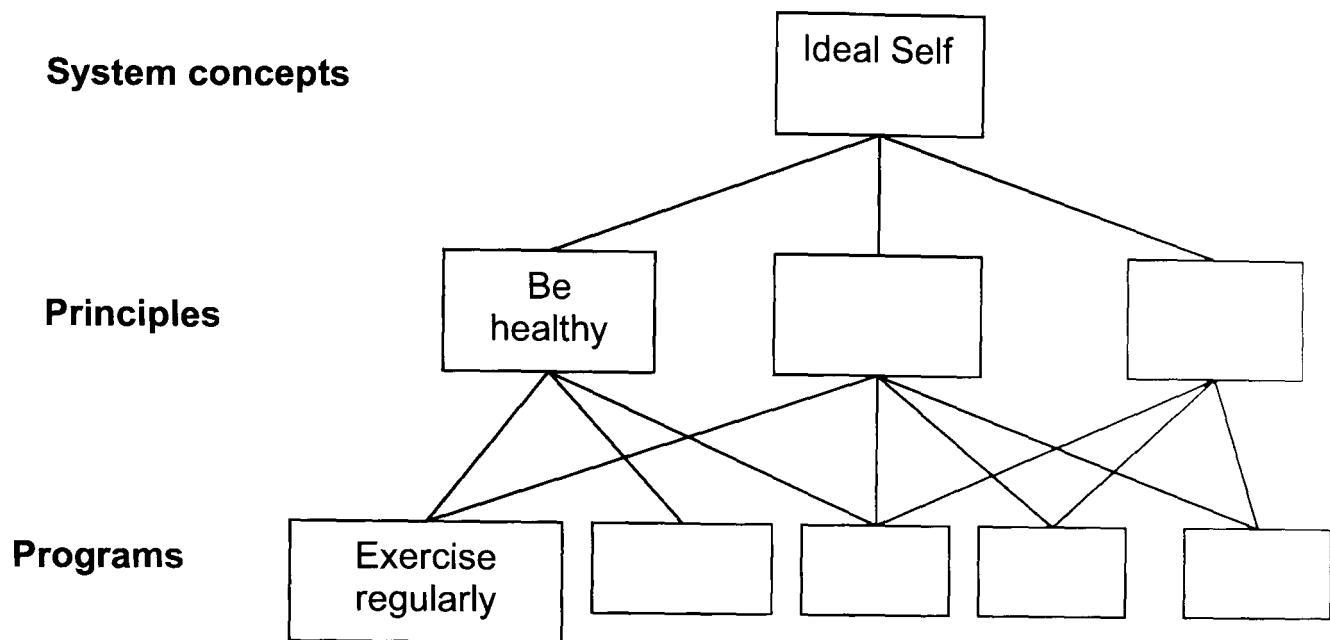
Figure 6 - A hierarchy of goals (adapted from Scheier and Carver, 2003)

This hierarchy of goals allows the way in which goals often interconnect and interact to be seen clearly; highlighting consistency between goals and how certain behaviours can be in response to various different goals (Scheier and Carver 2003).

Another important aspect of self-regulation models is the inclusion of both *abstract* and *concrete-experiential* information. (Johnson and Leventhal 1974). Abstract information is "conceptual, propositional knowledge and thought" (Leventhal et al. 2003). It is more controlled and involves more effort to process. Concrete-experiential information includes "imagery and perceptual-affective memories" (Leventhal et al. 2003) and is usually more automatic and

emotionally reactive than abstract information. Cognitive representations within the self-regulation model contain both abstract and concrete-experiential information. For example, in terms of diabetes, an individual with diabetes may have abstract information about the symptoms of having a hypo[3] and what to do in those circumstances gained from their health care professionals; however, they will also have concrete-experiential knowledge of the symptoms and process of having a hypo. Brownlee et al. (2000) suggest that it is the concrete-experiential knowledge and processes that have a greater affect on behaviour. This means that for the individual with diabetes it would be their personal experiences of having a hypo that would influence how they behaved in order to avoid it happening again or what they did when they had a hypo to a greater extent than the information they had been given by their health care professionals.

The definition generally given for self-regulation processes only mentions *conscious processes*:

"A systematic process involving conscious efforts to modulate thought, emotions and behaviours in order to achieve goals within a changing environment" (Zeidner et al. 2000).

However, *unconscious processes* are also a vital part of self-regulation. Conscious processes are influenced by unconscious processes. Both abstract and concrete-experiential information can be accessed through unconscious processes and therefore can affect how information is processed and in doing

---

[3] Low levels of blood glucose (usually levels < 4 mmol/L however individuals may experience symptoms of hypoglycaemia, such as sweating, anxiety, feeling shaky, heart pounding, confusion and irritability. at different blood glucose levels) (www.diabetes.org.uk).

60

so affect emotional processing and behaviours too without it being consciously acknowledged (Leventhal et al. 2003). For example, if an individual unconsciously wants to maintain their past perception of self they may interpret information in a way which reduces any risk to that past self by unconsciously ignoring information that threatens it.

1.5.2 The origins of the CSM

As mentioned previously, there are a range of self-regulation models that have been developed. Some models have been developed specifically for health and illness such as the Commonsense Model (Leventhal et al. 1980). Leventhal et al. (2003) suggest that the advantage of using a health specific model, such as the Commonsense Model, is that "it allows more specific hypotheses" and "introduces new structural and functional mechanisms into the self-regulation system". Brownlee et al. (2000) assert that although general models are useful for starting points, they only become theory when "they define specific, content variables within substantive domains". The Commonsense Model developed from fear-arousing communication studies carried out by Leventhal et al. (Leventhal et al. 1967; Leventhal 1970) which looked at issues such as smoking behaviour and tetanus. The basis of this research was the Fear-Drive Model (Dollard and Miller (1950), cited in Cameron and Leventhal 2003) which proposed that if a message that produced a high fear response was given to participants they would be more likely to respond to the health threat. During these studies some of the participants were placed in groups where they were encouraged to develop coping strategies to deal with the health threat. Leventhal (1970) found that a high fear message would encourage participants to change their attitudes towards the health threat but

this was only a temporary reaction and did not change health behaviour; however, when a high fear message was combined with developing a coping strategy or action plan the health behaviour of the participants changed. From this Leventhal (1970) produced the parallel processing model:
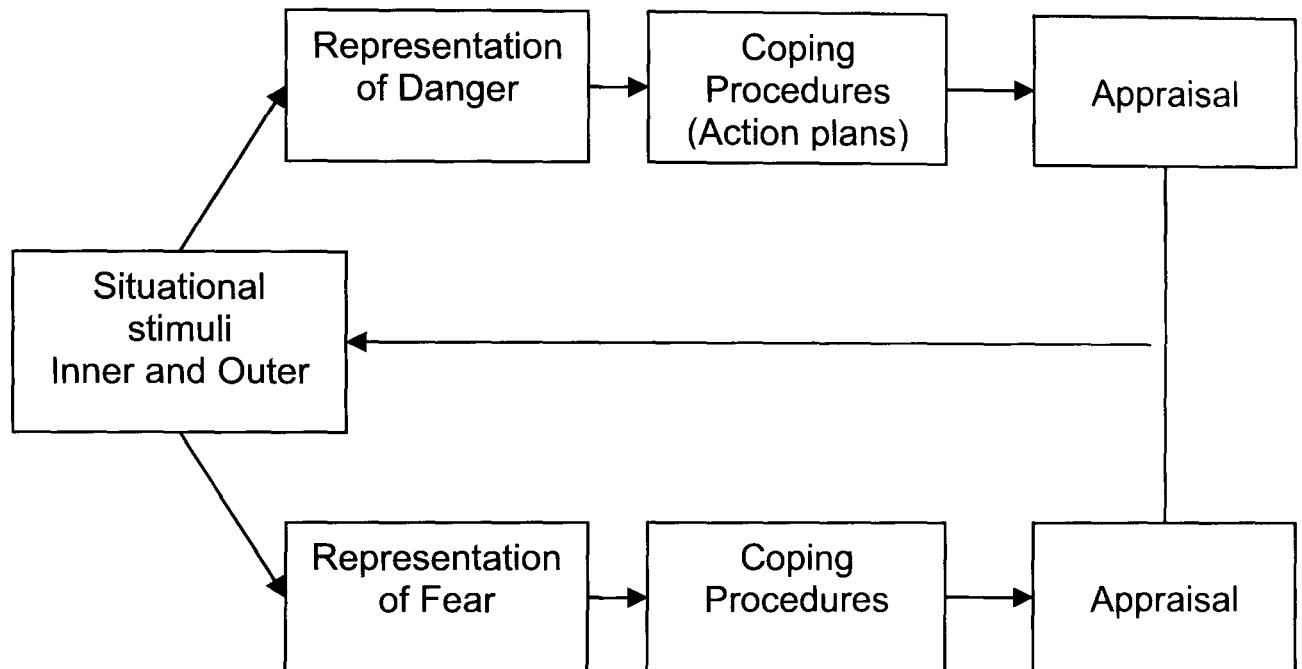
Figure 7 - The parallel processing model (Leventhal 1970)

The health threat (perceived via inner and outer stimuli) would produce an emotional response to the threat and a cognitive representation of the threat. A way of dealing with the emotional and cognitive threat was needed (fear control and danger control respectively) and so action plans (or coping behaviours) were developed. The action plans were then carried out and an appraisal of their efficacy was assessed using the feedback loop.

Past research has suggested that it was an individual's "concrete, perceptual experience" of a health threat which caused it to be motivating (Leventhal et al. 2003). Not only was this shown in the fear studies mentioned

above, but it was also demonstrated in research looking at the Health-Belief Model (Rosenstock et al. 1988) where it was found that "perceived risk was best assessed by accessing visual images of the patient as either healthy or sick" (Leventhal et al. 2003). This encouraged Leventhal to focus on perception and conduct a study involving unpleasant medical procedures and measuring how the behaviour of patients varied depending on the way they were encouraged to perceive the procedure (Johnson and Leventhal 1974). In this study Johnson and Leventhal used the unpleasant procedure of an endoscopy examination. Participants who had the procedure explained to them in pleasant terms and coping strategies were suggested had less gagging on the endoscope (the emotional response) and a more controlled rate of swallowing the endoscope (the behavioural response). Johnson and Leventhal suggested this supported the idea that health threats are processed on two levels: "semantically as abstract knowledge" and "perceptually as concrete experience". The physical experiences of the endoscopy produced fear via a bottom-up process; however, abstract information such as what the physical experiences indicated and how to deal with them could reduce this bottom-up process via a top-down process.

This research on the perception of somatic experiences, combined with other research looking at somatic experiences, such as cancer symptoms and worries (Easterling and Leventhal 1989) and symptoms of hypertension and the taking of medication (Meyer et al. 1985) led to Leventhal et al. concluding that the experience of physical symptoms and their interpretation was important not only for the emotional response to such experiences but also to the development of the identity of health threats. From these studies Leventhal developed the first illness representation – *Identity* – which is a combination of the symptoms experienced with the label given to those symptoms. Four other

illness representations were suggested as a result of a range of different studies (Bauman and Leventhal 1985; Bishop and Converse 1986). These were *timeline, consequences, causes and controllability*. For example, in an individual with type 1 diabetes the illness representations could be:

Identity – symptoms such as thirst, excessive urination, tiredness, weight loss combined with the label of type 1 diabetes given by a health care professional.

Timeline – age of onset is under 30 and the duration is life long unless a cure is found.

Consequences – potential diabetes complications, occurrence of hypos and so on.

Cause – auto-immune response to viral infection, it's in the family.

Controllability – it is possible to control diabetes most of the time, insulin injections work very well although there are 'slight hiccups' now and then.

Leventhal's research suggested that these illness representations were used by the individual to create goals for self-care behaviour, strategies for attaining these goals and ways of evaluating if these self-care goals had been reached effectively. In addition, as discussed earlier, each representation is made up of semantic and perceptual information and is experienced on an abstract and concrete-experiential level. For example, in terms of the *consequences* illness representation, for an individual with type 1 diabetes the knowledge of hypos may be on a semantic, abstract level as information about what hypos feel like and how to deal with them was learnt from the diabetes nurse on diagnosis; however knowledge about hypos is also processed and held on a perceptual and concrete-experiential level due to personal experience of having a hypo, the somatic experiences and the personal coping strategies and emotions that result from that experience.

Leventhal et al. (2003) suggest that when a health threat is detected the first illness representation to form is *identity* when the symptoms being experienced are given a label. The connecting of a perceptual experience, such as symptoms, to an abstract concept of a label for the health threat "provides depth to the representation". Following this, as further information is absorbed about the health threat from a variety of sources, such as further illness related symptoms and experiences, vicarious experience or from society and the cultural context (for example, the media, health care professionals and so on), the representations develop to take the form of all five of the domains: *identity, timeline, consequences, causes and controllability* (Hagger and Orbell 2003).

Leventhal et al. (2003) also suggest that there are five rules which govern the way in which health threat data is processed. The first is the *symmetry rule* which requires symptoms to be connected to a label to describe the somatic experience. Leventhal et al. posit that this interaction is bi-directional and symmetrical with symptoms seeking to be connected to a label and labels seeking to be connected to symptoms. For example, prior to diagnosis with diabetes, an individual may experience a variety of symptoms such as tiredness, thirst and excessive urination. According to Leventhal's symmetry rule, the individual will be seeking a label to explain the physical sensations. This may involve talking to friends or family or to health care professionals in order to explain and gain a label for the somatic experience. Equally, according to Leventhal's symmetry rule, if a label for a health threat is suggested the individual will seek out symptoms. For example, if an individual is diagnosed with type 2 diabetes whilst visiting the GP for a regular health check-up, the individual may search for symptoms or physical sensations they have felt recently that may have indicated the presence of the health threat now labelled as diabetes. The second and third rules are the *stress-illness rule* and the *age-*

illness rule. These are similar in that in essence the rules ask if the symptoms being experienced are as a result of stress or age rather than a health threat. It is suggested that if stress or age seems a more likely cause of the symptoms, for example feeling tired and having a headache after a very busy day, then that is the interpretation that will be made. It is suggested that the interpretations of symptoms being due to stress or age are limited by two factors – the nature of the symptoms and the duration of the stressor (Bauman et al. 1989). For example, if the symptoms being experienced are unusual for stress or age or are at a severity level which would be unusual for stress or age they may be interpreted as being a health threat rather than being due to stress or age. Also if the symptoms, thought to be from stress or age, continue for a long period of time or continue after the stress-causing factor has finished they may be attributed to a health matter rather than stress or age. The fourth rule is the *prevalence rule* (Croyle and Jemmott (1991), cited in Leventhal and Cameron 2003). This dictates that if the symptoms being experienced are seen frequently amongst other people they are regarded as less serious. And finally the fifth rule is the *duration rule* where the duration of the symptoms is used as a way of telling how serious the health threat is, for example the longer the symptoms persist the more serious the condition and the more likely an individual is to seek some help (Mora et al. (2002), cited in Leventhal et al. 2003).

According to self-regulation model theorists, the development of illness representations and performance of self-care behaviours do not occur in a vacuum. The Commonsense Model, as well as other models of self-regulation (such as Carver and Scheier's self-regulation model as mentioned earlier), stress the importance of self, identity and social context. Leventhal et al. (2004) describe how the self and cultural context effect illness representations and that

illness representations also have an impact on beliefs about self and cultural beliefs. Brownlee et al (2000) describe the *self-system* in the Commonsense Model as including the same representations for self and identity as exist for illness and health threats: identities, timelines, causes and consequences. They also state that this information is both abstract and concrete/experiential and that the self-system interacts with the Commonsense Model in a top-down and bottom-up way. For example, an individual who has just been diagnosed with type 2 diabetes in middle age may have an *identity* as an inactive person. The individual may consider that the *cause* of this inactive identity may be the lack of time due to other roles which need to be performed such as worker, mother and so on. The individual may think the *consequences* of this identity are a slight increase in weight as time goes by. The *timeline* may be indefinite and the individual may feel the situation is *uncontrollable* as they feel they have no time to exercise. After their diagnosis they may have been given information and direction from health care professionals to take daily exercise (which is *abstract information*). This is added to by the *concrete-experiential information* of knowing they have little time to exercise and the corresponding fluctuations in blood sugar levels when they do manage to do some exercise. The *top-down* impact of this identity on their diabetes is a low self-efficacy for doing regular exercise therefore an inclination to lower their goals in terms of amount of time spent exercising and intensity of exercise. The *bottom-up* affect of this identity may be worry and stress over the need to exercise and an inability to do so. Brownlee et al. (2000) suggest that the self-system interacts with the Commonsense Model in three different ways: 1) The self-system provides a foundation for and effects the choice of goals and which coping strategies are used; 2) The self-system is a "biophysical mechanism" that needs to be monitored, altered and maintained in order for it to "function effectively"; and 3)

Self, identities and self-related procedures within the self-system can be targets for change within the Commonsense Model.

In addition to the self-system the role of social and cultural context is also vital. The identification of a health threat relies on self-knowledge and social input in terms of recognising symptoms and getting a diagnosis either from lay knowledge, vicarious experience or an expert such as a doctor (Leventhal et al. 2003). Kulik and Mahler (1987) showed that patients who spent time with people who had the same condition as them but who had had the condition for longer gained knowledge about their condition and altered their expectations accordingly. The goals and therefore the reference values that individuals adopt in the self-regulation system can be influenced by social expectations or social relationships. For example, watching others go through the same experiences may give individuals something to aim for and receiving advice from others or from health care professionals may affect how the individual copes with the health threat. Leventhal et al. (2003) suggest that the Commonsense Model acknowledges the impact of social and cultural influences in two main ways: by providing the "linguistic labels" which describe different aspects of the health threat and that "social contacts" may affect how symptoms and experiences are interpreted and the action plans developed to cope with these experiences. However, Leventhal et al. (2003) also assert that "the self remains the primary agent of self-regulation" in that the self experiences the health threat and the personal cognitive and emotional responses to the threat on a personal level and uses this subjective information. This suggests that although external social context has an influence it is the self which provides the ultimate self-regulation. Issues surrounding identity (as discussed earlier, for example Charmaz (1983)) are important in the formation of illness representations, self-regulation strategies (such as coping strategies) and the action plans carried out. These

include past identities, 'illness identities' and the impact, both physically and emotionally, that this may have on an individual. Self-efficacy is also suggested as an important factor which effects illness representations and action plans within the Commonsense Model. The development of action plans will take into account the self-efficacy of the individual regarding specific tasks and (as discussed earlier) tasks for which the individual has high self-efficacy are more likely to be performed than those tasks for which the individual has low self-efficacy. All of these aspects combine to form the Commonsense Model of Self-Regulation of Health and Illness (CSM) (figure 8). Leventhal describes various ways in which the socio-cultural context and the self-system may relate to illness representations, emotional representations, action plans and the feedback loop. However, one of the primary ways in which the socio-cultural context and self-system interact with the rest of the CSM is their moderation of the relationship between illness and emotional representations and the action plans or self-care behaviours performed. It is this suggested relationship which is investigated in this research and this is reflected in the representation of the CSM seen in figure 8:

Socio-cultural context
Eg institutional roles, groups, language, culture.

Self-System
Identity, Timeline, Cause-Source of attributes, Consequences ie future selves and identities
Self-efficacy
Self-regulation strategies (eg coping strategies)

Cognitive representation of health threat:
Identity
Timeline
Consequences
Cause
Controllability

Coping efforts (Action plans)

Situational stimuli – inner/outer
Eg.
Symptoms, past experience of illness, lay knowledge, expert information

Appraisal

Representation of Emotion

Coping efforts (Action plans)

Self-System

Socio-cultural context
Eg,
institutions/groups/roles

Figure 8 - The Commonsense Model of Self-Regulation of Health and Illness

(adapted from Brownlee et al. 2000).

1.5.3 Previous research using the CSM in long-term conditions

There have been many research studies using the Commonsense Model of the Self-Regulation of Health and Illness to look at various long-term conditions such as diabetes, myocardial infarction, psoriasis, asthma, chronic fatigue syndrome and rheumatoid arthritis (Pimm and Weinman 1998; Cooper et al. 1999; Steed et al. 1999; Scharloo et al. 2000; Horne and Weinman 2002; Jessop and Rutter 2003). This research has investigated different aspects of the CSM such as the impact of illness representations and coping strategies on the performance of self-care behaviour. In recent years much of the ongoing research into this area has made use of either the Illness Perception Questionnaire (IPQ) (Weinman et al. 1996) (and its revised version the IPQ-R (Moss-Morris et al. 2002)) or semi-structured interview guides such as the Personal Models of Diabetes Interview (PMDI) (Hampson et al. 1990).

Illness representations and self-care behaviour

Steed et al. (1999) conducted a study looking at the illness representation *identity* for individuals with atrial fibrillation. Atrial fibrillation is an ideal condition for this type of study because it can be symptomatic and asymptomatic. They hypothesised that if a participant was symptomatic they would integrate their current symptoms with "previous illness schema", culture, social communication and past experiences of illness and symptoms. If a participant was asymptomatic they were hypothesised to rely more on social communication to develop their representations for their condition. Surprisingly, Steed et al. found that, with the exception of the illness representation *identity*, whether the participant was symptomatic or asymptomatic had no impact on any of the

other illness representations. They suggested that this may be as a result of the nature of atrial fibrillation as individuals with it may be more reliant on social communication than symptom experience and that this may vary with different conditions. The suggestion that the importance of symptoms may vary with different conditions is supported by the assertions made by Hampson (1997) regarding the role of symptoms and *identity* in the self-management of diabetes. She suggests that "the representation of symptoms may be a determining factor in self-management decisions". She cited studies by Gonder-Frederick and Cox (1990) and Diamond et al. (1989) who looked at the ability of people with type 1 and type 2 diabetes respectively to estimate blood glucose levels from symptoms alone as examples of the importance of symptom recognition and *identity* for the self-management of diabetes. Hampson also cites a study by Bond et al. (1992) who found that for adolescents with type 1 diabetes, beliefs about the symptoms they experienced predicted the self-management behaviour they performed.

The role of *cause* (another aspect of the CSM) in the self-care of long-term conditions has been investigated in a number of studies. Jessop and Rutter (2003) conducted a study looking at "adherence" to asthma medication and found that whether participants attributed their asthma to internal or external causes was important in terms of their self-care behaviour. Participants who felt their asthma was caused by internal factors were more likely to take their medication "presumably in the hope of removing the causal factor and consequently eliminating or controlling the illness" (p. 605). In contrast, those who felt their asthma was caused by external causes felt they had no control over it and so did not take their medication as much. These findings were similar to those found by Weinman et al. (2000) who looked at causal attributions in patients who had had a myocardial infarction. The results of their

study suggested that participants who thought their lifestyle choices were responsible for their myocardial infarction were more likely to change their lifestyle to a healthier one in terms of diet and exercise; whereas those who considered their condition a result of stress or genetic factors were less likely to make healthy changes. Interestingly, it was the views of the participants' spouses about the cause of their myocardial infarction that had the biggest impact on levels of exercise after six months. The previous research by Jessop and Rutter (2003) and Weinman et al. (2000) is particularly relevant for this thesis as one of the main differences between type 1 and type 2 diabetes is the cause of the conditions. Type 1 is thought to be caused by a combination of genetic factors and an external cause such as an infection; whereas, type 2 is generally recognised as being caused by genetic factors but also lifestyle aspects such as a sedentary lifestyle, being overweight and dietary habits. If the findings from Jessop and Rutter with asthma and Weinman et al. with myocardial infarction are applied to diabetes this suggests that causal beliefs may be significantly related to the performance of self-care behaviour and that this may differ between participants with type 1 and type 2 diabetes. Hampson et al. (1995) used the PMDI (Hampson et al. 1990) to look at personal models of diabetes for individuals with type 2 diabetes. Personal models of diabetes refer to the cognitive and emotional beliefs that an individual holds in relation to their diabetes. The illness and emotional representations described in the CSM (Leventhal et al. 2003) are an example of a framework for individuals' personal models of diabetes. Hampson et al. (1995) did not use the CSM as a framework but found similar cognitive and emotional beliefs in the personal models of diabetes of their participants to the illness representations described by Leventhal et al. (2003). They found that personal responsibility causes were predictors of dietary behaviour; however, there was a stronger association in the women than the men.

Beliefs about the *controllability* of long-term conditions have been considered in a number of studies. Petrie et al. (1996) and Cooper et al. (1999) investigated the role of illness representations in the recovery from cardiac conditions. Both studies found that a greater belief in the controllability of the condition was significantly associated with greater attendance at cardiac rehabilitation. Similar results were seen by Scharloo et al. (2000) who found that initial levels of perceived control in patients with psoriasis was associated with more use of out-patient services. Additionally, Moss-Morris et al. (1996) found that for participants with chronic fatigue syndrome those who believed they had some control over their condition had significantly more positive coping strategies and significantly less behavioural disengagement. *Controllability* has also been shown to be a strong predictor of self-care behaviour for individuals with diabetes. Much of the research around *controllability* has been through personal model research where representations are developed independently of those suggested by Leventhal; however, the treatment effectiveness representation is closely linked to Leventhal's *controllability* representation. This is shown by Lawson et al. (2004) who found that both treatment effectiveness (from the PMDI) and control (from the IPQ) were associated with levels of clinic attendance, and treatment effectiveness was significantly associated with regular care seeking. Hampson et al. (1990, 1995) have used the PMDI to investigate the personal models of participants with type 2 diabetes. They found, in both studies, that treatment effectiveness was a significant predictor of diet and exercise behaviour. Interestingly, they found that there was no predictive power for blood testing or medication taking behaviour. As with the *causes* of diabetes mentioned previously, in the 1995 study the same researchers discovered that there was a gender difference for the significance of treatment effectiveness at predicting exercise behaviour – it had a much stronger predictive power for the women than for the men.

As well as treatment effectiveness, Hampson et al. (1990, 1995) found that beliefs about the seriousness of diabetes was a predictor of dietary and exercise behaviour. This was supported by Lange and Piette (2006) who found that perceived seriousness was a good indicator of blood sugar control except where participants were more fatalistic. The representations of *consequences* have also been shown to be important within various other long-term conditions. Moss-Morris et al. (1996) found that for participants with chronic fatigue syndrome serious consequences, a strong illness identity and a long duration had significant associations with the adoption of an emotion-focussed coping strategy. Petrie et al. (1996) found that those participants who believed that their myocardial infarction had more serious consequences were slower to return to work and to other social and domestic responsibilities.

Other aspects of the CSM

There are a range of studies which have focussed on specific aspects of the CSM such as the emotional and psychological well-being of the participants and the context in which coping strategies are employed and goals are chosen (the self-system and socio-cultural context). For example, Lange and Piette (2006) looked at how contextual factors such as age, sex, income level, ethnicity and disease severity influenced the illness representations *seriousness* (the equivalent of Leventhal's *consequences* illness representations) and *controllability*. They found that socio-cultural factors were more associated with *controllability* representations - how controllable individuals considered their condition to be and that disease factors, such as physical symptoms, had more association with seriousness representations. Skinner and Hampson (1998) investigated the relationships between social

support (family and friends), illness representations, self-care behaviour and well-being for adolescents with type 1 diabetes. They found that beliefs about the *impact of diabetes* and support from friends were able to significantly predict depression. They also observed that family support was a predictor of self-care behaviour and that the more participants thought that their treatment regime would control their diabetes the more dietary self-care behaviours they performed. Their research also suggests that beliefs about *treatment effectiveness* partially mediate the relationship between family support and dietary self-care behaviour. Edgar and Skinner (2003) in a study of adolescents with type 1 diabetes, observed that *perceived impact* and *identity* were significantly correlated with well-being as were social support and the cognitive re-structuring coping scale. They found that the illness representation *treatment effectiveness* mediated the relationship between cognitive re-structuring and positive well-being. The importance of illness representations for well-being have been demonstrated by Law et al. (2002) in a study of adolescents with type 1 diabetes. They found no significant associations between illness representations and self-care behaviour but did find significant associations between illness representations and anxiety and positive well-being. In adults the relationships between illness representations and well-being or quality of life has been investigated by Watkins et al. (2000). Their data suggested that greater beliefs about the *controllability of diabetes*, along with *illness coherence* were associated with increased performance of self-care behaviours, less disruption to "social and personal functioning" and less negative emotional representations. Additionally performing more dietary self-care behaviours was significantly associated with "greater interference with social and personal functioning".

The impact of gender and illness representations has been suggested in a number of studies. In Hampson et al. (1995) the illness representation *cause* was found to have a greater impact on self-care behaviour for women than for men, and women who felt less personally responsible for causing their diabetes performed more diet self-care behaviours. Brown et al. (2000) also found differences between men and women for health beliefs in a Mexican American population with type 2 diabetes. Women reported lower levels of beliefs about control and social support in relation to diet than the men who participated. However, Eiser et al. (2001), who were looking at the relationship between illness representations and psychological well-being for individuals with diabetes, found no effect of gender on illness representations. The impact of gender on illness representations has not been widely researched; however, the findings of what research has been done suggest that gender may be important when investigating illness representations and beliefs about diabetes.

Different models for different conditions

The suggestion that different conditions may result in different patterns of illness representations and their importance for self-care behaviours (Hampson 1997; Steed et al. 1999) has led to research focussing on comparisons between different conditions and the resulting different 'personal models of illness'. Hampson (1997) claimed that comparing diseases allows theory and practice to advance and that the theory surrounding illness representations needs to move further than the initial theoretical models. Hampson compared individuals with type 2 diabetes with individuals with osteoarthritis. She found that the participants with type 2 diabetes had higher levels of self-blame (for example in terms of eating habits), greater knowledge of the consequences of

their condition, greater belief in the efficacy of their condition, found their condition less easy to control and more participants thought that aspects of their treatment made them feel worse. More importantly, Hampson found that the five illness representations suggested by Leventhal did not form independent constructs and "hence were not optimum representation of the personal models". She suggested that different components for type 2 diabetes and osteoarthritis were more important for the management of the conditions, for example, for diabetes the personal models were significant predictors of the lifestyle elements of the self-care regime (such as diet and exercise) but not for medication taking and blood testing behaviour. Also for participants with diabetes the least reliable scale was the symptoms scale which Hampson posits may be because of the idiosyncratic nature of diabetes. In contrast to this, for participants with osteoarthritis the symptoms scale was a reliable predictor of self-care behaviour as those who thought their condition was more symptomatic and more serious used more self-management methods than those who did not.

Similar findings were produced by Heijmans and de Ridder (1998) who compared the personal models of Addison disease and chronic fatigue syndrome by conducting interviews with the participants. They found personal models that were different from Leventhal's five illness representation structure and which were different for each condition. For chronic fatigue syndrome they found four representations which they named manageability, seriousness, personal responsibility and external cause. They suggested that one of the most important aspects for individuals with chronic fatigue syndrome was recognising that there was a biological cause for their condition. In contrast, for individuals with Addison disease Heijmans and de Ridder found that the four representations were seriousness, cause, chronicity and controllability and that

the most important aspect was recognising the condition as long-term rather than acute.

These studies suggest that the five illness representations developed by Leventhal et al. (1980) are not rigid and set, and that for different long-term conditions individual 'personal models' should be found using factor analysis. This is supported by Leventhal and Nerenz's (1983) assertion (cited in Heijmans and de Ridder 1998) that illness representations are not fixed but adapt under different circumstances. At this point it is worth noting that rather than viewing the illness representations as independent predictors of health behaviour, Leventhal suggests that they interact with each other in order to form patterns of beliefs. In most research using the CSM, due to the methodological choices made, the dynamic interactions between illness representations are not considered and the relationships between illness representations and other aspects of the CSM are measured independently. This may explain the differences in cognitive framework suggested by Leventhal et al. (2003) and other researchers such as Hampson (1990; 1995). In addition, Hagger and Orbell (2003) completed a meta-analysis of 45 research studies using illness representations and the CSM as a theoretical framework. They concluded that although there were variations, the original five dimensions developed by Leventhal et al. were the result of "extensive pilot work" and that the factors produced by the factor analysis in the 'personal model' studies such as those by Hampson (Hampson et al. 1990; Hampson et al. 1995; Hampson 1997) did not differ to a significant extent from the original five dimensions of *identity, timeline, cause, controllability* and *consequences*. They suggest that using the five illness representations for future research allows comparable results to be produced. However, Hampson's assertion that different conditions produce different patterns of illness representations and

different relationships to coping strategies and outcome measures is salient, particularly for this thesis which compared the illness representations of individuals with type 1 and type 2 diabetes.

There has been previous research comparing the illness beliefs of individuals with type 1 and type 2 diabetes. Fitzgerald et al. (1996) investigated the different beliefs of individuals with type 1, tablet treated type 2 and insulin treated type 2 diabetes using a measure (the Diabetes Care Profile) based on the Health Belief Model (Janz and Becker 1984). They found that those with type 1 diabetes understood their diabetes self-care behaviours to a greater extent than those with type 2 diabetes, participants with tablet treated type 2 diabetes felt that their condition had less impact on their lives than those with insulin treated type 2 diabetes, and individuals with type 1 diabetes found their medication regime more difficult to follow than the participants with either tablet or insulin treated type 2 diabetes. However, another study using the Diabetes Care Profile (Watkins et al. 2000), which modelled the relationships between cognitive representations, diabetes-specific health behaviours and quality of life, found no significant differences in the models for type 1, tablet treated or insulin treated type 2 diabetes. Eiser et al. (2001) used Leventhal's CSM to look at psychological well-being for people with type 1 and type 2 diabetes. They found that for those with type 1 diabetes well-being was associated with the extent to which diabetes impacted on their lives whereas for those with type 2 diabetes there was no such association. Interestingly it was only in the participants with type 2 diabetes that the number of diabetes complications was associated with a decrease in reported psychological well-being. An analysis was performed to ascertain if this was due to the type of treatment that the participants were receiving (ie tablets versus insulin) however no differences were found. This study did not look at the impact of these illness beliefs on self-

care behaviour. Although these studies have investigated similar areas to this thesis, as far as the researcher is aware no studies have specifically investigated how the experiences of individuals with type 1 and type 2 diabetes relate to Leventhal's CSM in terms of illness representations, self-efficacy and the impact on self-care behaviour. In addition to this, there is limited research on the differences in illness beliefs between individuals with type 1 and type 2 diabetes using qualitative or mixed methods approaches.

1.6 The CSM and Social Cognitive Theory

This thesis makes use of two theories when considering the relationship between the personal experiences of diabetes and self-care behaviour, these being the CSM (Leventhal et al. 1983) and Social Cognitive Theory (Bandura 1977). There are distinct similarities between the assumptions and components of these two theories. As described earlier, both theories assume that people are 'active shapers' rather than 'passive reactors' in that they do not just react to events but shape what is happening to them. Both theories are interactive and dynamic, contain cognitive and emotional aspects and recognise the importance of both personal and environmental factors in the performance of behaviour. Illness representations in the CSM and self-efficacy beliefs in Social Cognitive Theory are considered to be formed in similar ways, through personal experience, vicarious experience, social persuasion and affective pathways. Both theories suggest that beliefs are formed using concrete and abstract information from past and present sources. The internal personal factors described by Bandura (1997), including cognitive, affective and biological events, and the external environmental aspect of Social Cognitive Theory are

comparable with the socio-cultural context and self-system components of the CSM suggested by Leventhal (figure 9). Self-efficacy has been used in previous research to represent elements of the self-system in the CSM. In this research the relationship between self-efficacy and the rest of the CSM will be investigated.
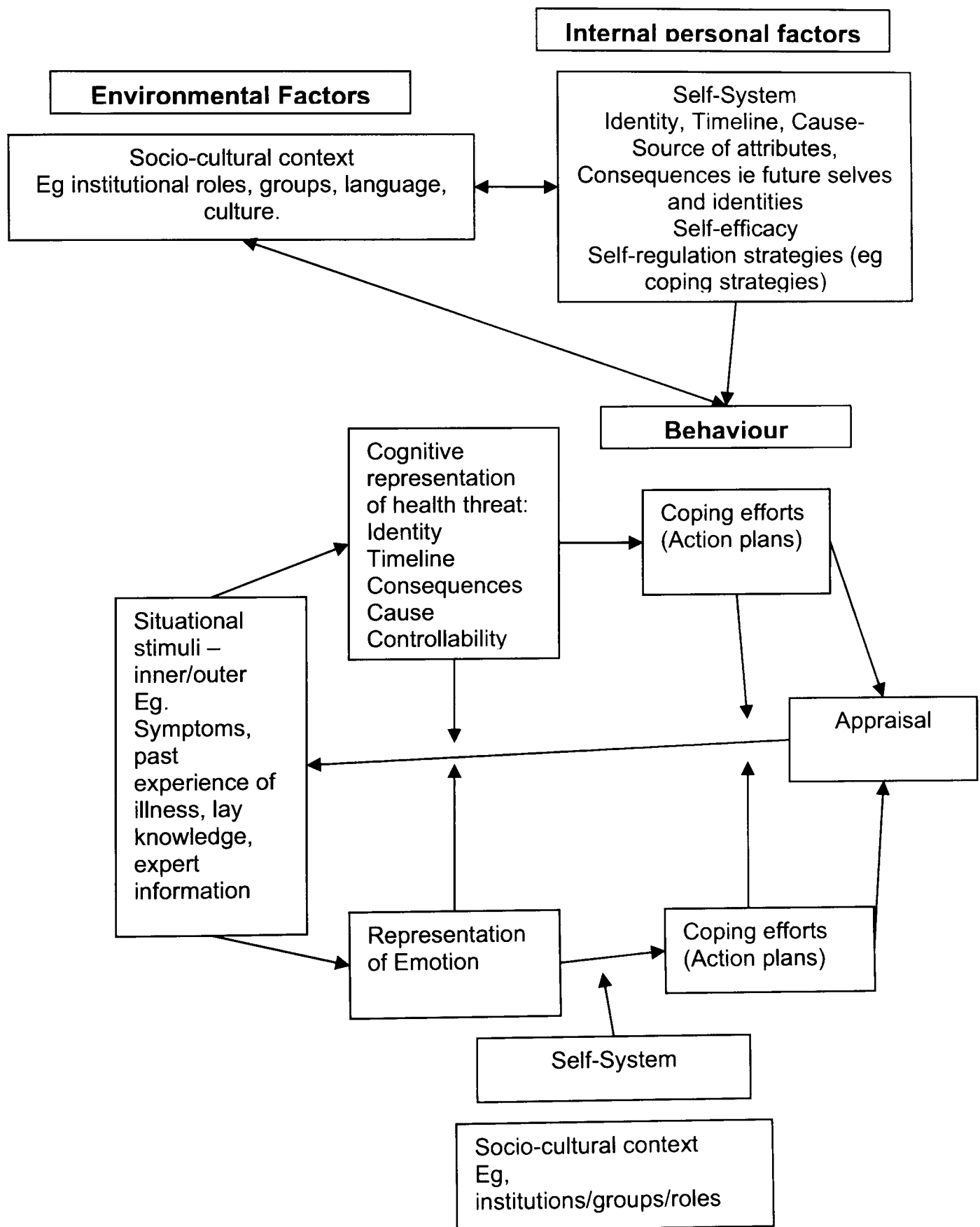
Figure 9 - The hypothesised interaction of the CSM and Social Cognitive Theory

There are a variety of models and theories which describe the relationship between beliefs about illness and health behaviour. These include the Health Belief Model (Rosenstock et al. 1988) and the Theory of Planned Behaviour (Ajzen 1985). This research uses the CSM and Social Cognitive Theory as opposed to these other models for a number of reasons. The self-regulatory, interactive nature of the CSM is in contrast to the Health Belief Model and the Theory of Planned Behaviour. This dynamic, interactive, feed-back loop process is potentially more representative of the reality of living with a long-term condition. In addition to this the Health Belief Model is based on largely rational propositions such as perceived costs and benefits. There is also no role for social or environmental factors. The Theory of Planned Behaviour includes elements of 'irrationality' in the relationship between beliefs and behaviour and includes aspects of social and environment factors through normative beliefs; however, this is not to the same extent as can be found in the CSM or Social Cognitive Theory. The parallel processing model used by the CSM emphasises the equal importance of emotional representations which is not represented in the Health Belief Model or the Theory of Planned Behaviour.

Chapter Two

Finding answers: methodology, data collection and other issues.

This chapter will discuss the methodological issues of using a mixed-method approach, where the research was carried out, the research process for both stages of the study including details about the measures and methods used, the participants and the analysis carried out. The concluding sections will provide an overview of the data collection process including the problems encountered and their solutions.

2.1 Methodological Issues

This research was designed to examine the relationships between the illness representations, self-efficacy and self-care behaviour of individuals with diabetes, and if this differed for people with type 1, tablet treated and insulin treated type 2 diabetes. From the literature it can be seen that there has been limited research on the differences between type 1 and type 2 diabetes, in terms of illness representations or beliefs about diabetes and self-care behaviour. Furthermore the qualitative research that has been conducted has not specifically compared people with type 1 and type 2 diabetes (for example Kelleher 1988; Hampson et al. 1995; Hernandez 1995; Murphy and Kinmonth 1995; Schoenberg et al. 1998; Hornsten et al. 2004; Lai et al. 2005; Lawton et al. 2005). The development of illness representations and self-efficacy and the differences between type 1 and type 2 diabetes are embedded in the personal

experience of the condition. Therefore, to enable a deeper understanding and to be able to explain the different relationships between illness representations, self-efficacy and self-care behaviour this research used a mixed methods approach. Stage one consisted of a self-completed quantitative survey asking fixed response questions. Stage two of the study consisted of qualitative semi-structured interviews which were analysed using thematic analysis. This meant that the research followed neither one tradition nor the other and instead used a combination of the two which raised certain methodological questions and issues. Both quantitative and qualitative methodologies have different philosophical assumptions and paradigms associated with their use. There are also distinct advantages and disadvantages to the methods involved and the theoretical basis for their paradigms.

Quantitative research is derived from the experimental approach used by the natural sciences such as chemistry and biology. There are four main concepts which are important in quantitative research (Bryman 1988) – measurement, causality, generalisation and replication. Quantitative research is concerned with measuring observable phenomena, finding links between one observable, measurable phenomena and another, applying sampling procedures and experimental design so the research is generalisable and replicable. This usually involves random sampling techniques and assignment to experimental conditions and controlling all factors, the environment and the researcher. The aim is to ensure an objective view of what is happening and so any effect seen will be from the experimental or independent factor(s) being measured. This approach includes many aspects of a positivist approach such as the idea that the techniques used in the natural sciences can be transferred to look at the social sciences (Bryman 1988). Quantitative methods are frequently used to test theories or existing hypotheses.

There are certain advantages to quantitative methodology. The long history of quantitative research has led to the development of distinct traditions and rules about the performance of this kind of research. This means that the research process is systematic, rigorous and retains a relative simplicity and clarity (Bryman 1988). The measurement of observable phenomena means that the research can be replicated and so be shown to be reliable. In some quantitative studies the use of large numbers of subjects and the use of representative sampling procedures can show that the results obtained may be generalised to a wider population which is particularly useful in different types of research (Silverman 2005). Added to which the objectivity employed throughout the research process attempts to reduce bias and so diminish the impact of values held by the researcher.

However, there are disadvantages to using quantitative methods, particularly when looking at the social world. Interactions within the social world, involving people are complex, fluid and multi-dimensional. It is impossible to control all the relevant factors when outside of the laboratory. Taking quantitative research into the real world involves losing the complete objectivity that can be found in the natural sciences. Positivist approaches use observable, measurable phenomena; however, when researching subjects - such as the experience of living with diabetes - aspects of that experience will include abstract phenomena, such as feelings, and subjective experiences which are not directly observable. There is also the fundamental question – 'what is truth?'. Positivism suggests that by observing phenomena we can accept them as truth; however, with subjective experiences and less tangible phenomena there may be multiple realities for different people who have different meanings and interpretation for the same events (Bryman 1988).

Many of these criticisms are addressed by qualitative research methodology. The philosophical underpinnings of qualitative methods come from, amongst others, phenomenology, symbolic interactionism and naturalism. Bryman (1988) suggests that one aspect of qualitative methodology involves being able to 'see through the eyes of' the person or people being studied. This stems from phenomenology which highlights the importance of using an understanding of meaning to interpret the world. Bryman also suggests that in qualitative research a certain amount of description is usually involved, although usually qualitative researchers go beyond this and analyse and interpret the events being researched. Qualitative research stresses the importance of understanding events being researched from within their context. Naturalism suggests that the researcher should study phenomena as naturally as possible so that any changes resulting from being studied will be minimised. Qualitative research also places an emphasis on not just looking at the cause and effect but the process which is gone through as well. Flexibility and lack of structure is an important aspect of qualitative methods and frequently qualitative researchers will approach data collection with no firm theories in mind but often will use the data to develop theories (Bryman 1988).

There are several criticisms of qualitative research. These include suggestions that it is subjective, anecdotal, unrepresentative, lacks rigour, not systematic, on a small scale, biased and involves no numbers (Larkin 2004). Yet, the validity, reliability, objectivity and generalisability of qualitative research can be equal to that of quantitative research, although in a slightly different way, if carried out using rigorous research techniques (Strauss and Corbin 1998). Validity is demonstrated not through the traditional quantitative idea of accuracy or 'truth' but showing that the research is methodologically clear – that what is being represented is what the study is designed to represent. The research

must be coherent in that the account of a person's world would be one which they would recognise and should convey subjective meanings and experiences of that world. The interpretation carried out should be "credible, plausible, trustworthy and well-founded" (Ziebland 2004). The reliability of the study is shown not in the sense of replicability but in the consistency of the research for example in data collection and interpretation. Another researcher should be able to look at the research and see how conclusions were reached following the path of analysis, or consistency should be found if the same data was looked at again by the same or a different researcher (Strauss and Corbin 1998). Objectivity is maintained by recognising any bias that may exist for the researcher – by being reflexive and clear about the researcher's position and possible influences (Larkin 2004). The research must also avoid any structural, systematic bias built in to the study – for example only looking at certain types of people (Ziebland 2004).

Generalisability is one of the major criticisms of qualitative research. Because it does not deal with a representative sample of the population it is sometimes assumed that it cannot be used to represent the population at large. In a statistical sense this is correct however the interpretations and explanations for views and behaviours expressed through qualitative research can be generalised to the population. One of the major advantages of qualitative research is the aim to gather all views that are available until data saturation is reached and therefore minority views, which may be over looked during quantitative research and which, sometimes, are the most informative and interesting views, are represented clearly and given a voice (Ziebland 2004). Whether the results from qualitative research can be generalised to populations other than the ones sampled is based on judgements of how similar the settings and populations are as with quantitative research.

This is a very brief and simplified discussion of the theoretical, epistemological and methodological differences between quantitative and qualitative research methods. It would be possible to write a whole thesis on the two paradigms; however, that is not the intention here. Instead the purpose of this overview is to demonstrate that despite the differences in the philosophical underpinnings of quantitative and qualitative methodology they can be combined to produce effective, rigorous and relevant research which will produce a more in-depth and comprehensive study than if either method was used alone. As Denzin (1970) says "by combining multiple observers, theories, methods and data sources, sociologists can hope to overcome the intrinsic bias that comes from single-method, single-observer, single-theory studies." (cited in Fielding and Fielding 1986). This combination of methods can be called 'triangulation' (Bryman 1988). Triangulation allows the researcher to test, confirm and develop the concepts and hypotheses being suggested by using different techniques and by doing so strengthens the conclusions reached. There are four main methods of triangulation: 1) data triangulation which can include looking at the effect of time using longitudinal research designs; 2) investigator triangulation where a number of people investigate the same situation; 3) theory triangulation where the data is examined from the perspective of different theories, and; 4) methodological triangulation, which is the type of triangulation used in this study, where different methods are used to assess the same thing and then the results are compared (Fielding and Fielding, 1986). In this thesis, for example, the results from the questionnaire stage and the interview stage are compared and contrasted in order to investigate how Leventhal's Commonsense Model represents the relationships between illness representations, self-efficacy and self-care behaviour and the differences and similarities between participants with type 1 and type 2 diabetes.

The comparison between the findings for stage one and two also allowed reflection on the use of the mixed method approach for type of research. Other researchers have commented on these methods, for example Cox (2003) compared the effectiveness of in-depth interviews and structured questionnaires in researching the quality of life of cancer patients. She found that there were significant differences between the results obtained from each method with patients seeming to minimise their emotional and physical discomfort in response to the structured questionnaire. Cox suggested several reasons for these differences - the rating on the questionnaire being carried out over 'the last week' whereas the interviews covered a broader period of time, the short time given to reflect on the answers to the questionnaires, patients trying to 'normalise' their answers - "patients often struggled with where they were on the scale against 'what was normal'" (Cox, 2003) and the interviews covering a broader concept of quality of life than was addressed in the limited domains on the questionnaire.

Another reason for using a mixed method design is that the data gained from the survey stage of the study can facilitate the sampling process for the interview stage (Bryman 1988). In order to get a wide range of views on the experience of diabetes interviewees were chosen on the basis of their level of self-reported self-care behaviour, in conjunction with type of diabetes and gender. This information was obtained from the questionnaires they completed in the first stage of the research. An additional advantage of a mixed method design is the opportunity for clarification and explanation of interactions between variables. As Bryman (1988) says:

"The researcher who establishes a correlation between two variables, or who believes that a causal connection has been discerned, is faced with the problem of interpreting the relationship – how does it come about?" (p. 145).

The interview stage provided the chance to confirm (or contrast) any interactions between variables but it also allowed the investigation of the reasons why these variables interact (Patton 1987).

Despite the clear advantages of using a combined approach there are a few issues with doing so. Sim (2005) suggests that by using mixed methods the research becomes part of a paradigm 'no mans land' in that it falls between the dominant paradigms of the moment of 'positivist quantitative' and 'constructivist qualitative'. It therefore becomes what could be called a pragmatist approach to research in the real world as opposed to being constrained by either abstract theoretical model, whether quantitative or qualitative, debated in the 'paradigm wars' (Morgan 2005). Morgan argues that it is possible to integrate quantitative and qualitative methods to produce a 'new paradigm' which is outside of the 'binary box' produced by 'positivism' and 'constructivism' and involves a completely different way of looking at things. This is argued against by others such as Sim (2005) who suggest that such radically different assumptions about the role of the researcher, the levels of analysis and issues such as the meaning conferred on objects and the actual phenomena being studied, mean that integration will never be completely possible. Sim does, however, concede that there are advantages to using mixed methods as long as these differences are recognised and that the research is designed in order to make the best of the strengths and weaknesses of the methods employed.

Another issue that has been raised with mixed method research is that frequently one paradigm gains dominance over the other and is favoured as being more accurate or more important. This does not need to be a problem. As Freshwater (2005) says, why does it matter if one or the other gains dominance? Both methods should be considered equally accurate at examining the phenomena they are designed to measure as long as the design is rigorous and valid. Which method is given prominence during the write up and evaluation will depend on the research being undertaken and the strengths of the researcher. As long as it is acknowledged that the different methods will have strengths and weaknesses and are looking at things from different perspectives and the researcher is not intending to fully integrate the methodologies then the dominance of one method over the other becomes unimportant.

By taking the advantages of both kinds of methods the study can provide a wider, broader and more in-depth look in to the experiences of people with diabetes. Taken alone each research method can provide insights into these experiences but taken together this is combined and enhanced to provide an overall, greater picture:

"The more flexibly scientists work or are allowed to work, the more creative their research is apt to be." (Strauss and Corbin, 1998 pg 30).

2.2 Research setting

The study was carried out with the support of Milton Keynes General Hospital Diabetes Clinic who facilitated access to patients. The clinic is part of an urban hospital with approximately 2000 patients attending each year for appointments. Milton Keynes has a population of approximately 222 000. In Milton Keynes people with diabetes are generally seen at the hospital between one and three times a year depending on the type of diabetes and their needs as defined by the health care professionals at the clinic. They may then see their GP as and when they feel they need to or the GP requests to see them. By choosing to recruit participants at the hospital rather than through GP surgeries it was ensured that everyone who took part was receiving the same secondary care whether they have type 1 or type 2 diabetes (although the number of visits per year may vary). Milton Keynes was chosen as a location for several reasons including the pragmatic advantages for example, the existing relationship between the Open University and Milton Keynes General Hospital, the close geographical location of the hospital and the good accessibility to patients.

There were two diabetes clinics every week. On Tuesday morning from 9am to 11.30am a clinic was run primarily for people with type 1 diabetes. The first Tuesday of every month was solely a clinic for adolescents with diabetes and so recruitment did not take place on those weeks. On Thursday mornings from 9am to 11.30am a clinic was run primarily for people with type 2 diabetes.

2.3 Ethical Considerations

The process of gaining access to the participants started with making contact with the diabetologist in charge of the diabetes clinic, who agreed to act as sponsor for the study. The research proposal was submitted to Milton Keynes NHS Ethics Committee and was approved subject to minor changes followed by complete approval after the second submission. Following approval by the Ethics Committee the research proposal was approved by the Hospital and PCT Research and Development Committee. After a Criminal Records Bureau check an honorary contract was signed enabling the research to commence. The research proposal was also submitted to the Open University Human Participants and Materials Ethics Committee and was approved.

There were a number of ethical considerations taken into account when conducting this research. One of the prime concerns for all the ethics committees and the participants involved in the study was confidentiality. Participants were allocated a number in order to identify them and no identifying information appears on either their questionnaires or on the interview transcripts. All audio-tapes of the interviews were destroyed after transcription as requested by the hospital ethics committee. The researcher was given no access to the medical records of those who participated and any information required from them was retrieved by a healthcare professional working at the clinic who would already have access to the records.

Informed consent was obtained for each stage of the study (appendix L). When participants were approached in the diabetes clinic for the questionnaire stage they were given a detailed information sheet to read and take away. They

were given the opportunity to ask for further information or any questions they may have before signing the consent form. Those participants who participated in the interview stage of the study were given another information sheet which explained the interview in more detail. They were then asked to sign a second consent form with the relevant information about the interview. Participants were given contact details for the researcher and were encouraged to contact her at any time before, during or after completing the questionnaires or interview if they had any questions or wished to withdraw from the research.

Due to the personal and potentially distressing nature of the research all participants were given a list of where and how they could gain further information or support for their diabetes. At the end of the interviews during the debriefing participants were asked if they had any problems and if necessary were informed how they could get help.

2.4 Research process

As noted earlier, this research consisted of two stages. Stage one involved the self-completion of 5 questionnaires and stage two consisted of semi-structured interviews with a sub-set of the participants who took part in the questionnaire stage.

2.4.1 The questionnaire stage

Participants

Originally it was intended that 150 participants would be recruited; however, due to practical considerations, accessibility of potential participants and data collection issues 101 participants took part in stage one of this study. A decision was taken to include those aged between 30 and 55 in order to restrict the effects of major life events (such as puberty, university, death of spouse). Participants had all been diagnosed for at least one year to allow for the initial period of adjustment to the diagnosis and the condition. The population of Milton Keynes Diabetes Clinic was predominantly Caucasian and as a result it was decided to only approach participants who were Caucasian as it would have been impossible to obtain a representative sample of adults from other ethnic groups. There were 57 participants with type 2 diabetes and 44 of the participants had type 1 diabetes. Out of this sample 50 participants were women and 51 were men. As far as possible participants were age and gender matched (age matched to within 5 years) for type 1 and type 2 to ensure that

comparisons could be made between type 1 and type 2 diabetes and between men and women. Participants were approached by the researcher when attending for their regular appointment at the diabetes clinic. All participants were provided with an information sheet which described the research in detail and were given the opportunity to ask further questions about the research process. Participants were required to sign a consent form before participation and were informed that ethical approval had been obtained from the local research ethics committee.

Sample size and power calculation

There was a lack of previous literature comparing illness representations in individuals with type 1 and type 2 diabetes; however using values obtained from previous research using the Illness Perception Questionnaire (IPQ-R) (one of the questionnaires used in this research which measures illness representations), to detect differences in illness representations for different samples (Lawson et al. 2004; Barnes et al. 2004) an effect size of 0.51 was used to calculate that the intended sample size of 150 participants had an 85% power to detect a difference of 1.5 between means of those participants with type 1 and type 2 diabetes for illness representations (with $p < 0.05$, two tailed, using power table from Howell 2002). In practice the sample size of 150 participants was unobtainable but a sample size of 101 was recruited. Using a power calculation for unequal sample sizes it was calculated that this had a power of 75% to detect a difference of 1.5 between means of those participants with type 1 and type 2 diabetes for illness representations (with $p < 0.05$, two tailed, using power table from Howell 2002). Similarly there is a lack of literature comparing self-efficacy beliefs for individuals with type 1 and type 2 diabetes. Therefore an effect size of 0.5 was used based on previous research using

Grossman et al.'s (1987) self-efficacy scale (Howells et al. 2002) which is used in this thesis and standardised effect sizes (Howell 2002) to calculate an 85% power for detecting a difference of 3 between the means of participants with type 1 and type 2 diabetes for a sample size of 150 and a 71% power for a sample size of 101 participants.

Method

Stage one of this study consisted of a set of self-completion questionnaires.

1) *The demographic information questionnaire* (appendix A) asked participants for details about their age, gender, type of diabetes, age of diagnosis with diabetes, type of treatment for diabetes, highest level of education, marital status, ethnicity and employment status.

2) *The Revised Illness Perception Questionnaire (IPQ-R)* (appendix B) has been used in numerous research studies looking at illness representations and long-term conditions, for example Steed et al. (1999) and Scharloo et al. (1999). It has been adapted for use with a variety of long-term conditions and the questionnaire for diabetes has been used in studies such as Griva et al. (2000). Moss-Morris et al. (2002) have shown that the IPQ-R is psychometrically valid for measuring patients' perceptions of their illness. The IPQ-R is a generic measure of illness perceptions rather than a diabetes specific one; however, previous research has demonstrated its validity, it has been used in previous research for people with diabetes and it covers all the aspects of the CSM which this thesis addressed.

The IPQ-R scale is made up of 9 subscales: Identity, Consequences, Personal control, Treatment control, Timeline acute/chronic, Timeline cyclical, Illness coherence, Emotional representations and Cause. The Identity subscale is made up of a list of possible symptoms and respondents are asked to indicate if they have experienced the symptom since their diagnosis and if this symptom is related to their diabetes. The Cause subscale consists of a list of 18 possible causes of diabetes and respondents are asked to place each cause on a Likert scale of 'strongly disagree' to 'strongly agree'. Respondents are also requested to list their top three causes. The remaining subscales are combined in a questionnaire with 38 items using a Likert scale of strongly disagree to strongly agree.

As suggested by Moss Morris et al. a principal components analysis was performed on the Cause section of the questionnaire in order to identify factors to use in the analysis. Seven factors were identified. The remaining portion of the questionnaire was analysed to confirm that the variables the questionnaire items were grouped into by Moss Morris et al. were appropriate for this sample. More detail of these analyses can be found in chapter three (p.133).

3) *The Summary of Diabetes Self-Care Activities Measure (SDSCA)* (appendix C) has also been used in many studies such as Glasgow et al. (2000), reported by Toobert et al. (2000). Toobert et al. (2000) analysed 7 studies which made use of the SDSCA and found that it was a reliable and valid method of measuring people with diabetes' self-care behaviour by self-report with the added benefit that it is relatively brief. They also suggested a few alterations to the original scale, such as a simplified scoring system, which were developed into the revised version used here.

The SDSCA consists of two sections. The first section asks respondents to indicate on how many of the last seven days they performed a specific self-care behaviour. The scale includes questions about diet (5 items), exercise (2 items), blood testing (2 items), medication (1 item), foot care (5 items) and smoking behaviour (2 items). The second section of the scale asks respondents to indicate what advice they have been given by healthcare professionals regarding diet, exercise, blood testing and medication taking.

4) *The Self-Efficacy Scale* (appendix E) used was an adapted version of the scale used by Grossman et al. (1987) (appendix D). This scale was developed for use with adolescents with type 1 diabetes in the USA; however, it has been adapted for use in different populations in previous research (Griva et al. 2000; Aalto et al. 2000; Howells et al. 2002; Pinar et al. 2003) and, as a diabetes specific rather than a generic measure, it followed Bandura's recommendations for task specific questions relating to self-efficacy (Bandura 1997). It was adapted for this thesis by removing 9 items which were inappropriate for adults, such as 'Sleep away from home on a class trip or at a friend's house where no one knows about my diabetes'. Some of the wording was also changed from American English to English English, for example 'Prevent having reactions' to 'Prevent having hypos' and some of the items were re-worded in order to make them suitable for type 2 diabetes as well as type 1 diabetes, for example 'Change the amount of time I get insulin when I get a lot of extra exercise' to 'Change the amount of insulin or increase the amount of food I eat when I do a lot of exercise.'. The original scale by Grossman et al. had 35 items which were grouped into three sub-scales: diabetes specific self-efficacy (24 items), medical situations self-efficacy (5 items) and general situations self-efficacy (6 items). After the changes required to make the scale appropriate for the participants in this research it was decided to re-evaluate the subscales

contained in the new version of the scale. Statistical tests including Kaiser-Meyer-Olkin test, Bartlett's test for sphericity, correlation matrices and a principal components analysis were conducted and, combined with contextual information, six factors were developed, relating to different aspects of self-efficacy, and used in the analysis. More details of the analysis can be found in chapter three (p.135). The revised self-efficacy questionnaire was piloted with 2 participants and was found to be understandable and easy to complete. The questionnaire was not piloted further due to practical recruitment issues such as access to sufficient numbers of participants for a separate pilot and the full study and also because of the positive feedback received from the 2 participants it was piloted with.

5) *The complications checklist* (appendix F) consisted of a list of possible complications which can occur as a result of diabetes. Respondents were asked to indicate any complications which they thought they had or their doctor had said they had as a result of their diabetes. Respondents were also asked to record an approximate date for when they found out they had these complications.

The questionnaires took an average of 20 minutes to complete. The questionnaires were piloted with one participant. No changes were made and the questionnaires were implemented with the rest of the sample. After all the questionnaires were completed the HbA1c results for the participants were collected. The majority of questionnaires were completed on or very near the date of the individual's hospital appointment so the HbA1c result used was the one taken at that appointment. The questionnaires were completed at the clinic by 63 participants and taken home and posted back by 38 participants. For 10 of the participants the questionnaires were returned as a result of reminder

letters and so the HbA1c result used was the one nearest to the date of completion. The data collection for stage one took 11 months overall, from November 2004 to September 2005. During this period 40 data collection visits to the diabetes clinic were made.

Analysis

The questionnaire data was entered into the SPSS software package and accuracy was checked by another researcher. The data was then analysed using SPSS. The following statistical analyses were performed:

1) A Kolomogorov-Smirnov test was used to test for normality and the distribution of the data.

2) Descriptive analyses and frequencies were performed on the demographic data to look at how similar the different sub-groups of the sample were. Differences between the groups were investigated using Mann-Whitney U as the data was non-parametric.

3) For each questionnaire Cronbach's alpha or principal components analyses were performed to develop the most appropriate variables for this sample. Cronbach's alpha calculations were performed on the suggested variables in the main section of the IPQ-R to assess their reliability and if they were appropriate for the participants in this study. The Cause section of the IPQ-R was analysed using a principal components analysis and contextual information (for example, the type of cause addressed in the item and its contextual similarity to other causes) to reduce the number of variables. Further details of the analysis can be found in the next chapter (p.133)

4) The adapted Self-Efficacy Scale was analysed using Kaiser-Meyer-Olkin test, Bartlett's test for sphericity, correlation matrices, and a principal components analysis in conjunction with contextual information and scree plot analysis to group the items on the revised questionnaire into variables. Cronbach's alpha was used to assess the appropriateness of the variables that emerged. Further details of the principal components analysis can be found in the next chapter (p.135)

5) Cronbach's alpha was also used to confirm that the grouping of items into particular variables suggested for the Summary of Diabetes Self-Care Activities Scale were applicable.

6) Mann-Whitney U was used to investigate the differences between illness representations, self-efficacy and self-care behaviour for participants with type 1, tablet treated type 2 and insulin treated type 2 diabetes.

7) The correlations between the variables for the three groups of participants were analysed using Kendall's tau. This was used as the data was non-parametric and was chosen over Spearman's coefficient as it is more reliable for data sets with large numbers of tied ranks (Field 2000). Spearman's coefficients were also calculated and the same results were found.

8) For some of the relationships examined, significant correlations were found between self-care behaviour, illness representation and self-efficacy. To ascertain if self-efficacy moderated the relationship between self-care behaviours and illness representations the sample was divided into high and low self-efficacy groups, based on the 50th percentile. The correlations were then performed again for illness representation and self-care behaviour to see if the relationship was independent of the level of self-efficacy.

2.4.2 The interview stage

Participants

Eleven people took part in the interview stage of this research. The interviewees were selected from the participants who completed the questionnaires and had indicated on their consent form that they would be interested in being interviewed. Out of the 101 questionnaire stage participants 80 indicated they would be interested in being interviewed. There were no significant differences between those who indicated they were willing to be interviewed and those who did not want to be interviewed for HbA1c level, type of diabetes, age, gender, age at diagnosis with diabetes, duration of diabetes, and marital, education or employment status. Potential interviewees were selected by gender, type of diabetes and by the level of self-care behaviour as indicated on the stage one questionnaires. To select the interviewees the 80 participants who agreed to be interviewed were divided into men and women, and then into those with type 1 and type 2 diabetes. Each participant within these 4 sub-groups was then ranked on the basis of their composite self-care score from the SDSCA questionnaire in stage one. Those with the highest and lowest self-care scores within each of the 4 sub-groups were approached for interview. Participants were approached by letter and then a follow up telephone call. There were three individuals who agreed at the questionnaire stage to be interviewed but when subsequently selected for interview and approached declined to take part. One was a man with type 2 diabetes who felt he was too busy to take part. The other two were women with type 2 diabetes who had low levels of self-care behaviour. One woman made two appointments for the interview but cancelled just before each appointment. The other woman

also arranged two appointments, cancelled the first one and failed to turn up for the latter.

Method

Stage two of the study involved the collection of qualitative data and utilised semi-structured interviews. This method was chosen because it allowed existing theoretical ideas and principles (in this case illness representations, self-efficacy and self-care) to be introduced, unlike unstructured interview techniques which just use broad open ended questions. However, it did not restrict the data as in a structured interview, which relies on the same questions asked in the same order in every interview. A topic guide was developed (appendix G), with suggested phrasing of questions, from the questionnaires used in stage one. The questions covered illness representations – identity, consequences, treatment and causes – self-efficacy and self-care behaviour. Prompts and probes were also developed for instances where answers were not forthcoming. Although suggested wording for the questions was produced these were intended to be used as and when appropriate and were used flexibly depending on how the interview progressed. The phrasing and wording were altered depending on the interviewee's interpretation and vocabulary (Mathieson 1999). The questions were put in an order to facilitate the conversation – starting with the easier questions and moving on to the more difficult ones (Britten 1995). However in practice the order of the questions was fluid and the lead was taken from the interviewee, asking questions as and when they seemed to fit. Although the order changed from interview to interview, all of the questions were asked or the topic area covered without prompting by the interviewee, in every interview.

The questions about illness representations were as open and non-specific as possible (Smith and Osborn 2003). Question one ("To start with could you just tell me a bit about yourself") was intended to start the interview gently and get people to talk a bit about their life and present situation – background or demographic information. A discussion about the type of diabetes the interviewee had, how they found out what type they had and so on was encouraged. This had been an issue on many of the completed questionnaires at stage one, with people not knowing what type of diabetes they had. The interviewee's perceptions of the differences between type 1 and type 2 diabetes were also discussed as this may be an important factor when comparing the illness representations of people with type 1 and type 2 diabetes. The experience of diagnosis was discussed and was intended to encourage the interviewee to tell their illness narrative. This helped the interviewee to settle into the interview but also produced useful information about the experiences and prior knowledge of diabetes which are thought to shape illness representations (Cameron and Leventhal 2003). Whilst recruiting participants in stage one of this study it became clear from talking to numerous people whilst waiting in the diabetes clinic that nearly everybody seemed to have a narrative of how they were diagnosed and felt comfortable talking through this narrative. The following questions asked about illness representations, self-care behaviour and self-efficacy in an open and neutral way. The final questions asked interviewees to talk through their last clinic visit and the day before the interview in terms of their diabetes and how they felt about the future. These questions were intended to pick up on any bits of information which may have been missed during the other more abstract questions by focusing on particular events.

The interviews lasted for an average of an hour and a half and took place at Walton Hall, the main Open University campus. It was decided to interview in this location for several reasons. For practical reasons it was easier to interview away from the clinic – it would have been very difficult to find a suitable room which would enable a quiet and undisturbed interview to take place at the hospital. There were certain advantages to interviewing away from the clinic environment. By distancing the interview process from the hospital where the usual diabetes appointments take place the interview was distinguished from an appointment with a health care professional and so encouraged frank, open and honest answers to the interview questions. It has been suggested that people have a tendency to exaggerate their performance of self-care behaviours when talking to health care professionals (Ferzacca 2000; Paterson 2001).

A pilot interview was conducted. There was one question on the topic guide which was found to be problematic – 'Are there any things which are different about your body since your diagnosis with diabetes?' and this was re-phrased to 'Are there any symptoms or differences in your body or health since your diagnosis with diabetes?'. The pilot interview also revealed several areas which were not covered in the initial topic guide. These were developed in to questions about how the interviewees felt about the future and their perceptions of how others – family, friends, the media, the world in general – considered diabetes as it relates to them personally and in general. Following these changes the revised topic guide was used for another interview. No further changes were made and the rest of the interviews were conducted using these questions. The interviews were recorded and transcribed. Notes on other aspects of the interview such as particularly striking body language or tone of voice were taken during the interview and from the interview recordings. The

data collection period for the interview stage was 4 months, from October 2005 to January 2006.

Analysis

The interview data was entered into N6 (a qualitative data analysis software package formerly know as Nudist) and was analysed using thematic analysis. Thematic analysis was chosen for several reasons. It was decided that Grounded Theory was inappropriate due to the fact that the interviews were semi-structured around existing theoretical ideas and so it would not be possible to analyse the data from a truly bottom-up approach. In addition, it was not possible to reach data saturation in the way ascribed by Grounded Theory due to the restrictions on the number of interviews possible from a time perspective and the approval from the NHS Ethics Committee. The use of discourse analysis was similarly rejected as being too focused on the detailed analysis of specific language usage rather than on the broader themes and concepts which this research intended to look at. Thematic analysis offered an analytical approach which allowed for the integration of existing theoretical ideas with a broader analysis of the different aspects of the interviewees' experiences.

During the data analysis there were certain concepts, including self-efficacy and emotional experiences, which were extremely difficult to access directly during the interviews. When asked directly the majority of interviewees described feeling confident about their diabetes and further probing about areas they might feel less confident (or more confident) about yielded few results. When asked about emotions relating to their diabetes, again direct questions

usually resulted in positive responses about how 'they were fine'. This meant that when using a thematic analysis approach, looking directly at the transcripts for phrases or statements that indicated levels of self-efficacy or emotional representations, few examples were found. However, on re-reading the transcripts and notes it was found that recalling voice inflections, tone of voice, body language, the way things were said and the associations between certain statements led to information about self-efficacy and emotional representations emerging from the data. By using contextual and non-verbal information the analysis went beyond thematic analysis.

The interview transcripts were coded individually with codes emerging from the data. After each new interview was coded, the interviews which had already been looked at were re-coded with any new emerging concepts and codes from the new interview. Overall 62 codes emerged. After all the interviews were coded the codes were analysed and grouped into over-arching themes produced by the data. This produced 4 broad themes. Following the initial thematic analysis the data was re-analysed. Self-efficacy was analysed by looking at each description or example of self-care behaviour within the interview data and then analysing the description of this behaviour using contextual and non-verbal information such as voice inflections, tone of voice, body language and the use of language around the specific self-care behaviour. Emotional experiences were analysed in a similar way by looking at each section of the interview where non-verbal information suggested an emotional aspect to the experience. This included the tone of voice used, facial expressions, body language and the use of language, not in direct quotes but around the experience being described. This resulted in 2 further broad themes being developed. Each theme was considered individually and the pattern within the theme in terms of type of diabetes, gender and level of self-care

behaviour was analysed. Analysis focussed on the differences and similarities in the interview data. Finally the interview data was re-analysed using Leventhal's Commonsense Model of the Self-Regulation of Health and Illness (CSM) as a framework. The 6 themes were mapped onto the CSM diagram to ascertain how they related to each other and if the same patterns as suggested by the CSM were found.

2.4.3 Combined analysis of the questionnaire and interview data: triangulation of data

Once the separate analyses of the questionnaire and interview data had been conducted the findings from each stage were compared and contrasted. This process had three main stages:

1) Comparison of the two data sets to enable cross-validation of the results.

2) Use of interview data to explain the relationships found in the questionnaire analysis.

3) Examination of divergent findings to ascertain why this may have occurred and further analysis where necessary.

Firstly the findings from the questionnaire stage were compared and contrasted with the findings from the interviews. For example, the questionnaire and interview data were compared to see if the interview data supported the differences found between illness representations, self-efficacy and self-care behaviour for participants with type 1 and type 2 diabetes in the questionnaire stage. Following this analysis the reverse was done and the interview findings were compared with the questionnaire findings to see if aspects of illness

representations, self-efficacy and self-care found to be important in the interview data were also found in the questionnaire analysis. As a result of this it was decided to re-analyse the questionnaire data to perform correlation analysis between illness representations, self-efficacy and self-care behaviour for men and women separately. Secondly, the interviewees were compared individually with the correlations suggested by the questionnaire stage to see how representative they were of the questionnaire findings. Finally, comparison of the questionnaire and interview data revealed findings which were not replicated in the other data set. These findings were examined and explanations for the divergence suggested, using contextual information, such as the data collection methods used, and previous research.

2.5 Collecting and Managing the Data

2.5.1 Data Collection Process

1) Ethics approval was requested and received from the Milton Keynes General Hospital NHS Ethics Committee and the Open University Human Participants and Materials Ethics Committee.

2) Leaflets and posters were placed around the Diabetes Clinic to make potential participants aware of the study and what it involved.

3) Potential participants were identified (by age) using the clinic appointment schedule.

4) Potential participants were approached at their usual clinic appointment. The study was explained to them and they were asked if they were willing to take part. If they agreed then they were given the information sheet to read and asked to sign the informed consent form before participating.

5) Participants were then given the questionnaires to complete. They were given the option of either filling them in at the clinic and returning them directly to the researcher in a sealed envelope or taking the survey home to be completed at their leisure and posted back in a pre-paid envelope to the researcher.

6) On the consent form participants were asked to complete a question regarding if they would be willing to participate in the interview stage of the study.

7) Addresses and contact phone numbers were taken so participants could be contacted about the interview stage if selected and be provided with feedback about the outcomes of the study.

8) HbA1c results were located by the diabetologist from respondents' medical records to gain a measure of their metabolic control during the previous 6 – 8 weeks prior to the blood being taken.

9) Initial analyses were made of the data produced by the questionnaire stage of the study. These were used to develop the questions and themes to be looked at in the interview stage.

10) From those respondents who indicated an interest in taking part in the interview stage of the study 11 individuals were selected on the basis of sex, type of diabetes and levels of self-care behaviour.

11) Interviews took place at the Open University and lasted between one and two hours. They were audio-taped and transcribed.

12) The quantitative data was analysed using SPSS. This included descriptive statistics and correlation coefficients to demonstrate links between the factors being looked at. The qualitative data was analysed using Thematic Analysis (as described earlier) looking for commonalities, differences and themes in the responses of people with type 1 and type 2 diabetes.

2.5.2 Data collection issues

There were various deviations from the original research plan as a result of the practicalities of data collection. The first alteration was in the way that potential participants were approached in the clinic for stage one of the study. Initially the plan was for the diabetologist to identify his patients who fitted the study criteria when they saw him at their clinic appointment. He was then going to give them a green information sheet and direct them to the researcher in the waiting room. However, in reality this was impractical for several reasons. Firstly, the diabetes clinic was exceptionally busy and the diabetologist was constrained for time which meant he had limited time to see if his patients fitted the criteria. Added to which when the participants were approached by the clinician they may have felt under an obligation to take part in the research. The

other main consideration was the fact that this approach did not fit well with the structure of the usual clinic visit. During busy periods patients were usually called in to see the nurse relatively quickly but could wait to see the doctor for up to half an hour. This meant that after seeing the doctor the majority of people were in a rush to leave and had little time to spend filling in a questionnaire. So the decision was taken that potential participants should be identified from the clinic list, which showed their date of birth, by the researcher and then approached whilst waiting to see the doctor.

This change in recruitment strategy worked much better however it did result in a further issue. Originally the research protocol had stipulated that participants should have no existing complications in order to avoid any impact these may have on health beliefs and illness representations. It was intended that as the diabetologist had direct access to their medical records when approaching them that this could be taken in to account. When the approach strategy was changed this was not possible. Added to which the large numbers of people with diabetes in the relevant age group with some form of complication meant that to produce a large enough sample with no complications would have been very difficult. As a result it was decided to produce a checklist of complications for participants to complete, which would make it possible to ascertain if the individual had complications or not, the severity of those complications and how long they had had them. Statistical analysis could then be conducted in order to establish if the presence of complications was associated with illness representations and self-care behaviour. The need to ascertain if participants had diabetes complications had previously been agreed by the NHS Ethic Committee and the use of the complications checklist was also ratified by the diabetologist and the Open University Human Participants and Materials Ethics Committee.

There were certain other difficulties experienced as a result of the change in approach. Some potential participants were not approached because either the nurses recognised them and so did not call their names, the names were called when the researcher was busy with another potential participant and so they were missed or there was no time between seeing the nurse and seeing the doctor and they were called straight in to see the doctor. This last problem occurred more frequently at specific times in the clinic and on specific days. During the first half hour of the clinics, when the first patients were coming in, it proved to be difficult to approach people as the whole appointment process was very fast from beginning to end. This was also the case towards the end of the clinic when fewer patients were arriving. The best period for data collection was an hour in to the clinic when the number of people arriving to see the doctor was greater than the number of people being seen and (unfortunately for the patients but luckily for the research) this resulted in a longer wait. The clinics where the diabetologist was away and the clinic held on Thursdays, which were mainly for older patients, were also much quieter and so it was more difficult to approach people due to the speed at which they went through the clinic process. However, the clinic appointments were not assigned on the basis of any criteria which may have biased the data collection process (with the exception of the Tuesday/Thursday age differences).

Another change which had to be made due to the practicalities of conducting research in the real world was where and when the questionnaires were filled in. Initially it was hoped that most people would fill the questionnaires in whilst at the clinic. However, due to the length of time it took to complete the questionnaires (up to 20 minutes), the time between seeing the nurse and seeing the doctor, and the varying willingness to stay after completing their clinic appointment, it was found that a large proportion of participants (38%)

preferred to take the questionnaires home for completion. Consequently, all participants were provided with stamped addressed envelopes to return the questionnaires and reminder letters were sent out after two weeks to those people who had not returned their questionnaires. The advantage of being able to take the questionnaires home was that participants were able to fill them in when they were away from the clinic in a more relaxed environment. Waiting to see the doctor was a stressful experience for many of the participants (as could be seen by their behaviour in the waiting room) and completing a questionnaire which asks how they feel about their diabetes and how they look after themselves whilst in that situation may not have produced the most accurate or realistic results. Also it enabled people who did not really want to take part in the research but felt unable to say no to a researcher when face to face the opportunity to decline from taking part without the stress of coming up with an excuse. As a consequence of this, the sample may be biased more strongly towards people who were interested in taking part in research, for a variety of reasons such as beliefs in the importance of research or that the research would benefit people with the same condition, as is frequently found in research (Hayman et al. 2001; Wong et al. 2004; Harris 2005; Garber et al. 2007). Although many of the questionnaires taken away were not returned (n = 27), 38% of the completed questionnaires were filled in away from the clinic which suggests that more questionnaires were completed overall because people were given the choice of where to fill it in. Those participants who completed their questionnaires at the clinic and those who posted them back were largely comparable in terms of demographics, illness representations, self-efficacy and self-care behaviour. However, those who took their questionnaires away were diagnosed with diabetes at a significantly older age (mean age $\pm$ SD: 34.34 ± 13.42 vs 28.20 ± 13.45 years, $p < 0.05$) and therefore had had diabetes

for a significantly shorter duration (mean duration ± SD: 10.97±9.28 vs 15.94±11.39 years, p < 0.05).

The other major change to the data collection process was regarding people who did not attend their clinic appointments and did not ring to cancel (known as DNA or Did Not Attend). Initially it was thought that it would be useful for the research if 50 DNA people were recruited (25 with type 1 diabetes and 25 with type 2 diabetes) in order to examine potential differences between attendees and non-attendees. However, in practice it was found that there were fewer DNA people than expected and that the response rate from the letters sent to these people was not particularly high, which was expected due to their non-attendance at the clinic. After every clinic where recruitment took place the names and addresses of patients who fitted the study criteria on the DNA list were collected and they were approached by letter. In total, 40 letters were sent out and 7 replies were received. This meant that it was not possible to obtain a big enough sample to make comparisons between people with diabetes who did not attend their appointments and people with diabetes who did.

2.5.3 Data Management

A spreadsheet of participants' name, address and date of consent was created. The raw questionnaire data was collated and kept in a locked cabinet. This data was inputted into SPSS ready for analysis. The interview data was transcribed from audiotape. Once the data was transcribed the audiotapes were destroyed as per the ethics committee requirements. The interview data was inputted in to N6 for analysis. All electronic data was stored in a password locked computer. Only the researcher and supervisors had access to the data.

Chapter Three

Illness representations, self-efficacy and self-care: analysis of the questionnaire data

This chapter details the statistical analysis of the quantitative data collected from the questionnaires in stage one. Firstly descriptive statistics are used to provide an overview of the participants who took part in the study. Then the initial analyses of the separate scales are detailed, showing what sub-scales for each questionnaire were developed and used in further analysis. Thirdly, differences between illness representations, self-efficacy and self-care behaviour for participants with type 1 and type 2 diabetes, marital status and education level are presented. Finally the relationship between illness representations, self-efficacy and self-care behaviour for type 1, tablet treated type 2 and insulin treated type 2 diabetes are described.

3.1 Overview of study participants

Gender, age, age at diagnosis and duration of diabetes

The five questionnaires were completed by a total of 101 participants. Of these, 44 (43.6%) had type 1 diabetes (22 were men and 22 were women) and 57 (56.4%) had type 2 diabetes (29 men and 28 women). Of the participants with type 2 diabetes, 19 (33.3%) were taking oral hypoglycaemic

tablets only (13 men and 6 women) and 38 (66.6%) were taking insulin (16 men and 22 women).

Figure 10 - The mean age, age at diagnosis and duration of diabetes for type 1 diabetes, tablet treated type 2 diabetes and insulin treated type 2 diabetes.
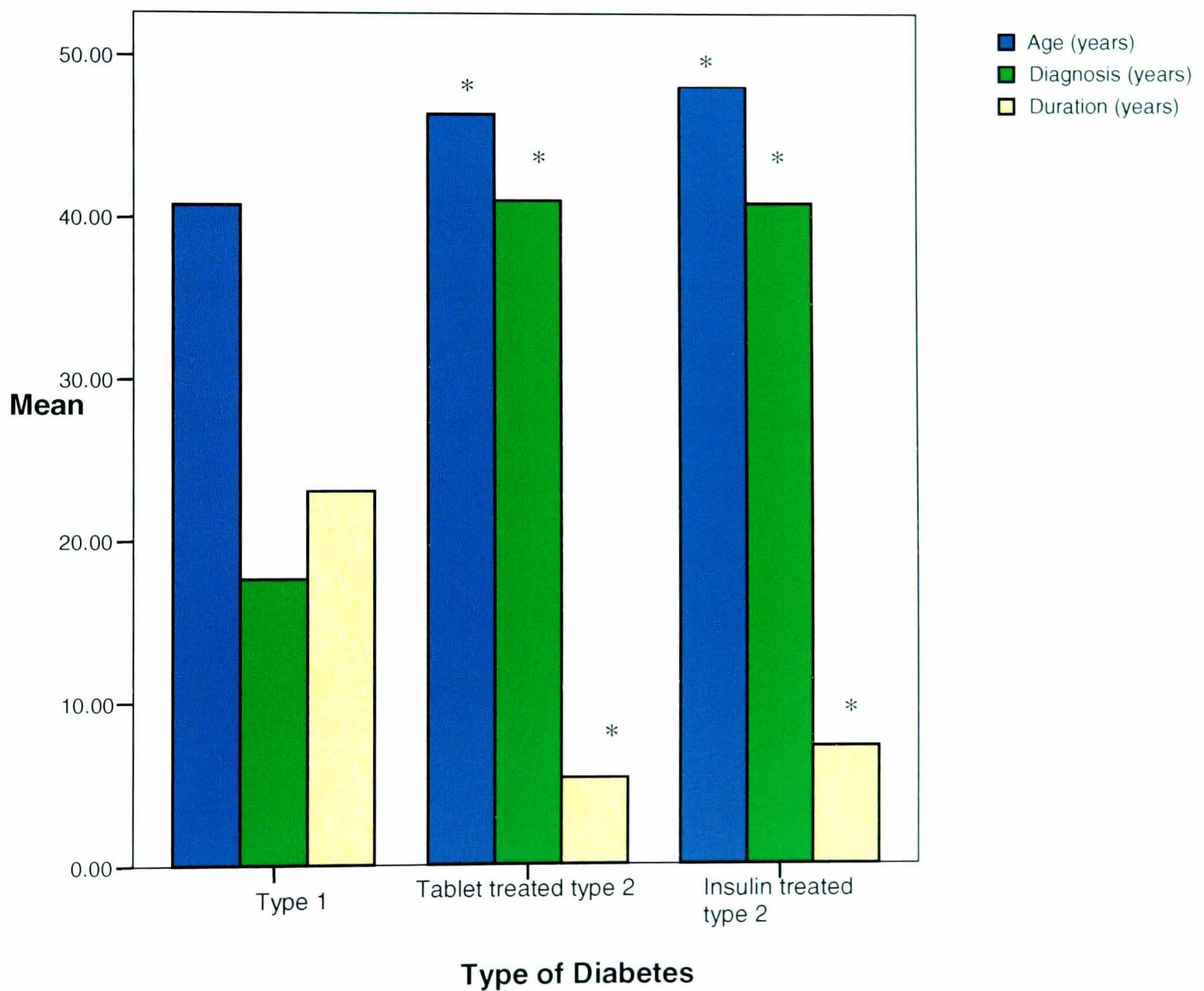
* = p < 0.001 compared to participants with type 1 diabetes.

Participants with type 2 diabetes (tablet treated and insulin treated) were significantly older than those with type 1 diabetes ($\overline{X} \pm$ SD age: 46.4 $\pm$ 6.1 years and 48.2 $\pm$ 4.8 years vs 40.6 $\pm$ 6.4 years respectively, p < 0.005). The differences in age between the type 2 diabetes groups were not significant.

Those participants with type 2 diabetes (tablet treated and insulin treated) were diagnosed at an older age than those with type 1 diabetes ($\overline{X}$ SD $\pm$ age at diagnosis: 41.1 $\pm$ 7.1 years and 40.9 $\pm$ 6.9 years vs 17.7 $\pm$ 7.8 years respectively, p = 0.000). The difference between the age of diagnosis for the type 2 groups was not significant.

Participants with type 1 diabetes had a significantly longer duration of diabetes than those with type 2 diabetes (tablet treated and insulin treated) ($\overline{X} \pm$ SD duration: 23.1 $\pm$ 8.9 years vs 5.4 $\pm$ 5.2 years and 7.3 $\pm$ 5.2 years respectively, p = 0.000). There was not a significant difference for duration of diabetes between the type 2 diabetes groups.

There were no significant differences between the men and women for age, age at diagnosis and duration of diabetes.

Marital status, education level and employment status

The marital status of the participants is shown in figure 11 below.

Figure 11 - Marital status for type 1, tablet treated type 2 and insulin treated type 2 diabetes.
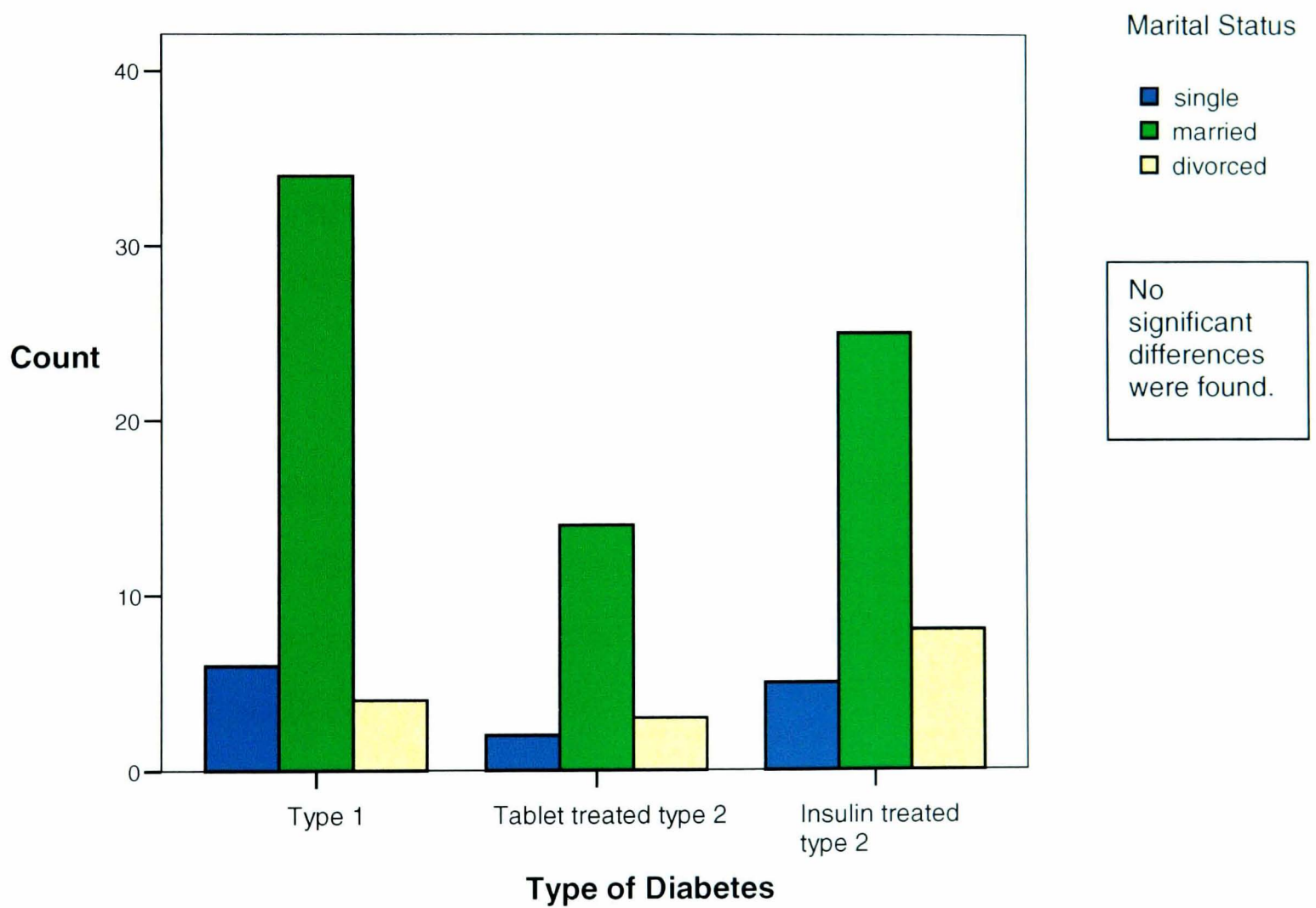
Overall 8 women and 5 men were single, 36 women and 37 men were married or living with a partner and 6 women and 9 men were divorced or separated. There were no significant differences between the men and women for marital status. Of those participants with type 1 diabetes 6 (13.6%) were single, 34 (77.3%) were married or living with a partner and 4 (9%) were divorced or separated. For those participants with tablet treated type 2 diabetes, 2 (10.5%) were single, 14 (73.6%) were married or living with a partner and 3 (15.7%) were divorced or separated. There were 5 (13.1%) single, 25 (65.8%) married or living with a partner and 8 (21%) separated or divorced participants with insulin treated type 2 diabetes.

Participants who were separated or divorced were significantly older than those participants who were single ($\overline{X} \pm$ SD age: 47.2 $\pm$ 6.9 years vs 40.5 $\pm$ 6.9 years, $p = 0.021$).

Participants who were separated or divorced were diagnosed with diabetes at a significantly older age than those who were single or who were married or living together ($\overline{X} \pm$ SD age at diagnosis: 38.9 $\pm$ 11.1 years vs 25.6 $\pm$ 12.9 years and 29.7 $\pm$ 13.8 years respectively, $p < 0.05$).

Educational attainment varied across the sample with participants reporting

their highest level of educational achievement.

**Figure 12 - Highest education level for participants with type 1, tablet
treated type 2 and insulin treated type 2 diabetes.**
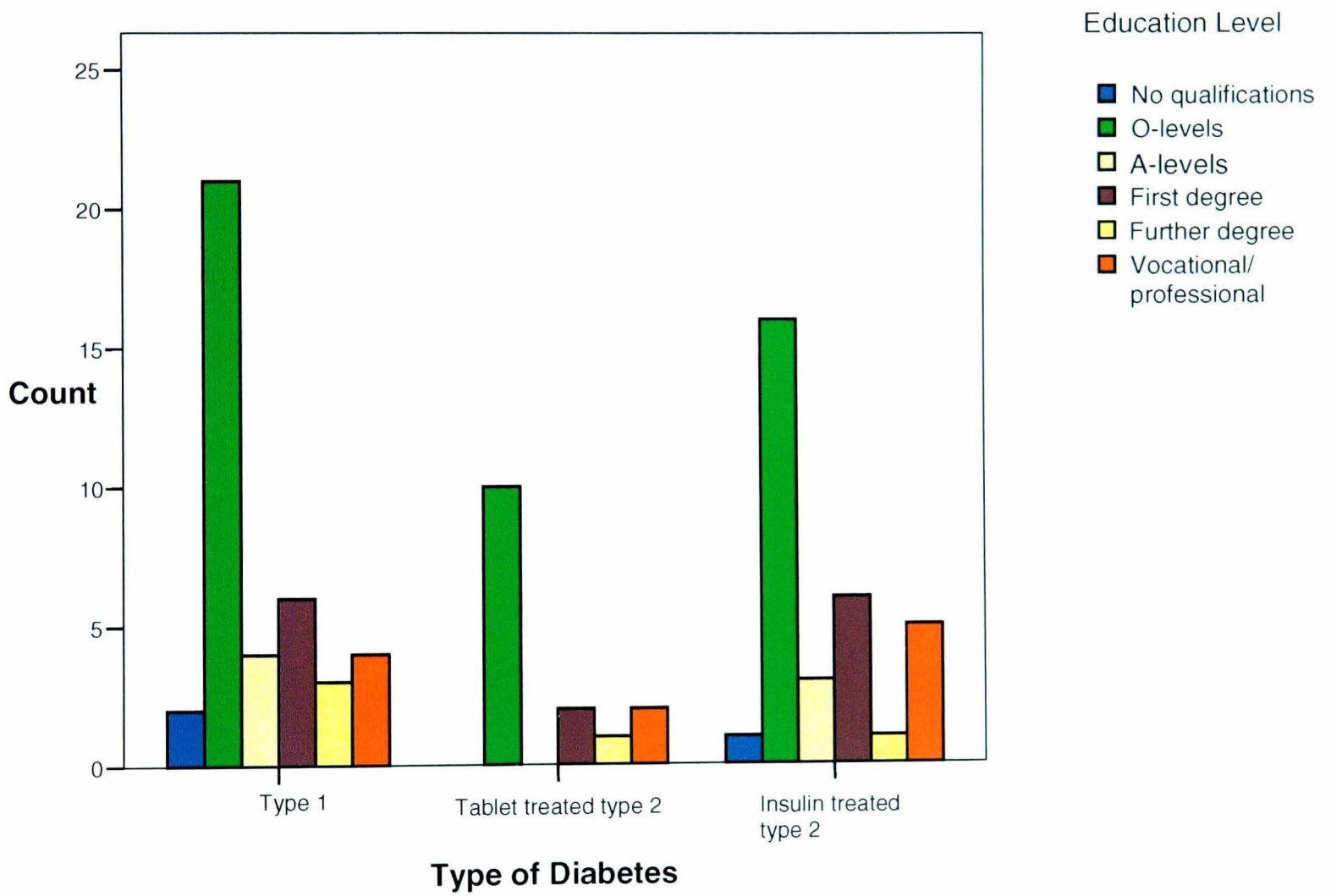
For the participants with type 1 diabetes only 2 (5%) had no qualifications, 21 (52.5%) had O-levels or the equivalent, 4 (10%) had A-levels, 6 (15%) had a first degree, 3 (7.5%) had a further degree and 4 (10%) of the participants with type 1 diabetes had vocational or professional qualifications.

Of those with tablet treated type 2 diabetes 10 (66.6%) had O-levels, 2 (13.3%) had a first degree, 1 (6.6%) had a further degree and 2 (13.3%) had vocational or professional qualifications.

Only 1 of the participants with insulin treated type 2 diabetes (3.1%) had no qualifications, 16 (50%) had O-levels, 3 (9.4%) had A-levels, 6 (18.7%) had a first degree, 2 (6.3%) had a further degree and 4 (12.5%) had vocational or professional qualifications.

Figure 13 - Education level for men and women
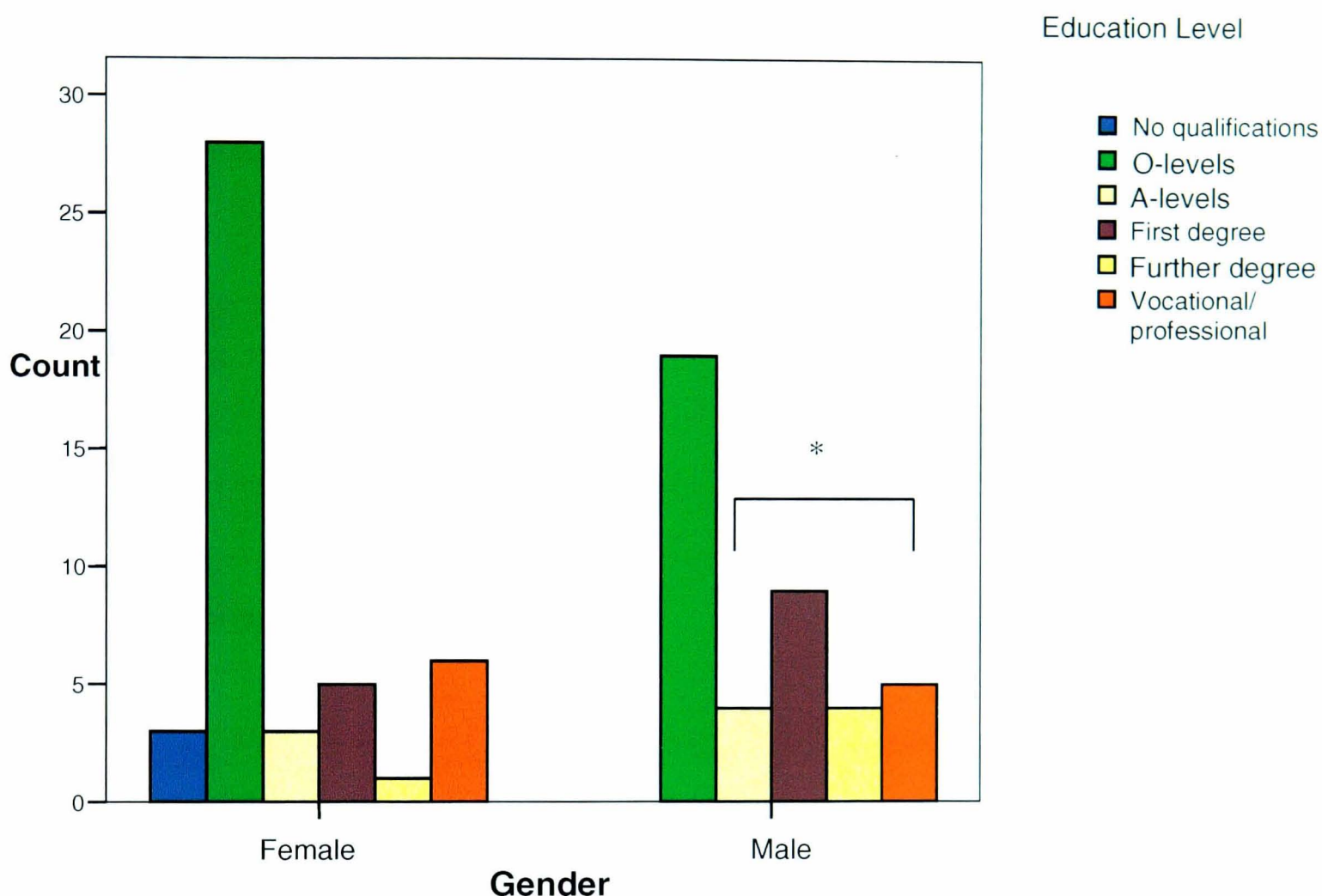
* = p < 0.05 compared to women with level of education of A-levels and above.

For the whole study population, only 3 had no qualifications and all these were women. There were 28 women and 19 men who had O-levels or the equivalent. Of the participants, 3 women and 4 men had A-levels, 5 women and 9 men had first degrees, a further degree was held by 2 women and 4 men, and 5 women and 5 men had vocational or professional qualifications.

There were no significant differences for educational status between participants with type 1, tablet treated type 2 or insulin treated type 2 diabetes;

however, there was a significant difference in the proportion of women and men with a higher level of education (A-levels and above) (13% vs 31.7%, p = 0.037).

Table 1 - The number of male and female participants with type 1, tablet treated type 2 and insulin treated type 2 diabetes who were employed and unemployed.

Type of diabetes	Gender	Employed	Unemployed
Type 1	Women	17	5
	Men	18	4
Tablet treated type 2	Women	4	2
	Men	12	1
Insulin treated type 2	Women	13	9
	Men	10	6
Overall	Women	34	16
	Men	40	11

There were no significant differences between type of diabetes or gender for employment status.

HbA1c results

The mean HbA1c result for participants with type 1 diabetes was 7.81% (±SD 1.05%), with tablet treated type 2 diabetes was 8.24% (±SD 1.45%) and for insulin treated type 2 diabetes was 8.42% (±SD 1.83%). There were no significant differences between HbA1c results for type of diabetes or any other demographic characteristics including gender.

Complications

A total of 81 out of 101 participants (80%) completed the diabetes complications checklist. Of these 34 (42%) participants indicated they had no complications. Those without complications were equally likely to have type 1 or type 2 diabetes. There were 47 (58%) participants who reported the presence of complications. Table 2 below shows the number of male and female participants with different types of diabetes who reported different types of complications.

Table 2 - Reported diabetes complications for men and women, participants with type 1, tablet treated type 2 and insulin treated type 2 diabetes.

Type of Diabetes	Gender	Foot complications	Eye complications	Kidney complications	Circulation complications
Type 1	Female	6	10	7	4
	Male	5	6	5	1
Tablet treated type 2	Female	2	0	0	0
	Male	5	2	0	1
Insulin treated type 2	Female	7	7	2	3
	Male	7	2	1	5
Overall	Female	15	17	9	7
	Male	17	10	6	7

For participants with type 1 diabetes higher HbA1c levels were associated with the presence of kidney complications ($\overline{X} \pm$ SD HbA1c with and without kidney complications: $8.6 \pm 1.3\%$ vs $7.39 \pm 0.8\%$ respectively, p = 0.028).

There were no significant differences for participants with tablet treated type 2 diabetes between the presence of complications and HbA1c.

For participants with insulin treated type 2 diabetes the presence of eye complications was significantly associated with a higher level of HbA1c ($\overline{X} \pm$ SD HbA1c with and without eye complications: $9.3 \pm 1.9\%$ vs $7.6 \pm 1.4\%$ respectively, p = 0.031)

Women were more likely to have eye complications if their HbA1c was higher, they had been diagnosed at a younger age and they had had diabetes for a longer duration ($\overline{X} \pm$ SD HbA1c with and without eye complications: 8.9 $\pm$ 1.8% vs 7.5 $\pm$ 1.3% respectively, p = 0.020, $\overline{X} \pm$ SD age of diagnosis with and without eye complications: 22.6 $\pm$ 14.4% vs 34.4 $\pm$ 13.5% respectively, p = 0.021, $\overline{X} \pm$ SD duration with and without eye complications: 19.5 $\pm$ 10.4% vs 11.1 $\pm$ 10.8% respectively, p = 0.009).

There were no significant differences between the men who had complications and those who did not for the other demographic variables.

Summary

- Participants with type 2 diabetes were significantly older, had been diagnosed later in life and had diabetes for a shorter duration than participants with type 1 diabetes.
- There were no significant differences for age, age at diagnosis or duration of diabetes between participants with tablet or insulin treated type 2 diabetes.
- There were no significant differences for age, age at diagnosis or duration of diabetes between men and women.
- Participants who were separated or divorced were significantly older and had been diagnosed later in life than those who were single or married.
- No significant differences were found for marital status between participants with type 1 or type 2 diabetes and men and women.
- There were no significant differences between type of diabetes for education or employment status.

- Men were significantly more likely to have educational qualifications at A-levels and above than women.

- Participants with type 1 diabetes and kidney complications had significantly higher HbA1c levels than those without kidney complications.

- Participants with insulin treated type 2 diabetes and eye complications had significantly higher HbA1c levels compared to those without eye complications.

- Women with eye complications had significantly higher HbA1c levels, had been diagnosed at a younger age and had a longer duration of diabetes than those without eye complications.

- Women with kidney complications had significantly higher HbA1c levels and had a longer duration of diabetes compared to those without kidney complications.

- No significant differences were found for men between those with or without complications.

3.2 Questionnaire Analysis

A Kolmogorov-Smirnov test was carried out on all of the questionnaires (the IPQ-R, Self-Efficacy scale and SDSCA) to assess the normality of distribution for the questionnaire data. This showed that there was a significant difference between this set of data and what would be expected from normally distributed data. This meant that the data was not normally distributed and so subsequently non-parametric statistical tests were used to analyse the data. A summary of all the variables from the questionnaires can be found in appendix H.

3.2.1 Illness Perception Questionnaire – Revised (IPQ-R)

The IPQ-R consisted of two main sections (see chapter two for detailed discussion and appendix B). The first contained sub-scales asking about timeline, consequences, personal control, treatment control, illness coherence, timeline cyclical and emotional representations. The second section contained a list of potential causes of diabetes not grouped into sub-scales. Reliability analyses were carried out on the data from the first section of the IPQ-R to assess if the sub-scales suggested by Moss-Morris et al. (2002) were valid for the population being looked at here. The items were divided into the sub-scales suggested and Cronbach's Alpha was calculated for each scale (the acceptable range for Cronbach's Alpha is 0.70 and above).

For **Timeline** (items 1, 2, 3, 4, 5, 18) Cronbach's alpha = 0.742.

For **Consequences** (items 6, 7, 8, 9, 10, 11) Cronbach's alpha = 0.697.

For **Personal Control** (items 12, 13, 14, 15, 16, 17) Cronbach's alpha = 0.803.

For **Treatment Control** (items 19, 20, 21, 22, 23) Cronbach's alpha = 0.459.

One of the items in this subscale (item 20) asked participants to indicate whether they strongly agree, agree, neither agree nor disagree, disagree or strongly disagree with the statement 'My treatment will be effective in curing my diabetes'. From a face value analysis of the questionnaire this item appeared to be incongruent with the answers given for other items in the scale and also with the nature of diabetes as at present diabetes is not curable. Therefore a reliability test was done removing item 20 and this gave a Cronbach's alpha = 0.592. Replacing item 20 into the scale and removing the other items in the sub-scale in turn made Cronbach's Alpha even lower so it was decided to remove item 20 from the Treatment Control Scale.

For **Illness Coherence** (items 24, 25, 26, 27, 28) Cronbach's alpha = 0.934.

For **Timeline Cyclical** (items 29, 30, 31, 32) Cronbach's alpha = 0.747.

For **Emotional Representations** (items 33, 34, 35, 36, 37, 38) Cronbach's alpha = 0.889.

The Cronbach's Alpha results for all other scales were within an acceptable range ($\geq$ 0.7) so it was decided to include all items except item 20 in the Treatment Control scale.

Item 20 was analysed separately as **'curing diabetes'**.

For the second section of the IPQ-R, Moss-Morris et al. (2002) suggested using factor analysis in order to produce groups of causes that were most relevant for the participants in each study therefore a Principal Component Analysis was performed. A Kaiser-Meyer-Olkin test for sampling adequacy (= 0.819) indicated that the analysis should yield distinct and reliable factors as the value was between 0.8 and 0.9 (Field 2000). Bartlett's test for sphericity was significant ($p < 0.0001$) showing that a principal components analysis was an appropriate test. An orthogonal and an oblique rotation principal components analysis were conducted to facilitate the interpretation of the data. The oblique rotation showed negligible correlations between the extracted factors which suggested it was acceptable to use the orthogonal rotated solution and assume that the factors were independent (Field 2000). A scree plot was analysed to support the interpretation of the components. Seven principal components were extracted with an eigenvalue greater than 1.0. The variance explained by these 7 factors was 77.59%. In addition to the principal components analysis, contextual information from the individual questions was used to develop the seven factors. Although there was a large number of items and a relatively small sample size it was decided that due to the contextual suitability of the factors the analysis was adequate.

Factor one was called **personal responsibility** and contained items: C4, *diet or eating habits*, C6, *poor medical care in my past*, C8, *my own behaviour*, C9, *my mental attitude*, C13, *ageing*, C14, *alcohol*, C15, *smoking* and C17, *my personality*.

Factor two was called **mental state** and contained items: C1, *stress or worry*, C10, *family problems or worries*, C11, *overwork* and C12, *my emotional state*.

Factor three was called **accident or illness** and contained item: C16, *accident or injury*.

Factor four was named **external** and contained items: C3, *a germ or virus* and C7, *pollution in the environment*.

Factor five was called **altered immunity** and contained item: C18, *altered immunity*.

Factor six was called **hereditary** and contained item: C2, *hereditary – it runs in my family*.

Factor seven was called **chance** and contained item: C5, *chance or bad luck*.

3.2.2 Self - Efficacy Scale - Revised

The items used in this questionnaire were taken from the measure of self-efficacy developed by Grossman et al (1982). The original scale was adapted for use with this sample (see chapter two for a detailed explanation and appendices D and E). The original groupings of items for the scale were diabetes specific self-efficacy, medical self-efficacy and general situations self-efficacy. They were formed through conceptual and theoretical means rather than statistical methods. Once the alterations had been made to the items for

inclusion in the revised version of the scale it was decided that too many changes had been made to use the original scales.

A principal components analysis was carried out to group the 26 items into suitable factors. A Kaiser-Meyer-Olkin test for sampling adequacy (= 0.867) indicated that the analysis should yield distinct and reliable factors as the value was between 0.8 and 0.9 (Field 2000). Bartlett's test for sphericity was significant ($p < 0.0001$) showing that a principal components analysis was an appropriate test. A correlation matrix of the items and the determinant (< 0.00001) were examined. No items were highly significantly correlated (> 0.8) and therefore all items were retained (Field 2000). An orthogonal and an oblique rotation principal components analysis were conducted to facilitate the interpretation of the data. The oblique rotation showed negligible correlations between the extracted factors which suggested it was acceptable to use the orthogonal rotated solution and assume that the factors were independent (Field 2000). According to recommended methods, the factors were selected on the basis of eigenvalues greater than 1. A scree plot was analysed to support the interpretation of the factors. As a result five principal components were found. The factors are listed below and account for a variance of 64.84%. Although there were a large number of items and a relatively small sample it was decided that as the main factors had four or more loadings of greater than 0.6 it was reliable (Field 2000). In addition to this, contextual information about the items indicated that the factors derived were appropriate and Cronbach's alpha confirmed this. The exceptions to this were factors four and five (as shown below). It was decide to still include these factors in further analyses but to interpret any results involving these factors with caution.

Factor one was called **General diabetes self-efficacy** and contained items:

7) Prevent having hypos.

9) Keep myself free from high blood sugars.

10) Avoid having ketones in my urine.

14) Do activities or exercises which require a lot of energy.

16) Prevent complications from my diabetes.

24) Believe that I have the ability to have control over my diabetes.

25) Follow my doctor's recommendations for taking care of my diabetes.

26) Run my life the same as I would if I didn't have diabetes.

General diabetes self-efficacy had a Cronbach's alpha of 0.873.

Factor two was called **Flexibility diabetes self-efficacy** and contained items:

1) Be in charge of giving my own injections or taking my own tablets

2) Work out my own meals and snacks at home.

3) Work out what foods to eat away from home.

4) Keep track of my blood sugar levels.

5) Change the amount of insulin or increase the amount of food I eat when I

do a lot of exercise.

6) Work out how much insulin I need to give myself or how much I need to eat

if I am ill.

Flexibility diabetes self-efficacy had a Cronbach's alpha of 0.880.

Factor three was called **Assertive diabetes self-efficacy** and contained items:

8) Talk to the doctor about my diabetes and ask for things I need.

12) Ask for help from other people if I feel ill.

15) Argue with my doctor if I feel he/she is not being fair.

18) Get as much attention from others when my diabetes is under control as when it isn't.

22) Regularly wear a medical tag or bracelet which says I have diabetes.

Assertive diabetes self-efficacy had a Cronbach's alpha of 0.769.

Factor four was called **General social self-efficacy** and contained items:

19) Easily talk to a group of people at a social or work event when I don't know them.

20) Make a work colleague, friend or family member see my point of view.

General social self-efficacy had a Cronbach's alpha of 0.597.

Factor five was called **Rebellious behaviour self-efficacy** and contained items:

17) Do things I have been told not to do when I really want to do them.

23) Sneak food not on my diet without getting caught.

Rebellious behaviour had a Cronbach's alpha of 0.421

There were several items which were difficult to place from the principal components analysis. For example, item 11 – 'Feel able to stop a hypo if I have one' was placed under component four ('general social self-efficacy') however it referred to a diabetes specific behaviour rather than general social self-efficacy and did not show a great deal of variance in either factor one or two (general diabetes or flexible diabetes self-efficacy) where logically it could be expected to fit. Item 21 (Show my anger when someone has done something to upset me) and item 13 (Tell friends and colleagues that I have diabetes) were also difficult to place. In the principal components analysis they grouped under the same factor however item 21 is negative and item 13 is positive therefore they were contrasting items rather than co-occurring.

As a result it was decided to analyse these items separately from the factors created.

Item 11 was named **stopping hypo self-efficacy**

Item 13 was named **revealing diabetes self-efficacy**

Item 21 was named **showing anger self-efficacy**

3.2.3 Summary of Diabetes Self Care Activities Questionnaire (SDSCA)

Items in the self-care questionnaire were grouped according to the recommendations of Toobert et al. (2000). Reliability analyses were calculated

to assess whether these groupings were applicable to the participants in this thesis.

The **General Diet** scale (items 1 and 2) had a Cronbach's alpha of 0.949.

The **Specific Diet** scale (items 3, 4 and 5) had a Cronbach's alpha of 0.547.

The **Exercise scale** (items 6 and 7) had a Cronbach's alpha of 0.792.

The **Blood Testing scale** (items 8 and 9) had a Cronbach's alpha of 0.914.

The **Medication scale** was just item 10.

The **Foot Care scale** (items 11, 12, 13, 14 and 15) had a Cronbach's alpha of 0.105. When item 14 ("On how many of the last seven days did you soak your feet?") was excluded the Cronbach's alpha was 0.626. Excluding any of the other items resulted in a lower Cronbach's alpha than when all were included therefore the marking scheme used excluded item 14.

In summary, with the exception of one item, the scoring system developed by Toobert et al. appeared entirely appropriate for this study population.

Smoking was assessed using two questions asking if the participant smoked and if yes then how many cigarettes a day. For the analysis the question used was the number of cigarettes smoked a day.

3.3 Differences for illness representations, self-efficacy and self-care behaviour

3.3.1 Differences between type 1 and type 2 diabetes and gender

It was hypothesised that due to the different characteristics and experiences of type 1 and type 2 diabetes the illness representations and levels of self-efficacy and self-care behaviour would differ between these two groups. This was investigated using Mann-Whitney U tests due to the non-parametric nature of the data. For the overall sample including men and women significant differences were found between type of diabetes for illness coherence, personal responsibility causes, flexible diabetes self-efficacy and blood testing behaviour. There were no significant differences between participants with type 1, tablet treated type 2 and insulin treated type 2 diabetes for any other illness representation sub-scales, including emotional representations, self-efficacy and self-care behaviours.

Table 3 - Differences between type 1, tablet treated type 2 and insulin treated type 2 diabetes for the overall sample.

Type of Diabetes	Type 1 (n = 44)	Tablet treated type 2 (n = 19)	Insulin treated type 2 (n = 38)
Illness coherence (higher score = greater illness coherence)	21.39 (4.16)*a	18.78 (4.12)	18.86 (4.85)
Personal responsibility causes (higher score = feeling more personally responsible for cause of diabetes)	13.66 (5.73)**b	21.12 (5.17)	18.21 (5.99)
Flexible diabetes self-efficacy (higher score = more self-efficacy about caring for diabetes in flexible way.)	40.43 (2.71)**c	35.69 (6.15)	38.17 (5.35)*d
Blood testing behaviour (Higher score = more frequent regular blood tests performed)	5.74 (2.41)**e	3.29 (2.12)	5.82 (2.06)**f

*a = p < 0.05 compared with participants with tablet treated and insulin treated type 2 diabetes.

**b = p < 0.005 compared with participants with tablet treated and insulin treated type 2 diabetes.

**c = p < 0.005 compared with participants with tablet treated type 2 diabetes.

*d = p < 0.05 compared with participants with type 1 diabetes.

**e = p < 0.005 compared with tablet treated type 2 diabetes.

**f = p < 0.005 compared with tablet treated type 2 diabetes.

Participants with type 1 diabetes reported significantly greater illness coherence than participants with tablet treated or insulin treated type 2 diabetes. They also reported significantly less attribution to personal responsibility causes than those with type 2 diabetes (tablet or insulin treated). Additionally, participants with type 1 diabetes showed significantly greater flexible diabetes self-efficacy

than either participants with tablet treated or insulin treated diabetes. Both participants with type 1 diabetes and those with insulin treated type 2 diabetes reported significantly more performance of blood testing behaviour than participants with tablet treated type 2 diabetes.

Significant differences for illness representations, self-efficacy and self-care behaviour between participants with type 1 and type 2 diabetes were found; however, the significant differences for age and duration of diabetes between participants with type 1 and type 2 diabetes may have influenced these differences. Due to the small sample sizes it was not possible to investigate this further.

In previous research studies it has been suggested that men and women show different patterns of illness representations and self-care behaviours (Hampson et al. 1995; Eiser et al. 2001). Therefore, the illness representations, self-efficacy and self-care behaviours for men and women were compared. There was only one significant difference between men and women which was for the timeline cyclical illness representation.

Table 4 - Differences between men and women.

Gender	Women (n = 50)	Men (n = 51)
Timeline cyclical (higher score = more cyclical illness pattern.)	12.12 (3.57)*a	10.86 (3.03)

*a = p < 0.05

Women were significantly more likely to report a cyclical illness pattern than men. There were no other significant differences for men and women.

Following the lack of significant differences for illness representations, self-efficacy and self-care behaviour between men and women it was hypothesised that there may be an interaction between gender and type of diabetes. As a consequence, it was decided to look at the men and women separately in terms of type of diabetes. Significant differences were found for men between type of diabetes for illness coherence, personal responsibility causes, chance causes and blood testing behaviour (see table 5). For the women significant differences were found between type of diabetes for personal responsibility causes and stopping hypos self-efficacy (see table 6). In the separate gender analyses, there were no significant differences between participants with type 1, tablet treated type 2 and insulin treated type 2 diabetes for any other illness representation sub-scales, including emotional representations, self-efficacy and self-care behaviours.

Table 5 - Differences between type 1, tablet treated type 2 and insulin treated type 2 diabetes for men.

Type of diabetes	Type 1 (n = 22)	Tablet treated type 2 (n = 13)	Insulin treated type 2 (n = 16)
Illness coherence (higher score = greater illness coherence)	22.41 (3.24)*a	18.83 (4.82)	18.00 (5.13)
Personal responsibility causes (higher score = feeling more personally responsible for cause of diabetes)	13.39 (5.01)**b	20.73 (4.73)	19.42 (5.40)
Chance causes (higher score = more likely chance was cause of diabetes)	3.11 (1.45)*c	2.54 (1.04)	1.77 (1.24)
Blood testing behaviour (Higher score = more frequent regular blood tests performed)	5.75 (2.33)	3.32 (2.00)*d	5.72 (2.00)

*a = p < 0.05 compared with men with insulin treated type 2 diabetes.

**b = p < 0.005 compared with men with tablet treated and insulin treated type 2 diabetes.

*c = p < 0.05 compared with men with insulin treated type 2 diabetes.

*d = p < 0.05 compared with men with type 1 and insulin treated type 2 diabetes.

As table 5 shows, men with type 1 diabetes had significantly more illness coherence and attributed chance causes of their diabetes significantly more than men with insulin treated type 2 diabetes. (However the differences may be

due to a significant difference in duration of diabetes - this could not be analysed due to the small sample sizes). Both men with tablet treated type 2 diabetes and men with insulin treated type 2 diabetes perceived their diabetes to be caused by things they could take personal responsibility for to a significantly greater extent than the men with type 1 diabetes. Men with type 1 diabetes and men with insulin treated type 2 diabetes reported significantly higher levels of blood testing behaviour than men with tablet treated type 2 diabetes.

Table 6 - Differences between type 1, tablet treated type 2 and insulin treated type 2 diabetes for women.

Type of diabetes	Type 1 (n = 22)	Tablet treated type 2 (n = 6)	Insulin treated type 2 (n = 22)
Personal responsibility causes (higher score = feeling more personally responsible for cause of diabetes)	13.9 (6.44)*a	21.83 (6.31)	17.50 (6.35)
Stopping hypos self-efficacy (higher score = more confident about stopping hypos)	6.36 (1.49)	4.67 (1.75)*b	6.55 (0.80)

*a = p < 0.05 compared with women with tablet treated type 2 diabetes.

*b = p < 0.05 compared with women with type 1 and insulin treated type 2 diabetes.

Women with tablet treated type 2 diabetes perceived their diabetes to be caused by things they could take personal responsibility for to a significantly

greater extent than women with type 1 diabetes. Women with type 1 diabetes and insulin treated type 2 diabetes had significantly more self-efficacy about stopping hypos once they have started than women with tablet treated type 2 diabetes.

3.3.2 Differences for marital status

Differences between illness representations, self-efficacy and self-care behaviour for different marital status were investigated. The only significant difference found between marital status for the overall sample was for identity (ie physical symptoms identified as caused by diabetes).

Table 7 - Differences for marital status for the overall sample.

Marital status	Single (n = 13)	Married/living together (n = 73)	Separated/divorced (n = 15)
Identity (higher score = more physical symptoms identified as caused by diabetes)	2.77 (3.08)	2.16 (5.51)*a	4.00 (2.54)

*a = p < 0.05 compared with participants who were separated or divorced.

Participants who were separated or divorced reported significantly more symptoms as being caused by their diabetes than participants who were married or living together. Additionally, although it did not quite reach significance level (p = 0.052) there was a marked difference between the number of symptoms reported for participants who were single (and reported

fewer) and those who were separated or divorced (and reported more symptoms).

The literature suggests that social support (and therefore marital status) has a different impact on men and women and how they look after themselves (Kaplan and Hartwell, 1987). Therefore the data was analysed, specifically to look for any differences in illness representations, self-efficacy and self-care behaviour for participants with different marital status and in men and women.

For men there were significant differences between marital status for identity only.

Table 8 - Differences for marital status for men.

Marital status	Single (n = 5)	Married/living together (n = 37)	Separated/divorced (n = 9)
Identity (higher score = more physical symptoms identified as caused by diabetes)	3.20 (2.17)	1.97 (2.29)*a	4.22 (2.43)

*a = p < 0.05 compared with men who were separated or divorced.

Men who were divorced or separated identified significantly more symptoms as being caused by their diabetes than the men who were married or living together.

For women, there were significant differences between marital status for personal responsibility causes, curing diabetes and specific diet self-care behaviour.

Table 9 - Differences for marital status for women.

Marital status	Single (n = 8)	Married/living together (n = 36)	Separated/divorced (n = 6)
Personal responsibility causes (higher scores = feeling more personally responsible for cause of diabetes)	20.38 (6.12)	16.48 (6.79)	10.40 (2.88)**a
Curing diabetes (higher score = more likely to think diabetes is curable)	2.38 (1.06)*b	1.17 (0.89)	1.17 (0.41)
Specific diet (higher score = perform more specific diet behaviour such as carbohydrate spread out through the day)	3.29 (1.81)*c	5.07 (1.60)	5.00 (0.98)

**a = $p < 0.005$ compared to women who are single or are married/living together.

*b = $p < 0.05$ compared to women who are married/living together or separated/divorced.

*c = $p < 0.05$ compared to women who are married/living together.

Women who were single and women who were married or living with a partner attributed personal responsibility causes to their diabetes significantly more

than the women who were separated or divorced. Women who were single were significantly more likely to indicate that they thought diabetes was curable than women who were married/living together or divorced/separated. Women who were married performed significantly more specific diet behaviours than the female participants who were single.

3.3.3 Differences for levels of education

Differences between illness representations, self-efficacy and self-care behaviour for participants with different education levels were investigated. Education was divided into two groups – lower education (O-levels or below) and higher education (A-levels or higher qualifications). Initially, the data was analysed using the whole sample followed by analysis of men and women separately due to the differences found between men and women in other demographic characteristics such as marital status and type of diabetes.

Table 10 - Differences for high and low education levels for the overall sample.

Education level	Lower (O-levels or below) (n = 68)	Higher (A-levels and above) (n = 19)
Identity (higher score = more physical symptoms identified as caused by diabetes)	2.82 (2.78)*a	1.37 (1.92)
External Causes (higher score = greater belief that external factors caused diabetes (eg. pollution, environment).	3.75 (1.59)*a	4.92 (1.26)
Showing anger self-efficacy (higher score = more self-efficacy about showing anger to other people.)	6.01 (1.16)*a	5.58 (1.07)
General social self-efficacy (higher score = more self-efficacy about general social situations)	11.41 (2.25)*a	12.58 (1.50)

a* = p < 0.05 compared to participants with a high education level.

Participants with a low education level reported significantly more symptoms as being due to their diabetes, were significantly less likely to attribute their diabetes to external causes, felt significantly more able to show anger to others and reported significantly less self-efficacy in general social situations than participants with a high level of education.

For women, there were significant differences between participants with higher and lower levels of education for external causes, altered immunity causes and general social self-efficacy and for men there were significant differences

between participants with higher and lower education level for identity, mental state causes and general diet behaviour.

Table 11 - Differences for lower and higher educational status for women.

Education Level	Lower (O-levels or below) (n = 40)	Higher (A-levels or above) (n = 6)
External causes (Higher score = more likely to think diabetes caused by external causes such as pollution)	3.8*a (1.64)	5.8 (1.30)
Altered immunity causes (higher score = more likely to think diabetes caused by auto-immune response)	2.24*b (1.26)	3.6 (1.14)
General social self-efficacy (higher score = more confident in social situations)	11.13*c (2.48)	13.5 (0.84)

*a = p < 0.05 compared with women with a higher levels of education.

*b = p < 0.05 compared with women with a higher level of education.

*c = p < 0.05 compared with women with a higher level of education.

Women who had a higher level of education attributed their diabetes significantly more to external factors (such as a germ or virus or pollution) than the women who had lower levels of education. Women who had a higher level of education also attributed their diabetes significantly more to altered immunity causes than women who had lower levels of education. Finally women who had a higher education level had significantly more social self-efficacy than women with a lower education level. There were no significant differences for men for external factors causes, altered immunity causes or general social self-efficacy.

Table 12 - Differences for lower and higher educational status for men.

Education Level	Lower (O-levels or below) (n = 28)	Higher (A-levels or above) (n = 13)
Identity (higher score = more physical symptoms identified as caused by diabetes)	3.11**a (2.53)	0.85 (1.14)
Mental state causes (higher score = more likely to think own mental state caused diabetes)	8.12*b (3.59)	11.13 (2.05)
General diet behaviour (higher score = perform more general diet behaviours such as low fat, high fibre diet)	5.27*c (1.62)	3.77 (2.41)

**a = $p < 0.005$ compared with men with higher levels of education.

*b = $p < 0.05$ compared with men with higher levels of education.

*c = $p < 0.05$ compared with men with higher levels of education.

Men who had a higher level of education attributed fewer physical symptoms to their diabetes than men with a lower level of education. Men who were educated to a higher level also attributed the causes of their diabetes significantly more to mental states than those who were educated to a lower level. Men who were in the higher education category performed less general diet behaviours than those who were in the lower education category. There were no significant differences for women of different education levels for identity, mental states causes or performance of general diet behaviours.

3.3.4 Differences for levels of HbA1c

As discussed earlier in this chapter, there were no significant differences found between HbA1c levels for type of diabetes, gender or any other demographic characteristics. The distributions of the HbA1c results are shown in figure 14 below. These graphs show that for participants with type 2 diabetes HbA1c results fall into 2 distinct groups. The two groups had significantly different HbA1c levels ($\overline{X}$ 7.67 $\pm$ 1.05% vs $\overline{X}$ 11.16 $\pm$ 0.52%, p = 0.000). Differences between these 2 groups were investigated; however due to the very small numbers in some of the groups, the results should be interpreted with caution.

In the sub-sample of participants with insulin treated type 2 diabetes, those with higher HbA1c levels (n = 7) had significantly higher rebellious self-efficacy compared to those with lower HbA1c levels (n = 27) ($\overline{X}$ 12.6 $\pm$ 1.3 vs $\overline{X}$ 9.3 $\pm$ 2.6 respectively, p = 0.003). In the same sub-group, those with higher HbA1c levels had significantly lower levels of general diet behaviour compared to the participants with lower HbA1c levels ($\overline{X}$ 3.8 $\pm$ 1.2 vs $\overline{X}$ 5.4 $\pm$ 1.5, respectively, p = 0.013).

The cause of diabetes was significantly attributed more to chance by participants with tablet treated type 2 diabetes and who had lower HbA1c results (n = 14) than the participants with tablet treated type 2 diabetes and higher HbA1cs (n = 3) ($\overline{X}$ 2.4 $\pm$ 1.0 vs $\overline{X}$ 1.0 $\pm$ 0.0, p = 0.020).

Figure 14 - HbA1c results for participants with type 1, tablet treated type 2 and insulin treated type 2 diabetes.
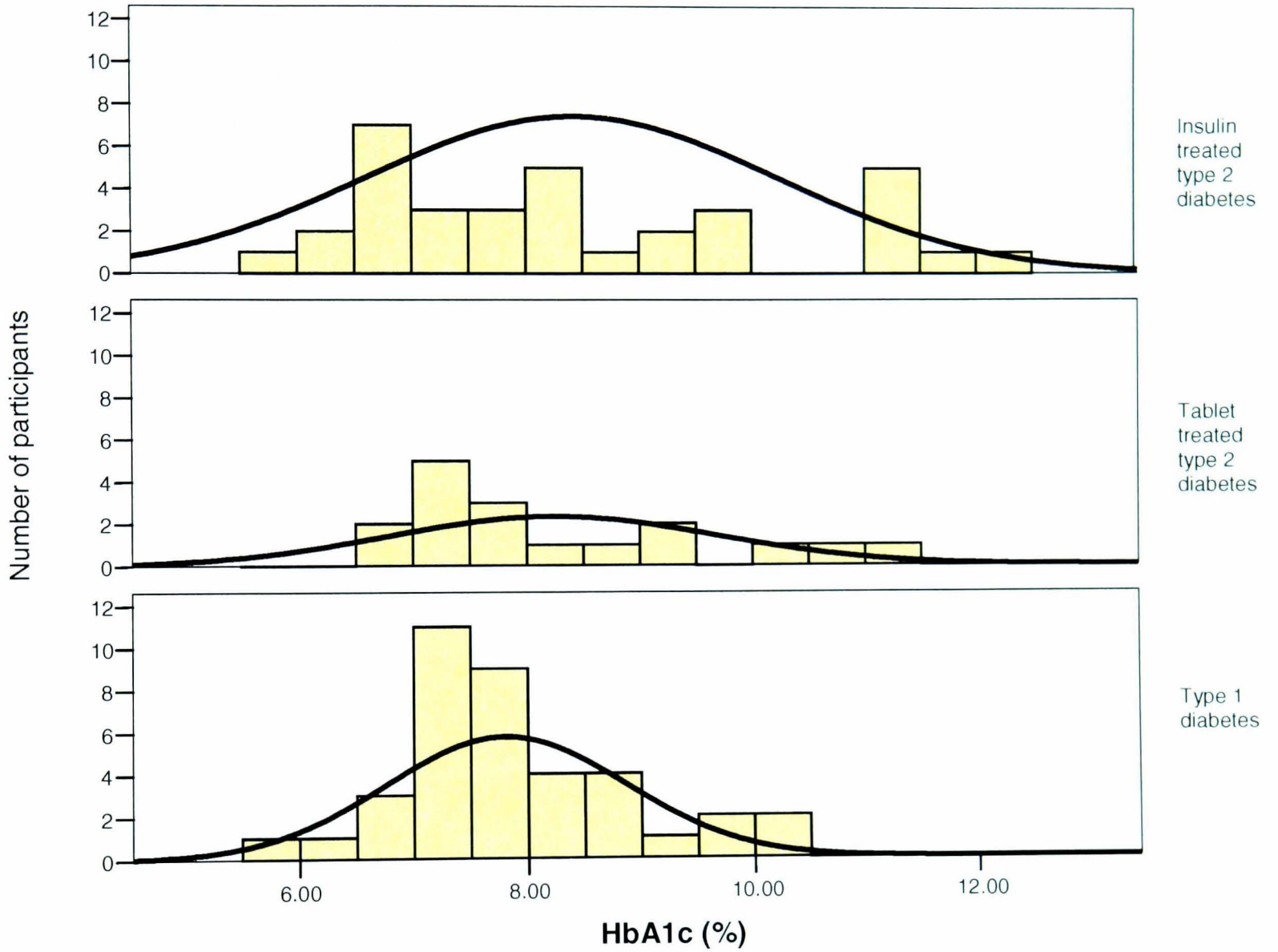
3.4 Relationships between the variables

Correlation analysis was performed in order to explore the relationships between self-care behaviour, self-efficacy, illness representations, HbA1c levels and demographic characteristics. Previous research has shown that there may be little correlation between the performance of different self-care behaviours by the same individual (Kelleher 1988; Orme and Binik 1989; Glasgow and Eakin 1998), so it was decided to consider each self-care behaviour separately:

1. Diet behaviour – general and specific

2. Blood testing behaviour

3. Medication taking behaviour

4. Exercise

5. Foot care

6. Smoking behaviour

7. HbA1c

The theoretical model used as a framework for this research was Leventhal's Commonsense Model for the Self-Regulation of Health and Illness (CSM) (Cameron et al. 2003). The CSM suggests that illness representations influence the choice of action plans (for example, the performance of self-care behaviours) and that self-efficacy moderates this relationship. Therefore, the relationships between illness representations and self-care behaviour were investigated and the position and importance of self-efficacy for moderating the relationship between the illness representations and self-care behaviours within the theoretical model was considered and investigated where appropriate. Correlations were conducted using Kendall's tau due to the data being non-

parametric. It was hypothesised that the relationship between illness experiences and illness representations may differ according to type of diabetes so correlations were performed for participants with type 1, tablet treated type 2 and insulin treated type 2 diabetes separately. A summary of the significant correlations can be found in appendix J.

3.4.1 Diet Behaviour – general and specific

The performance of diet behaviour is vital to people with diabetes both for overall health and in the metabolic control of diabetes; however, research suggests up to 75% of the population with diabetes do not perform dietary related self-care behaviours (Surwit et al. 1982). Various aspects of dietary care were measured. General diet behaviour included the type of food being eaten (such as low sugar, low fat, high fibre, five fruit and vegetables a day) and specific diet behaviour identified specific dietary care behaviours for diabetes (such as spacing carbohydrate out throughout the day). General and specific diet behaviour correlated highly with each other for participants with type 1, tablet treated and insulin treated type 2 diabetes. However, it was decided to analyse general and specific diet behaviour separately as different variables were found to correlate with each of them.

Table 13 - Type 1 diabetes and general diet behaviour (n = 44)

	Correlation with general diet behaviour (r)	Significance level
Duration	0.230	< 0.05
Emotional representations	-0.304	<0.05
General diabetes self-efficacy	0.239	<0.05
Specific diet behaviour	0.434	<0.005
Medication taking behaviour	0.347	<0.005

The participants with type 1 diabetes who scored higher on the **general diet** scale (and therefore performed more general dietary self-care behaviour) had a longer duration of diabetes, reported lower negative emotional representations, higher general diabetes self-efficacy, higher specific diet behaviour and higher medication taking scores.

For participants with type 1 diabetes significant correlations were observed between general diet behaviour and emotional representations (see table 13), and between emotional representations and general diabetes self-efficacy ($r = -0.425$, $p < 0.005$). This indicates that participants with type 1 diabetes who performed more general diet behaviour had more general diabetes self-efficacy and less negative emotional representations. According to the Commonsense Model of Self-Regulation and Social Cognitive Theory, self-efficacy may have an affect on the relationship between illness representations and self-care behaviour. This was investigated for participants with type 1 diabetes, by

dividing general diabetes self-efficacy into two categories – high and low self-efficacy and analyzing the correlations between general diet behaviour and emotional representations for each category. The dividing point between high and low general diabetes self-efficacy was the mean score on this variable (47), which was also the median and the 50th percentile.

Results showed that in the low general diabetes self-efficacy category (n = 29) the correlation between emotional representations and general diet behaviour was significant (r = - 0.577, p = 0.008); however for the high general diabetes self-efficacy category (n = 14) there was no correlation. This suggests that general diabetes self-efficacy may moderate the relationship between emotional representations and general diet behaviour.

Of the participants with type 1 diabetes only those with lower general diabetes self-efficacy showed high negative emotional representations if they had low general diet behaviour. For those participants with higher general diabetes self-efficacy, there was no relationship between general diet behaviour and negative emotional representations; therefore the relationship between general diet behaviour and negative emotional representations was dependent on the presence of low general diabetes self-efficacy.

According to Social Cognitive Theory, affective state can have an impact on self-efficacy regarding a particular behaviour, such as general diet behaviour (Maddux, 1995). The possibility of emotional representations (as an indicator of affective state) affecting the relationship between general diet behaviour and general diabetes self-efficacy was investigated using the method described above but no differences were found between high and low emotional representation categories. This suggests that emotional representations, or

rather the level of negative emotional representations, did not moderate the relationship between general diabetes self-efficacy and general diet behaviour.

Table 14 - Type 1 diabetes and specific diet behaviour (n = 44)

	Correlation with specific diet behaviour (r)	Significance level
Education	0.254	<0.05
Consequences of diabetes	-0.251	<0.05
General diabetes self-efficacy	0.314	<0.05
Flexible diabetes self-efficacy	0.319	<0.005
General diet behaviour	0.434	<0.005
Foot care behaviour	0.288	<0.05

The participants with type 1 diabetes who scored higher on the **specific diet** scale had a higher education level, reported fewer consequences to their diabetes, higher general diabetes self-efficacy, higher flexible diabetes self-efficacy, higher levels of general diet behaviour and higher levels of foot care. There were no significant correlations with any of the other factors including emotional representations.

Given the relationship between higher specific diet behaviour and higher general diabetes self-efficacy (see table 14) and between general diabetes self-efficacy and lower consequences of their diabetes (r = -0.548, p < 0.005), this was further analysed as described earlier by looking at high and low self-

efficacy separately. There were no significant correlations between consequences and specific diet behaviour, in either low or high general diabetes self-efficacy groups suggesting that general self-efficacy did not moderate the relationship between specific diet behaviour and participants' beliefs about the consequences of diabetes.

For those with type 1 diabetes significant correlations were also found between specific diet behaviour, flexible diabetes self-efficacy and consequences of diabetes (see table 14 for correlations with specific diet behaviour – for flexible diabetes self-efficacy and consequences of diabetes r = -0.324, p < 0.05). For those with low flexible diabetes self-efficacy there was no correlation between specific diet behaviour and consequences of diabetes; whereas for participants with high flexible diabetes self-efficacy there was a significant (although low) correlation between specific diet behaviour and consequences (r = - 0.252, p = 0.049). This suggests that the participants with type 1 diabetes who performed more specific diet behaviours only reported lower levels of consequences when they had high flexible diabetes self-efficacy. For those participants with low flexible diabetes self-efficacy there was no correlation between consequences and specific diet behaviour. This may be because the consequences scale includes items about how diabetes affects the participant and the people around them. This could be interpreted in terms of how performing high levels of certain self-care behaviours such as specific diet behaviour impacts on their lives. Flexible diabetes self-efficacy in essence concerns how adaptable the participant feels their diabetes regime is. The significantly lower levels of consequences for those participants who feel they have flexibility in their diabetes regime and yet are able to eat a specific diet may reflect this. Those individuals with lower flexible self-efficacy, who therefore did not feel their

diabetes regime was flexible, demonstrated no such relationship between consequences and high specific diet behaviour.

Table 15 - Tablet treated type 2 diabetes and general diet behaviour (n = 19)

	Correlation with general diet behaviour (r)	Significance level
General diabetes self-efficacy	0.477	<0.005
Specific diet behaviour	0.643	<0.005
Exercise behaviour	0.729	<0.005
Foot care behaviour	0.362	<0.05

The participants with tablet treated type 2 diabetes who reported higher **general diet behaviour** had higher general diabetes self-efficacy, higher specific diet behaviour, higher levels of exercise and higher levels of foot care behaviour.

In contrast to the participants with type 1 diabetes there were no significant correlations with emotional representations, duration or medication taking.

Table 16 - Tablet treated type 2 diabetes and specific diet behaviour

(n = 19)

	Correlations with specific diet behaviour (r)	Significance level
General diabetes self-efficacy	0.603	<0.005
General social self-efficacy	0.474	<0.05
Rebellious self-efficacy	-0.475	<0.05
General diet behaviour	0.643	<0.005
Blood testing behaviour	0.434	<0.05
Exercise behaviour	0.400	<0.05
Foot care behaviour	0.404	<0.05

The participants with tablet treated type 2 diabetes who scored higher for **specific diet** behaviour showed higher general diabetes self-efficacy, higher general social self-efficacy, lower rebellious self-efficacy, higher general diet, higher levels of exercise, more blood testing behaviour and higher levels of foot care.

There were no significant correlations for any of the other factors including emotional representations. In particular, unlike the participants with type 1 diabetes, there were no significant correlations with flexible diabetes self-efficacy or level of education.

Table 17 - Insulin treated type 2 diabetes and general diet behaviour

(n = 38)

	Correlations with general diet behaviour (r)	Significance level
Chance causes	0.296	<0.05
Flexible diabetes self-efficacy	0.355	<0.05
Specific diet behaviour	0.624	<0.005
Blood testing behaviour	0.345	<0.05
Exercise behaviour	0.274	<0.05

The participants with insulin treated type 2 diabetes who had higher scores on the **general diet** scale showed higher chance causes, higher flexible diabetes self-efficacy, higher specific diet behaviour, higher levels of exercise and more blood testing behaviour.

In contrast to the participants with type 1 diabetes there were no significant correlations between general diabetes self-efficacy, emotional representations or duration of diabetes.

Table 18 - Insulin treated type 2 diabetes and specific diet behaviour

(n = 38)

	Correlations with specific diet behaviour (r)	Significance level
General diet behaviour	0.624	<0.005
Blood testing behaviour	0.500	<0.005
Exercise behaviour	0.326	<0.05
Foot care behaviour	0.254	<0.05

The participants with insulin treated type 2 diabetes who reported more **specific diet** behaviour reported higher general diet behaviour, higher levels of exercise, did more blood testing and had higher levels of foot care.

There were no significant correlations with the other variables, including emotional representations. In particular, in contrast to the participants with type 1 diabetes, no significant correlations were found with general diabetes self-efficacy, flexible diabetes self-efficacy, consequences or level of education. Similarly no significant correlations were found for general social self-efficacy or rebellious self-efficacy unlike the participants with tablet treated type 2 diabetes.

3.4.2 Blood Testing Behaviour

The performance of blood testing behaviour is essential for monitoring glycaemic control of diabetes and, where necessary, for calculating adjustments to the diabetes regime. The aspects of blood testing measured in the questionnaire consisted of how frequently blood testing was performed and if this followed recommendations from health care professionals.

Table 19 - Type 1 diabetes and blood testing behaviour (n = 44)

	Correlations with blood testing behaviour (r)	Significance level
Identity	-0.456	<0.005
Emotional representations	-0.317	<0.05
Personal responsibility causes	0.314	<0.05
HbA1c level	-0.401	<0.005

The participants with type 1 diabetes who had higher levels of **blood testing behaviour** had lower HbA1c results, reported lower identity scores, lower negative emotional representations and higher personal responsibility causes scores. No significant correlations were found with self-efficacy beliefs.

Table 20 - Tablet treated type 2 diabetes and blood testing behaviour (n = 19)

	Correlations with blood testing behaviour (r)	Significance level
Illness coherence	0.398	<0.05
Specific diet behaviour	0.434	<0.05
Medication taking behaviour	0.419	<0.05

The participants with tablet treated type 2 diabetes who had higher levels of **blood testing behaviour** reported higher illness coherence, higher levels of specific diet behaviour and higher levels of medication taking.

There were, however, no significant correlations with identity, emotional representations, personal responsibility causes or HbA1c results as found for the participants with type 1 diabetes. Similar to the participants with type 1 diabetes, there were no significant correlations with self-efficacy beliefs.

Table 21 - Insulin treated type 2 diabetes and blood testing behaviour (n = 38)

	Correlations with blood testing behaviour (r)	Significance level
Age	0.266	<0.05
General diet behaviour	0.345	<0.05
Specific diet behaviour	0.500	<0.005
Exercise behaviour	0.317	<0.05

The participants with insulin treated type 2 diabetes who had higher levels of **blood testing behaviour** were older, reported higher levels of general diet behaviour, specific diet and exercise.

In contrast to the participants with type 1 diabetes no significant correlations were found for identity, emotional representations, personal responsibility causes or HbA1c results. There was also no significant correlation with illness coherence, in contrast to the significant correlation between illness coherence and blood testing behaviour found for participants with tablet treated type 2 diabetes. As with participants with type 1 and tablet treated type 2 diabetes there were no significant correlations with self-efficacy beliefs in this group.

3.4.3 Medication taking behaviour

The performance of medication taking behaviours is a key aspect of self-care for people with diabetes. Tablets or insulin are required on a daily basis to maintain glycaemic control. It is generally recognised as the most regularly performed self-care behaviour (Kelleher 1988); however, it has been shown that 13-31% of prescribed medication is not ordered from the pharmacy and therefore not taken as prescribed (Mason et al. 1995; Morris et al. 1997; Paes et al. 1997; Brennan 2000; Donnan et al. 2002; Rubin 2005) which suggests that performance of medication taking behaviour does vary. For this study medication taking behaviour was measured by asking how many times out of the last seven days the participant had taken their recommended medication.

Table 22 - Type 1 diabetes and medication taking behaviour (n = 44)

	Correlations with medication taking behaviour (r)	Significance level
Emotional representations	-0.280	<0.05
General diabetes self-efficacy	0.333	<0.05
General diet behaviour	0.347	<0.05

The participants who had type 1 diabetes and higher levels of **medication taking behaviour** reported lower negative emotional representations, higher general diabetes self-efficacy and higher general diet behaviour.

Significant correlations were observed between medication taking behaviour, general diabetes self-efficacy and negative emotional representations (see table 22 for correlations with medication taking behaviour – for general diabetes self-efficacy and negative emotional representations $r = -0.425$, $p < 0.005$). In order to examine whether general diabetes self-efficacy moderated the relationship between medication taking behaviour and emotional representations, further analyses were carried out by dividing general diabetes self-efficacy into high and low self-efficacy as described earlier. Similar correlations were found for high and low self-efficacy groups between medication taking behaviour and emotional representations, suggesting that general diabetes self-efficacy did not moderate the relationship between medication taking behaviour and emotional representations.

The impact of emotional representations on the relationship between medication taking behaviour and general diabetes self-efficacy was also analysed. This was analysed using the technique described earlier by investigating those with high and low emotional representations. Similar correlations were found for the high and low emotional representations groups, demonstrating that the relationship between medication taking behaviour and general diabetes self-efficacy was not moderated by emotional representations in this group.

Table 23 - Tablet treated type 2 diabetes and medication taking behaviour (n = 19)

	Correlations with medication taking behaviour (r)	Significance level
Blood testing behaviour	0.419	<0.05

The participants who had tablet treated type 2 diabetes and higher levels of **medication taking behaviour** also reported higher blood testing behaviour.

No significant correlations were found between medication taking and emotional representations or general diabetes self-efficacy unlike the participants with type 1 diabetes.

Insulin treated type 2 diabetes and medication taking behaviour (n = 38)

There were no significant correlations for **medication taking,** including no significant correlations with emotional representations, general diabetes self-efficacy or blood testing behaviour as found with participants with type 1 diabetes and tablet treated type 2 diabetes respectively.

3.4.4 Exercise

Exercise is an integral part of looking after diabetes and is needed to maintain general health and improve responses to medication such as tablets and insulin. Exercise was measured with two questions about general levels of activity and more specific sessions of exercise (see appendix C).

Type 1 diabetes and exercise behaviour (n = 44)

There were no significant correlations associated with **exercise.**

Table 24 - Tablet treated type 2 diabetes and exercise behaviour (n = 19)

	Correlations with exercise behaviour (r)	Significance level
General diet behaviour	0.729	<0.005
Specific diet behaviour	0.400	<0.05
Foot care behaviour	0.390	<0.05

The participants who had tablet treated type 2 diabetes and higher levels of **exercise** reported higher levels of general diet behaviour, specific diet and foot care.

Table 25 - Insulin treated type 2 diabetes and exercise behaviour (n = 38)

	Correlations with exercise behaviour (r)	Significance level
Age	0.256	<0.05
Emotional representations	-0.273	<0.05
Altered immunity causes	0.289	<0.05
General diabetes self-efficacy	0.358	<0.005
Stopping hypos self-efficacy	0.266	<0.05
General diet behaviour	0.274	<0.05
Specific diet behaviour	0.326	<0.05
Blood testing behaviour	0.317	<0.05
Foot care behaviour	0.278	<0.05

The participants with insulin treated type 2 diabetes and higher levels of exercise were older, reported lower negative emotional representations, higher altered immunity causes scores, higher general diabetes self-efficacy, higher self-efficacy for stopping hypos, higher general diet, higher specific diet, higher levels of blood testing and foot care.

There were correlations between exercise, general diabetes self-efficacy and emotional representations (see table 25 for correlations with exercise behaviour – for general diabetes self-efficacy and emotional representations $r = -0.390$, p

< 0.005) and also between exercise, hypo stopping self-efficacy and emotional representations (for hypo stopping self-efficacy and emotional representations r = -0.370, p < 0.05). These correlations were investigated in the manner described earlier and similar correlations were found between exercise and emotional representations for high and low self-efficacy categories, suggesting neither general diabetes self-efficacy nor hypo stopping self-efficacy had moderated the relationship between exercise behaviour and emotional representations.

The possibility of emotional representations moderating the relationship between general diabetes self-efficacy and exercise and stopping hypos self-efficacy and exercise was also analysed. No moderation was found.

The large number of variables which correlated significantly with exercise behaviour for participants with insulin treated type 2 diabetes contrasts markedly with the distinct lack of significant correlations between variables for participants with type 1 and tablet treated type 2 diabetes. There may be a number of explanations for this other than differences in illness beliefs, self-efficacy and exercise for those with type 1, tablet treated type 2 and insulin treated type 2 diabetes. These may include methodological issues such as small sample sizes and the questionnaires used. These issues are discussed in further detail in chapter six (p. 392).

3.4.5 Foot Care

The performance of foot care behaviours, such as checking feet on a daily basis and ensuring they are clean and dry, are important for two reasons. Firstly, people with diabetes need to take good care of their feet due to the symptoms of neuropathy such as loss of sensitivity and reduced sweating which means feet are more likely to become dry and cracked. The risk of neuropathy and loss of feeling also means that by providing daily foot care any injuries or foot problems which have not been noticed due to neuropathy can be found and treated at an early stage. Foot care was measured with five questions about checking, washing and drying feet and checking shoes (see appendix C).

Table 26 - Type 1 diabetes and foot care behaviour (n = 44)

	Correlations with foot care behaviour (r)	Significance level
Duration	0.264	<0.05
Altered immunity causes	-0.284	<0.05
External causes	-0.280	<0.05
Specific diet behaviour	0.288	<0.05

The participants with type 1 diabetes and higher levels of **foot care behaviour** had had diabetes for longer, reported lower altered immunity causes, lower external causes and had higher specific diet behaviour.

Table 27 - Tablet treated type 2 diabetes and foot care behaviour (n = 19)

	Correlations with foot care behaviour (r)	Significance level
Age	0.529	<0.005
Altered immunity causes	0.476	<0.05
General diet behaviour	0.362	<0.05
Specific diet behaviour	0.404	<0.05

The participants with tablet treated type 2 diabetes and higher levels of **foot care behaviour** were older, reported higher altered immunity causes, higher general diet behaviour and higher specific diet behaviour.

There were no significant correlations between foot care and external causes, duration of diabetes or employment status as had been observed for the participants with type 1 diabetes.

Table 28 - Insulin treated type 2 diabetes and foot care behaviour (n = 38)

	Correlations with foot care behaviour (r)	Significance level
Specific diet behaviour	0.254	<0.05
Exercise behaviour	0.278	<0.05

The participants with insulin treated type 2 diabetes and higher levels of foot care behaviour reported higher specific diet behaviours and higher levels of exercise.

This contrasts with the correlations for participants with type 1 and tablet treated type 2 diabetes in that there were no significant correlations between foot care and altered immunity causes, external causes, age, employment status or duration of diabetes.

3.4.6 Smoking

Smoking behaviour was measured by asking if the participant smoked with a dichotomous yes or no answer. In addition, the participants who reported that they smoked were asked to indicate how many cigarettes they smoked a day. The number of cigarettes smoked per day were used in the correlation analysis.

Type 1 diabetes and smoking behaviour (n = 44)

There were no correlations between number of cigarettes smoked and illness representations, self-efficacy or other self-care behaviours for participants with type 1 diabetes.

Table 29 – Tablet treated type 2 diabetes and smoking behaviour (n = 19)

	Correlation with smoking behaviour (r)	Significance level
Personal responsibility causes	0.410	<0.05
General social self-efficacy	-0.544	<0.05

The participants with tablet treated type 2 diabetes who smoked more reported higher beliefs that they were personally responsible for their diabetes and lower levels of general social self-efficacy.

Table 30 – Insulin treated type 2 diabetes and smoking behaviour (n = 38)

	Correlations with smoking behaviour (r)	Significance level
Altered immunity causes	-0.310	<0.05
Blood testing behaviour	-0.355	<0.05

The participants with insulin treated type 2 diabetes who smoked more reported lower levels of altered immunity causal beliefs and lower levels of blood testing behaviour.

3.4.7 HbA1c levels

Table 31 - Type 1 diabetes and HbA1c level (n = 44)

	Correlations with HbA1c level (r)	Significance level
Emotional representations	0.292	<0.05
Chance causes	-0.277	<0.05
Accident or illness causes	0.266	<0.05
General diabetes self-efficacy	0.264	<0.05
Blood testing behaviour	-0.401	<0.005

The participants with type 1 diabetes who had higher **HbA1c levels** (and therefore poorer glycaemic control) had higher scores for negative emotional representations, lower scores of chance causes, higher accident and illness causes, lower general diabetes self-efficacy and lower blood testing behaviour.

Whether or not general diabetes self-efficacy moderated the relationship between HbA1c and emotional representations was examined in those with high and low self-efficacy. Similar correlations between HbA1c and emotional representations for the high and low general diabetes self-efficacy groups were found suggesting that general diabetes self-efficacy did not moderate the relationship between HbA1c and emotional representations.

Table 32- Tablet treated type 2 diabetes and HbA1c level (n = 19)

	Correlations with HbA1c level (r)	Significance level
Identity	0.415	<0.05
Timeline cyclical	0.400	<0.05
Emotional representations	0.379	<0.05
Chance causes	-0.447	<0.05

In the participants with tablet treated diabetes those with higher **HbA1c levels** had higher levels of identity, higher scores for timeline cyclical, higher emotional representations and less chance causes.

There were no significant correlations with general diabetes self-efficacy or accident/illness causes unlike the correlations found for participants with type 1 diabetes.

Table 33 - Insulin treated type 2 diabetes and HbA1c levels (n = 38)

	Correlations with HbA1c level (r)	Significance level
Foot care behaviour	-0.291	<0.05

In those participants with insulin treated type 2 diabetes, higher **HbA1c levels** were significantly correlated with lower levels of foot care behaviour.

Compared to participants with type 1 and tablet treated type 2 diabetes there was a distinct lack of significant correlations between illness representations and self-efficacy. There were no significant correlations between emotional representations, general diabetes self-efficacy, chance causes, accident/ illness causes, identity or timeline cyclical.

3.5 Conclusions

The results discussed in this chapter indicate that the participants in this study have some of the characteristics to be expected from a sample of people with diabetes and the wider population of people with diabetes in the UK, for example the participants with type 1 had diabetes for a significantly longer period of time than the participants with type 2 diabetes. There were no significant differences between the demographic characteristics of the participants with type 1, tablet treated type 2 or insulin treated type 2 diabetes except for age. This was not intended and may be a by-product of the fact that people with type 2 diabetes are usually diagnosed after the age of 40 due to the diagnostic criteria used by health care professionals (Pickup and Williams 2003; DeFronzo et al 2004; Kahn et al. 2005). As the inclusion criteria for participants was being aged between 30 and 55 then this bias towards participants with type 2 diabetes being older is to be expected.

There were fewer differences between illness representations, self-efficacy and self-care behaviour for participants with type 1, tablet treated type 2 and insulin treated type 2 diabetes than expected from the hypothesis. The differences that were found and possible reasons for them will be discussed in greater detail in the discussion (chapter six).

There were, however, very different relationships found between the variables for participants with type 1, tablet treated type 2 and insulin treated type 2 diabetes. For example, for exercise behaviour there were no correlations with any of the factors for participants with type 1 diabetes or for participants with tablet treated type 2 diabetes, the only correlations observed being with the

self-care behaviours general diet behaviour, specific diet behaviour and foot care. This was in contrast to the participants with insulin treated type 2 diabetes, where exercise behaviour correlated with multiple factors including: stopping hypos self-efficacy, emotional representations, altered immunity causes, general diabetes self-efficacy, age, general diet behaviour, specific diet behaviour, blood testing behaviour and foot care behaviour. This supports the hypothesis that different factors will be more or less important for different types of diabetes.

According to the Commonsense Model of Self-Regulation of Health and Illness (Cameron and Leventhal 2003), illness representations are responsible for predicting actions (for example self-care behaviours) in response to health threats. Self-efficacy was included in this research as it is thought to be increasingly important in the performance of self-care behaviours. However, the variance explained by illness representations and self-efficacy is surprisingly low. For some of the self-care behaviours (for example foot care behaviour for participants with insulin treated type 2 diabetes) there were no correlations with illness representations or self-efficacy at all. This suggests that there are other factors influencing the performance of self-care behaviour which have not been measured by the questionnaires. Either these are additional illness representations and aspects of self-efficacy or other factors un-related to illness representations or self-efficacy but equally, if not more, important. The next chapter describes the findings from the interview stage of this research and within these findings other explanations for the variance in self-care behaviour are suggested and explored.

Chapter Four

A face to face exploration of the experience of diabetes

This chapter reports the findings of the analysis of the data from the eleven semi-structured interviews carried out in the second stage of the study. The data was analysed using thematic analysis as described in chapter two (p.108). During the analysis six over-arching themes emerged. These were:

1)   Causes of my diabetes

2)   Looking after myself

3)   Myself and my diabetes

4)   Emotional experience

5)   Consequences of my diabetes

6)   Self-efficacy

The details of these are discussed and the differences between the themes for interviewees with type 1 and type 2 diabetes, men and women and levels of self-care behaviour are explored. An overview of the themes and sub-themes found can be found in appendix M.

4.1 The Interviewees

The interviewees were selected on the basis of type of diabetes, gender and level of self-care behaviour (for more discussion see chapter two p. 104). This resulted in a range of ages, occupations and durations of diabetes. The majority of the interviewees were aged between 45 and 55 and all the interviewees had children. The characteristics of the interviewees are described in table 34 (and can be found in appendix K for reference throughout the following chapters).

Table 34 - Characteristics of the interviewees

Name	Type of diabetes	Age	Duration of diabetes (years)	Marital status	Occupation	Level of self-care*	Complications **
Mr B	2	50	22	Divorced (2 children)	Registered disabled	High	Yes
Ms C	2	53	22	Married (2 children)	Social worker	Medium	No
Mr D	1	48	25	Married (4 children)	Warehouse worker	Low	No
Ms E	1	51	43	Married (2 children)	Teacher	Medium	Yes
Mr F	2	50	7	Living with partner (3 children)	Warehouse worker	High	Yes
Mr G	2	47	8	Married (2 children)	Registered disabled	Low	Yes
Mr H	1	46	23	Married (2 children)	Retail Manager	Low	No

Ms J	2	43	5	Married (2 children)	Nurse	High	No
Mr K	1	48	18	Married (3 children)	Warehouse worker	High	Yes
Ms L	2	55	5	Widowed (3 children)	Decorator	Medium	No
Ms M	1	33	28	Married (1 child)	Nurse	High	Yes

* High/low/medium self-care based on composite score of responses to SDSCA questionnaire. High > 33, Medium 30 to 33, Low < 30.

** Presence of complications based on yes/no response to whether participants had one or more of retinopathy, neuropathy, nephropathy or cardio-vascular complications.

All interviewees were taking insulin to treat their diabetes. It has been suggested in previous research (Anderson et al. 1997; Fitzgerald et al. 2000) that the type of treatment (ie tablets vs. insulin) may result in different beliefs, for example about perceived severity. Therefore due to the need to restrict the number of interviewees from a practical perspective (time and resources) and the need to obtain an adequate sample in terms of gender, type of diabetes and level of self-care behaviour it was decided to only interview individuals treated by insulin. This meant that comparisons could be made between those with type 1 and type 2 diabetes without the additional treatment modality factor as a potential confounding variable.

4.2 Causes of my diabetes

The cause of diabetes formed an important part of the narrative surrounding the interviewee's illness experience. It had a vital part to play in the story of their diagnosis and for some of the interviewees helped with the adjustment to and their understanding of their condition. From the interview data there emerged different perceptions of the causes of diabetes for interviewees in terms of gender and type of diabetes. Women with both types of diabetes, the men with type 1 and the men with type 2 diabetes all identified different causes for their condition.

All the three men with type 1 diabetes (Mr D, Mr H and Mr K) identified stress and shock due to an accident as the triggering factor in their diabetes. For example:

"I think um, I think mine was when I was when I came out of hospital the doctor said it was probably because I'd had an accident.."
Mr H, type 1, low self-care

Two of the men with type 2 diabetes, Mr B and Mr F, who reported high self-care and high levels of knowledge about their diabetes, both thought their diabetes was caused by obesity, poor diet, lack of exercise and a genetic connection:

"he [his doctor] said a lot of it is hereditary ....But I think someone else in the family's been diagnosed with it since ....they are prime candidates for it so they are grossly overweight, both of them,"
Mr F, type 2, high self-care

Mr G, the other man with type 2 diabetes, who in contrast had low self-care behaviour and low levels of knowledge about diabetes, was very unclear about the cause of his diabetes and this lack of knowledge fitted in with his experience of diabetes in general – one of confusion, lack of understanding and worry:

"No, they only ever told me what's ..and where, well it's just you've eaten and I said well I've ate the same all me life, ...no, nobody ever really told me anything or what was this, that and the other."
Mr G, type 2, low self-care

All of the women interviewed, whether with type 1 or type 2 diabetes and regardless of the level of their self-care behaviour, thought that their diabetes was caused by an infection or virus of some sort. Out of the women interviewed the majority (four out of five) also stated genetic factors as part of the reason they had diabetes:

"Um, I don't know, I suppose part of it I think is genetic and I I was really ill about 18 months before I developed it and I often wonder...."
Ms J, type 2, high self-care

Only Ms L did not state genetic reasons. She did, however bring it up as an option but she suggested that as she was adopted she had no knowledge of

her biological family and therefore no way of knowing if other members of her family had diabetes or not.

Other causes of diabetes were suggested by some of the interviewees regardless of gender, type of diabetes and level of self-care behaviour. That getting diabetes was a matter of chance or luck was talked about by three of the interviewees (Mr B, Mr D and Ms M):

"if you don't look after yourself like I haven't I said you run the risk of becoming diabetic I said its luck or chance as to whether or not you don't. There's a lot of overweight people that aren't diabetic I'm just unlucky and unfortunate enough that I was susceptible to becoming diabetic anyway."
Mr B, type 2, high self-care

There were several sources of information mentioned regarding the causes of diabetes by the interviewees and no pattern regarding type of diabetes or gender. These were from health care professionals, from family knowledge and from personal research and reading. Only five interviewees mentioned *how* they knew what caused their diabetes. Mr D and Ms C were told by their doctors that it was hereditary; however Mr D disagreed and said it was due to stress as there was no family history of it:

" Cos obviously the whole thing is that it runs in the family which I disagree with cos the only one in my family was my great grandad's brother and in them days they just put you up in the attic and all you did was drink from the tank, eat fruit and died. That's how it worked."
Mr D, type 1, low self-care

Mr H was informed by his doctor that his diabetes was caused by an accident he was in, Mr K said his family thought it was caused by a car accident he had but he was not too sure and finally Ms E mentioned she had read about the causes of diabetes.

Summary – Causes of my diabetes

1) The men with type 1 diabetes thought their diabetes was caused by stress or shock due to an accident.

2) The men with type 2 diabetes and high self-care thought obesity, poor diet, lack of exercise and hereditary factors caused their diabetes.

3) The man with type 2 diabetes and low self-care did not know what caused his diabetes.

4) All the women (with type 1 and type 2 diabetes) thought that their diabetes was caused by a virus or infection and hereditary factors.

5) Four interviewees (male, female, type 1 and type 2 diabetes) thought luck or chance was part of the cause of diabetes.

6) The interviewees found out what caused their diabetes from health care professionals, family knowledge and their own research, regardless of their gender or type of diabetes.

The cause of their diabetes was clearly an important aspect of the way the interviewees thought of their diabetes. The other aspect of the diabetes experience which made up a large part of the interviewees' illness narrative was how they looked after themselves and their diabetes. This leads on to the next theme to emerge form the interview data: *Looking after myself.*

4.3 Looking after myself

The self-care regime for diabetes is complex and there are many different behaviours to be performed, often multiple times daily. As a result the theme, *looking after myself,* was understandably a major part of the interview data. Interviewees described in detail aspects of their lives which involved looking after themselves and their diabetes. The data fell into four sub-themes:

1.   Why I look after myself

2.   How I know how to look after my diabetes

3.   How I look after myself

4.   How I know I'm looking after myself

4.3.1 Why I look after myself

Although there was a wide range of reasons that emerged from the interview data for why the interviewees felt they looked after themselves and their diabetes, no differences emerged from the data according to type of diabetes or gender. The most prominent reason cited, mentioned by ten out of the eleven interviewees with the exception of Mr G, was in order to avoid diabetes complications. Those interviewees (such as Ms C and Mr D) who had no existing complications wanted to avoid developing any and those with existing complications (for example Mr B, Mr F and Mr K) wanted to avoid getting any more or their existing complications getting any worse:

"Looking after this foot [points to non-wooden leg] cos it's bloody hard having one leg and I don't think I'd be able to, well I would but it wouldn't be the same…. I always worry about sort of kidneys and liver and everything else yes, yeah, me eyes, cos you always hear of people,"

Mr K, type 1, high self-care

Mr G was the exception in that he seemed to have no awareness of how developing complications was linked to how he looked after his diabetes. When asked if he thought there was anything he could do to prevent getting further complications Mr G responded:

"No because I don't know what to do cos I don't know what I'm looking for."

Mr G, type 2, low self-care

Interestingly, the complications which interviewees mentioned as wanting to avoid were neuropathy, retinopathy and nephropathy with only one mention of cardio-vascular complications by Ms E in connection to her smoking status, despite two out of the eleven interviewees already having cardio-vascular complications.

Three interviewees (Mr B, Ms E and Ms L) connected not looking after their diabetes with dying at a younger age. This was, in each case, brought up in connection with a friend or relative that they had known who died as a consequence of not looking after their diabetes and the interviewee stating how they wanted to avoid this happening to them:

"my friend's two brother and sister [laughs] that's an example if you don't sort of thing..... One other friend's father had his leg amputated and then died and that was through lack of good control. Yeah I think you only need a few scares like that sort of thing."

Ms L, type 2, medium self-care

Six interviewees described more short term advantages to looking after their diabetes. Ms C, Mr D, Ms E and Mr G felt that they needed to look after their diabetes in order to avoid feeling ill on a daily basis. Ms C and Mr D explained this in terms of avoiding getting other illnesses, Ms E felt very unwell if her blood sugar levels fluctuated so controlled her diabetes to avoid this and Mr G performed his injections and took his tablets so he could avoid being admitted to hospital:

"Well if I did not I wouldn't be here. I'd be in hospital flat out."

Mr G, type 2, low self-care

Mr F had recently experienced his first hypo and so was very concerned about the possibility of this happening again. As a result he was very conscious about looking after his diabetes to avoid hypoglycaemia. In addition to this Mr F and Mr K attributed a large part of why they looked after themselves to their partners. From the interview data it appeared that Mr F felt his partner was in control of his diabetes self-care, particularly in terms of his diet:

"Food as well, you know you've got to watch everything you eat like my missus now my partner she just monitors everything I eat tightly,"

Mr F, type 2, high self-care

Mr K also explained his high self-care behaviour as a response to his wife's influence and suggested that without this he may not look after himself to quite the same extent.

Additional reasons for looking after their diabetes were mentioned by a few of the interviewees. Mr K identified keeping his driving licence as an important motivation for looking after himself, particularly as his livelihood depended on having the ability to drive:

"I never know why but my licence was delayed coming back and I've always religiously, ...but I'll be grieved if I don't get one, well, I would I think I would be upset cos I mean I've tried,"
Mr K, type 1, high self-care

Mr D, Ms E and Ms M found motivation from the need to be well and functioning now and in later life for their family, in particular their children:

"I can just do what I can for me to try and keep everything functioning which I do. Keep my family functioning, do that."
Mr D, type 1, low self-care

Ms M also felt that she had a genetic susceptibility to other medical conditions and as a result wanted to control her diabetes to the best of her ability in order to have a better chance of recovering from these other medical conditions if they occurred:

"I think if I can keep my diabetes under reasonable control if I had something like cancer or something, you know something major illness I would stand a better chance of recovery."

Ms M, type 1, high self-care

Ms M and Ms J were both health care professionals. They suggested that in order to provide a good example to other people with diabetes they needed to look after themselves too:

"I've always, I've always tried I suppose because of the profession I'm in and I tend to think you should practise what you preach really."

Ms J, type 2, high self-care

4.3.2 How I know how to look after my diabetes

There were two main sources of information and knowledge which emerged from the data as being most used by the interviewees to know how to look after their diabetes: health care professionals and personal experience. Ten out of eleven interviewees (with the exception of Ms J) referred to getting advice and support from their hospital consultant and the team of health care professionals at the hospital such as diabetes nurses, dieticians and podiatrists. Ms J explained the fact she did not receive information from the hospital because of her role as a practice nurse and that the assumption was that she already had all the knowledge and expertise she needed. She suggested that occasionally she would have liked more support.

Although the majority of the interviewees received advice about how to look after themselves from health care professionals at the hospital, the majority of these interviewees (Ms C, Mr D, Mr G, Ms M, Mr K and Ms L – type 1 and type 2 diabetes, men and women) felt that the advice was inappropriate on occasions, did not work or was in direct conflict with their own personal experience of living with diabetes. For example, Ms C felt that she was treated in a patronising manner by registrars at the hospital who did not know her case history and were not dealing effectively with the individual complexity of diabetes:

"when you've been to the diabetic clinic and been admonished like a naughty child it's (laughs) which is all you go for really um it's you know other people have an understanding you know people who don't have it don't know and it's all very well to quote the text book at you but the life is somewhat more complex than that and diabetes is somewhat more complex than that…. So it's not as simple as it sounds."
Ms C, type 2, medium self-care

Mr D, Ms M, Mr K and Ms L all disagreed with their consultant or diabetes nurse on advice they were given which they felt did not work for them or correspond with how they had experienced their diabetes. Mr G felt that some health care professionals had offered him no education or advice about looking after his diabetes, did not know what to do about his lack of control and had given up on helping him as shown by his description of his last clinic visit.

These disagreements with the health care professionals were striking and suggested how much importance the interviewees placed on their own personal experience of living with diabetes. It emerged from ten out of the eleven

interviews that personal experience, commonsense and trial and error played an enormous part in how the interviewees learnt how to look after themselves successfully whilst maintaining their lifestyle as they wished. For example, Ms E talked about how she no longer counted carbohydrate:

"I mean I did but as I say I think you just develop an eye for it then you've had it for so long. And you know what's sensible."
Ms E, type 1, medium self-care

The interviewees' personal experience was combined with information and knowledge from the hospital health care team but also from a range of other sources. Four interviewees described receiving help from their GP (Mr B, Ms C, Mr F and Mr G). All of these interviewees had type 2 diabetes, which was logical as most people with type 2 diabetes are initially diagnosed and dealt with at their GP surgery. In contrast to this Mr D (with type 1 diabetes) explicitly stated that he had never seen his GP despite receiving his prescriptions from him. Diabetes UK and/or the internet were mentioned as sources of information by four interviewees (Mr B, Ms E, Mr F and Ms M – with medium to high self-care levels):

"once I became diabetic I thought I'll study it, and I go on the internet, cos I never used to be on the internet got diabetes went on the net thought this I've got to find out what's going on here so off I went, thought this is good, this is fantastic getting all this information through"
Mr B, type 2, high self-care

For Mr F it was his partner who used the internet and read the Balance magazine and then passed on this knowledge to him. The data suggested that

it was mainly Mr F's partner who did the research and learnt about how to look after diabetes and then implemented this for Mr F:

"she's well into it she's bought books and everything oh yeah ...got onto the diabetes people rung them somewhere, got me all books and that she reads them religiously....."
Mr F, type 2, high self-care

It may be significant that it was the two men with type 2 who considered their diabetes to make them 'different' who carried out this in depth research from other sources. The influence of a partner on knowledge and expertise was also seen in the case of another man interviewed - Mr K - who described his wife's expertise as a nurse and her research about diabetes as one of his main sources of information about how to look after himself and his diabetes:

"I've never really, I've never really had any instruction sort of um my wife she goes to the seminars so she'll keep me informed, it was her who kept me informed about this levemir..."
Mr K, type 1, high self-care

The effect of other people who did not work in the health care profession on knowing how to look after diabetes seemed to be more important for men than for women. The examples mentioned above support this but also the fact that out of all the interviewees there were three men, Mr B, Mr F and Mr K, who described the positive effect on looking after themselves of knowing somebody else with diabetes and asking them for advice and comparing notes. Mr K knew somebody with diabetes before he was diagnosed and identified him as a valuable source of information at diagnosis:

"you're on insulin you know I'd sort of asked him questions and he'd sort of put my mind at rest"

Mr K, type 1, high self-care

Mr B and Mr F both had groups of friends or work colleagues who had diabetes who they would talk to and compare notes and tips about looking after themselves:

"Oh yeah, it's always good, I mean one person may be treating themselves slightly different to the way I would treat me and I would give them a bit of advice and say if you do this and I do and things can work and we've often gone out to the pub together and had a drink..."

Mr B, type 2, high self-care

However, this was not the case for the other three men who were interviewed. Mr G and Mr H did not know anybody else with diabetes so did not have that resource to use. Mr D did know others at work with diabetes but saw himself as different from them as he was on insulin and they were on tablets, therefore he appeared to consider them as inappropriate support due to the fact he saw himself as different and his diabetes as more serious than theirs:

"Yeah, type 2 is the same kind of things they can take tablets or they can do diet or they can do weight loss now that can reduce it and stop them taking tablets. I've got ugh? Nothing. Injections. ...so in my company I think there's about 4 diabetics. Most of them are on tablets, I'm the different one."

Mr D, type 1, low self-care

The majority of the women interviewed knew other people with diabetes but the analysis of the interview data suggested that they did not view this as a resource to be used to obtain information or exchange knowledge. For example, Ms C saw her fellow work colleagues as an opportunity for support in rebelling against healthy eating rather than a chance to swap tips on looking after diabetes:

"we can then be bad together. I mean we are not bad [laughs] we are aware but I think we don't sort of beat ourselves up about it too much."
Ms C, type 2, medium self-care

Ms E, Ms M, Ms J and Ms L all knew of people with diabetes but none considered it to be useful to them to compare notes or as helpful for expanding their expertise. The women appeared much more insular and self-contained in terms of looking after their diabetes. They made no reference to help or support from their partners in contrast to Mr F and Mr K. For the women (four of whom had current partners) it was *their* diabetes and their partners only had a role if they were incapable of looking after themselves for example during a severe hypo. In a more general way this was demonstrated by the consistent use by the majority of the men of 'we' when describing activities related to the self-care of their diabetes. In contrast to this the women all used 'I' rather than 'we'.

4.3.3 How I look after myself

Various aspects of diabetes self-care behaviour were talked about by the interviewees. This sub-theme will deal with each one separately: diet, medication, blood testing, exercise, foot care and other aspects of diabetes self-care.

Diet

Dietary behaviour was mentioned by all of the interviewees. One interviewee (Mr D – low self-care) had no specific diet and reported eating what he felt like when he felt like it:

"whatever they dish up. Nah, that way I don't measure it or nothing. Used to but not now. ....slap it on, I'll eat it."
Mr D, type 1, low self-care

Ms C and Mr G (with medium to low self-care overall) showed awareness of what diet they were recommended to eat by their health care professionals and indicated that they followed that diet most of the time if not in its entirety (although this was in contrast to their reported dietary behaviour in the questionnaire stage of the study). The remaining eight interviewees (men and women, type 1 and type 2 diabetes, high and low levels of self-care behaviours) described eating the recommended healthy diet, such as lots of fruit and vegetables, low fat, low salt, high fibre and keeping a track of carbohydrate. Two of these interviewees (Ms M and Ms L) felt that they had flexibility in what and when they ate:

"Yeah, I'm not a creature of habit. I know one of the diabetic nurses says we all are, but I'm not at all and I'll eat according to my activity and what's going on. I try and stay steady but if you've got an alternative lifestyle then..."
Ms M, type 1, high self-care

The other interviewees (Mr B, Ms E, Mr F, Mr H, Ms J and Mr K) ate at regular times or ate regular amounts of carbohydrate throughout the day.

All of the interviewees mentioned diet during their interviews and the majority (ten out of eleven) felt they were knowledgeable about the type of diet they should be eating (for example, low fat, low sugar, high fibre, lots of fruit and vegetables) whether they ate a diet like that or not. The exception was Mr G who, although mentioning diet in his interview and describing his diet as low fat with lots of vegetables still felt that he was not knowledgeable enough about what that diet should be:

"Just eat what's there. If I'm hungry I eat it if I'm not hungry I don't eat it. That's it I just don't know. Nobody's ever said oh you've got to weight this for that or this is that for that, nah.."
Mr G, type 2, low self-care

Medication

As with dietary self-care, all of the interviewees described taking medication as a significant part of what they did to look after their diabetes. Six out of the eleven interviewees (Ms C, Mr H, Ms M, Ms J, Mr K and Ms L) were on four or more injections a day and altered the timing of injections and

amounts of insulin according to what their blood sugars were or how much they were eating:

"depending on what meal I'm having I just tweak it a couple of points cos I think you know if I'm having a meal and there's gonna be a lot of carbohydrate in this I just do a couple of extra points or whatever."
Mr H, type 1, low self-care

Mr B, Mr D, and Ms E were all on two injections a day; however, altered their doses or added in extra fast acting insulin when necessary. Mr F and Mr G were also on two injections a day but felt they had less flexibility about changing their insulin amounts and did not alter their doses unless their diabetes control worsened or by first discussing it with health care professionals at the diabetes clinic. None of the interviewees mentioned missing injections on purpose or not taking their insulin. Mr B, Mr H, Ms C and Ms L described instances when they worried they had forgotten to take their insulin or had taken two injections instead of one:

"the other morning I got up, totally forgot to inject I did everything else, took all me other tablets but forgot the insulin..."
Mr B, type 2, high self-care

They suggested this was because the injection process had become second nature and was so routine they did it automatically:

"Yes I mean there are four things, take your tablets, you know clean your teeth, wipe your make-up off and have your injections those are the four things which sort of mentally tick off in my mind (laughs)."
Ms C, type 2, medium self-care

The fact that all the interviewees performed their injections religiously is indicative of how vital the injections are to life with diabetes. Without insulin a person with diabetes feels unwell and eventually becomes extremely ill which is shown by the fact that the interviewees in this study appeared to consider taking insulin as the most important self-care behaviour they could perform. This was nicely summed up by Mr H:

"I mean the questionnaire says the, one of the questions was how many times have you missed, missed taking insulin in the last 7 days well it wouldn't be an option for me, you just take it and that's it, it's not an option sort of thing."
Mr H, type 1, low self-care

The contrast between the necessity of taking insulin and other self-care behaviours, in particular other oral medication, was important for Mr D. He had low self-care behaviour and taking insulin injections was the only self-care behaviour he performed without fail. He was prescribed medication to lower his cholesterol and blood pressure but had decided that because he could not see what it was doing he would only take it sporadically. This shows how essential taking insulin was considered to be by Mr D – it was not the fact that it was medication that was prescribed by the doctor that made him take the insulin but that he could see a direct relationship between taking it and how he felt, which perhaps explains why he performed no other self-care behaviours as the short term benefits were not visible:

"If I'm taking something I wanna know it's working. What's the point in sitting taking lots of tablets when they do nothing?...I like to know it's working or why. Don't just give me it and say there you go. What's that for?"
Mr D, type 1, low self-care

Blood testing

The majority of the interviewees (ten out of eleven) performed at least two blood tests a day. Their motivation for doing the tests appeared to be so they could monitor how well they were looking after their diabetes, to make necessary alterations to their insulin doses or to check if they had high or low blood sugars. There was no mention by any of the interviewees about how many blood tests their health care professionals had recommended that they do. Two interviewees (Mr D and Ms L) described concerns that they were doing too many blood tests and that their GP may restrict strips, although this had happened to neither of them. Ms M and Ms L described doing more frequent blood tests (five to eight a day) as a consequence of unpredictable blood sugars and flexible lifestyle. Interestingly it was these two interviewees who described eating a flexible diet which may be why they felt they needed to do more blood tests:

"I'm fine but um it fluctuates a lot more than it ever used to um and I find it a lot harder to control. It's always been quite difficult to control but I find it a lot harder to control so I do frequent blood tests."
Ms M, type 1, high self-care

Mr D and Mr K performed blood tests before they drove as a consequence of incidents which had happened to them when behind the wheel (this will be

discussed in greater detail in the *consequences* theme p. 245). Mr H reported doing blood tests regularly when he was off work; however, when he was at work he did not do any. The only interviewee not to do regular blood tests was Mr G. Despite reporting feeling frequently unwell (which may or may not have been due to fluctuating blood sugars), in particular when driving, Mr G performed on average only two blood tests a month:

"I don't do me sugar count anymore cos it's just getting depressing. I mean my sugar count the last one I did was 25.7. yeah it's never gonna come down, there's something wrong somewhere else and there is they can't put their finger on it."
Mr G, type 2, low self-care

It emerged that he only did blood tests twice a month because he thought he should do and did no more because the results depressed him as they were always very high. This may have been because he did not have the knowledge to know what to do with the result or feel able to change his behaviour in a way to alter his blood sugar levels:

"Oh I can do me blood tests it's just the results that depress me."
Mr G, type 2, low self-care

Exercise

The data analysis suggested that the majority of the interviewees (eight out of eleven) felt they should be doing exercise but did not. Mr F and Mr G had other long-term health conditions which meant it was difficult for them to do

exercise but the remaining six interviewees cited no particular reason why they did not do exercise just that they did not:

"I don't do much exercise [laughs] ….nah, the only exercise is working the remote control on the telly [laughs] in the evenings, which isn't very good I suppose."
Mr K, type 1, high self-care

Ms M did do exercise but for reasons other than her diabetes. She felt that there was a significant risk of other health problems in her family and that exercise was a good way to combat them. Two of the three interviewees who did do exercise (Mr B and Ms J) were very clear about the benefits for their diabetes of doing regular exercise. Ms J was a practice nurse and so dealt with people with diabetes and had significant medical knowledge and Mr B had done much research on the topic of diabetes.

There were no differences in exercise levels between men and women. Of the four men who were physically able to exercise only one (Mr B) did so whereas of the five women who were able to exercise two did so (Ms M and Ms J). Mr D and Mr K both had physically demanding jobs and considered that they got enough exercise at work, as did Ms L. Added to which Ms M and Ms J were both health care professionals and so appeared to be more aware of the importance of exercise for diabetes self-care. This was particularly relevant as only one of the interviewees (Ms M) described being advised that they should do regular exercise by their health care practitioners:

"right from the start it was mentioned that um that exercise was a good thing to have regularly and that's been since I was tiny."

Ms M, type 1, high self-care

Feet

Only four out of eleven interviewees mentioned checking feet as something they did to look after themselves and their diabetes. These four all reported medium to high levels of self-care behaviour in the other aspects of diabetes self-care. Mr F knew somebody with diabetes who had experienced problems with their feet and so had become quite obsessive about checking his feet:

"Yeah, probably is um we've got a friend who's lost their legs for it and it's really made me sit up and start thinking [laughs]. Yeah I've yeah since this er it's scared the living daylights out of me...., where would it be check your feet, sometimes I do it twice a day,"

Mr F, type 2, high self-care

Ms L had experienced problems with her feet and so had had to find herself a chiropodist to sort out the problem. Ms J checked her feet on a daily basis as did Ms M, although not because of her diabetes but because she power walked and had to have her feet in optimal condition. Mr H mentioned reading leaflets which told him to check his feet but made no mention of doing so. Mr G and Mr K had neuropathy and so had their feet checked regularly at the hospital but made no mention of looking after their feet themselves.

Out of the specific self-care behaviours described in the data by the interviewees it was clearly the behaviours that either had a visible, tangible effect on their diabetes (such as medication taking and performing blood tests) or had been learnt through personal or vicarious experience to be important to maintain health that were performed regularly. An example of this was carrying glucose in case of a hypo or checking feet for those who knew somebody else with neuropathy. Self-care behaviours such as exercise and foot care appeared to be less relevant for the majority of the interviewees. Perhaps this was because the impact on their diabetes was less direct and noticeable or it was harder to integrate these behaviours into the interviewees' lifestyle unless they had additional motivational factors such as avoiding other illnesses or through vicarious experience. No differences in self-care behaviour between those interviewees who had type 1 or type 2 diabetes or whether they were men or women emerged from the data.

4.3.4 How I know I'm looking after myself successfully

There was a range of ways mentioned in the interview data for how interviewees evaluated the success of their diabetes self-care. There were no clear differences between participants with type 1 or type 2 diabetes. There were different patterns of evaluation methods mentioned by men and women with much more variety coming from the men. All of the women who were interviewed measured how they looked after their diabetes on the basis of blood sugar results – either their own blood glucose monitoring or from the HbA1c tests performed at the diabetes clinic. Ms C, Ms E and Ms L used their own blood testing to see if they were looking after themselves:

"Yeah it's the testing. That's what I go by."

Ms C, type 2, medium self-care

Ms M and Ms J said they based the measurements of their success in looking after themselves on the HbA1c results from the clinic. The men were slightly more varied in measuring techniques. Mr H and Mr F both used blood sugar tests to check if they were looking after themselves. Mr F also stated the length of time between appointments as another measure for if he was doing well. Interestingly Mr D also described this as the only way he knew if he was looking after himself well as he felt that the doctors were the experts and not him:

"I think I'm pretty good. I've never been less than 6 months go and see the specialist, twice a year. And as he said, obviously if you're a bit lost you'll be there every 2 months or whatever it is. I've never came to that….. Well that's what I think cos obviously they're the experts. I'm the patient…"

Mr D, type 1, low self-care

Mr G and Mr K evaluated how their diabetes was going on the basis of how they felt. Mr G used how he felt in terms of mood and Mr K kept track of how often he was ill and was unable to go to work:

"If I'm in a good mood I'm happy. If I'm in a bad mood there's something not right… It's how you feel on the day. It's the only way I can describe it."

Mr G, type 2, low self-care

Ms C and Ms M also mentioned how they felt as an indication of how their diabetes was; however, in contrast to this, Ms J said that she felt it was

impossible to judge how well diabetes was being controlled on the basis of how she felt:

"I mean we have people coming in who say 'oh I base it on how I feel', not very scientific really [laughs] and yes as I say, I know when I'm going hypo cos I feel hypo and usually if I'm a bit sort of floppy and tired I am a bit higher than normal but I'd never judge it by that"
Ms J, type 2, high self-care

Finally, Mr B described a more personal and specific set of criteria. He mentioned his blood sugar levels, although not explicitly in terms of measuring how he looked after himself; however, he also looked at whether his weight was reducing, if he could do more exercise and if his insulin dose was lower.

It was interesting to note that the actual level of self-care behaviour described did not always correspond with how well the interviewees felt they were looking after their diabetes. For example, Ms C and Ms L both had self-reported medium self-care and from the interviews it appeared that they both performed similar self-care behaviours; however, the way that Ms C talked about her performance of self-care behaviours for her diabetes was in very negative terms. She appeared to consider that she should be doing much more to look after herself and that she felt she had quite low levels of self-care behaviour. In contrast to this Ms L described her self-care activities as being excellent and considered that she performed a very high level of self-care.

Summary – Looking after myself

1) The majority of interviewees looked after their diabetes primarily in order to avoid diabetes complications.

2) Some of the interviewees looked after their diabetes to avoid dying at a younger age, to feel healthy on a daily basis, to prevent hypos, because of the influence of partners, to keep their driving licence, to keep healthy in order to look after their family, to provide a good example to others with diabetes and avoid becoming a burden in older age. There were no differences found between type of diabetes or gender.

3) The majority of interviewees got advice on how to look after their diabetes from health care professionals.

4) The majority of interviewees found that their personal experience of diabetes differed from the advice they were given by health care professionals and used their own personal experience to guide how they looked after their diabetes.

5) Only interviewees with type 2 diabetes mentioned getting advice about their diabetes from their GPs.

6) Four of the interviewees with high levels of self-care behaviour carried out their own research about diabetes on the internet or through Diabetes UK.

7) Only the men interviewed described getting advice or help from friends or colleagues with diabetes.

8) Diet, medication taking and blood testing were the most regularly carried out self-care behaviours. There were no differences on the basis of type of diabetes or gender.

9) Exercise and foot care were the least performed self-care behaviours. Those interviewees who did exercise felt that exercise was a vital part of looking after

diabetes to a greater extent than those who did not. The interviewees who reported high levels of foot care either had existing foot problems or were health care professionals themselves. There were no differences on the basis of type of diabetes or gender.

10) The women who were interviewed used their own blood sugar monitoring or HbA1c results to evaluate if they were looking after their diabetes successfully.

11) The men evaluated how their diabetes was being looked after by how they felt, blood test results, how often they were asked to attend the diabetes outpatient clinic or whether they had succeeded in their aims such as losing weight.

4.4 Myself and my diabetes

This theme emerged from looking at the data on how the interviewees viewed their diabetes in relation to themselves. Previous literature has shown that long-term conditions can have a significant impact on identity and self (Charmaz 1983) and this emerged as being particularly important for the men with type 2 diabetes, with much less significance for the men with type 1 diabetes or for all the women who were interviewed. Within the theme of *myself and my diabetes* there were three main sub-themes suggested by the interview data: b*eing special/being normal, roles and status,* and *ownership and responsibility.*

4.4.1 Being 'different'/being 'normal'

The majority of the interviewees (eight out of eleven) considered that despite having diabetes they were still 'normal' and that their diabetes did not mark them as different from everybody else. These interviewees included all the women interviewed and all the men with type 1 diabetes. These interviewees performed self-care behaviours but did not consider it to be something 'special' or something which divided them from the general population of people without diabetes. For example in relation to healthy eating:

"really it's just the sort of healthy eating and healthy living plan the same as for everybody else in society."

Ms C, type 2, medium self-care

The remaining three interviewees – the men with type 2 diabetes - felt that their diabetes made them 'different' and saw it as a defining element of their identity. They described the way in which their diabetes set them apart from other people in a variety of ways. Mr B and Mr F reported high levels of self-care behaviour and expressed very similar experiences in terms of how and why their diabetes made them 'different'. Both showed a significant conscientiousness towards their diets and believed in the importance of following a rigorous 'diabetic' diet. They felt this distinguished them from family and friends around them.

"Um, the diet has changed yes. It's more um smaller sized meals now obviously but very much more fibre than there used to be in the past. I mean, I like me meat and they says to me no red meat.... I do find I still tend to eat a little bit of beef every now and then but the beef I eat is so thinly sliced you wouldn't even know it was beef."
Mr B, type 2, high self-care

Mr B was very aware of the health implications of having diabetes and this appeared to strengthen his beliefs that diabetes made him 'different' from people without diabetes. He considered diabetes to be a serious threat to his well-being:

"you used to see these signs, diabetes is a killer is it really going to take me out like that, um although it is the biggest killer in the world of anything really I mean more people die of complications due to diabetes than any other disease even if they've got leprosy or cancer diabetes is the biggest killer of the lot people kind of say well you can control it I said yeah you can control it but there's no cure.... diabetes will progressively get worse...."

Mr B, type 2, high self-care

This was very similar to Mr G who was the third man with type 2 diabetes interviewed. He was different from Mr B and Mr F in that he reported very low levels of self-care behaviour which he explained by this lack of knowledge. He had experienced severe ongoing difficulties with his health and had also been hospitalised on numerous occasions. He did not stick to a specific diet, in contrast to Mr B and Mr F. He considered his diabetes to be a major health threat and so saw it as something which marked him as 'not normal'. This is typified by his experiences when applying for his carer's allowance. He appeared to feel that the fact he had a carer's allowance for life, which is very difficult to get, showed how ill he was with his diabetes. The experiences of severe illness and hospitalisation may be a factor in the development of this feeling of being 'different' or 'special' for the men with type 2 diabetes. But this was not present for Mr F, who also considered himself to be distinguished by his diabetes and the medical threat of diabetes and hospitalization had also been experienced by other interviewees who did not consider themselves to be 'different' as a result of their diabetes. The second sub-theme that emerged in the over-arching *myself and my diabetes* theme was *roles and status* and it is within this theme that explanations for Mr B, Mr F and Mr G's 'diabetes identity' can be found.

4.4.2 Roles and status

This sub-theme emerged from discussions about how diabetes affected the roles that the interviewees performed and consequently their status in society. Again there was a marked segregation between the majority of the interviewees and Mr B, Mr F and Mr G who were the men with type 2 diabetes. The other eight interviewees (all the women and the men with type 1 diabetes) described performing roles in their life in terms of being parents, being husbands or wives, their careers and so on. The role of being somebody with diabetes was very much a secondary role which fitted around the main roles in their lives.

"I work in a betting shop so the environment is not particularly a good one.....it can be quite hard to you know take injections and stuff when I'm at work, finding the time to give myself, ...So it's not an ideal job,"
Mr H, type 1, low self-care

However, for Mr B, Mr F and Mr G diabetes took a more prominent place in the roles being performed. Diabetes provided Mr B with status and with a 'group' to belong to, in terms of being identified by and identifying with others because of his diabetes. His position and status was provided by his self-taught knowledge of diabetes and the ability to share this knowledge with others who needed his help. Mr B had a variety of careers before being forced to retire on medical grounds and live on disability allowance. He continued to use the knowledge he learnt from those careers but in terms of diabetes and this provided him with a continuation of the status he was afforded during his working life.

"I suppose I'm lucky I've got the knowledge to be able to do that its all up here and I can impart it to others.."

Mr B, type 2, high self-care

Diabetes provided the opportunity for Mr B to feel he belonged. He saw diabetes as a reason to talk to and bond with other people. It enabled him to have regular contact with people at the hospital and gave him connections to others.

"Meeting other people who've got it and seeing how positive they are about it yeah, I've met a lot more people since being diabetic um through diabetes meetings and stuff like this and um and seeing how they deal with things and making some good friends doing it so that's the positive aspect."

Mr B, type 2, high self-care

The same was true, although to a lesser extent, for Mr F. He reported enjoying the same opportunities for feeling like he belonged as Mr B. He also described providing advice to his friends who had diabetes in order to help them and again this afforded him status within the group and provided another role for him to fulfil:

"Yeah yeah, I mean you know if you have got someone you can compare stuff with one another....we have these little diabetes meetings where we sit in a little room like this and we chat about stuff, once or twice a week or it might not be for a few weeks and we all sit and chat about it."

Mr F, type 2, high self-care

The other interviewee for whom diabetes provided a role was Mr G; however the role that Mr G had taken on was in complete contrast to Mr B and Mr F. Mr G described a life in which diabetes had removed any status he used to have and the role he fulfilled now was a *sick role*. He, like Mr B, was on disability allowance and his wife cared for him. Having diabetes (and another long-term condition) had become his main role in life. His diabetes had not provided him with opportunities to meet others but instead he seemed to feel isolated and greatly restricted by his diabetes and the consequences of his diabetes:

"I mean I don't I don't drink as much as like I used to I go out maybe once a week and that is it...but I don't go out and battering it every day of the week, which I can't afford cos its too expensive but nothing..... so I sit at home and watch me telly,"
Mr G, type 2, low self-care

Mr G displayed all four of the criteria Parsons (1951) lays down for adopting the *sick role*: he was exempt from normal responsibilities (and had this legitimised by health care professionals); he had the right to be cared for and this had been confirmed by the health authorities granting him disability and carer's allowance; he wanted to get better; and he thought he co-operated with appropriate medical help. Mr G's adoption of the *sick role* was greatly facilitated by the people around him and this was a key similarity between Mr G, Mr F and Mr B. Whilst Mr B and Mr F, the other men with type 2 diabetes, maintained active roles and status in society and did not continually adopt the sick role they still saw themselves as set apart and 'different'. The role of being 'a person with diabetes' was strengthened and facilitated by the way that friends and family around them 'specialised' their circumstances and the fact they had diabetes.

For example, Mr B described a visit to the pub with his son and the way that other people in the pub protected him from a potential bar fight due to the fact he had diabetes. This was in direct contrast to the other interviewees (regardless of level of self-care behaviour) who described their social world as one in which people around them considered them in other roles first, for example mother, husband or work colleague, and acknowledged their diabetes only when necessary.

"And I have to sort of remind them that yes I do have this condition actually and I do have to eat oh I'm feeling a bit funny oh I'll go and get something to eat now...."
Ms C, type 2, medium self-care

It is important at this point to clarify the use of the *sick role* in more detail. Mr G was distinguished from the other interviewees because of his use of the *sick role* however it was not the *sick role* that caused that distinction but his use of it. The other interviewees described taking on the *sick role* at various points in their lives with diabetes. For example, Mr B described adopting the *sick-role* on various occasions when he became ill and was worried about the impact of his diabetes on his illness; however, he also clearly described how he took responsibility for his own diabetes when he was better and how he resumed his normal social responsibilities. Once the need for the *sick role* had passed, the other interviewees no longer remained in that role but took on other roles, such as mother, worker and so on. The *sick role* remained as an option for when they experienced difficulties but was not part of their everyday life and as such they took responsibility for their own self-care and their own health. Mr G, in contrast, had remained in the *sick role* since his diagnosis, never reaching the

point where he could relinquish the *sick role* and take on other roles. This leads on to the next sub-theme to emerge from the *myself and my diabetes theme – ownership and responsibility.*

4.4.3 Ownership and responsibility

The narratives of the interviewees showed that living with a long-term condition and coping with it on a day to day basis had led to a close relationship developing between the person and the condition. Throughout the interviews aspects of this relationship, such as how diabetes was visualised, how it had been integrated into everyday life and the adjustment process needed in order to become accustomed to the relationship, were described by the interviewees. This sub-theme was called *ownership and responsibility* in order to indicate the issues surrounding the relationship with, control of and therefore ownership of the condition which impacted on the level of responsibility taken for the diabetes. Within this sub-theme there were four types of relationships with diabetes:

1. Active decision to take control.
2. Diabetes integrated into everyday life.
3. A lack of control due to circumstances.
4. Diabetes controlling them.

Active decision to take control

Three of the interviewees (Mr B, Ms J and Ms L) described making an active decision to control their diabetes. All these interviewees had type 2 diabetes and medium to high levels of self-care behaviour, Mr B had had diabetes for 22 years and Ms J and Ms L had had diabetes for 5 years. For example Mr B discussed how his diabetes used to control him but now he controls it:

"my main aim is…, to control it and to get much more control over it, rather than it controlling me, me control it, I'm getting there….it did [control me] at the first part, …for about 4 years it controlled me and I thought no I've had enough, I've got to take control…."
Mr B, type 2, high self-care

In making an active decision to control their diabetes and perform the self-care behaviours necessary Mr B, Ms J and Ms L took responsibility for their own health. They believed that they were responsible for their behaviour and their behaviour would affect their diabetes and their long term health.

"I want both my feet, I want both my eyes, I want to be able to see my grandchildren, I don't want to you know go down that road thank you very much and anything I can do to stop it I will. [Laughs]"
Ms J, type 2, high self-care

Diabetes integrated into everyday life

Four of the interviewees (Ms E, Ms M, Mr K and Mr D) talked about their diabetes as being integrated into their lives. These interviewees all had type 1 diabetes and had had diabetes for at least 25 years. They all described diabetes as a normal part of their life and the length of time they had had it meant they were adjusted to its presence. For example, Ms E talked about how the control of what she ate had become part of her life (see quote on p. 197). Mr D described living with his diabetes as being a member of a partnership:

"We've been pals for nearly 23 years now so we're used to each other. Bad days, good days. Good days, bad days. It's just what pops up that's the way I look at it. Some days I just the partnership may break up but um no I just look at it from that whole circle really......It's just, I'm normal 'cept I've just got a problem"
Mr D, type 1, low self-care

However, these interviewees varied in terms of taking responsibility for looking after their health. Ms E, Ms M and Mr K reported how they felt that they were responsible for looking after their diabetes and their health. However, Mr K also displayed a certain amount of joint responsibility with his wife. He admitted that without his wife's input he may not have looked after his diabetes to the same extent:

"though part of the reason I'm not going to say I would if I wasn't married to a nurse but um yeah I think that helps a lot.....She keeps on at me ....I'd rather get on with it for a quiet life [laughs]"
Mr K, type 1, high self-care

Ms E, Ms M and Mr K all had medium to high levels of self-care behaviour; however, contrasting with these interviewees was Mr D who had low levels of self-care behaviour. Despite describing how his diabetes was integrated into his life he ascribed a large part of his health and the chance of potential complications to chance. He reported feeling he had less control over the consequences of his diabetes and so seemed to not take as much responsibility for his diabetes as the other three interviewees in this group, which in turn may explain why his level of self-care behaviour was lower despite having integrated his diabetes into his life.

Lack of control due to circumstances

Two of the interviewees (Ms C and Mr H – with medium to low self-care behaviour) explained their lack of control over their diabetes as a result of external circumstances happening around them. They felt that their working situations meant that they were unable to take the measures necessary to take full control of their diabetes and so they had not successfully integrated their diabetes into their lives despite having the ability to control it when away from work.

"when I was off work I ate very regularly and ate much earlier than I do now but I don't finish work 'til 7 o'clock so I'm eating far too late. I know. I know I'm eating late but what can you do? So um yeah that's wrong but I do it. But when I was at home I could actually eat much earlier...."

Ms C, type 2, medium self-care

The interview data suggested that both Ms C and Mr H acknowledged that they were responsible for their health and looking after their diabetes. However, they

felt that despite this the constraints of their lives prevented them performing certain self-care behaviours.

Diabetes controlling them

The remaining two interviewees (Mr F and Mr G – both men with type 2 diabetes) described a relationship with their diabetes where it was controlling them, although in very different ways. As mentioned previously Mr G had limited understanding of how his diabetes worked and as a result experienced severe symptoms from his condition. Because of these severe symptoms and their unpredictable nature he described experiencing significant limitations to his life due to the inability to make plans in advance in case he was unable to proceed because of his diabetes:

"As I say it comes and goes. You can never you couldn't predict like say oh tomorrow I'm gonna have this or I'm gonna do this I couldn't I can never look forward to a day look to the day I'm on."
Mr G, type 2, low self-care

Mr F was also controlled by his diabetes but in contrast to Mr G it was not by the physical affects of lack of control and understanding but due to the rigidity and restriction he placed on his life because of the diabetes. Significant factors in his life, such as his eating patterns, were controlled by his diabetes rather than the other way round and he showed no sign of taking that control himself. The striking similarity between Mr F and Mr G was the lack of knowledge about diabetes. In Mr G this exhibited itself by very low self-care however Mr F had high self-care behaviour levels. Mr F's lack of knowledge meant that, with the

help of his partner, he followed his prescribed diabetes regime precisely leaving no room for flexibility or taking control of his diabetes himself.

"Carbohydrates everything just watch and really read everything before you buy it. ....I'm not a cereal eater in the morning but I'm looking at it and Ready Brek and Scots porridge oats is one of the best things you can eat in the morning so I'm eating that now every day."

Mr F, type 2, high self-care

Mr G's adoption of the *sick role* meant that he felt he was not responsible for his health or for looking after his diabetes. He had passed all responsibility and control of his diabetes to health care professionals. The interview data suggested that Mr F assumed responsibility for his health in that he performed all the necessary self-care behaviours to look after his diabetes. As with Mr K, Mr F's partner played a significant role in looking after his diabetes; however, the extent to which Mr F's partner took responsibility for his diabetes and health was much greater. Mr K acknowledged his wife's part in finding out about diabetes and keeping an eye on what he was doing but Mr F reported an altogether greater joint responsibility. When talking about performing self-care behaviours, in particular what he ate, Mr F described how his partner had complete control over what he ate by preparing all his food and providing written instructions in his lunch box about what he should eat and when:

"she writes it all down, oh yeah, I find little notes in me box, you will eat this eat this biscuit, alpine good biscuit, yeah nice, like cardboard."

Mr F, type 2, high self-care

There may have been several consequences of this joint responsibility. As mentioned earlier, by accentuating the 'diabetes diet' by way of the precise eating instructions Mr F's partner may have reinforced the view of diabetes making Mr F 'different'. It raised the question of the consequences and impact on self-care behaviour for Mr F if his partner was no longer there. In addition, joint responsibility may result in issues if something went wrong, for example if Mr F developed serious diabetes complications. By taking joint responsibility for Mr F's health his partner may have taken on an element of responsibility and blame for any potential negative consequences of his diabetes.

Summary – Myself and my diabetes

1) The majority of the interviewees considered themselves to be 'normal' despite having diabetes; however the three men with type 2 diabetes considered that their diabetes made them different from the general population and 'different'.

2) For the majority of the interviewees their roles and status were to do with being a member of a family or their working life. In contrast the men with type 2 diabetes used diabetes as a primary role in their life and it provided status for them.

3) One of the men with type 2 diabetes had adopted the sick-role.

4) Three of the interviewees, with type 2 diabetes, had made an active decision to take control and responsibility for their diabetes.

5) Four of the interviewees, with type 1 diabetes, had integrated their diabetes into their everyday life.

6) Two of the interviewees, with medium and low self-care behaviour felt that their working life stopped them from looking after their diabetes to the extent they would like to.

7) Two of the interviewees, both men with type 2 diabetes, described how their diabetes controlled their lives.

8) Two of the men interviewed (both with high self-care) shared responsibility for their diabetes self-care with their partners.

4.5 Emotional experience

Throughout the interviews there emerged a pattern of emotional experiences common to all of the interviewees. Regardless of whether the interviewees had adapted to their diabetes or adapted their diabetes to their lifestyles, the emotional journey they went through was the same, with the exception of Mr G who will be discussed in more detail later. Four stages in the emotional journey were described:

1. Reaction to the diagnosis

2. Acceptance of the diagnosis

3. Specific events causing emotional upheaval

4. Everyday emotional experiences.

The emotions experienced during certain periods of the interviewees' lives were expressed verbally but also more importantly by their tone of voice, body language and facial expressions during the interview.

4.5.1 Reaction to the diagnosis

The majority of the interviewees expressed their shock at their diagnosis with diabetes, even those who were knowledgeable about diabetes (such as practice nurse Ms J):

"I was thinking well I've got this, this, this doesn't look very good. I'd better do my blood sugar when I get to work so I did my blood sugar and it was 23 and I looked at the monitor and though oh shit this can't be right [laughs]"

Ms J, type 2, high self-care

The shock at diagnosis was accompanied by a range of emotions. Mr B, Ms C, Mr G and Ms L (all with type 2 diabetes) described feeling scared or frightened at their diagnosis:

"you know this a life a life long….. and it was scary it was scary. I mean had I been a more less robust person I would have probably cried or something…"

Ms C, type 2, medium self-care

Mr D expressed his anger about the consequences of his diagnosis on his army career and this anger continued throughout his interview in terms of the unfairness of what had happened to him:

"Oh I was choked and angry, very shocked and angry cos I thought, shows how much I knew, ….Said you ain't going anywhere, you're finished. Yeah, you're finished. I just realised and went ok fair enough. So when I got out I was still really gutted…"

Mr D, type 1, low self-care

Relief was described by Mr F, Ms M and Ms J as a result of having a diagnosis to explain their various symptoms.

4.5.2 Acceptance of the diagnosis

Acceptance and adjustment to having diabetes was seen by the interviewees as an important aspect of their emotional experience of diabetes. Three of the interviewees (Mr B, Ms J and Ms L - all with type 2 diabetes and medium or high self-care behaviour) described how they took an active decision to deal with their diabetes diagnosis and to take control of the situation:

"yeah, once I became diabetic I thought I'll study it, and I go on the internet ...I'm out on a limb, I'm on my own here I've got to get it sorted meself and I did and that made me look more into it..."
Mr B, type 2, high self-care

This active decision appeared to be a turning point where practical coping strategies were decided upon and implemented to replace the fear, anxiety and uncertainty caused by the diagnosis. Mr D described how after his diagnosis and because of the anger he felt about the consequences of his diagnosis on his career and self-image, he was in denial about the effect that diabetes would have on his life and as a consequence did not tell people he worked with about his diabetes until he was in a situation where it was important for his health that they knew:

"At the time I thought it was a weakness and after I come out of the army I say I can do anything and I said I can still do anything and I tried to do it. But obviously over the years I realised..... But when I went to [current employment] I told them and I told the people I worked with cos it's changed..... I had one er incident I was having a hypo ....."

Mr D, type 1, low self-care

Mr D as well as Ms C and Mr H (with medium or low self-care behaviour) did not describe an active process of deciding to take care of their diabetes but described an attitude of making the best of the situation and coping with their diabetes within their lives:

"Quite quickly. I mean I didn't have any time off. I went straight on to the injections and just got on with it. Life went on as I say.....well it's either that or die really isn't it so you just have to get on with it."

Ms C, type 2, medium self-care

4.5.3 Specific events causing emotional upheaval

The exceptions to the two sub-themes above were Ms E and Ms M, who both had type 1 diabetes and were the interviewees diagnosed at the youngest ages. Although Ms M described feeling some relief at finding out what was making her so thin there were few clues to their emotional experiences that emerged from the interview data. However, the young age of diagnosis for these two interviewees did mean that they had diabetes during a particularly important period of their lives – pregnancy – unlike any of the other interviewees. The interview data suggested that Ms E (who had her children

approximately 20 years ago) experienced significant anxiety about whether or not she could have children due to comments made by her doctor when she was younger:

"Um, I was told when I was first diagnosed that I would never be able to have children by the doctor then and at that time I thought (shrugs) but you know that did bother me for a long time that I wouldn't be able to as I got older and then you know I went to see the doctor and he said well of course you can, you've got a womb haven't you?!"
Ms E, type 1, medium self-care

She described relief at finding out that she could have children despite her diabetes and pride in her successful pregnancies and breast feeding experiences:

"My file in fact, my GP still quotes my pregnancies to other diabetic women because I kept my blood levels so good all the way through both my pregnancies I was really, really lucky. Um, I was also told by a nurse at the hospital that I wouldn't be able to breast feed cos I was diabetic so I breast fed B for 14 months and M for 12."
Ms E, type 1, medium self-care

In contrast to this Ms M had no doubts about her ability to carry a child, worked very hard at maintaining low HbA1c levels with the support of health care professionals and yet had a very different experience on giving birth. Her child experienced severe difficulties immediately after being born and as a result Ms M described her distress, grief and despair about what happened and how it was dealt with. Ms M described being judged by health care professionals

about her control of her diabetes during pregnancy and her own responsibility for the ill health of her child. The interview data hints at the guilt and personal responsibility she felt for the condition of her child and the frustration and anger about the fact that she did everything as it should have been done and yet her child was ill and she was blamed for this by other people:

"I'd always been led to believe that if you had decent HbA1cs you'd have a nice normal sort of baby and it didn't happen in my case. If somebody had said to me we're we will do our best um and if you've got normal HbA1cs things should be ok but there's a possibility that would have saved an awful lot of distress on our, on our part. We don't know if everything's down to me being diabetic but um she, she, I was very, very unwell.....um it was just such a shock...."
Ms M, type 1, high self-care

There were other specific events which caused emotional upheaval which emerged from the interview data. Mr B, Ms E, Mr F, Ms M and Mr K (with medium or high levels of self-care behaviour) described how either personal or vicarious experience of diabetes complications had accentuated the worry and fear of complications for them.

"[Complications] can be quite nasty um a friend of mine that had I don't know if you can call it severe diabetes because I mean diabetes is diabetes but hers was um not through her own fault a lot harder to control than mine and hers was actually a late onset diabetes...."
Ms E, type 1, medium self-care

234

4.5.4 Everyday emotional experiences

The interview data suggested that the majority of the interviewees (ten out of eleven) had reached a point in their emotional journey where the intense shock, confusion and fear at diagnosis had been replaced by a range of emotions which were lived with on a daily basis. The worry and fear of complications remained; however, it appeared to be tempered by an understanding of what could be done to prevent complications and an acceptance of the risks being taken in exchange for particular lifestyles and the part that chance played in developing complications:

"fair enough I can see that but it can happen, it might not happen I'm nay trying to do it, I'm just doing what I usually do. And just juggle the figures. That's what it's about. That's why it's called balance [laughs]."
Mr D, type 1, low self-care

The fear or worry about complications may have been tempered but there were other fears which were not fully recognised by the interviewees at the point of diagnosis of diabetes and only developed through personal experience of living with their diabetes, regardless of type of diabetes or gender. One of these fears was of hypos. There were six out of eleven interviewees who described feeling worry or fear of having hypos (three with type 1, three with type 2 diabetes and four high self-care, two with medium or low self-care). Mr D and Mr K had had bad hypos whilst driving and as a result performed frequent tests to ensure they did not have a hypo at the wheel. Ms C and Ms L were generally concerned about having hypos:

"I never leave the house without dextrose and a mobile phone, I mean even a 5 minute,….. If I walk down the shop and get halfway down the hill and its only 3 or 400 yards and I don't have dextrose I'll go back again"

Ms L, type 2, medium self-care

Both Ms M and Mr F had had personal experience of bad hypos and wanted to avoid having them again. Interestingly Mr B mentioned being worried about hypos but he had an alarm fitted so if he was feeling unwell he could press it and get help from an outside agency and this allayed his fears.

For three of the men interviewed (Mr D, Mr F and Mr K) anger emerged in response to various limitations placed on their lives by their diabetes – driving, career and financial consequences:

"when I applied for my licence the last time they ….they took it down to a year whereas we had it for 3 years …. but I'll be grieved if I don't get one, well, I would I think I would be upset cos I mean I've tried, …I would be absolutely gutted if they said well you can't drive no more you know I think there's some people that would like us to stop driving."

Mr K, type 1, high self-care

Several interviewees (Mr B, Ms E, and Mr H) felt embarrassed and stigmatised about doing injections in public:

"I've seen people actually do their injection up front, if they're sitting in a café or something they'll just do it but I just I don't know I can't...I've thought about it a few times but I just haven't done it yet you know would people wonder what I'm doing?"

Mr H, type 1, low self-care

There were three male interviewees (Mr D, Mr F and Mr G) who mentioned emotional consequences directly due to their diabetes. These emotions were described in relation to fluctuating blood sugars (either high or low) and took the form of anger or depression. None of the women interviewed reported that their fluctuating blood sugars resulted in fluctuating emotions. The impact this had on their partners was particularly important to the male interviewees:

"I suppose my wife, ..., well she knew nothing about it, but she's seen all the stages now, being on the table wanting to be a tree and things like that. ....and she's gotta pick up the pieces...."""

Mr D, type 1, low self-care

The emotions mentioned so far, with the exception of relief, have all concentrated on the negative side of the spectrum; however, there were positive emotional experiences that emerged from the data. Several interviewees, in particular Mr H, told of how they felt disappointed if their blood sugars were higher than they would like:

"For me it would probably be about 9 to 11 or something like that if it was really high for me it would be something like 14 to 16 you know and then I think wow [laughs] that's bad..... Yeah, disappointed."

Mr H, type 1, low self-care

However, they also felt pleasure and pride when their blood sugars were within their target range:

"Yeah, I feel satisfied. [Laughs} I think oh you clever girl."
Ms L, type 2, medium self-care

In addition to this, some interviewees (Mr B, Ms E, Ms M, Mr K and Ms L – with medium or high levels of self-care behaviour) felt satisfaction, pride and pleasure when they were praised by health care professionals. A strong determination was expressed by several of the interviewees with high self-care behaviour (Mr B, Ms M and Ms J) to strive to do their best and to succeed at looking after their diabetes:

"you know I do the best I can to um sort out my diet, exercise, lifestyle, food, insulin balance and I just think well you know I've given it my best shot and, and that's kind of gonna have to be good enough. If things go wrong which they haven't so far then at least you know I've tried so."
Ms M, type 1, high self-care

Other positive emotions that emerged from the interview data were hope and gratitude. Five interviewees (Mr B, Ms C, Mr D, Ms E and Ms M) told of feeling hopeful about the future, hopeful that they would avoid complications and hopeful that a cure or better treatment would be discovered to help either themselves or their children. There was a significant sense of relief and gratitude pervading five of the interviews. This seemed to relate to the fact that it could have been much worse, that diabetes was not as bad as many other illnesses and conditions a person could have and that relatively speaking they were lucky to only have diabetes:

"I thought don't be daft [laughs] he could have told you its cancer or something, it's only blooming diabetes. ….I figure I got away with it for 40 odd years [Laughs] so I'm lucky."

Ms L, type 2, medium self-care

The interviewees who mentioned this were all women – Ms C, Ms E, Ms M, Ms J and Ms L – with no mention of being lucky that it was not worse from any of the men. In fact one man, Mr B, directly contrasts diabetes to cancer and considers it to be worse because there is a cure for cancer and not for diabetes (see quote on p. 216).

Mr G has not been mentioned throughout the previous discussion about the emotional journey, from diagnosis to everyday emotions. He was the exception to the general pattern in that he described shock at diagnosis and his reaction shortly after diagnosis (such as fear or depression as mentioned by other interviewees such as Mr B and Ms L); however, he seemed to be stationary at this post-diagnosis position which may have been due to his adoption of the sick-role. He spoke of intense anger, confusion and distress due to his diabetes despite being diagnosed for eight years:

"Yeah, yeah. Makes me angry. I never I never go I go higher and higher. I know my sugar counts high in any case but if I did it I've done it, I've checked it and then when I've had an argument over just something stupid and I know it's gone up. ….nobody's ever sat down this is what this is and this is what that is. "

Mr G, type 2, low self-care

He found that doing blood tests made him depressed. He had regular mood swings which involved feeling angry, depressed and helpless and told of how he would cope with these emotions by drinking or avoiding people:

"It's like now I know it's stress, if I get wound up or I get really you know irritated I get sort of snappy yeah I know and I just go and sit in a room or I go and do something different or have a drink and I can calm myself down sometimes..."
Mr G, type 2, low self-care

It appeared that for some reason, possibly his lack of knowledge about diabetes and his lack of desire to find out about it independently from the health care professionals or his adoption of the *sick role*, he had not made the same emotional journey that the other interviewees described successfully navigating. Despite the lower levels of self-care behaviour for some of the other interviewees (for example Mr D, Ms C and Mr H) they appeared to have adjusted emotionally to their diabetes and gone through an adaptation process. Mr G did not seem to have done this.

Summary – Emotional Experience

1) The majority of the interviewees described feeling shocked, scared, angry or relieved at their diagnosis with the exception of two women with type 1 who were diagnosed as young children and could not remember much detail about their reactions to their diagnoses.

2) Three interviewees, with type 2 diabetes, described making an active decision to deal with their diabetes and how this led to acceptance of their condition.

3) The two women with type 1 who were diagnosed as children had experienced emotional upheaval due to their pregnancies.

4) Five interviewees with medium or high levels of self-care behaviour (type 1 and type 2 diabetes, men and women) described fear and worry as a consequence of personal or vicarious experience of diabetes complications.

5) Six of the interviewees (type 1 and type 2 diabetes, men and women) reported feeling worried about having hypos.

6) Three of the men interviewed experienced anger as a consequence of how diabetes limited their lives in terms of career or driving.

7) Five interviewees (all with high levels of self-care behaviour) described feeling proud when their blood sugars were being controlled.

8) All the women who were interviewed mentioned feeling lucky and a sense of relief that they only had diabetes and that it could have been a much more serious condition. None of the men described feeling that way.

4.6 Consequences of my diabetes

The interviewees described many different consequences that had occurred or might occur due to their diabetes. There were five sub-themes of consequences which emerged from the interview data: *practical, physical, future* and *positive* consequences. The consequences the interviewees described were for themselves their partners and children.

4.6.1 Practical consequences imposed by others

There were three main areas which were described by the interview participants where diabetes had a consequence on practical non-diabetes specific aspects of life: employment, financial and driving. Significant consequences were felt by five of the interviewees on their past and prospective employment prospects. No differences between those interviewees with type 1 and type 2 diabetes emerged but there were differences between men and women. Mr D, Mr F, Mr G and Mr K (all men) explained how their diabetes had had a significant negative impact on their employment:

"obviously I never knew that but obviously I was told by my old man and then like you say that's it. Served 12 years in the army that finished my career. Somebody just told me I had it...Yep, Yep I would have done 22 easy. Takes some man 5 minutes reading it out of a book to say you're finished. Was not happy."

Mr D, type 1, low self-care

Only one woman who was interviewed, Ms M, mentioned her diabetes as having negative consequences for her employment. Whilst arranging work experience as part of her nursing training she was unable to take a placement on an ambulance crew despite planning for any possible consequences of her diabetes:

"People do close doors to you…..when I arrived at the ambulance station and they realised I was diabetic they said no. I do know that doors are closed to me with different jobs."
Ms M, type 1, high self-care

She also felt it necessary to hide her diabetes when going for job interviews. However, her diabetes did not prevent her from having the career she wanted, rather she was forced to adapt what she did to accommodate her diabetes, such as choosing different work experience.

The limitations caused by diabetes for three of the men who were interviewed in terms of career had definite financial consequences. This was mentioned by Mr D, Mr F and Mr K:

"Er the worst bit, [pause], the worst bit is hypos and not really being able to do the things I used to do like lorry driving and all that you know, that is the worst thing with it especially money side of it I can never earn now what I could earn on the lorries you know,"
Mr F, type 2, high self-care

There were also other financial consequences felt by five of the other interviewees. Mr B felt that the food he ate as part of his dietary self-care was

much more expensive than the food he ate before he was diagnosed with diabetes. Mr G was unable to work as a result of his diabetes and found living on disability benefits left him in a significantly worse financial state than when he had been working. In addition his wife was unable to work as she had to care for him and that made their financial circumstances much worse:

"Yeah, you can't work, so I've got no money to work. And it's really hard to live on. ....cos the wife can't work ....in the end it was costing me £20 to send her to work and I was losing rent and everything so I said no so she stopped so of course she's at home all the time and she's giving me earache you know cos she can't work.."

Mr G, type 2, low self-care

The other financial consequence of diabetes mentioned by three interviewees (Mr D, Mr H and Ms M) was getting insurance, such as life, car, wedding and travel insurance. All three of these interviewees expressed frustration that they considered themselves to be the same as people without diabetes, that they looked after themselves and felt they were penalised when they should not be. Significantly all of the men who were interviewed mentioned financial consequences whereas it was only Ms M who brought up the subject from the women who were interviewed. Ms M had only recently got married and so had just recently had to purchase wedding insurance and it was quite prominent in her mind. In contrast, although one of the men interviewed (Mr D) had recently been purchasing insurance the rest of the men interviewed were not talking about a specific recent financial consequence but more of an overall financial consequence and therefore this gender divide is quite significant.

Another important, practical consequence for the interviewees was the effect of their diabetes on driving. None of the female interviewees mentioned driving in relation to their diabetes; however, all six of the men who were interviewed brought up driving and the effect of diabetes on driving in some way. Four of the men interviewed (Mr B, Mr D, Mr K and Mr G – high and low self-care, type 1 and type 2 diabetes) described having a problem with their diabetes whilst driving. Mr B had to stop driving altogether after failing to detect a hypo when behind the wheel. Mr D and Mr K had both had bad hypos whilst driving and were stopped by the police and had become very cautious and performed blood tests before driving:

"I'll test before I drive ....so sometimes its 5 or even 6 tests......, [his doctor] always advised it,... I did have a funny turn at the wheel. .....so ever since now, well now, I really do test and make sure I'm right, make sure I have plenty when I'm in there I need,"
Mr K, type 2, high self-care

And Mr G felt unable to drive for long distances without somebody with him in case he experienced physical symptoms due to his diabetes and had to stop.

The government policy of people with diabetes renewing their driving licence every three years (or every year for Mr D and Mr K who had experienced undetected hypos at the wheel) was mentioned by four of the men interviewed – Mr D, Mr F, Mr H and Mr K. Significantly none of the women interviewed mentioned driving or renewing driving licences. This obvious difference between men and women in terms of the importance of driving is striking. All of the women interviewed drove on a daily basis for work and so would have to renew their licence as regularly as the men however none of them raised it as

an issue. Five of the six men had negative experiences of their diabetes when driving (undetected hypos) and as a result this may have made the issue of driving and diabetes more prominent for them.

4.6.2 Practical consequences imposed by self-care regime

The interview data suggested a variety of ways that looking after themselves impacted on the interviewees' lives. There were four main aspects that emerged as most prominent for the interviewees: *restriction and freedom, continuous routine, constant planning* and *balance.*

Restriction and freedom

Food was an important area of restriction for nine of the eleven interviewees. Mr B, Ms C and Mr F (all with type 2 diabetes) were very aware of the type of food they should be eating. In particular Mr B and Mr F spoke at length about the way their diet was adapted for their diabetes and how they felt they were restricted from eating certain types of food:

"That is a difficult one that one. I mean I go in to Thorntons take a deep breathe with the nose and the mouth and you get the smell and the flavour and that's it. And then walk away."

Mr B, type 2, high self-care

There were five interviewees (Ms E, Mr H, Ms M, Ms J and Ms L – three with type 1 diabetes, two with type 2 diabetes, two with high self-care, two with

medium self-care and one with low self-care) who felt restricted by the need to eat when they did not want to. They all described having to force themselves to eat when if given a choice they would not have, for example when ill and feeling sick or early in the morning when they were not a natural breakfast eater:

"If there was one thing I could change about diabetes it would mean that I didn't have to eat breakfast in the morning cos I would really much rather have a cup of coffee and then go off to work...."
Ms E, type 1, medium self-care

Four of the interviewees (Mr D and Mr G – men with low self-care – Ms M and Ms L – women with high and medium self-care) explicitly stated that they ate what they wanted and were flexible about diet. Mr D, Ms M and Ms L described eating what they wanted to but adapting the insulin they took to meet the demands of their diet and so maintaining good control of their diabetes:

"I think at the beginning obviously in the old days when I first got it I had to measure stuff out ....Cos it was all at that stage you did what you were told and I thought this is bollocks so we just started I'll eat what I want. Obviously I don't go eating tons of sugary stuff but I'll eat when I want, when I do then I'll sort it, that's how I look at it, I'll sort it. "
Mr D, type 1, low self-care

In contrast Mr G ate what he wanted but did not have the necessary skills or knowledge to adapt his insulin doses to accommodate his flexible diet. This contrast between Mr G and the other three interviewees fits in with the idea of Mr G taking on the sick role as discussed earlier. Mr D, Ms M and Ms L (high and low self-care) did not see themselves as 'sick' and so had assumed the

responsibility for their own health and self-care behaviour. By taking on the 'sick role' Mr G had put himself in the hands of the medical profession and so did not perform the behaviours necessary to maintain a flexible lifestyle without jeopardising diabetes control.

There were four interviewees (Mr B, Mr D, Mr F and Mr G – all men, two with high self-care, two with low self-care) who felt they had to take their medication (including insulin injections) at specific times of the day and that this led to restrictions on their life, particularly in terms of having a lie in:

"I could lay in bed all day long if the pleasure took me but now ...there was something inside that said wake up its time to do a blood test so there is like a small sort of alarm clock inside which is saying you are diabetic go and do a test..."
Mr B, type 2, high self-care

Continuous routine

All of the interviewees described a continuous, regular routine with regards to their diabetes. They had developed strategies over time to help them to incorporate their diabetes within their lifestyles, for example Mr B and his jelly mould container for the syringe he was using that day:

"Cos I usually use the same needle all day long and then throw it away well I what I do to mark it, the plastic cap on the end of it I put that into my sin bin so I know which needle I'm using, that sin, I've got a mould from a mousse um which it's the chefy thing, ...I got one of those sitting there, the two insulins in there, insulatard and novomix and the needle"

Mr B, type 2, high self-care

Even Ms M and Ms L, who described their lifestyles as very flexible and changeable, also detailed routines and guidelines they used on a regular basis to work out what they needed to do to look after themselves. For example Ms M followed certain rules when adapting her insulin requirements to different meals at different times:

"I knew that my blood sugar had dropped a little bit um was dropping this afternoon so instead of taking my um testing my blood sugar then I had something to eat, had something long lasting and did it a little time after to make sure it had come up to 7.6...."

Ms M, type 1, high self-care

The interviewees who had lower levels of self-care, such as Mr G, Mr H and Mr D, also had regular routines in their life which allowed them to deal with their diabetes; however their routines did not involve the diabetes self-care behaviours but did involve coping strategies for living with their diabetes. For example, when Mr H was at work he did not do any blood tests or eat at regular times but he had learnt when he was most likely to have a hypo and how to counteract this whilst at work:

"I don't do a blood test on working days no so I'd have breakfast about half 7,

....and then depending on the workload I'd think about lunch between half past

12 to half past 1......The longer it goes on, the longer it goes on there's more

chance of a hypo coming on I can feel that there might be a hypo coming"

Mr H, type 1, low self-care

Despite these continuous routines the majority of the participants had

experienced periods in their lives where their diabetes did not respond in its

usual way to their self-care and described how they had adapted their routine to

cope with these fluctuations and the dynamic nature of their diabetes:

"sometimes later on or not I mean I am a bit hit and miss with that ....if things

have been a bit unusual I will test more regularly."

Ms C, type 2, medium self-care

There emerged an impression of resignation to the routine, of accepting it was

necessary, finding it frustrating at times but developing techniques for

integrating what the individual interviewee thought was necessary into their

lives. During the interviews many of the interviewees found it difficult to

describe what they did to look after themselves with regards to their diabetes

due to the integral nature of their routine. For example Mr H only mentioned

blood testing and taking his insulin injections to start with despite performing

many other self-care behaviours such as diet and hospital visits.

Ms C summed up the automatic, continual nature of the diabetes regime very

succinctly:

"Well, it's boring really, that's all I can say it's boring and tedious that's about it....., the routine of it."

Ms C, type 2, medium self-care

Constant planning

The interviewees all described the need for additional consideration and planning because of their diabetes in one form or another. This planning allowed them to perform the self-care behaviours that were necessary and to cope with the restrictions that they felt the self-care regime placed on them in terms of what they were able to do and when. The need to plan was constant and continual which is understandable considering the, previously described, continuous and never ending nature of the diabetes self-care behaviours performed.

Three interviewees (Mr F, Ms M and Ms L) expressed their frustration with the constant need to carry equipment related to diabetes and glucose in case of hypo:

"I'd love that. I'd love to go out without all the paraphernalia I'd love to just go out and not have to worry about taking anything with me but um and that's not meant to sound miserable or down..."

Ms M, type 1, high self-care

The need for planning before going on holiday was raised in the interviews by four of the interviewees. Ms E, Mr F, Mr G and Ms M (low and high self-care) all raised the need for extra planning if going abroad, for example Ms E described discussing how to adapt her insulin plan with the diabetes consultant at the

hospital before going on a long haul flight. Another factor which needed to be planned for was allowing the time to perform the necessary self-care behaviours. Four interviewees mentioned the time they spent on looking after their diabetes (Mr B, Mr G, Mr H and Ms J – high and low self-care). For example, Mr B described how he spent time looking at every food label before buying his shopping:

"you've got to monitor everything that you're doing, like I said your glycaemic index has got to be changed um you see people in the stores and they're looking at the tins, oh I can have these baked beans they're no problem I pick up a tin of baked beans I think reduced sugar,"
Mr B, type 2, high self-care

The necessary medication taking and blood testing also took time which a person without diabetes would not have to spend looking after themselves. For example, Mr G had twenty-five different tablets to take on a daily basis:

"[Shows very long repeat prescription] and there's a few missing off that cos I've got one that's a tablet that I've been given to help me lose weight which is a new one and I've got this one.....Its 25 now.....I've just done one for 25 and I've got the oxygen at home.....There's me tablets, me shake rattle and roll job."
Mr G, type 2, low self-care

Mr H used the lack of time as a reason for why he did not do any blood tests whilst at work. However, Ms J (who was a practice nurse who dealt on a regular basis with people with diabetes) explicitly stated how little time blood tests take and how she felt that it was a poor excuse for not doing them:

"people come in and say I don't have time to do my blood sugar in the morning I'm like well it takes 2 seconds you know you do it stick it go and do something else while its cooking and goes ping and you look at it."

Ms J, type 2, high self-care

In addition to the daily diabetes self-care behaviours required, all of the interviewees attended the hospital for diabetes check-ups on a regular basis and had their eyes screened. In addition to this some of the interviewees (for example Mr B, Mr F, Mr G, Mr K) saw a podiatrist, their GP or other health care professionals as a consequence of their diabetes. All of these appointments took planning and time to fulfil the needs of being a person with diabetes.

Mr B and Ms J (both with high self-care) described the time taken on performing self-care behaviours as necessary for their diabetes and Mr G (with low self-care) felt that his medication was equally essential for his health; however Mr H (also with low self-care) considered that when at work blood testing could be neglected which suggests a connection between how the individual viewed the importance of the self-care behaviour and whether they performed it or not. Therefore this suggests a possible difference in those with high self-care and those with low self-care in terms of the self-care behaviours they feel are vital and those that are not. This relates to the placement of priorities as discussed in the next section on balance.

Balance

The need for balance between the self-care requirements of diabetes and everyday life was an issue raised by the majority of the interviewees. For some

of those interviewed, for example Ms C, Ms M and Mr D, this was explicitly stated:

"I mean I do try to be good. I don't um you know I suppose I'm always thinking you know.... And it sort of affects the quality of your life so there has to be a balance doesn't there."
Ms C, type 2, medium self-care

The majority of the remaining interviewees also described experiences and examples of finding a balance between their lifestyle and their diabetes. Sacrifices were made and choices about the priorities for the individual led to the pattern of the interviewees' self-care behaviour and the consequences of those self-care behaviours on their lives. The threat of complications was important for the majority of interviewees but it seemed that there were other priorities, advantages and disadvantages to the self-care regime that were of equal or even greater importance.

The priorities for each interviewee were distinct. For those interviewees with high self-care[4] the advantages gained by performing high levels of self-care behaviour were important for the individuals and their lifestyles. Mr B and Mr F had lives where their diabetes outweighed their previous lifestyle but had positive consequences on the healthiness of their lifestyles now. Mr B had made an active decision to look after his diabetes as best he could by following all the advice he could find encouraged by his experiences of diabetes as marking him as 'different'. Mr F's rigorous self-care was led by his view of diabetes as something which made him 'different' but also largely by his partner

---

[4] Level of self-care behaviour based on composite score from SDSCA questionnaire (see chapter 2 p. 104 for more detail)

and her control over his eating and general lifestyle. Ms M and Ms L had chosen flexible diabetes regimes in order to fit around their active and changeable lives but had also made the decision to look after themselves in order to function for their family and work. Interestingly the extent to which this choice related to their diabetes self-care was different for Ms M and Ms L. Ms M reported very high levels of self-care whereas Ms L reported medium self-care behaviours. Another interviewee to report medium levels of self-care was Ms E. She was diagnosed at a very young age but still made conscious decisions to maintain aspects of a rigid regime as any blood sugar fluctuations made her feel unwell. However, there were aspects of diabetes self-care that she chose not to perform as she did not feel they had a direct influence on her blood sugar levels.

For those interviewees with lower self-care the disadvantages of performing high levels of self-care behaviour were too many to fit with their competing priorities and so they performed the self-care behaviours that gave them enough benefits in order to live the life they wanted to but without the disadvantages that would prevent them from doing so. Mr H performed high levels of self-care behaviour whilst at home but on working days his self-care was reduced to just doing his injections because he had decided that his work and his role of manager did not allow him time or space to do the self-care behaviours he would otherwise have done. Mr D and Ms C (with medium reported self-care on the questionnaire although Ms C considered herself to have low self-care) had both incorporated the self-care behaviours necessary to function at work and in their family life but chose not to perform additional self-care behaviours that could have a negative impact on their working life or family lifestyle. Finally Mr G felt he had no choices about what he did to look after his diabetes and the impact this had on his lifestyle because of his lack of

knowledge about diabetes and how it affected him; however this in itself was a choice and decision he had made. The education and knowledge about diabetes is freely available from health care professionals, the internet and books which he had access to and it was Mr G who himself had decided not to look for this knowledge but to hand over control and responsibility to others and conform to the sick role. (For a more detailed discussion of this sub-theme see chapter six p. 372)

Ms J made an interesting point that the ease of adjusting to and incorporating looking after diabetes into a lifestyle depended on the lifestyle that was being led before the diagnosis. She described herself as someone who liked routine, who enjoyed exercise and who was not really focussed on food which meant that when she was diagnosed with diabetes the adjustments necessary to her lifestyle were minor and easy to implement:

"I'm not really bothered by food. I live you know I eat to live I don't live to eat….. and I think well I don't need any more I don't want it, it doesn't bother me…"
Ms J, type 2, high self-care

4.6.3 Physical consequences

Excluding the possibility of future diabetes complications (which will be discussed at the end of this section) there were a range of physical consequences to having diabetes experienced by the interviewees. Two of the interviewees (Mr B and Ms E) felt that they caught and recovered from other medical conditions or illnesses slower as a result of their diabetes:

"I think I don't heal as well. Um, just cuts and grazes or things like that tend to take longer to heal on me and things like flu and that or perhaps last, whereas some people would be back at work after 3 days it might be 5 or 6 before I can get back because um I think anything else that goes wrong is slightly complicated."

Ms E, type 1, medium self-care

Ms M had experienced traumatic consequences of her diabetes during and after her pregnancy as described in more detail in the *emotional experiences* theme. There were four interviewees who described day to day physical consequences of their diabetes. They all had type 2 diabetes - Mr B, Ms C, Mr F and Mr G. All four of these interviewees reported being more tired as a consequence of their diabetes and less able to be physically active. In addition to feeling more tired, Mr F had experienced erectile dysfunction as a consequence of his diabetes and Mr G described a list of physical ailments which were attributed to his diabetes such as lumpy injection sites, weight gain, red eyes and loss of temperature control. Mr B was single, however Mr F and Mr G had partners and described clearly the effect these physical consequences had on their partners:

"hormones, yes very, very low, I've hardly got any hormones in my blood evidently so [his doctor] said the other week and they give me this gel but its so frightening to use it, I'm not allowed near the missus with it or anything when I've got it on, it could make her grow facial hair and all,...she was frightened of it as well so I said nah I ain't using that I ain't using that,"

Mr F, type 2, high self-care

The interviewees who experienced day to day physical consequences of diabetes all had type 2 diabetes and so, in contrast to the interviewees with type 1 diabetes, had a much clearer memory of how they felt physically before they were diagnosed with diabetes. This was particularly noticeable in the interviews with Ms M and Ms E who were diagnosed as children:

"KS: Do you get any symptoms because of your diabetes?

M: No. I wouldn't know the difference though would I [laughs]."
Ms M, type 1, high self-care

4.6.4 Future consequences

The future consequences of diabetes described by the interview participants had three main dimensions: for the interviewees themselves, for their partners and for their children. The possibility of diabetes complications in the future was a motivating factor for looking after themselves for the majority of interviewees (ten out of eleven). With the exception of Mr G, all the interviewees talked about avoiding complications in order to be healthy in later life.

"Yes, it is important because like I say later on in life I want to be I don't want to have any problems. I look after myself now when I I'll last longer [laughs] I don't want to be worried about my feet and stuff like that when I'm older bad feet, bad circulation, complications like."
Mr H, type 1, low self-care

As well as being healthy when older there were a few specific motivations such as being around to see grandchildren and being able to maintain their independence when older. Nine of the eleven interviewees had some form of vicarious experience of complications. Mr B, Ms E, Mr F and Ms L all knew friends who had experienced severe complications or died as a result of their diabetes and Mr D and Ms C had older relatives who had had severe diabetes complications:

"Insulin, but quite late onset, he probably had it for a number a long time it was just picked up when he, he went in for an operation in later life and it was picked up then…..but this was many years ago so things have changed since then. He did have to yeah, he was just about to have his leg amputated when he died."
Ms C, type 2, medium self-care

Ms M had experienced quite a traumatic incident as a child when newly diagnosed with diabetes and attending a diabetes outpatients appointment that had left a lasting fear of complications:

"one of the things that got me though was when I was 5 I was misdirected I didn't go to the paediatric unit, I went up to the um diabetic outpatients in the main building in the hospital and I saw these, they were two women with their legs amputated and I just said being 5 while my mums at the counter hello why's your leg been chopped off [laughs] oh because we're diabetic love, you don't want to be diabetic. And I was just like oh, and that was a kind of kick start, I don't ever want to be like that."
Ms M, type 1, high self-care

Ms J, who was a practice nurse, and Mr K, whose wife was a nurse, heard about people with complications on a day to day basis. Of the nine interviewees who reported vicarious experience of complications cited hearing or seeing of somebody else with severe complications as a significantly motivating factor in looking after their diabetes. In addition to these vicarious experiences Mr B and Ms L mentioned reading about diabetes complications in Balance (the Diabetes UK magazine) and how that motivated them to look after their diabetes.

Overall five of the interviewees had complications. Ms E and Ms M had background retinopathy but the only interviewees to report having existing severe complications were Mr B, Mr G and Mr K. Mr B and Mr K both stated that their existing complications and the need to prevent any further ones developing was an important factor in their current self-care behaviour. Mr B had complications soon after being diagnosed with type 2 so he had not changed his self-care behaviour in response to the complications. For Mr K the situation was similar in that his self-care behaviour had not changed as a result of the neuropathy and foot amputation; however, he maintained (and his self-reported self-care behaviour supports this) that he has always taken good care of himself:

"Looking after this foot [points to non-wooden leg] cos it's bloody hard having one leg and I don't think I'd be able to, well I would but it wouldn't be the same…. I don't think I've altered a lot, no I don't think, its always been about the same, always done what I've needed to do or what I need to do yeah, no I don't think there is a difference at all."
Mr K, type 1, high self-care

This was related to the attitude of five of the interviewees (Ms C, Mr D, Ms E, Ms M and Mr K – two with high self-care, two with medium self-care and one with low self-care) who felt that part of the probability of getting diabetes complications was down to luck and that although they tried their best to look after themselves they were not wholly responsible for the outcome:

"cannay do anymore. I'm playing the game and you just hope you get the good result of it. Now you can play the game and get the bad result. But what can you do? You can't do nothing. Without, if it's gonna happen to you it's happened. Then you just gotta think again and go oh. Can I cope without that? I suppose I can."
Mr D, type 1, low self-care

Mr G again contrasts with the rest of the interviewees. He had neuropathy and possible complications of the cardio-vascular system and yet appeared to be unaware of any potential future risks. When talking about complications he seemed to be living solely in the present and coping with his existing complications with no regard for future complications that may develop.

"KS: Do you think there's anything you can do to prevent getting more complications?

G: What on me feet?

KS: Yeah, or anywhere else.

G: No because I don't know what to do cos I don't know what I'm looking for."

Mr G, type 2, low self-care

This may be due to the fact he was the interviewee most affected by his complications at present and that they caused significant difficulty for him. However, Mr B and Mr K also experienced problems as a result of their neuropathy. Another possibility is that due to Mr G's seeming lack of knowledge about diabetes he may have been unaware of the progression of diabetes complications or considered that complications were a normal and unavoidable part of having diabetes. As mentioned previously Mr G's 'sick role' necessitates him to relinquish responsibility for his medical condition to health care professionals and as such perhaps he considered the possibility of future complications to be out of his hands and within the domain of the medical profession instead of his own responsibility.

The other future consequence that was mentioned by eight of the eleven interviewees was the possibility of passing diabetes on to their children. Two of the interviewees (Mr D and Mr F) had children who were overweight and as a consequence were concerned they would develop diabetes. Mr F described

how he encouraged his son to exercise in order to lose some weight and reduce his risk of diabetes:

"keep a strict eye on the boy cos he's a little bit overweight. ….the other week I see him I said J get your weight down boy get it down…"
Mr F, type2, high self-care

Mr B had advised his children to be tested for diabetes when he received his diagnosis. Ms E, Mr H, Mr K and Ms L also described being worried about their children; however, Ms E was slightly reassured by the fact they were now older than she was when she was diagnosed and Ms L felt that her children were now past the age at which they were likely to get type 1 diabetes:

"that is how I see it, to get type 1 so I figure they've gone past the type 1 so they've gotta wait for type 2. And they're all long and skinny so they're not gonna get it cos they're overweight and they're not Asian so they might be unlucky like me by which case they'll have a cure…"
Ms L, type 2, medium self-care

Ms J's circumstances were slightly different in that one of her sons had already been diagnosed with diabetes. She described in great detail how she encouraged him to look after himself to keep him healthy and how she encouraged her other son to do exercise in order to avoid developing diabetes.

4.6.5 Positive consequences

The majority of the consequences mentioned by interviewees were negative however there were five interviewees who mentioned positive consequences of having diabetes. Mr B and Mr F (both men with type 2 diabetes) described a positive consequence in the community that they had found through diabetes (discussed earlier in terms of roles and status) (see quote on p. 218). In addition to this Mr F also reported free prescriptions as another positive financial consequence of diabetes. The other three interviewees to describe positive consequences were Ms E, Ms M and Ms J (all women) who thought that their diabetes had led them to lead a healthier lifestyle:

"I wouldn't have thought so no. There's no bonus with it. I suppose in the way that it makes you think about your health a bit more and consider what you are eating a bit more."

Ms E, type 1, medium self-care

Summary – Consequences of my diabetes

1) Four of the men interviewed (with type 1 and type 2 diabetes) felt that their diabetes had had negative consequences on their employment experiences and prospects. One woman mentioned difficulties in terms of her career caused by her diabetes.

2) Other financial consequences were mentioned by five interviewees, such as eating more expensive food, being unable to work and getting insurance. It was

---

primarily men who found their diabetes had a negative consequence on their finances.

3) Four of the men (and no women) thought that their diabetes had a negative impact on driving.

4) Nine of the interviewees felt the food they could eat was restricted in some way. Three interviewees (all with type 2 diabetes) reported that they could only eat certain types of food and had to avoid other food they would have liked to eat. Five interviewees (with type 1 and type 2 diabetes) described having to eat when they did not want to because of their diabetes. Three of the interviewees (with type 1 and type 2 diabetes) felt able to eat what they liked and adapt their insulin to meet their requirements. The man with type 2 diabetes and low self-care who had adopted the sick-role ate what he liked but felt he did not know how to adapt his insulin or diet to look after this diabetes.

5) Four of the men interviewed (and no women) felt they had to take their insulin injections at the same time every day, regardless of type of diabetes. All of the interviewees had developed strategies for incorporating diabetes into their lives. The majority of interviewees commented on the continuous, tedious and inconvenient nature of the self-care routine.

6) All of the interviewees described the need for constant planning in order to ensure they could cope with various aspects of the self-care routine and the restrictions placed on them. For example, the need to carry round diabetes equipment, planning before holiday and looking at food labels when shopping.

7) The majority of the interviewees reported the importance of finding a balance between looking after their diabetes and maintaining a 'normal' everyday life. Individual interviewees had chosen different ways to do this depending on their lifestyles, priorities in life and individual preferences.

8) Physical consequences discussed by the interviewees included getting other illnesses more easily (type 1 and type 2 diabetes), being more tired and less

physically able (type 2 diabetes only), erectile dysfunction and other physical ailments such as lumpy injection sites and weight gain (men with type 2 diabetes only).

9) The majority of the interviewees talked about avoiding the potential future consequence of diabetes complications. Nine of the interviewees had vicarious experiences of complications which all of them considered to be a highly motivating factor for looking after their diabetes. Five of the interviewees had existing complications but it emerged from the interviews that seeing others with very severe complications was more motivating than experiencing complications personally, particularly when they were minor such as background retinopathy. No differences in this regard were found between type of diabetes or gender.

10) Only the two men with type 2 diabetes described meeting others with diabetes as a positive consequence of their diabetes.

11) Three of the women interviewed (and no men) felt a positive consequence of their diabetes was that they now led a healthier lifestyle.

4.7 Self-efficacy

Self-efficacy was a difficult concept to enquire about directly and as a consequence the interviewees' self-efficacious beliefs emerged throughout the interviews encompassed within many of the issues previously discussed. When the interviewees were asked about their self-efficacy regarding their diabetes invariably the answer was positive; however, whilst talking about aspects of their diabetes (such as how they looked after their diabetes, the emotional experience of diabetes and the consequences of diabetes), the interviewees self-efficacy beliefs emerged in two ways – through how they described how they felt and what they did, in terms of the language used and tone of voice, but also direct and overt statements of self-efficacy surrounded by other aspects of the diabetes experience. Three aspects of self-efficacy emerged from the interview data:

1. How self-efficacy developed

2. Self-efficacy beliefs held

3. Outcome expectations and achievement of goals

4.7.1 How self-efficacy developed

There were eight main ways in which the interviewees suggested their self-efficacy beliefs were developed or which emerged from the interview data as it was analysed: *personal experience, social persuasion, vicarious experience, personal research and knowledge, continuous automated routine, no option but to do it, with the aid of partners* and *affective states.*

The most important influence on developing self-efficacy came from the interviewees' *personal experience* of their diabetes. All the interviewees described how living on a day to day basis with diabetes had caused them to experience different situations and learn how to (or how not to) cope with the situation and resulted in developing self-efficacy (or not) in their abilities to deal with those situations. For example, Ms L described learning how to alter her insulin doses to cope with eating different amounts:

"that's just something I've learnt, if I'm having a big meal and I have plenty of insulin it goes through too quickly so I wait a couple of hours and have a top up and then bedtime, um, the slow acting."
Ms L, type 2, medium self-care

As a result of this she felt that she could adjust her insulin doses correctly as and when required, demonstrating high self-efficacy. In contrast to this Mr G doubted his ability to lower his blood sugar results which had caused him to stop doing blood tests and therefore indicated low self-efficacy.

Social persuasion involved the interviewees listening to and learning from health care professionals. Although it emerged that more than half of the interviewees (six out of eleven) disagreed with their doctors or diabetes nurse about certain aspects of their diabetes care, just less than half of the interviewees (Mr B, Mr D, Ms E, Mr F and Ms I – type 1 and type 2 and men and women) suggested that their self-efficacy about their abilities to look after their diabetes was increased and developed by the interaction with health care professionals. For example, Ms M described getting reassurance from her

health care professionals that she knew what she was doing and that what she was doing was right:

"they look at me and they look at what I'm doing and they're all kind of like, [her specialist] like you're doing what you can and you know you kind of you're interested and you're doing what you can...."

Ms M, type 1, high self-care

Mr F and Mr D both used feedback from the length of time between clinic appointments as reinforcement for the self- efficacy belief that they were looking after themselves well (see quote on p. 210).

Vicarious experience took the form of learning how to manage diabetes from other people with the condition. The interviewees who described an increase in their self-efficacy due to vicarious experiences were all men (Mr B, Mr F and Mr K). These interviewees developed self-efficacy in their abilities to look after their diabetes as a consequence of talking to friends and work colleagues about their diabetes and how they looked after themselves, Mr B's self-efficacy about his diabetes self-care was so high that he considered himself to be able to impart his knowledge to others with diabetes. For example he described telling a friend who also had diabetes about the dangers of not looking after himself:

"I say have you got any idea of if it's uncontrolled high blood sugars or low blood sugars the damage you could be doing to your body? Oh, he said it's just a load of twaddle now he's got both his hands strapped up, neuropathy, I did tell him. ...but he, he wouldn't listen."

Mr B, type 2, high self-care

There were four interviewees who suggested that their *personal research and previous knowledge* had increased their self-efficacy. All four of these interviewees had medium or high levels of self-care behaviour. Mr B and Ms L described learning about diabetes from the internet and Diabetes UK and how this increased their confidence about certain aspects of their diabetes care:

"Um, in the last few years I would say my confidence has grown because I've learnt that much more about my condition and how I can control it um.."
Mr B, type 2, high self-care

As nurses, Ms M and Ms J used their professional knowledge to supplement their self-efficacy regarding their diabetes. For example, Ms J used her professional knowledge to diagnose herself and her son and manipulated the health care system to get her son seen as quickly as possible.

The *continuous routine* of the diabetes regime clearly contributed to the self-efficacy of a large number of the interviewees. The continuous nature of the diabetes self-care behaviours resulted in an almost automatic process whereby many of the interviewees did not consciously think about performing injections or blood tests, but instead just performed them without registering it. By becoming an automatic process doubts about self-efficacy were negated as it became obvious the self-care behaviours could be performed as they were done on such an automatic level of consciousness. Six interviewees described examples of where the continuous nature of the diabetes regimen had contributed to their self-efficacy (Mr B, Ms C, Mr D, Ms E, Mr H and Ms J – men and women, type 1 and type 2 diabetes, high and low self-care behaviours).

Another aspect of living with diabetes which aided the development of self-efficacy beliefs was the lack of choice about the matter and having *no option but to do it.* (See quote on p. 204). Even Mr G, who reported very low self-efficacy about virtually all aspects of diabetes self-care, had self-efficacy when it came to taking insulin injections and tablets because he considered that he had no option but to take them as the alternative was to end up in hospital. This was the case for all the interviewees; however, the self-care behaviours it applied to depended on how important the interviewee considered the behaviour to be for their long term or short term health. For example, Mr B, Ms M and Ms J considered exercise to be a necessary part of treating their diabetes, whereas Ms C, Mr D, Ms E, Mr G, Mr H, Mr K and Ms L did not place great importance on exercise and did not consider it to be essential and so did not have positive self-efficacy beliefs about their ability to change their lifestyle and do exercise:

"I don't do as much as I should. I don't drive so I do sort of walk a fair bit I walk into work quite often, But you know, I should do more. We keep saying about joining a gym but that's one of those things that we will do (laughs) when we get round to it. I just think that's a general thing for somebody of my age that we really should be looking after ourselves,"
Ms E, type 1, medium self-care

An interesting aspect of the self-efficacy beliefs Mr F and Mr K had about their diabetes concerned the *role of their partners* in their diabetes care. These interviewees received a great deal of support for their diabetes care from their partners and as such shared the responsibility of looking after their diabetes with them. Mr K explicitly stated that if he did not have his wife (who was a nurse) he would not have looked after his diabetes to the same extent.

There was only one clear example of affective state influencing self-efficacy beliefs within the interview data, possibly due to there only being one interviewee who reported extremes of affective state when talking about his self-care behaviour – Mr G. Of all the interviewees Mr G demonstrated the strongest emotional response to self-care behaviours and his diabetes in general. The most striking example was when he described how he knew how to do blood tests but had no self-efficacy beliefs about what to do with the results or how to control his diabetes in order to prevent them from being as high as they always were:

"Oh I can do me blood tests it's just the results that depress me."
Mr G, type 2, low self-care

He reported feeling depressed as a consequence of seeing his blood test results when he did do them.

4.7.2 Self-efficacy beliefs held

Overall the data suggested that self-efficacy for specific self-care behaviours was relatively high for the majority of the interviewees. All of the interviewees showed particularly high self-efficacy beliefs for administering injections, taking tablets and doing blood tests. Even Mr G, who reported having low self-efficacy overall had high beliefs regarding taking medication. As discussed earlier, self-efficacy beliefs for exercise, with the exception of Mr G and Mr F who could not exercise because of other health problems, seemed to be high despite the fact that exercise was the least performed self-care

behaviour. Three interviewees (Mr B, Ms M and Ms J – all with very high self-care behaviour) had high self-efficacy about exercise and did do exercise. Five of the interviewees (Ms C, Mr D, Ms E, Mr H and Mr K – high, medium and low self-care) talked about exercise in a way that suggested they believed that they could do exercise but chose not to. This suggested that for behaviours such as medication taking, blood testing, dietary and exercise, it was not self-efficacy beliefs regarding the individual's abilities to perform the behaviours that prevented them from being performed but other factors, such as how the self-care behaviours related to the interviewees' outcome expectancies.

Other specific activities where references to self-efficacy occurred included smoking behaviour, altering insulin doses and preventing hypos. Those interviewees who were smokers (Mr D, Ms E and Mr F) reported knowing they should give up but felt unable to:

"I've put it down [on the questionnaire] but I am doing something about it ... cos of the diabetes and all it does and all that they say it's not healthy, well it's not for you, putting smoke down your throat."
Mr F, type 2, high self-care

Three of the interviewees (Mr D, Mr F and Mr G) emerged as having low self-efficacy beliefs about altering their insulin doses:

"Same dose every day. I've been told, I don't touch me dosages. The only person that's changes them is the doctors. I don't touch anything otherwise cos I don't know what I'm doing."
Mr G, type 2, low self-care

These interviewees were all men and were all on two injections a day rather than a multiple injection regimen. This meant their regimen had less flexibility and all three reported being on virtually the same dose of insulin since they were diagnosed which meant they had no experience of altering their insulin doses and therefore this may have led to low self-efficacy about altering insulin doses.

"I get up in the morning look at that, high I know by dinner time I'm going to go down, just take the normal amount and I never in 20 years ....I've been on the same, 10, 20, 10, 20. It's never altered."
Mr D, type 1, low self-care

There were two other interviewees who were on two injections a day (Mr B and Ms E); however, they differed from Mr D, Mr F and Mr G as Mr B had lots of experience of adding in additional doses of fast acting insulin when required and Ms E had had diabetes for 43 years during which time she had been on a variety of insulin regimens.

The prevention and treatment of hypos was an area where self-efficacy was important. Six of the interviewees expressed concerns over being able to detect and treat hypos by themselves (Mr B, Mr D, Ms E, Mr F, Mr G and Ms M):

"probably about 19 and I was having nocturnal hypos that I was having trouble waking up out of I remember my dad having trouble getting me up out of one. ....I'm still nervous about the fact that I might have nocturnal hypos and we know that I do dip in the night..."
Ms M, type 1, high self-care

However, all of the interviewees had developed coping strategies for if a hypo occurred and they were unable to stop it. Mr B, who lived on his own, had a personal alarm installed which connected to a central point so if he was ill or became unconscious somebody would notice. Ms C, Mr D and Ms E made sure that their work colleagues were aware of their diabetes and knew how to treat it in case they became incapacitated by a hypo:

"I'm always extremely open with people um you know when I start a new job or anything like that I always say straight away because hypo conditions can be similar to drunkenness and you don't want them to think you know that I'm turning up for work drunk (laughs)"
Ms E, type 1, medium self-care

Ms E, Mr H and Ms J ensured that they ate regular snacks to keep their blood sugars above a hypo level. Ms M found her blood sugars could drop rapidly and so made sure she did frequent tests at times she knew she may be low. Mr D and Mr K also tested before driving after having experiences of having hypos without warning whilst driving. Mr G and Mr F were relatively inexperienced with hypos and as a result had low self-efficacy regarding treating them and were anxious not to experience them again. Mr G had only ever had one hypo, whilst in hospital. Mr F had recently experienced his first hypo while away on holiday and had been treated by his partner. As mentioned earlier regarding Mr F's dependency on his partner, his personal self-efficacy about treating hypos was low but he was confident that his partner knew what to do and would help him if necessary:

"Yeah it was cos that be the first time, I just felt me legs were like, I don't know it was weird, …. and I just sat there and as I said my missus just grabbed me …P [his partner] says he's hypoed, and she went and got me a sweet tea, …, got me a bar of chocolate and then went and got me another cup of tea and I was alright"

Mr F, type 2, high self-care

The final area of self-efficacy beliefs discussed was feeling able to ask for help and find out information about their diabetes. All of the interviewees, with the exception of Mr G, felt able to ask for help and find out what they wanted to know; however, whether they asked for help from health care professionals depended on their beliefs about the efficaciousness of the advice provided by the diabetes nurses and doctors. Seven of the interviewees (Mr B, Mr D, Ms E, Mr F, Mr H, Ms J and Mr K) said they felt confident about asking for help and about the advice received. For example, Mr B had strong positive beliefs about the effectiveness of advice he received from health care professionals:

"I did lose control a couple of months back and the moment I'd lost control I rang up the hospital and spoke with [the diabetes nurse] and said look my blood sugars are hitting the roof again I need to talk to you, …"

Mr B, type 2, high self-care

Ms M reported that depending on who she managed to speak to at the hospital she would be confident about the advice received. Whereas, Ms C, Mr G and Ms L were much less confident about the relevance of the health care professionals' advice and so did not ask for help despite having the self-efficacy to do so:

"KS: And do you feel confident about going to ask people for advice at the hospital?

C: Not terribly

KS: Do you ever......

C: Very rarely because you just I don't know either they give you the textbook answer which is like 'no your blood sugars should be between', yeah I know that but you know when this happens or that happens or why you know that sometimes I think there are hormone things there are other influences and things and it's never quite as simple as that."
Ms C, type 2, medium self-care

The interviewees had developed a level of self-efficacy about looking after their diabetes; however, it emerged from the interview data that the interviewees felt that certain circumstances or external events had had an impact on the strength and magnitude of the self-efficacy beliefs held and caused them to be re-evaluated. The interviewees described certain circumstances and expressed their lack of confidence and belief in their own abilities when these events occurred.

Three of the interviewees (Mr B, Ms C and Ms M – type 1 and type 2 diabetes, men and women, high and medium self-care behaviours) found that during certain periods in their lives their diabetes had become unpredictable and as a result effected their self-efficacy beliefs. Mr B felt that in circumstances such as ill health his self-efficacy beliefs were reduced. For example, he felt that he caught other illness very easily as a result of having diabetes and found

that once he was ill he usually ended up being hospitalised. This had negatively affected his self-efficacy about looking after himself during times of ill health. Ms M described how coping with illness made her diabetes more difficult to control:

"It really gets me when I'm ill. That's the only time my diabetes really, really, really gets me if I'm vomiting cos that's very difficult to cope with.... just trying to keep the blood sugars fairly stable."
Ms M, type 1, high self-care

Ms C's experience of ill health had had the opposite effect. She had been off work waiting for an operation and had found that when away from the working environment her diabetes was much easier to control causing her self-efficacy about being able to look after her diabetes successfully to increase; however, she then believed that it was only in certain circumstances that she could do this and so when she returned to work her expectations of how well she could look after her diabetes reduced (see quote on p. 224).

4.7.3 Outcome expectations and achievement of goals

Self-efficacy beliefs refer to beliefs about the ability to perform a specific behaviour; however, there are other important aspects of Social Cognitive Theory including outcome expectations and the importance of the goal which the specific behaviour is being performed to achieve. As discussed previously, interviewees had various goals and reasons for looking after their diabetes such as feeling well on a day to day basis and avoiding potential diabetes complications. It was the latter that was mentioned most frequently in terms of self-efficacy beliefs and outcome expectations. Three interviewees suggested

that they felt their behaviour would not prevent complications. Mr D, Ms E and Mr K all felt that a large part of getting complications was due to chance or luck and so they did not feel they were able to prevent complications purely by their own behaviour. For example, Ms E compared herself to a friend who also had diabetes, looked after herself but got complications anyway:

"I think sometimes it's a bit random like that that she really got the short end of the stick and you know she'd had a stroke and different things and she was quite a few years younger than me so everything had gone wrong with her diabetes whereas I've been lucky with mine."
Ms E, type 1, medium self-care

Ms M had extremely high self-efficacy about the performance of self-care behaviours; however, she had no confidence in her abilities to have a normal, healthy pregnancy outcome after her experiences during her first pregnancy (see quote on p. 234). Mr D and Ms E identified the passing of time as a factor which affected their expectations that they could avoid diabetes complications. Mr D felt that as he was approaching fifty and had now had diabetes for twenty-five years he was more likely to experience problems as a result of his diabetes and had little control over this – it was just a consequence of having diabetes for this length of time and being that age and he had a lower expectation that he could prevent that from happening:

"I'm still confident but obviously things are changing. So I'm just coming to the next stage. Cos obviously you are coming up to the in two years I'll be 50 so you are coming in to the when things are gonna start happening and it's, it's gonna start happening then."
Mr D, type 1, low self-care

Similarly Ms E was concerned about her increasing age. This was exacerbated by her experiences of going through the menopause and the fact that her diabetes had become harder to control, so reducing her expectations as a result. Ms E was one of the interviewees who had recent vicarious experiences, as well as Mr F who knew someone who had had to have leg amputations as a result of her diabetes, which impacted on outcome expectations. The data suggests that this had influenced the views of both interviewees on their abilities to prevent complications and as a consequence may have affected their outcome expectations in a negative way:

"we've got a friend who's lost their legs for it and it's really made me sit up and start thinking [laughs]….. er it's scared the living daylights out of me it has…"
Mr F, type 2, high self-care

These changing circumstances, such as ill health or ageing, may have had an effect on the interviewees' self-efficacy beliefs about preventing complications but the self-efficacy beliefs for the specific behaviours themselves, such as blood testing and taking medication, remained strong. In addition to that, the specific self-care behaviours contributed to achieving other goals. For example, for Ms E performing self-care behaviours was not just about avoiding complications but also about feeling healthy on a day to day basis.

Summary – Self-efficacy

1) Eight ways that self-efficacy was influenced emerged from the data: personal experience, social persuasion, vicarious experience, personal research and knowledge, continuous automated routine, no option but to do it, with the aid of partners, and affective states.

2) All of the interviewees attributed some of their self-efficacy to personal experience.

3) Five interviewees (type 1 and type 2 diabetes, men and women, high and low self-care) described enhanced self-efficacy from social persuasion from health care professionals.

4) Three interviewees (all men) felt their self-efficacy was increased by vicarious experiences.

5) Four interviewees (all with high or medium self-care behaviours) enhanced their self-efficacy through personal research and knowledge.

6) Six interviewees (type 1 and type 2 diabetes, men and women, high and low self-care behaviours) felt the continuous routine influenced their self-efficacy.

7) All of the interviewees felt having no option but to perform the behaviour increased their self-efficacy; however, the choice to perform the behaviour or not depended on how important the individual considered the self-care behaviour to be for their diabetes (for example insulin injections versus exercise).

8) Two interviewees (both men) had partners who shared responsibility for their diabetes self-care and so influenced their self-efficacy.

9) Only one interviewee (with the most extreme emotional reaction to his diabetes) displayed any effects of affective state on self-efficacy.

4.8 The Commonsense Model of the Self-Regulation of Health and Illness (CSM)

The intention of this research study was to see if the CSM (Leventhal et al. 2003) could be used to understand the personal experience of diabetes and self-care behaviour in this sample and to investigate any differences in the model for individuals with type 1 and type 2 diabetes (for a discussion of the CSM see chapter one p. 54). In order to prevent the theoretical model influencing the data analysis the interview data was initially analysed without reference to the CSM. Following the thematic analysis of the interview data the themes and findings were analysed to ascertain if the data supported the interactions suggested by the CSM.

As can be seen in figure 15 it emerged that the findings supported the interaction of stimuli, illness representations, self-efficacy, action plans and appraisal suggested by the CSM.

Figure 15 - How the interview analysis fits with the CSM

Socio-cultural context and self-system
Self-efficacy
Myself and my diabetes

Illness representations
Identity
Consequences
Controllability (ie treatment)
Causes

Coping efforts/action plans
Looking after myself

Stimuli (inner and outer)
Personal experience
Symptoms
Health care professionals
Friends/family
Others with/without diabetes
Diabetes UK
Internet

Appraisal
Blood tests
How I feel (symptoms)
HCP feedback
Judgement

Emotional representations
Emotional experience

Coping efforts/action plans
Looking after myself

Socio-cultural context and self-system
Self-efficacy
Myself and my diabetes

4.8.1 Stimuli (inner and outer)

The stimuli that emerged from the interview data included both inner and outer stimuli as suggested by the CSM. Inner stimuli were represented by *personal experience* and *symptoms*. Outer stimuli were represented by *health care professionals, friends and family, people with and without diabetes, Diabetes UK* and *the internet*. Stimuli (inner and outer) were related to illness representations (identity, cause, controllability, timeline and consequences), emotional representations (disappointment, anger, pride and so on) and the socio-cultural context and self-system (*self-efficacy* and *myself and my diabetes*).

Personal experience and *symptoms* (inner stimuli) were generally the most important stimuli for developing the illness representation *controllability*. They also contributed to the development of *self-efficacy* and *myself and my diabetes* themes. For example, both Ms C and Ms M reported using how they were feeling in themselves (ie any symptoms they had) as an indication of how controlled their diabetes was:

"I often go by how I'm feeling in myself."
Ms M, type 1, high self-care

All of the interviewees reported that personal experience enhanced their self-efficacy. For example, Ms L used personal experience of her lifestyle and her blood sugar levels to build her self-efficacy about changing insulin doses:

"I said what I did and they said oh you can't keep adjusting your levels I said well if I'm climbing ladders all day I don't need as much insulin ....I pretty quickly started adjusting that"

Ms L, type 2, medium self-care

In addition, personal experience influenced the formation of interviewees' identity and self-image for example, Mr B, Mr F and Mr G (the three men interviewed with type 2 diabetes) all described how the behaviour of other people suggested that they were 'different' from other people because of their diabetes:

"People push it two, two ways, too far away. Like I've got me step mother and when I go down there 'you can' t eat this, you can't eat that you can't do this you can't do that' and I'm thinking hang on its me....,"

Mr G, type 2, low self-care

Vicarious experience (outer stimuli), for example watching friends or family with diabetes cope with diabetes complications, influenced the interviewees' beliefs about the *consequences* and *controllability* of diabetes and their *self-efficacy* about preventing complications. An example of low self-efficacy regarding preventing complications, was Ms E and her understanding of the consequences of diabetes in response to witnessing her friend with diabetes experience complications and eventually die from them.

Social persuasion (outer stimuli) from sources such as *health care professionals, Diabetes UK* and *the internet* provided sources of information from which the interviewees developed illness representations such as *identity, cause, consequences,* and other aspects of the CSM such as *self-efficacy* and

myself and my diabetes. At diagnosis it was information from health care professionals that gave ten out of eleven of the interviewees (with the exception of Ms J who as a practice nurse recognised her own diabetes) the label to attach to the symptoms they were experiencing:

"I kept putting on weight,..... And I was getting uppers and downers all the time and went to see the doctor, he told me I had yuppie flu, ...and this went on for quite a long time I kept going back ....I was telling him my symptoms and he looked up and he went dear boy you're a diabetic..."
Mr F, type 2, high self-care

The majority of interviewees learnt what caused their diabetes from either health care professionals or Diabetes UK. The *consequences* illness representation was heavily influenced by input from health care professionals or information from Diabetes UK, as shown by Mr B and his internet research (see quote on p. 197).

As was described previously, feedback and comments made by health care professionals influenced interviewees' self-efficacy, perceptions of themselves and the emotional experiences of the majority of the interviewees in a negative or positive way. For example, Ms E felt proud, that she was approved of and reported an increased sense of self-efficacy after praise by her health care professionals.

The views of other people with or without diabetes in a socio-cultural context had an impact on interviewees' perceptions of themselves too for example the three men with type 2 diabetes and their perceptions of being 'different' because of their diabetes, in particular Mr G and how receiving a carer's

allowance influenced his view of diabetes as something which marked him as 'different':

"wanted me carer cos I was on low care and a said I wanted the middle rate and they said oh well it all depends what tablets ...And they sent it back within three days, you've got it, tarda. We don't have to look at your medical, ...and they give it me for life which is hard to get hold of so I got it for life...."

Mr G, type 2, low self-care

As suggested by the CSM the stimuli attended to involved both concrete (such as symptoms) and abstract information (such as information from health care professionals). There were no differences between interviewees with type 1 and type 2 in terms of the type of stimuli that were recognised as providing input. However, the data suggested that there were gender differences. Both men and women appeared to use inner stimuli such as symptoms and outer stimuli such as information from health care professionals. The differences occurred in terms of input from other people such as friends and family. The interviews with the men revealed how the men felt other people affected their diabetes. This was illustrated, for example, by Mr K, Mr F and Mr G's spouses looking after them and their diabetes and Mr B, Mr F and Mr K's friends with whom they shared information and support about diabetes with. Additionally, throughout the interviews with the men there was significant usage of 'we' when talking about their diabetes. This is in direct contrast to the interviews with the women who only mentioned friends and family in connection to their diabetes when describing occasional specific events such as a bad hypo where they were unable to help themselves. When describing their diabetes self-care on a day to day basis they made no mention of the input from other people, other than health care professionals.

4.8.2 Illness representations

All five of the illness representations suggested by Leventhal et al. (2003) emerged independently from the interview data.

Identity

The symptoms experienced and the label given to those symptoms was an important aspect of the interviewees' illness experience. Leventhal suggests that individuals require symptoms to have a label and labels to have symptoms and this can be clearly seen in the interviewees' recollections of their diagnoses:

"Listless didn't want to do anything um I became listless a few years ago, ...and I thought could it be diabetes cos I was going to the toilet a lot and drinking a lot so it could be diabetes ...and the doctor turned round and said no you are not diabetic but I think there is something wrong with your thyroid gland so got all that checked out...., got all that sorted and the whole thing started all over again so I went back, ...She says you're diabetic..."
Mr B, type 2, high self-care

As suggested in the CSM the connection between symptoms and label was facilitated by stimuli such as health care professionals, family and friends and personal experience:

"I was thirsty that was the first, ... a friend's brother and sister both had diabetes so ...she did say you must go to your doctor, get some test and she kept on and on 'til I went and that's when I found out the blood sugar was really high."

Ms L, type 2, medium self-care

Interestingly the specificity of the label was not equally important for all interviewees. Seven out of eleven interviewees were knowledgeable about the type of diabetes they had (all of the interviewees with type 1 and two with type 2); however, two of the interviewees with type 2 diabetes (Ms C and Mr G) were unsure whether they had type 1 or type 2 and two (Mr F and Ms L) considered that they had type 1 diabetes, despite the descriptions of their diagnosis and the circumstances surrounding it suggesting that they had type 2 diabetes, because they were on insulin. This was influenced by their socio-cultural understanding of the differences between type 1 and type 2, such as the traditional view of insulin being for people with type 1 (encouraged by the use of the terms 'insulin dependent diabetes mellitus (IDDM)' for type 1 and 'non-insulin dependent diabetes mellitus (NIDDM)' for type 2 in the recent past). Additionally, Ms L considered that as she was not overweight and did not lead a sedentary lifestyle, both of which she considered to be causes of type 2 diabetes, she could not have type 2 diabetes:

"Type 1..... Because it's insulin controlled..... type 1 is insulin, type 2 is medication or tablets or diet controlled cos I think the body is still producing some insulin with type 2 whereas with type 1 it isn't producing any at all. Is that right?...Um, type 1 I think is generally um what younger children get and type 2 is overweight people, Asian people predominantly. Is that?"

Ms L, type 2, medium self-care

The specificity of this label for their condition had an impact on the subsequent illness representations that developed. As mentioned above, beliefs about the cause of their diabetes was affected by the label and vice versa but also beliefs about the severity of the condition as shown by Mr F's belief that type 1 was more serious than type 2 and had more complications connected with it (although it is important to point out that he considered anyone on insulin to have type 1 diabetes):

"type 2s not so bad, type 1s the worse one. And that's what I've got into now type 1 but I'd much prefer to be the type 2s stayed with the type 2s. ...type 1 is the damaging one where limbs and feet that bit frightens me it does really frighten me ....Yeah, I know that type 2s can get it but I don't think it's as bad as the type 1s can get it."
Mr F, type 2, high self-care

As predicted by the CSM, *identity* influenced how interviewees looked after themselves in terms of the impact of symptoms on self-care behaviour. Interviewees would recognise which symptoms related to their diabetes and react accordingly. For example, Mr B described recognising when his blood sugars were high or low and responding accordingly:

"I start to shake, sometimes the eyes go. And you think oh something's not right. And I'll probably do a test to see what's going on. I normally test twice a day but if I feel that there's something wrong ie feeling a little bit butterflies or hungry in the stomach then I think um shouldn't be feeling hungry cos I only ate 10 minutes ago. So obviously something's wrong so I do a blood test."
Mr B, type 2, high self-care

In addition, having the label of someone with diabetes was very important in predicting levels of self-care for certain individuals. As discussed in detail previously, the interview data suggested that the men with type 2 diabetes (Mr B, Mr F and Mr G) incorporated the identity of diabetes into their own identity and responded by adapting their lifestyle in a particular way. Mr B and Mr F performed significantly high levels of self-care behaviour, particularly in terms of dietary self-care, and Mr G used his diabetes identity to adopt the sick role and be exempt from usual social and personal responsibilities.

"I'm just saying I hope I've still got 20 years and people say what do you mean you hope? You're a young man, you've got plenty in front of you yet, yeah but I've got diabetes, oh that's different oh that's different and they start putting the gloves on to handle you,"
Mr B, type 2, high self-care

Contained within the identity representation for each of the interviewees was information that was concrete and that was abstract. All of the interviewees had received a diagnosis from a health care professional which was abstract in terms of the label of diabetes and the information given to them relating to that label. In addition to this, all of the interviewees had similarly experienced concrete symptoms of what diabetes meant to themselves and their bodies (for example, tiredness and thirst). The differences between interviewees with type 1 and type 2 diabetes, in terms of identity, stemmed from the label that the individual had adopted to account for their symptoms. All the interviewees with type 1 diabetes knew they had type 1 diabetes; whereas, four interviewees with type 2 diabetes were either unsure what type they had or thought they had type 1. This may be due to lack of education about diabetes or due to the fact that all the interviewees interviewed were on insulin and that as the old labels for

diabetes indicated which type it was on the basis of the type of treatment being received.

Timeline

Throughout all the interview data there was consensus that diabetes was a lifelong condition. There was some mention of future technological advancements in medical treatment that may be coming to 'cure' diabetes but all of the interviewees who mentioned this thought it very unlikely this would happen in their lifetimes:

"technology is getting better. It will nay help me but eventually they should be able to get rid of it cos they will be able to do tests like everything else and sort it, hopefully. Put the needle people out of business [Laughs]."
Mr D, type 1, low self-care

The illness representation *timeline* was associated with the coping efforts of all of the interviewees. The belief that diabetes was a lifelong condition was related to self-care behaviour in terms of the integration of different aspects of diabetes self-care behaviours into the interviewees' lifestyles (or not as the case may be). For example, Ms J described how she fitted in doing blood tests and eating enough carbohydrate into her daily routine:

"I suppose it's getting into a routine....I'm like well it takes 2 seconds you know you do it stick it go and do something else while it's cooking and goes ping and you look at it. Um, and, and again it is just getting into the mind set and once its part of your life its there, it is just pick a finger and go really [laughs]."
Ms J, type 2, high self-care

As with the other illness representations the timeline illness representation appeared to have been formed from concrete and abstract information, for example abstract information from health care professionals and Diabetes UK combined with the concrete-experiential information garnered from living with diabetes for a long period of time with no change in status of the condition. There appeared to be no difference in timeline beliefs between those interviewees with type 1 and type 2 diabetes or between men and women.

Causes

The *cause* illness representation was well represented in the interview data as can be seen by the *causes of my diabetes* theme. There is a suggestion from the data analysis that beliefs about the cause of diabetes may have been associated with self-care behaviour. As discussed in the thematic analysis, the two men with type 2 diabetes who believed their diabetes was caused by lifestyle factors such as being overweight, lack of exercise and diet (Mr B and Mr F) had very high self-care behaviours, particularly for lifestyle elements of the diabetes self-care regimen such as diet and exercise. The man with type 2 who did not know what caused his diabetes (Mr G) had very low self-care behaviour levels, which could possibly be partly due to the lack of connection between lifestyle causes and lifestyle self-care behaviours. For women this association could not be looked at due to the beliefs of the women interviewed about the causes of their diabetes. All of the women (whether type 1 or type 2) felt that the most important causes of their diabetes were an illness causing an auto-immune problem and genetic susceptibility (with the exception of Ms L who was adopted and therefore did not know previous family members' medical history).

Again, abstract and concrete information was used to form the *cause* illness representation with abstract information coming from health care professionals, family members or personal research and concrete information emerging from the interviewees' own personal experience of events around the onset of symptoms and diagnosis with diabetes. For example, Ms J, as a health care professional, had medical knowledge of what is thought to cause diabetes and combined this previous knowledge with her own personal experiences to form her personal representation of the cause of her diabetes (see quote on p. 188).

Controllability

The *controllability* illness representation was also well represented throughout the interview data. Two main aspects of this representation emerged: the ability of the treatment prescribed to control diabetes and how personally able the interviewees felt about controlling their diabetes. Perhaps the best example of treatment controllability was seen in the interview with Mr D. This was discussed in more detail in the *looking after myself* theme, where Mr D described not taking certain tablets because he did not believe they would help his diabetes (see quote on p. 205). This connection between Mr D's beliefs about the effectiveness of his tablets and his decision not to take them shows a clear association between the *controllability* illness representation and the action plan carried out. In a different area of self-care behaviour Mr G demonstrated a similar connection. As mentioned in the *looking after myself* theme, he described not doing many blood tests because they made him depressed and he did not know what to do with the results. Mr G believed that for him blood tests were not effective in terms of controlling his diabetes because he did not have the knowledge or self-efficacy to act on the results of

his blood tests. Both Mr D and Mr G had low levels of self-care behaviour; however, interestingly, it was not the beliefs about the treatment effectiveness that impacted on all of the interviewees with low self-care. For example, Mr H and Ms C believed that their treatment was effective however did not necessarily perform the behaviours recommended, citing the pressures of their lifestyle as the reason why, which will be discussed in greater detail later on.

For three of the interviewees (Mr B, Ms E and Mr G) beliefs about their personal abilities to control diabetes were also important when explaining the performance of self-care behaviour. These beliefs were closely inter-linked with the self-system (described in chapter one), particularly self-efficacy (as looked at in the *self-efficacy* theme). For example, when Mr B described how under certain circumstances (such as having very high blood sugars) he would ask for help from health care professionals. Mr B had reduced self-efficacy with regard to his ability to control his diabetes under such circumstances following his experiences in the past. As a result he had altered his self-care behaviour and changed his action plans to involve talking to the diabetes nurse or contacting the hospital if he felt it was necessary.

There was again evidence of abstract and concrete information forming the *controllability* illness representation with abstract information from health care professionals about the effectiveness of treatment and then concrete information from personal and vicarious experience about the day to day controllability of diabetes. As suggested by Leventhal et al. (2003) the relationship between controllability and self-care behaviours appeared to be moderated by self-efficacy. There were no clearly different patterns of controllability beliefs for interviewees with type 1 or type 2 diabetes and men or women. The most important concept that explained self-care behaviour was the

belief in treatment effectiveness and having the self-efficacy to perform that behaviour.

Consequences

From the thematic analysis of the interview data emerged a theme about the consequences of having diabetes which corresponded directly to the *consequences* illness representation. According to the CSM, the *consequences* illness representation impacts on self-care behaviour and this relationship was found in the consequences theme. The practical consequences of diabetes, in terms of lifestyle consequences, were found to be associated with the performance of self-care behaviours. This relationship was moderated by the socio-cultural context and self-system. For example, practical consequences of diabetes, such as time spent on doing blood tests and injections and dietary considerations were minimised by Ms C and Mr H which was related to the performance of self-care. Ms C recognised the importance of maintaining a healthy diet but the demands of her job meant this is difficult to achieve. For Ms C, values from her self-system and socio-cultural surroundings had influenced her to prioritise her work life over her diabetes self-care as was the case for Mr H and doing blood tests at work as mentioned previously. Similarly, Ms M prioritised the health and welfare of her family:

"well I always do my injections afterwards….it's not for reasons of my diabetes it's the fact that because my daughter has allergic reactions, my dog is diabetic and has had a hypo previously [laughs] and is epileptic and recently and I had my dog go and have a fit in the middle of me having eating but I'd already given my insulin and I just thought never again, this is madness and I was madly trying to sort out a fitting dog, a four year old and eat at the same time and I just though this is silly, I could be on the floor with them…"
Ms M, type 1, high self-care

Other practical consequences mentioned by the interviewees were the impact of diabetes on driving and financial consequences. There was a significant gender divide for these consequences with all of the men who were interviewed and none of the women mentioning driving and all of the men and only one woman mentioning financial consequences. The suggestion made in the consequences theme was that this was related to differences in the socio-cultural context for men and women in terms of roles and status. This represents the impact of the socio-cultural context and self-system on the formation of illness representations.

The other main aspect of the consequences of diabetes that influenced self-care was the possibility of diabetes complications. Interestingly it was vicarious experience of severe complications that had a larger impact on the formation of the *consequences* illness representation than personal experience of less severe complications. The majority of the interviewees (ten out of eleven) reported the possibility of diabetes complications as having a direct impact on how they looked after their diabetes.

The role of chance or luck had an important part to play for five of the interviewees (Ms C, Mr D, Ms E, Ms M and Mr K) as described in the *consequences of diabetes* theme. They believed that although the treatment for diabetes played a part in preventing complications much of it was due to chance or luck. Interestingly the relationship between the role of chance or luck and self-care behaviour was not the same for every interviewee who believed this. For those interviewees with low self-care, in particular Mr D for whom the role of luck came across as very important in his interview, it appeared that the fact that high levels of self-care behaviour could not be guaranteed to prevent complications mean that the interviewees would "do their best" but possibly not strive for the perfection that other interviewees with higher self-care behaviour, such as Ms M, were aiming for (see quote on p. 261). A possible explanation for this may be the interaction with the self-system and how personal characteristics or self-beliefs impacted on the association between beliefs in the role of chance or luck and the performance of self-care behaviours.

As predicted by Leventhal et al. (2003), the *consequences* illness representation was informed by abstract and concrete information. Health care professionals and Diabetes UK provided the interviewees with abstract information about diabetes complications and the interviewees' personal and vicarious experience of complications and other consequences provided the concrete information. In this illness representation it was worth noting that particularly for diabetes complications it was the personal concrete information that appeared to have the biggest impact on self-care behaviour. The data suggested no significant differences between the consequences illness representation for interviewees with type 1 and type 2 diabetes. There were gender differences in terms of certain practical consequences such as driving and financial aspects. The association between consequences and the action

plans used and the self-system could be clearly seen; however, there were no differences between how this occurred for interviewees with type 1 and type 2 diabetes or men and women.

4.8.3 Emotional representations

The majority of the interviewees (ten out of eleven) described the vital role that personal experience had played in developing how they look after themselves and their diabetes (see *looking after myself* theme for more detail p. 195). An integral part of personal experience was the emotional response that occurred alongside the cognitive experience. The importance of emotional experience on aspects of the CSM such as illness representations, action plans and the self-system has been demonstrated throughout the interview data. The emotional experience of the physical symptoms and the subsequent diagnosis with diabetes was described by all of the interviewees. For example, Mr D's anger and Ms L's tears due to shock after diagnosis (see quote on p. 230). This showed a clear link between the illness representation *identity* and *emotional representations* as suggested by Leventhal et al. (2003). Other illness representations that were linked to emotional representations included *cause*, for example Mr D's regret over his part in the accident that he felt caused his diabetes:

"Well I think the main thing was the accident that started it all off. I was on the Royal Guard...., got time off so one night we went out, I was driving but I went drinking came back for some stupid reason I decided would go for a drive....Worst decision of my life."

Mr D, type 1, low self-care

Controllability was also linked to emotional representations, as can be seen in Mr G's depression at his lack of control over his blood sugar levels mentioned previously. *Consequences* was associated with emotional representations as was shown by ten out of eleven of the interviewees describing worry and fear over the possibility of getting diabetes complications. In addition to this, emotional representations were shown to influence the performance of self-care behaviours. For example, Mr G's resignation and depression about his blood sugar levels had an influence on his ability to seek help with his diabetes control and his performance of self-care behaviours such as blood testing.

The relationship between emotional representations and the self-system was also important. For example, interviewees described experiencing negative emotions when their self-system (in terms of identity, roles and status) was threatened by their diabetes and positive emotions when they experienced something which increased their self-efficacy or which confirmed their self-image. One clear example of this was Mr D who described experiencing anger (and still experienced anger displayed in his tone of voice) regarding the impact of diabetes on his self-image. He hid his diabetes from his work colleagues as his diabetes threatened his previous self-image developed whilst in the army. Ms L reported feeling proud and happy when her blood sugars were at the level she was aiming for and this increased her self-efficacy (see quote on p. 238).

The illness representations discussed previously were formed with reference to abstract and concrete information. The emotional representations reported in the interviews were largely developed from concrete experiential information as a consequence of emotions being something experienced by the person as an individual rather than a cognition which can be informed by

external sources. However, there were three interviewees (Ms C, Ms J and Ms L - all women with type 2 diabetes) who described a desire for an external acknowledgement of the emotions they had experienced or reassurance that what they were experiencing was 'normal'. Ms C described how when she was put on insulin she was seen by a health care professional who seemed unaware of the emotional impact that this would make and how she would have liked understanding:

"when I went onto insulin yeah that was quite urrgghhh, that was quite something and then when I went to see the diabetic nurse she was most not unsympathetic what's the word, brusque, I would say and ....you know this a life a life long..... and it was scary it was scary. I mean had I been a more less robust person I would have probably cried or something .... She put the frighteners up me. ...(laughs) Oh and I wanted to say are you diabetic cos I bet you're not cos you wouldn't be talking to me like this if you were. (laughs)"
Ms C, type 2, medium self-care

Ms J felt that she would like more support with the decision making process around her own and her son's diabetes which she felt was lacking due to her own expertise as a nurse:

"I mean they're always very good, I don't know if they assume that you know things you know and I sometimes think I know that I do know them and I know them because of what I do and what I am and I suppose they don't want to sort of make I don't know, because I'm in the same profession but I often think to myself well yeah, maybe I'd ask a few more questions..."
Ms J, type 2, high self-care

The role of emotional representations emerging from the interview data seemed to fit in with the CSM framework. As Leventhal et al. (2003) suggested the emotional representation process worked in parallel with the illness representation process with all cognitive processes having an equivalent emotional process. No differences emerged for emotional representations between interviewees with type 1 and type 2 diabetes; however, there were gender differences which seemed to be centred around the relationship between gender and the socio-cultural context and the self-system which in turn affected how diabetes impacted on emotional representations and the self-system.

4.8.4 Coping efforts and action plan

As mentioned in the previous aspects of the CSM discussed, the coping efforts and action plans (self-care behaviours) adopted by the interviewees were shown to be strongly influenced by the illness representations, socio-cultural context and the self-system, as suggested by Leventhal et al. (2003). For example, the interviewees who had adopted the label of type 2 diabetes (*identity* illness representation) and the associated lifestyle causes (*cause* illness representation) had a higher level of performance of lifestyle related self-care behaviours than the interviewee with type 2 who adopted the label of type 2 diabetes but not the causes. The *timeline* illness representation was associated with how the self-care behaviours were adapted into the interviewees' lifestyles. In the *controllability* illness representation the effectiveness of different aspects of treatment and self-care activities was related to the performance of those self-care behaviours. A further influence on the self-care of the interviewees stemmed from the *consequences* illness

representation, where interviewees reported a relationship between their beliefs about developing complications, the vicarious experience of complications and other practical consequences such as driving (and the performance of blood tests before driving to ensure hypos were avoided). Other practical consequences influencing self-care were the priorities that interviewees chose such as work or family life over diabetes self-care.

The data analysis suggested that *socio-cultural context* and *self-system* were also related to coping efforts and the action plans implemented. The socio-cultural context and self-system was shown to be associated with self-care both directly and indirectly by influencing the formation of illness representations. Self-efficacy was vital for the performance of specific self-care behaviours; however, equally important were aspects of the socio-cultural system such as beliefs about the validity of advice given by health care professionals. Other aspects of the socio-cultural system which had an impact on the performance of self-care behaviours included beliefs about the applicability of a purely medical model and the influences of gender, and roles and status on illness representations. For example, Ms M prioritised her role as a mother over her diabetes in terms of the timings of her injections. She took her insulin after her meals rather than before as a consequence of her personal experience when she was unable to eat because she had to perform activities linked to being a mother which interrupted her eating.

The clear example of Mr G and the interaction between his affective state, self-efficacy and self-care behaviour showed the importance of emotional representations for self-care behaviour. There were other examples of the relationship between emotional representations and coping strategies which in turn were related to self-care behaviour, such as Mr D's anger and his

303

descriptions of how in the past his diabetes self-care was affected by his denial that he had to do anything different from a person without diabetes.

4.8.5 Appraisal

The appraisal of the action plans (self-care behaviours) employed is a vital part of the CSM according to Leventhal, and this was supported in the interview data. All of the interviewees described methods by which they evaluated how they were looking after themselves. For example, seven of the interviewees used their personal blood tests to assess their success by comparing these results to the blood sugar levels they were aiming for:

"Yeah, I mean I do always check up with blood tests and um checks to see if it's ok but normally it's within decent within a reasonable level."
Ms E, type 1, medium self-care

The comparison aspect of the appraisal system is an integral part of the feedback, self-regulation system. As discussed in the *looking after myself* theme, interviewees used a variety of comparators, including the presence or absence of physical or emotional symptoms or indicators, blood glucose results recommended by health care professionals (whether personal blood tests or HbA1cs), feedback from health care professionals and personal aims such as Mr B's aim to lose weight and reduce his insulin doses.

Leventhal et al (2003) suggest that the appraisal feeds back into the CSM through the input stimuli, illness representations and emotional representations.

This is supported by the interview data. The symptoms used to appraise the success of self-care are the same symptoms which act as stimuli and this is the case for feedback from the health care professionals. An aspect of the appraisal system which is not discussed by Leventhal et al is the impact of socio-cultural context and the self-system. This will be discussed in further detail in the socio-cultural context section.

As discussed in the *how I look after myself* sub-theme there were gender differences in how appraisals of the effectiveness of self-care behaviours were made. Women tended to use tangible, concrete information such as blood tests whereas men used a range of different methods such as input from their health care professionals including length of time between hospital appointments, or how they felt in terms of health and emotions. No differences emerged between interviewees with type 1or type 2 diabetes.

4.8.6 Socio-cultural context and self-system

In Leventhal's CSM, he suggests that socio-cultural context and the self-system interacts with the rest of the model through their moderation between illness or emotional representations and action plans (see chapter one for more detail). The interview analysis supports this theory for example, as described in the *controllability* illness representation regarding Mr G and his response to blood tests and in the *identity* illness representation describing the interaction of identity in terms of symptoms and label, combined with identity of the self and the self-care behaviours performed. For example, the interaction of Mr B's beliefs about the label of diabetes, the treatment required for his diabetes and

the consequences of diabetes combined with his adoption of a 'diabetic self' role and the way this role was supported by people around him to make him feel 'different' led to his high levels of self-care behaviour. However, the interview data also suggested that the socio-cultural context and self-system were involved in many other aspects of the model.

It emerged from the data that the stimuli (inner and outer) which formed illness and emotional representations were also important for the development and maintenance of the socio-cultural context and self-system. According to Social Cognitive Theory (Bandura 1986), self-efficacy is developed through a range of inputs such as personal experience, vicarious experience, social persuasion and so on. These same inputs can be found in the inputs which formed illness and emotional representations: personal experience, vicarious experience through family and friends, information from health care professionals and so on. In the interviews this was shown to be the case with all of the interviewees reporting that positive personal experiences built up their self-efficacy and six interviewees describing how social persuasion and vicarious experience also played a part (see quote on p. 269).

The interview data also suggested that the socio-cultural context and the self-system were associated with illness and emotional representations rather than just moderating the link between them and the action plans performed. Socio-cultural context was involved in the formation of identity, consequences, controllability, timeline and causes by virtue of the fact that family and friends provided input into the development of the illness representations but also in terms of the pervading beliefs about diabetes (for example in the media and the large amount of coverage about the causes of type 2 diabetes) and belief mechanisms such as believing in fate or in chance or luck, which several

interviewees used to describe the causes of their diabetes and their chances of getting complications. This relationship works both ways as the self-system is also related to illness and emotional representations. For example, as discussed earlier (and suggested in the self-efficacy literature (Bandura 1986) emotional representations are related in a bi-directional way to self-efficacy and status and roles.

The final aspect of the CSM which socio-cultural context and self-system interacted with and which emerged from this data was the appraisal and feedback loop system. In the CSM the appraisal of the success of the action plans or self-care behaviours performed feeds back into the self-system, for example by raising self-efficacy when the self-care activities were judged to be successful and lowering self-efficacy when they were judged to be unsuccessful. However, appraisal was also shown to have an impact on other aspects of the self-system such as the effect of input by health care professionals, other people and themselves on interviewees' self-image and identity. For example, as discussed in the *emotional experience* theme, Ms M felt judged by health care professionals after the birth of her child. The data suggests that these judgements by others and by herself and the emotional upheaval experienced had influenced her self-image as a mother:

"We don't know if everything's down to me being diabetic but um she, she I was very, very unwell. ...I'm never having a baby biologically again, no. We're adopting another one cos we're not going through it again not doing it.. I also think that I was judged I had I heard the nurses in report um and they were saying oh well she can't have had decent HbA1cs because look at her baby.."
Ms M, type 1, high self-care

This is a bi-directional relationship as the self-system impacted on what type of appraisal was used by the interviewees. For example, a number of interviewees including Mr G reported using how they were feeling physically as an indication of how successfully their self-care behaviours were controlling their diabetes (see quote on p. 210).

Socio-cultural context also had an impact on the type of appraisal used by the interviewees. For example, Ms J dismissed the use of how she was feeling as an accurate measure of successful management of her diabetes and instead relied solely on tangible results such as HbA1c blood tests. This difference can be explained by the socio-cultural context and self-system of Ms J. She was a practice nurse and as such was surrounded by the medical model which often dismisses subjective measurement techniques in favour of objective measurements such as blood tests. Mr D's methods for appraisal reflected his beliefs in the medical model and the medical profession which was shown by his reliance on the health care professionals to tell him if he was looking after himself well and judging it on the time between his appointments.

In the CSM, appraisal of the success of action plans relies on having a comparator and it is through the socio-cultural context and self-system that many of the interviewees found this comparator, whether it was comparing themselves to others with diabetes:

"he's just been diagnosed with it as well so me and him working together now we compare what we eat all through the day ....he's tablets yeah, yeah he's tablet controlled ...mind you he's overweight he's overweight, grossly overweight I mean probably in the region of 6, 7 stone overweight yeah and he's about 21 stone so he's quite overweight yeah."

Mr F, type 2, high self-care

Or against their own expectations:

"you know if you're eating something that you are not meant to be you know it's sort of being conscious of oh well this once won't hurt but yeah so I sort of allow myself a few naughty things now and again."

Ms C, type 2, medium self-care

There were differences between interviewees with type 1 and type 2 diabetes and between men and women for socio-cultural context and the self-system. The most striking difference was found in the men with type 2 diabetes (as discussed in the *myself and my diabetes* theme) compared to the other interviewees. The impact of diabetes on the identity, self-image and roles and status of these men and the impact of these on their approach to diabetes self-care and the action plans selected was significant. In addition to this the differing roles and status of men and women had an impact on their illness and emotional representations and the self-care behaviour performed. Individuals had differences between overall self-systems and socio-cultural contexts reflecting their personal experiences throughout life.

Summary

1) The interview data analysis supported the associations suggested by Leventhal's CSM.

2) Inner and outer stimuli were used to develop illness representations.

3) Identity (the label and symptoms) was an important part of all the interviewees' illness experiences and had an impact on self-care behaviour.

4) All the interviewees felt that diabetes was a life-long condition.

5) The majority of the interviewees (ten out of eleven) had beliefs about the cause of their diabetes and for two interviewees (Mr B and Mr F) this appeared to have a direct impact on self-care behaviours.

6) Controllability and consequences of diabetes were important for all of the interviewees and had a direct effect on self-care behaviours.

7) Emotional representations were also important for the interviewees, impacted on self-care behaviour but were also linked to illness representations as suggested by Leventhal.

8) The interviewees described using various appraisal methods which involved comparing themselves with a comparator and then using this information to form new inner and outer stimuli.

9) Concrete and abstract information was used to form the illness representations as suggested by Leventhal.

10) The socio-cultural context and self-system had an impact on all aspects of the CSM – illness representations, emotional representations, mediation between illness representations and self-care behaviour, self-care behaviour directly and the inner and outer stimuli and appraisal processes.

Chapter five

Contrasting stories or different parts of the same whole?

The analyses of the questionnaire and interview data produced interesting results; however, as discussed in chapter two, they each came from different methodologies and philosophical perspectives. With those different methodologies came distinct strengths and weaknesses and by combining the results from the quantitative and qualitative data collection and analysis techniques a clearer picture of the experience of diabetes for the participants emerged. This chapter discusses how the interview data was compared to the questionnaire data regarding differences between the illness representations, self-efficacy and self-care behaviours of participants with type 1 and insulin treated type 2 diabetes. It also considers how the interview data informed the questionnaire data analysis to investigate the relationships between illness representations, self-efficacy and self-care by gender and type of diabetes, and how these relationships were supported by or contrasted with the interview data. Finally, this chapter details how the individual interviewees were compared with the questionnaire data to evaluate how well the questionnaire analysis represented the views and beliefs of these individuals and how the Commonsense Model of the Self-Regulation of Health and Illness (Leventhal et al. 2003) represented the relationship between the personal experience of diabetes and self-care behaviour.

5.1 Differences between type 1 and type 2 diabetes and men and women

The questionnaire analysis found differences in illness representations, self-efficacy and self-care behaviour between participants with type 1 and type 2 diabetes. As the interviews were only conducted with participants who had type 1 or insulin treated type 2 diabetes, and not tablet treated type 2 diabetes, the questionnaire analysis discussed in this section, and throughout this chapter, reflects this by only using questionnaire data from the participants with type 1 and insulin treated type 2 diabetes. Due to the marked gender differences found in the interviews, the questionnaire results looked at in this chapter will also focus on the differences found between men and women.

The findings from the questionnaire analysis suggested that the men with type 1 diabetes had higher illness coherence, lower personal responsibility causes and higher chance causes than the men with insulin treated type 2 diabetes. From the interview data it emerged that there was little difference between illness coherence or the interviewees' understanding of their diabetes between those interviewees with type 1 and those with insulin treated type 2 diabetes. The three men with type 1 diabetes (Mr D, Mr H and Mr K – all with a duration of diabetes over 18 years) all described having an understanding of their diabetes, including what had happened to their body to cause diabetes, how they should look after themselves and what the potential complications of their diabetes were. Two of the men with type 2 diabetes (Mr B who had had diabetes for 22 years and Mr F who had had diabetes for 7 years) also reported having an understanding about their diabetes (although Mr F had slightly less

detailed knowledge possibly due to the comparatively shorter time since his diagnosis). Mr G (who had had diabetes for 8 years), the third man with type 2 to be interviewed, reported being much less knowledgeable. Further statistical analysis to investigate if the differences in illness coherence were due to type of diabetes or duration of diabetes was not possible due to the small sample sizes.

The men with type 1 diabetes who were interviewed attributed their diabetes to accidents they had had before they were diagnosed. Mr H blamed being run over, Mr D attributed his diabetes to a car accident he had and Mr K used a bike accident to explain his diabetes:

"both me and my brother got it at the same time, within a week of each other so don't know, ...um he had a bike accident and I had a bike accident, not at the same time but very short distance between them, ...and um there is a little bit I always say, he had a little hand in it up there as well."

Mr K, type 1, high self-care

In contrast to this, Mr B and Mr F (two of the men with type 2 diabetes) suggested during their interviews that their diabetes was due to lifestyle choices that they were personally responsible for. For example, Mr B's work as a chef and his subsequent weight gain and Mr F's work as a lorry driver resulting in a sedentary lifestyle and overeating of fatty foods:

"Yeah, lorry driving. Lorry drivers abroad, yeah yeah I will make no hesitation there its lorry driving abroad I was a tramper, ... definitely, not eating right, and everything, grab your food when you can, eating while you're driving,"

Mr F, type 2, high self-care

This supported the findings from the questionnaire analysis about the increased attribution of diabetes to causes the participants were personally responsible for in men with type 2 diabetes. Mr G, the third man with insulin treated type 2 diabetes interviewed, had no suggestion for what the cause of his diabetes was. The questionnaire findings indicated that men with type 1 diabetes thought their diabetes was due to chance more than men with type 2 diabetes. However, no differences between men with type 1 and insulin treated type 2 diabetes for an attribution of their diabetes to chance were found in the interview data. Mr D (with type 1), Mr B and Mr F (both with type 2) were the men who mentioned luck or chance. Although the men with type 1 diabetes thought their diabetes was caused by accidents and the men with insulin treated type 2 diabetes blamed lifestyle factors and genetics both groups mentioned chance or luck.

"You're talking about it with me today and tomorrow you could be a diabetic. There's nay set of rules, your pancreas decides it doesn't want to play anymore, that's it."

Mr D, type 1, low self-care

With regard to the questionnaire data, women with type 1 diabetes and women with insulin treated type 2 diabetes reported similar experiences of their diabetes. The similarity among the women was generally supported in the interviews. The only differences for women between those interviewees with type 1 and those with insulin treated type 2 diabetes were for the presence of everyday symptoms identified as being caused by diabetes and how they described adapting to having diabetes. The women with type 1 who were interviewed felt they had no symptoms as a result of their diabetes but suggested that as they had had diabetes since being children they were unable

to remember what it was like before; whereas the women with type 2 reported having symptoms from their diabetes. The women with type 1 described how their diabetes was integrated into their lives; however, the women with insulin treated type 2 explained how they had either made an active decision to take control of their diabetes or, in the case of Ms C, felt controlled by their diabetes. No other differences were found.

Men and women were found to differ in both the questionnaire data and the interview data, in terms of women feeling their diabetes control was in a cyclical pattern (*timeline cyclical*) more than the men. In the interviews Ms C and Ms E both mentioned their diabetes going through periods when it was worse or better for no discernable reason. Perhaps the most obvious reason for a cyclical pattern in women and not men would be fluctuations due to hormonal changes. This may be true for some women; however, for Ms C this was not the case as she specifically mentioned that she had tried to see if it fitted a monthly cycle and that it did not:

"Just sort of comes in phases ….It will just go through an episode and it will just sort of run quite high…..I was trying to think does it go in with the monthly cycle, not necessarily as I say there are time when it seems unusually high but for no apparent reason."

Ms C, type 2, medium self-care

There were other differences observed in the questionnaire data which could not be compared with the interview data. Differences for illness representations and self-efficacy for marital status could not be compared as the majority of the interviewees (nine out of eleven) were living with their

partners. Education status was not discussed in the interviews so direct comparisons were not possible and the differences in HbA1c investigated in the questionnaire analysis were between participants who had insulin and tablet treated type 2 diabetes rather than between participants with type 1 and insulin treated type 2 diabetes who were interviewed.

5.2 Relationships between illness representations, self-efficacy and self-care behaviour

This section focuses on self-care behaviour and the differences found between the relationship of illness representations and self-efficacy with self-care behaviour for type of diabetes and gender. In the questionnaire analysis the relationships between illness representations, self-efficacy and self-care behaviours were examined for each type of diabetes (type 1, tablet treated type 2 and insulin treated type 2 diabetes). However, throughout the interview analysis it became apparent that gender also had a vital role to play in explaining differences in these variables. For example, there were distinct differences in beliefs about the consequences of diabetes for men and women, differences in what the interviewees felt caused their diabetes for men and women and differences in how men and women evaluated the success of their self-care behaviour for looking after their diabetes (as discussed in chapter four). In the questionnaire analysis the illness representations and self-efficacy for men and women were compared; however, as mentioned previously, the only difference found was for the illness representation *timeline cyclical*. Following the differences in gender emerging from the interviews it was decided

316

to re-analyse the questionnaire data to look at the relationships between illness representations, self-efficacy and self-care behaviour for men and women separately. The results of this analysis are shown in table 35 below:

Table 35 - Correlations between the questionnaire variables for men and women separately.

	Men Positive relationship	Men Negative relationship	Women Positive relationship	Women Negative relationship
General diet behaviour	Specific diet**	None	Age* General diabetes self-efficacy* Flexible diabetes self-efficacy* Specific diet behaviour** Blood testing behaviour** Medication taking behaviour** Exercise** Foot care*	Emotional representations ** Rebellious self-efficacy*
Specific diet behaviour	Treatment control* Stopping hypos self-efficacy* Revealing diabetes self-efficacy* General diabetes self-efficacy** Flexible diabetes self-efficacy* Assertiveness self-efficacy* General social self-efficacy* General diet behaviour** Blood testing behaviour**	External causes**	Age* Duration* General diabetes self-efficacy* General diet** Exercise* Blood testing behaviour* Medication taking behaviour** Foot care**	None

Exercise	Duration* Diagnosis*	Medication taking*	Altered immunity causes*	None
Blood testing behaviour	Specific diet**	External causes*	External causes* General diabetes self-efficacy** General diet** Specific diet** Medication taking behaviour*	HbA1c* Identity* Emotional representations **
Medication taking behaviour	Timeline* Personal responsibility causes*	Exercise*	Age* Stopping hypos self-efficacy* General diabetes self-efficacy* Flexible diabetes self-efficacy* Assertiveness self-efficacy* General diet** Specific diet* Blood testing behaviour*	None
Foot care	Duration*	Hereditary causes*	Age* General diet* Specific diet**	None
HbA1c	Curing diabetes** Assertiveness self-efficacy*	None	Identity* Consequences* Timeline cyclical* Emotional representations * Eye complications* Kidney complications*	Hereditary causes* General diabetes self-efficacy* Blood testing behaviour*

* = p < 0.05
** = p < 0.005

Analysis of the questionnaire data showed clear differences between men and women in the illness representations and self-efficacy beliefs that were

318

connected to self-care behaviour. The following comparison of the questionnaire and interview data used the correlation analysis for type 1 and insulin treated type 2 separately as found in the questionnaire analysis chapter and the correlation analysis for men and women separately as above.

From the interview analysis there emerged several illness representations which appeared to be related to self-care behaviour which were not found to be correlated with self-care behaviour in the questionnaire analysis. The majority of the interviewees indicated that there were significant consequences to having diabetes, in particular potential diabetes complications (with the exception of Mr G). They all suggested that the possibility of complications was a major motivating factor in looking after their diabetes and performing self-care behaviours (see quote on p. 208). However, in the questionnaire analysis, the illness representation *consequences* was found to be correlated with only one self-care behaviour and then only for participants with type 1 diabetes. Consequences was negatively correlated with specific dietary behaviour for participants with type 1 diabetes, suggesting that participants who performed more specific dietary behaviours felt there were less consequences to their diabetes. There were no correlations between consequences and specific dietary behaviour for participants with insulin treated type 2 diabetes, or for any other self-care behaviour whether for participants with type 1 or insulin treated type 2 diabetes. This significantly contrasts with the findings from the interview analysis.

Another obvious contrast between the interview analysis and the questionnaire analysis was in the relative absence of significant correlations between *treatment control* (or treatment effectiveness) and the other variables in the questionnaire analysis. The only correlation between treatment control

319

and self-care behaviour was for specific diet behaviour in men. In contrast, the perceived effectiveness of treatment emerged as being very important for self-care behaviour in the interviews. For example, Mr D's decision not to take his cholesterol or blood pressure medication because he did not believe it worked or made a difference:

"he gave me tablets for it….He give me that about 6 months ago. The only difference with that is, …is there an end result are they working or not? That's all I wanted to know, are they working, are they worth taking. ….he give me ones for blood pressure but I just slung them….I never reordered them. …It's one of those mystery things, you can't see it. I can't go and measure it. It's not like taking a blood test…"

Mr D, type 1, low self-care

The interview data indicated that the interviewees appeared to perform the behaviours that they considered to be important for their diabetes, such as medication taking and blood testing; whereas, more lifestyle aspects of treatment such as exercise and diet were, overall, performed to a lesser extent. The lack of correlations between treatment control and the various self-care behaviours in the questionnaire analysis may be explained in a number of ways. These results may reflect the wording of the questionnaire and the interpretations made by the participants. For example, when the interviewees were asked about what treatment they had for their diabetes, without fail the first answer related to insulin injections.

"Er yeah, I have 2 types of insulin, 1 is sort of a er [pause] one for that lasts throughout for 24 hours of the day, supposed to keep me at a you know sort of level and then fast acting insulin just every time I have a meal which is 3 times a day so I have 4 injections altogether."

Mr H, type 1, low self-care

Other aspects of the treatment regime, such as diet and exercise, were mentioned later (although in the case of some of the interviewees had to be prompted). This focus on insulin injections or medication as 'treatment' may have influenced the way that participants answered the questionnaires. Other methodological issues, such as small sample sizes may also have had an impact on the lack of correlations and this will be discussed in more detail in chapter six (p. 392).

Emotional representations emerged from the interviews as an integral part of the illness experience and appeared to be related to self-care behaviour. However, in the questionnaire analysis there were only nine significant correlations between specific self-care behaviours and emotional representations. Three for women, none for men, three for participants with type 1 diabetes, one for participants with tablet treated type 2 diabetes and one for participants with insulin treated type 2 diabetes. It is important to note at this stage that the IPQ-R, which measured emotional representations, only asked about negative emotions experienced in regards to diabetes. Participants with type 1 diabetes who had high general diet behaviour, high blood testing behaviour and high medication taking behaviour reported fewer negative emotional representations. Participants with insulin treated type 2 diabetes who had higher levels of exercise reported lower levels of negative emotional

representations. Finally, women with high general diet behaviour and high blood testing behaviour reported lower levels of negative emotional representations. There were no significant correlations of emotional representations with self-care behaviour for the men who completed the questionnaires. In the interviews, negative emotional representations were generally associated with the experiences at diagnosis (such as shock, anger, fear and worry), emotional reactions to the limitations or difficulties faced during everyday life (such as frustration over driving restrictions and higher insurance premiums) and ongoing concerns about the future (in terms of worry about potential complications and the impact of diabetes on their children). Interestingly, the men who were interviewed expressed more negative emotional experiences than the women (in contrast to the findings in the questionnaire analysis). Overall the men emerged from the interviews as being angrier about their diabetes and it was only men who expressed emotions about the unfairness of the fact they had got diabetes and other people who did not look after themselves were perfectly healthy. In addition to this it was a man, Mr G, who displayed the most intense negative emotional representations of all the interviewees and exhibited the greatest impact of these emotional representations on his self-care behaviour. Mr G reported being angry, frustrated, confused and depressed about virtually all aspects of his diabetes and explicitly stated that these negative emotions stopped him from doing more blood tests. There may be several reasons for this contrast with the questionnaire data which demonstrated there were no significant correlations between emotional representations and self-care behaviour for the men. These will be discussed in more detail in chapter six.

As mentioned previously the IPQ-R only asked about negative emotional representations. The interview data revealed significant positive emotional experiences as a result of diabetes. These positive emotions were not captured by the IPQ-R but may have been related to self-care behaviour. For example, Ms L described feelings of pride and satisfaction when her blood sugars were within the limits she set for herself (as mentioned in previous chapters). Mr B appeared to derive pleasure from performing all of his self-care behaviours to the best of his ability and experienced great excitement and pleasure abut certain aspects of his self-care behaviours such as his blood test machine:

"I've got the infra red job which you know, put it on the computer, does all the graphs for me. That's fantastic. …. um most of them are within the target range I'm happy to say,…"

Mr B, type 2, high self-care

Four of the interviewees (Ms E, Mr K, Ms L and Ms M) expressed satisfaction when they received good feedback from health care professionals about their diabetes and how they were looking after themselves:

"she [his doctor] was absolutely ecstatic, I'm not saying, she was absolutely ecstatic with my readings she was really, really pleased, my blood pressure was brilliant all the reading were good and she was really, really pleased with that, ….. they were some good readings…"

Mr K, type 1, high self-care

These positive emotions were all described by interviewees with high or medium self-care behaviour. The extent to which these positive emotions related to self-care behaviour is difficult to assess; however, the impressions given during the interviews would suggest that receiving positive feedback,

positive emotions and therefore rewards for behaviour would encourage the behaviour to continue. This is in line with Social Cognitive Theory which suggests that a positive affective state in connection to a certain behaviour will increase self-efficacy which in turn increases the performance of that behaviour (Maddux 1995).

The *self-system,* which is part of the Commonsense Model of the Self-Regulation of Health and Illness (as described in chapter one p. 54) and includes aspects such as identity, timeline, cause, consequences for future selves and identities, self-efficacy and coping strategies, emerged as being very important to the choices interviewees made about their self-care behaviour. The aspect of the self-system measured in the questionnaires was self-efficacy which appeared to be important, as seen from the correlations between self-efficacy and self-care behaviour. For example, for participants with type 1 diabetes *general diabetes self-efficacy* was positively correlated with general and specific dietary behaviour and medication taking, and negatively correlated with HbA1c. This suggested that those participants with type 1 diabetes who had higher self-efficacy also had higher general and specific dietary behaviours, higher medication taking behaviours and lower HbA1c levels. For the participants with insulin treated type 2 diabetes *general diabetes self-efficacy* was positively associated with exercise behaviour, as was *stopping hypos self-efficacy.* These self-efficacy factors, as measured by the questionnaires, were also negatively correlated with negative emotional representations which suggested that those participants with insulin treated type 2 diabetes who had high levels of exercise also had lower levels of negative emotional representations and higher levels of general diabetes self-efficacy and stopping hypos self-efficacy. Self-efficacy was a difficult concept to

discuss in the interviews and directly posed questions about self-efficacy yielded little data. As a consequence of this the interview analysis dealt more with over-arching self-efficacy beliefs and less with the self-efficacy for the specific self-care behaviours measured by the questionnaires. Two areas of importance during the interviews in terms of self-efficacy were hypos (the treatment and prevention of hypos) and liaising with health care professionals. These areas were covered by two variables in the self-efficacy questionnaire: *stopping hypos self-efficacy* and *assertiveness self-efficacy*. Interestingly the only correlation with stopping hypos self-efficacy was for participants with insulin treated type 2 diabetes, with exercise. No mention of an association between self-efficacy about stopping hypos and exercise was made by any of the interviewees although Mr B did discuss his theories for why he had hypos when he exercised.

In the questionnaire data, for the men a higher level of assertiveness self-efficacy was significantly correlated with higher specific diet behaviour but also with higher HbA1c levels, suggesting that those men who felt confident about asking for help had poorer metabolic control. Of the five men interviewed who mentioned feeling confident about asking for help, four had high levels of dietary self-care behaviour and one had a low level of diet behaviour. In the questionnaires, for the women higher assertiveness self-efficacy was associated with higher levels of medication taking. In the interviews, the two women who talked about feeling confident asking for help had high levels of medication taking behaviour. However, the interviews revealed aspects of assertiveness self-efficacy not covered by the questions asked in the questionnaire. The questionnaire focused on self-efficacy about asking for help and being able to discuss things with the health care professional if necessary. The interviews found that the majority of interviewees felt *able* to ask for help

but whether they *did or not* depended on their past experiences with the health care professionals and their beliefs abut the efficacy of the advice they would receive. For example, Ms L and Ms M all felt able to ask for advice at the diabetes outpatient clinic; however, they had doubts as to the suitability of that advice for them:

"I'd have to be desperate to ring the diabetic nurses now cos I don't want to go anywhere near [nurse]. If [her doctor] says we'll just take you through to the nurses I think oh my god."

Ms M, type 1, high self-care

The comparison of the questionnaire and interview analyses for self-efficacy demonstrated the advantage of using different methodological approaches. The questionnaire enabled different aspects of self-efficacy to be assessed directly and the interviews introduced aspects of self-efficacy not covered by the questionnaire to be discussed in more detail.

The correlation analysis of the questionnaire data showed that the illness representations and self-efficacy variables measured only accounted for a maximum of 20% of the variance in self-care behaviour. From the interview analysis it was clear that aspects of the socio-cultural context and self-system were associated with all aspects of the CSM and consequently on the performance of self-care behaviour. This suggested that there were important aspects of how personal experience was related to self-care behaviour that either were not picked up by the questionnaires used or were not measured at all. Limitations of the various questionnaires will be discussed in more detail in chapter six. The main aspects of the CSM which emerged from the interview

326

analysis and were not covered in the questionnaires included aspects of the self-system other than self-efficacy, such as identity and self-image, and all aspects of the socio-cultural context in which the participants were placed. The interview data suggested that despite the fact that the participants all came from the same area and were seen at the same diabetes outpatient clinic they had distinct socio-cultural surroundings. Personal values and beliefs about priorities in life, combined with the input received from the social world around the interviewees had a large impact on their adoption and performance of self-care behaviours.

5.3 Comparing the interviewees and the questionnaire data

The final type of comparison made between the questionnaire analysis and the interview findings was looked at the interviewees and their illness representations, self-efficacy beliefs and self-care behaviours that emerged from the interview data, and compared these to the relationships between the variables found for the sample as a whole but according to the interviewees' specific type of diabetes and gender in the questionnaire analysis. Initially the interviewees were compared with the questionnaire data on the basis of type of diabetes as this was the main hypothesised difference in terms of illness representations, self-efficacy and self-care behaviour. Following the comparison between the interviewees and the questionnaire data based on type of diabetes, comparisons were made based on gender.

For those interviewees with type 1 diabetes the correlations suggested by the questionnaire analysis were partially supported by the interview findings.

For example, in all five interviewees with type 1 diabetes, the interviewees who reported higher general diet behaviour also reported lower negative emotional representations, and in four out of the five interviewees those with higher general diet behaviour reported higher general self-efficacy too. Both of these correlations were found in the questionnaire analysis and were supported by the interview data. However, there were variations, for example the negative association between specific diet behaviour and consequences, found in the questionnaire data, was only found in the interviewees with lower levels of specific diet behaviour (Ms E, Mr D and Mr H). The illness representations and self-efficacy variables with significant correlations to self-care behaviours found in the questionnaire data were compared with the interview data. The interview data was further analysed to ascertain whether there were relationships between the variables (ie illness representations and self-care behaviours) or if they were present in the interview data in the way suggested by the questionnaire analysis. However, these relationships were not replicated. This may have been because the associations were not there; however, as the interview data represents conscious processes, it may be that these relationships were on an unconscious level and therefore not evident in the interview data.

The way in which the data from the interview with Ms E corresponded with the questionnaire analysis can be seen in figure 16. The red lines indicate positive relationships which were found in both the questionnaire and interview data (eg in the questionnaire analysis a correlation was found between general diet behaviour and general diabetes self-efficacy for participants with type 1 diabetes. This relationship also emerged from the interview with Ms E), the blue lines indicate negative relationships which were found in both the questionnaire

and interview data (eg Ms E had a high level of blood testing and low levels of identity – symptoms attributed to her diabetes) and the black lines indicate correlations found in the statistical analysis for participants with type 1 diabetes but not found in the interview data for Ms E.

Figure 16 - How Ms E corresponded to the statistical analysis of participants with type 1 diabetes.
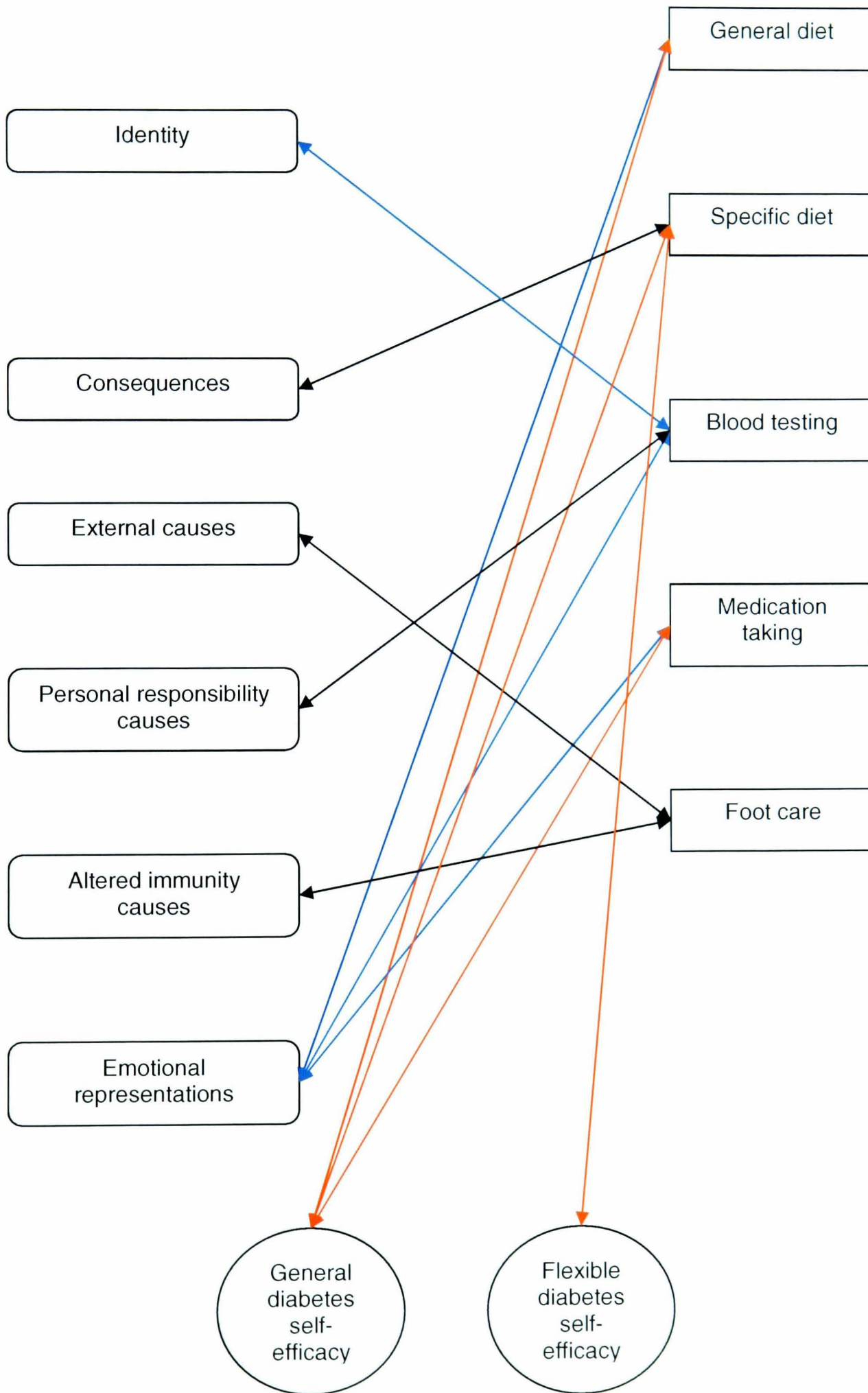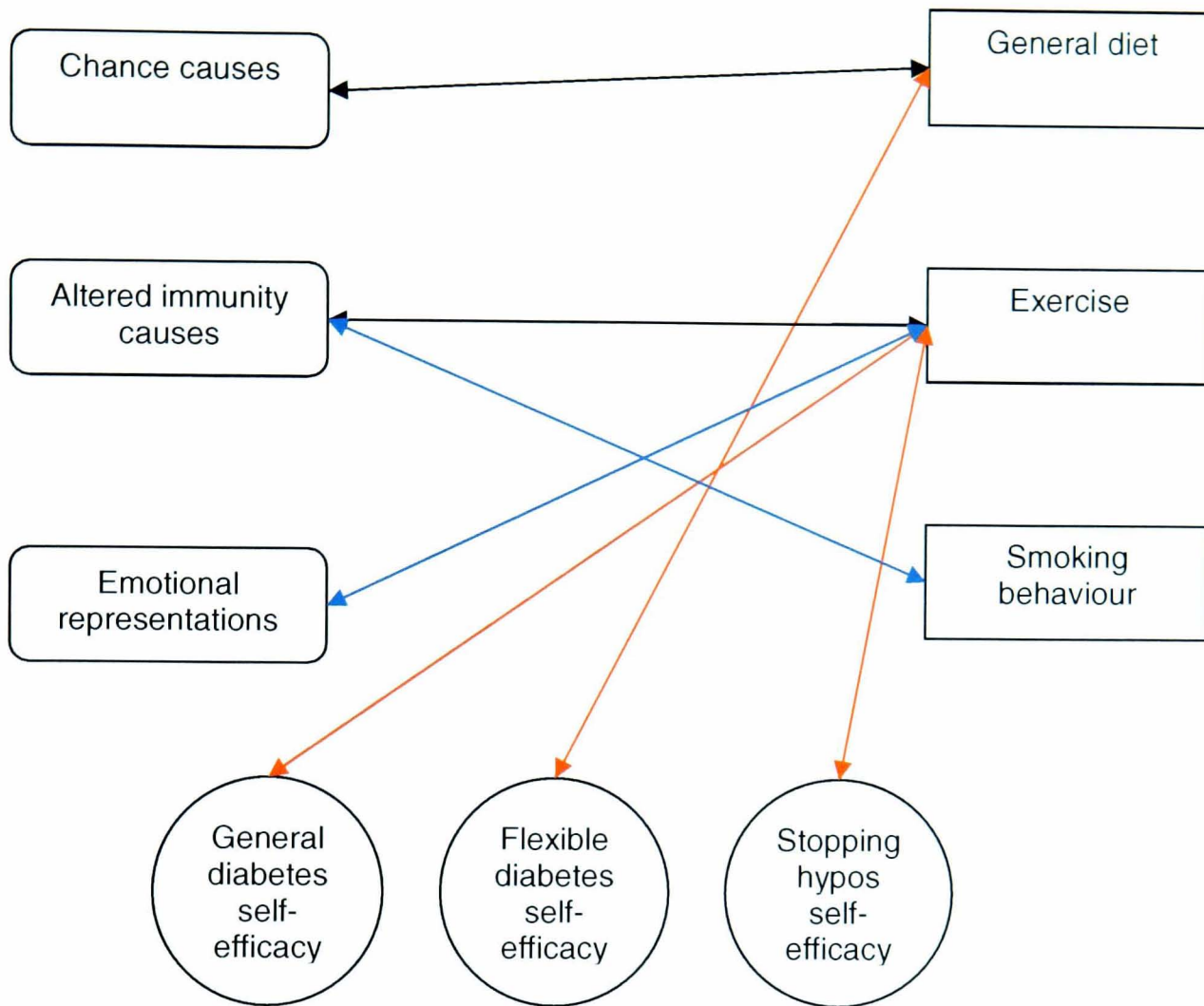
For Ms E the relationships between general diet, specific diet and medication taking and self-efficacy (whether general diabetes or flexible diabetes) suggested in the questionnaire data were found in her interview data. Her self-care behaviour and self-efficacy were clearly inter-connected; although whether the performance of self-care behaviours for other reasons led to an increase in self-efficacy or her self-efficacy led to regular performance of self-care behaviours was not clear. As discussed in more detail in chapters two and six, her self-efficacy came through from the way she talked about her self-care behaviours and the tone of voice and expressions she used rather than any particular statements regarding her confidence. Additionally, the links between emotional representations and diet, blood testing and medication taking were also found in her interview. The interview data suggested that she had generally few negative emotional representations about her diabetes (with the exception of concerns over diabetes complications and getting older). This lack of negative representations about her diabetes may have been due to the way in which she had adapted her diabetes self-care behaviours into her lifestyle. The performance of these behaviours had become an integral part of her life and were performed with such regularity that few negative emotional representations remained. There were several correlations from the questionnaire data which appeared to be found in Ms E's interview data but when explored at a deeper level the link between them was not found, for example, the association between foot care and external causes and altered immunity causes. There was no evidence in the interview data (either Ms E's interview or the other interviews with individuals with type 1 diabetes) that supported the link between these causal beliefs and foot care. Although Ms E believed her diabetes was due to external causes such as a virus and had low foot care behaviour, there appeared to be no connection between the beliefs and the behaviour. The final relationship suggested by the statistical analysis

for participants with type 1 diabetes and found for Ms E was between blood testing and identity (the number of physical symptoms attributed to diabetes). Although Ms E did not discuss explicitly the link between blood testing and identity she did perform regular blood tests to monitor how well she was looking after her diabetes and if her blood sugar levels were under control as a result then this could explain the lack of symptoms attributed to her diabetes.

For the six interviewees with type 2 diabetes, the interviews with Ms J and Ms L contained examples of the correlations seen in the questionnaire data with the exception of the correlation between general diet behaviour and chance causes. Mr G expressed beliefs and views that matched all of the correlations which were able to be compared (any correlations to do with causes of diabetes were excluded as Mr G expressed no views on what caused his diabetes). Ms J is described here as an example of how the interviewees with insulin treated type 2 diabetes compared to the questionnaire data for the whole sample. As before the red lines indicate positive associations found in both the questionnaire and interview data, the blue lines indicate negative associations found in both the questionnaire and interview data and the black lines represent associations found in the statistical analysis but not found for Ms J.

Figure 17 - How Ms J corresponded to the statistical analysis of participants with insulin treated type 2 diabetes.

The relationships between self-efficacy (general diabetes, flexible diabetes and stopping hypos self-efficacy) and general diet and exercise found in the questionnaire data were consistent with the data which emerged from the analysis of Ms J's interview. One of the most interesting associations was between stopping hypos self-efficacy and exercise. For a person with diabetes exercising causes issues surrounding altering insulin doses, altering eating patterns and dealing with hypos. Having the self-efficacy to deal with hypos may be linked to exercise as without that self-efficacy it would have been more difficult to exercise and cope with the constant risk of hypos. The negative association between exercise and negative emotional representations was discussed directly by Ms J who had high levels of exercise and low levels of

negative emotional representations. She talked about how if she was feeling a bit down or flat she would exercise to pick herself up:

"I do try and do that, if I'm feeling sort of uuurrgghhh and if it is high I will go out and do something because it will make me feel, it usually does make me feel, it perks me up and I just think come on get going, don't sit around, get off your bottom."

Ms J, type 2, high self-care

Ms J described both high exercise behaviour and high altered immunity cause beliefs; however, there did not appear to be a link between the two in contrast to the significant correlation indicated by the questionnaire analysis. There also seemed to be little logic behind this relationship. It was unclear why an individual would perform exercise more if they believed their diabetes was caused by an auto-immune response than if they did not. One possible explanation could be that if an individual believed their diabetes was caused by an auto-immune response they may also believe they were susceptible to other auto-immune conditions and therefore exercised in order to be healthy and so reduce their chances of developing such a condition. However, there was no evidence for this found in Ms J's interview. Ms J did not attribute her diabetes to chance and yet performed high levels of general diet behaviour which was why there was no correlation between chance causes and general diet behaviour. Again, this association did not appear to be logical and there was no evidence found in the interviews to explain or explore this further.

Comparisons between the interview data and the models suggested for gender by the questionnaire data were also carried out. Mr H is described here

(and shown in figure 18) as an example of how the male interviewees

compared to the questionnaire data for the whole sample.

Figure 18 - How Mr H corresponded to the statistical analysis for the men.
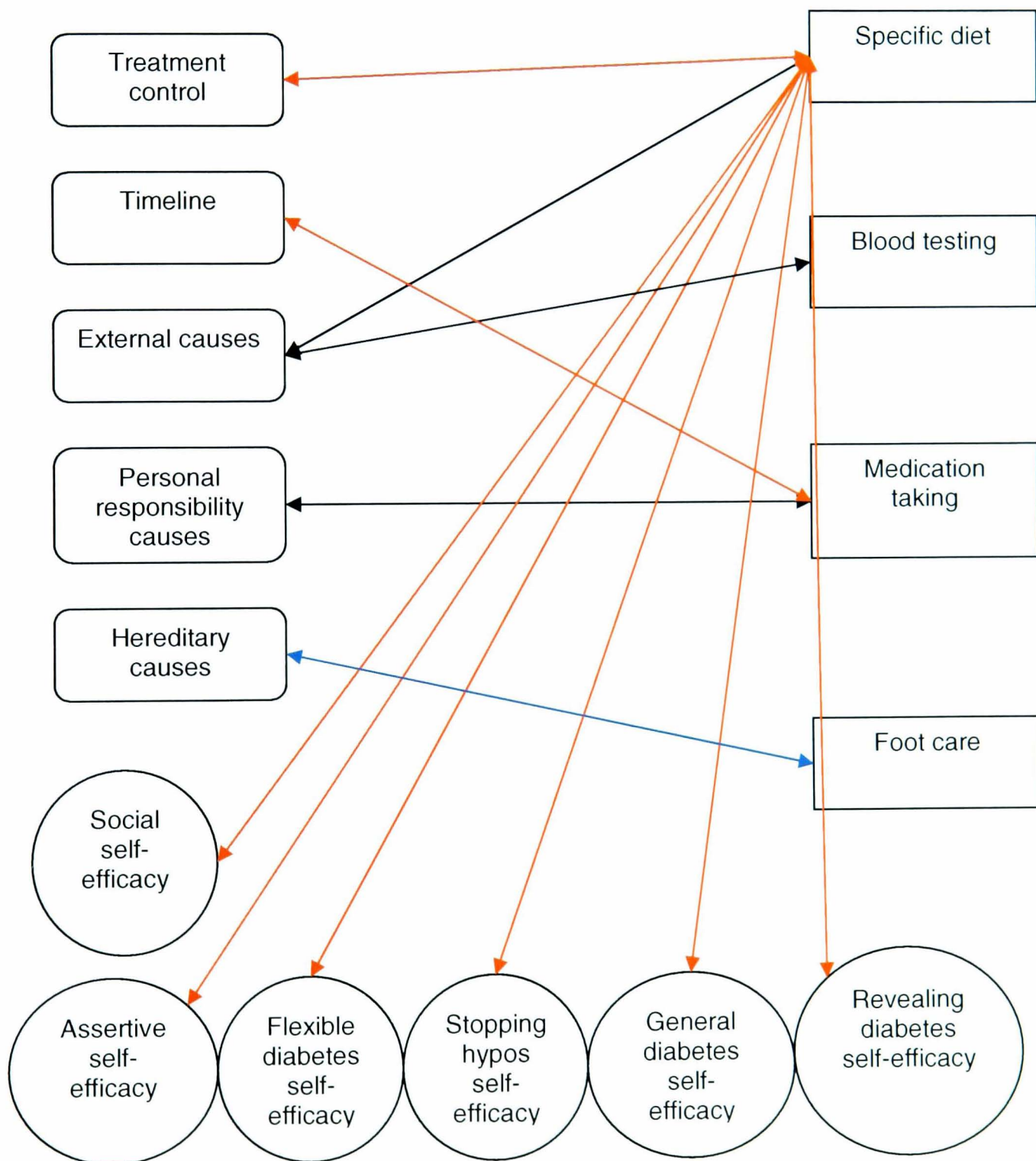
Mr H had high specific diet behaviour and high treatment control. This correlation was supported in the interview data by the fact that there was an overall connection between how effective the interviewees (including Mr H) felt their treatment was and whether they performed the self-care behaviour. In Mr H's case he believed that diet was an integral and vital part of his diabetes care which therefore linked to his high specific diet behaviour. As mentioned previously, throughout the interviews self-efficacy was found to be linked to the performance of self-care behaviour and this association between self-efficacy and self-care behaviour supports the links between the range of self-efficacy behaviours and specific diet suggested by the statistical analysis. Mr H's interview data did not show the significant relationship found between specific diet and external causes in the questionnaire analysis (he had high specific diet behaviour and high external causal beliefs whereas the questionnaire analysis suggested a negative significant correlation between these two variables). This relationship was only found in the men with type 2 diabetes, for example Mr F and Mr B, who reported high specific diet behaviour and low external causal beliefs. This may be because if there is a belief that diabetes was caused by something internal or some personal behaviour then the individual is more likely to perform self-care behaviours to compensate. Mr H described low blood testing behaviour and high external causal beliefs (as found in the questionnaire analysis); however, his lack of blood testing behaviour was linked to his working environment rather than his causal beliefs. He described low foot care and high hereditary causal beliefs which again supported the correlations found in the questionnaire analysis; however, in his interview Mr H did not indicate that there was a causal relationship between his performance of foot care behaviours and his high hereditary causal beliefs. The correlation between medication and timeline found in the questionnaire analysis was also found in the interview with Mr H to a certain extent. Mr H believed his diabetes was life-

long and had high medication taking behaviour. Mr H displayed a firm belief that taking his insulin injections was vital for his survival and his belief that diabetes was life-long in turn suggests that he believed he had no choice but to take his medication regularly (see quote on p. 204).

As an example of how the interview data from the women who were interviewed compares to the questionnaire data for the women in the whole sample, the relationships between the variables for Ms M are shown in figure 19.

Figure 19 - How Ms M corresponded to the statistical analysis for the women.
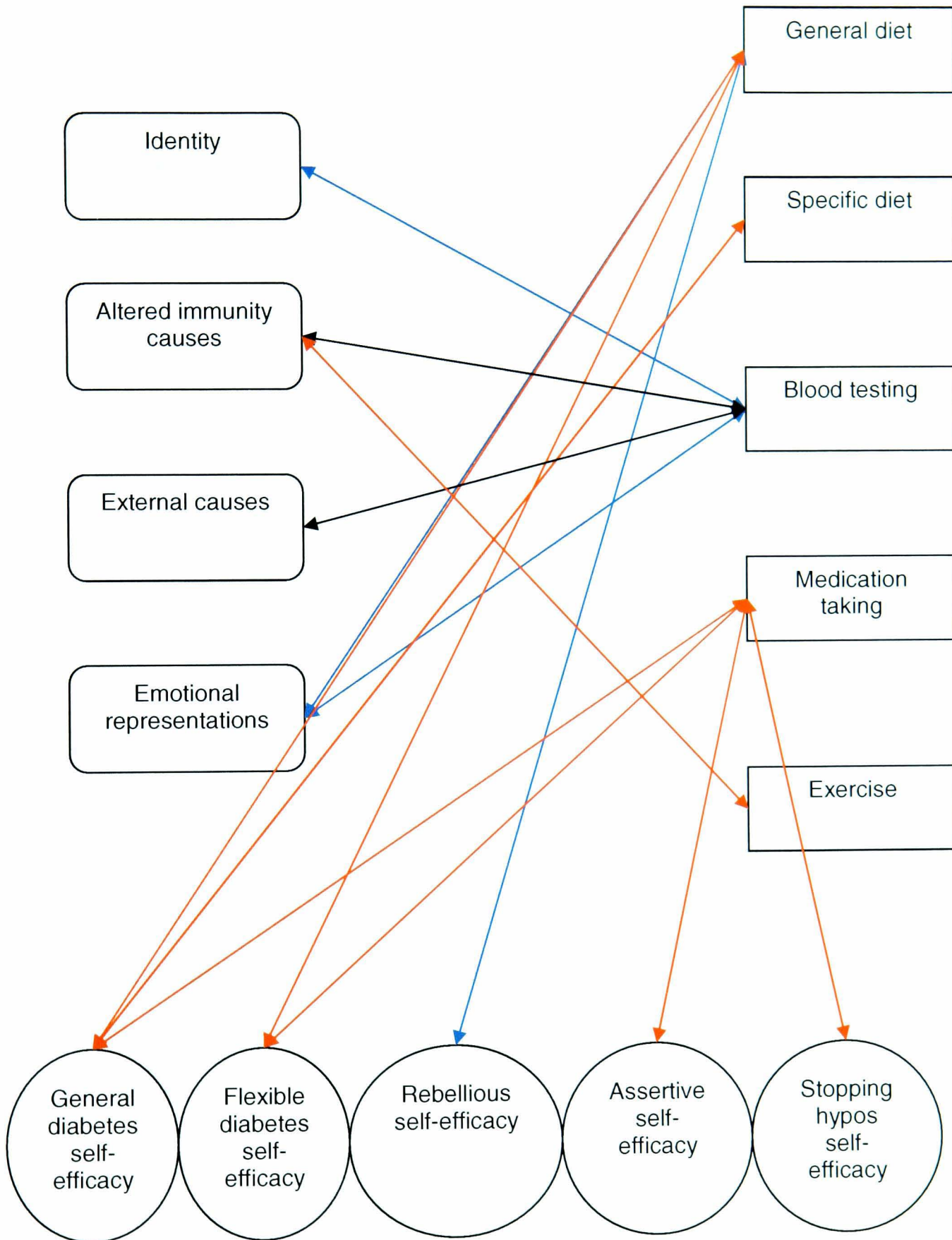
There were correlations between emotional representations and self-care

behaviours which were supported in the interview data from Ms M. In her

interview Ms M demonstrated low levels of negative emotional representations

and these appeared to be associated with high levels of general diet behaviour and blood testing behaviour. Ms M's low negative emotional representations for everyday life appeared to stem from the integration of her diabetes and self-care behaviours into her lifestyle. Also, as mentioned previously, the role of self-efficacy appeared to be linked to self-care behaviour for the questionnaire and interview data for Ms M. Some of the most interesting associations found in Ms M's interview were between general diet behaviour and medication taking with flexible diabetes self-efficacy. Ms M was one of the interviewees who felt very strongly about how her diabetes regimen could be flexible enough to adapt to her lifestyle and as a consequence she felt confident about her abilities to adapt it where needed whilst still maintaining a high level of self-care behaviour:

"the control you can have today and the flexibility you can have, people jump on me for all sorts of reasons, for eating different things and um …it's just part of my life…"

Ms M, type 1, high self-care

This corresponds with the correlations found in the questionnaire data for women between general diet behaviour and medication taking with flexible diabetes self-efficacy. Interestingly, there were no correlations found in the questionnaire data between flexible diabetes self-efficacy and blood testing behaviour; however, in the interview data two of the women (including Ms M) specifically mentioned performing blood tests to enable them to have flexibility in their diabetes regimes. There were no relationships between blood testing behaviour and the causal beliefs of altered immunity and external causes for Ms M despite correlations being present in the questionnaire analysis for women. A relationship was demonstrated by the statistical analysis between altered immunity causal beliefs and exercise for women. As discussed in the

example of Ms J this was also found for those participants with type 2 diabetes. There was no evidence of this link for Ms J; however, the suggestion that it may be to prevent other conditions is a possible one for Ms M. She felt very strongly that she was at risk of other medical conditions such as cancer. This may not have been directly related to an auto-immune response (although it is not possible to say as this was not discussed in the interview); however, causal beliefs in susceptibility to auto-immune conditions may be linked to Ms M's beliefs about cancer and therefore as she stated she exercised to reduce her risk of these conditions so exercise and auto-immune causal beliefs may be linked in some way.

As can be seen from the discussions above, on face value it appeared that the majority of the relationships found between the variables in the questionnaire analysis were also found in the interview data. However, on closer examination it became clear that many of the associations suggested in the questionnaire stage were in fact co-occurrences in the interview data rather than relationships. This reinforced the benefits of carrying out mixed methods research and the ability of this type of research to identify and explore the weakness and strengths in each type of methodology and thus give a clearer and more in-depth picture of the experience of diabetes.

Summary

1) The differences in *illness coherence* and *chance causes* between men with type 1 and insulin treated type 2 diabetes found in the questionnaire data was not supported by the interview data.

2) Men with insulin treated type 2 diabetes were found to attribute their diabetes to *causes they felt personally responsible* for to a greater extent than men with type 1 diabetes. This was supported by the interview data.

3) In the interview data differences were found between women with type 1 diabetes and with insulin treated type 2 diabetes for *identity* (symptoms attributed to diabetes) and *adjustment to diabetes*. Identity was measured in the questionnaire stage of this study but no differences were found for women. Adjustment to diabetes was not measured in the questionnaire data so no comparison could be made.

4) In the questionnaire data women reported that their diabetes went in a cyclical pattern to a greater extent than men and this was supported by the interview data.

5) The interview data suggested that there were differences between men and women in the relationships between illness representations, self-efficacy and self-care behaviour; therefore, further statistical analysis was performed on the questionnaire data.

6) *Consequences, treatment control, emotional representations* and aspects of the *self-system* emerged from the interview data as important for explaining self-care behaviour; however, few correlations were found between these variables in the questionnaire analysis. Reasons for this divergence were discussed.

7) Individual interviewees were compared with the relationships between illness representations, self-efficacy and self-care behaviour, found in the questionnaire data, on the basis of type of diabetes and gender. Comparisons allowed cross-validation and explanation of some of the relationships suggested by the questionnaire data and revealed divergences which were discussed. Overall, the questionnaire and interview data supported each other.

Chapter Six

Discussion

This chapter discusses the findings from the questionnaire and interview stages of the research. It explores possible explanations suggested by the data analysis, how these findings compare to previous research and the implications of personal experience for self-care behaviour.

6.1 Questionnaire findings

The descriptive statistics showed the participants with type 1, tablet and insulin treated type 2 diabetes to be largely comparable in terms of demographic characteristics. There were significant differences between age at diagnosis and duration of diabetes which were part of the diagnostic criteria for diabetes and so were to be expected. The participants with type 2 diabetes were significantly older than the participants with type 1 diabetes. In addition, the participants with type 1 diabetes had had diabetes for a significantly longer duration. The other difference between those with type 1 and those with type 2 diabetes was in marital status. Those with type 2 diabetes were more likely to be divorced or separated than those with type 1 diabetes. This may be attributable to the higher mean age of the participants with type 2 diabetes or other factors not measured. The participants with type 1 and type 2 diabetes were comparable for education status and levels of HbA1c.

Higher levels of HbA1c were associated with higher levels of kidney complications for those with type 1 diabetes and higher levels of eye complications for those with insulin treated type 2 diabetes. This association corresponds with the recognised link between levels of HbA1c and diabetes complications (DCCT, 1993). The small overall sample and small number of participants with complications may explain why there were fewer associations between level of HbA1c and diabetes complications. Interestingly, those with type 1 diabetes had comparatively higher levels of kidney complications compared with those with tablet and insulin treated type 2 diabetes, who had comparatively higher levels of foot complications than those with type 1 diabetes. This may be explained by the physiological mechanism for the development of complications and how this mechanism was affected by the longer duration of diabetes for those with type 1 diabetes and the characteristics of type 2 diabetes, such as length of time until diagnosis and the more gradual development of the condition or the biological mechanism of type 2 diabetes.

6.1.1 Differences between illness representations, self-efficacy and self-care

Although there were fewer significant differences found between the participants with type 1 and type 2 diabetes than expected there were some which were very plausible. The participants with type 1 diabetes reported significantly higher illness coherence than those with tablet and insulin treated type 2 diabetes. This meant that those with type 1 diabetes felt they understood their condition to a greater extent. There may have been several explanations for this. Firstly those with type 1 diabetes had had diabetes for a significantly

longer period than those with tablet or insulin treated type 2 diabetes. The interview data suggested that much of the interviewees' diabetes self-care was learnt by personal experience and trial and error. Additionally, aspects of diabetes care are frequently dealt with when the need arises rather than at diagnosis (Bradley 1995). This meant that those with type 1 diabetes would have had (on average) years more personal experience of diabetes and were more likely to have experienced different aspects of diabetes care which may have explained their higher illness coherence levels. The participants with type 1 and insulin treated type 2 diabetes also reported significantly higher levels of flexible diabetes self-efficacy. By treating diabetes with insulin greater flexibility is needed in order to balance insulin and dietary requirements than when compared to tablet treated diabetes.

The sample size for this study was too small to disentangle if the significant difference in duration of diabetes between the participants with type 1 and type 2 diabetes was related to illness coherence and flexible diabetes self-efficacy. Possible alternative explanations for these results may include differences in the way education about diabetes was conducted for people with type 1 and type 2 diabetes. The descriptions of the process of diagnosis that emerged from the interview data suggested that those interviewees with type 1 diabetes were hospitalised and received diabetes education from health care professionals at the hospital; whereas, the majority of the interviewees with type 2 diabetes went through a process of seeing their GP and being put on tablets followed by being transferred to insulin and therefore received their initial diabetes education from their GP. That there was a significant difference between participants with type 1 and insulin treated type 2 diabetes for illness coherence but not between type 1 and tablet treated type 2 diabetes is also interesting. There were several factors which may have been important in

creating this difference: the added complexity of taking insulin, for example calculating doses when dealing with extra food, extra exercise or coping with illness; initially controlling diabetes with tablets, which the majority of the participants with type 2 diabetes were likely to have done; a shorter duration of dealing with the demands of an insulin regime; a progression of their condition from tablets to insulin and so an increase in the complexity of their diabetes and perceived severity; and possibly a sense of (misplaced) failure related to having to take insulin rather than tablets, therefore they felt they did not understand their diabetes to the same extent as before. Hampson et al. (1990) suggest that the progression from treatment by tablets to treatment by insulin for some individuals with type 2 diabetes may be interpreted as an indication that their condition has become more severe. However, Hampson et al. also cite a study by Teza et al (1988) who suggested that individuals taking insulin often have more knowledge about their condition than those who do not take insulin. The illness coherence scale measured how participants felt they understood their diabetes rather than their actual knowledge, which may reflect this.

The respondents with type 1 diabetes felt less responsible for causing their diabetes than those with type 2 diabetes. This may reflect the fact that aspects of lifestyle, such as eating an unhealthy diet, being overweight and leading a sedentary lifestyle, are generally recognised as being a cause of type 2 diabetes. In contrast, type 1 diabetes is generally seen as being caused by non-lifestyle factors, particularly due to the younger age of diagnosis and the possible link to auto-immune conditions (Pickup and Williams 2003; DeFronzo et al 2004; Kahn et al. 2005). From the interviews it could be seen that the interviewees were generally knowledgeable about diabetes and this knowledge and awareness of the causes of diabetes may have led to those with type 2 diabetes feeling more personally responsible for their diabetes in terms of their

lifestyles prior to diagnosis with diabetes. These beliefs about the causes of type 1 and type 2 diabetes were reflected in the significantly higher beliefs for the men with type 1 diabetes that their diabetes was caused by chance. The final difference observed between those with type 1 and type 2 diabetes was blood testing behaviour. The participants with type 1 and insulin treated type 2 diabetes performed significantly more blood tests than those with tablet treated type 2 diabetes. This reflected current medical recommendations for blood testing for those with type 2 diabetes and the self-care requirements of the differing medications (www.nice.org.uk). In addition it has been shown in previous research that people taking insulin are more likely to perform blood tests than those who are on tablets, whatever their doctor's recommendations (Hampson et al. 1995). Due to the small sample sizes it was not possible to examine the differences between personal responsibility causes and blood testing behaviour in light of the significant difference between duration of diabetes for those with type 1 and type 2 diabetes.

There were significant differences found between respondents with different marital status. For the overall sample and for the men when analysed separately, lower identity scores were recorded for participants who were married compared to those who were divorced. This means that those who were married reported that they had fewer symptoms associated with their diabetes. This difference was not observed in the separate analysis for women. It is suggested in previous research (Charmaz 1994) and also in the interview analysis, that when men are married the relationship with their wife or partner helps them to look after their diabetes; whereas those men who are not married generally cope with their condition on their own. This difference between being married or not and the support received from a partner is not found for women (Charmaz 1994). This may account for the reduction in symptoms attributable

to diabetes for married men but not for single or divorced men or the women. However, for the women who participated there were significant differences for personal responsibility causes with divorced women feeling more personally responsible than those who were single or married. Those who were single were more likely to feel that diabetes was able to be cured and performed less specific dietary behaviours than those who were married or divorced. Specific diet behaviour includes dietary behaviours which are specific to diabetes such as spacing carbohydrates out throughout the day. It may be that the differences between single and married women for specific diet behaviour were due to potential differences in lifestyle which affected the performance of these behaviours. Another explanation may have been in terms of differences in age or duration of diabetes.. However, it is important to note that the sample sizes for these analyses were small so the results should be interpreted with caution.

The differences found in the statistical analysis with regards to educational status were also interesting. As described previously, participants were categorised as having low or high educational status on the basis of the highest level of education achieved. In the overall sample, those with low educational status had higher identity scores, lower external causes, higher showing anger self-efficacy and lower social self-efficacy. A possible explanation for the higher numbers of symptoms attributed to diabetes (as measured by the score on the identity variable) for those with lower educational status could be in the awareness and knowledge of medical issues such as which symptoms are related to diabetes and which are not. When the men were analysed separately, identity was also significantly higher for those with lower educational status. Those with lower educational status also reported greater beliefs that their diabetes was caused by their mental state (ie worry or stress) and performed more general diet behaviours (such as following a healthy eating

plan). When the women were analysed separately, those with lower educational status showed lower beliefs that external factors, such as pollution or poor medical care, and lower altered immunity causes, for example catching a virus, had caused their diabetes and lower levels of social self-efficacy, such as talking to people at a social occasion.

Although there were no significant differences between HbA1c results for type of diabetes, the analysis of the participants whose HbA1c levels fell into each part of the bimodal distribution for those with type 2 diabetes found some interesting results. For participants on insulin with type 2 diabetes those with higher HbA1c levels (and therefore poorer metabolic control) had higher rebellious self-efficacy and lower specific diet behaviour (for example, spacing carbohydrate evenly throughout the day). Rebellious self-efficacy measured how able participants felt to deviate from their prescribed regime. The fact that those who felt able to not follow their regime and those who performed less specific dietary self-care behaviours were associated with higher HbA1c levels supports previous research which suggests that there is an association between HbA1c and performing the recommended self-care behaviours (Wolever et al. 1999; Rhee et al. 2005). The higher attribution of diabetes to chance associated with having lower HbA1c results (and therefore better metabolic control) for those with tablet treated type 2 diabetes is also of interest. There may be several explanations for this result. It may be because of the level of understanding of diabetes held by this group or it may be as a consequence of the small numbers involved in this analysis and the overall good metabolic control found within the sample for this research. The interview stage of this research did not include participants who had tablet treated type 2 diabetes so it was not possible to examine this further.

6.1.2 Relationships between the variables

An examination of the correlations between the variables in each of the three types of diabetes provided the opportunity to look at the relationships between the variables and whether they reflected the theoretical links suggested by the Commonsense Model of the Self-Regulation of Health and Illness. (A list of the variables and correlations can be found in appendices H and J respectively). This discussion focuses mainly on the correlations and, therefore, suggested relationships between particular self-care behaviours and demographic characteristics, illness representations and self-efficacy as measured by the questionnaire data. However, it is important to note that there were significant correlations between the different self-care behaviours. For example, for participants with type 1 diabetes general diet behaviour was correlated with specific diet behaviour and medication taking. However, the fact that all the self-care behaviours did not correlate with each other supports the analysis of each self-care behaviour separately. For example, for participants with type 1 diabetes general diet behaviour did not correlate with blood testing behaviour, exercise or foot care behaviour and for participants with tablet treated type 2 diabetes general diet behaviour did not correlate with any of the other self-care behaviours measured. This supports previous literature which has shown that the performance of one type of self-care behaviour is not highly related to the performance of a different type of self-care behaviour (Glasgow et al. 1987).

Another important issue to mention is the restriction placed on the statistical analysis as a consequence of the small sample sizes, particularly when looking at sub-groups such as type of diabetes with type of treatment,

marital status and high or low reports of variables such as self-efficacy. Correlations were performed to find overall patterns; however, the small sample sizes prevented any further statistical modelling to look for causal relationships or predictive power of the CSM and some of the correlations performed should be interpreted with caution due to the small numbers involved.

Diet behaviour

The association between general diet behaviour and general diabetes self-efficacy for participants with type 1 and tablet treated type 2 diabetes suggested that those who reported high levels of self-efficacy for general aspects of diabetes also performed high levels of self-care behaviour. This corresponds with Social Cognitive Theory which suggests that the more self-efficacy an individual has for a behaviour the more likely they are to perform that behaviour (Maddux 1995). There was a negative association between general diet behaviour and negative emotional representations indicating that those participants who performed higher levels of general diet behaviour had fewer negative feelings about their diabetes. There are explanations for this in each causal direction, although from this analysis it is not possible to say in which direction a causal relationship lies. Eating a generally healthy diet that may have helped control their diabetes may have prevented a negative affective mood and prevented negative emotional representations. Alternatively, participants who felt less negative towards their diabetes may have been more inclined to follow a generally healthy diet. The correlations for general diet behaviour in participants with type 1 diabetes were particularly interesting because of the correlations with emotional representations and general diabetes self-efficacy. In the CSM it is suggested that self-efficacy moderates the relationship between illness representations and self-care behaviour

351

(Brownlee et al. 2000) therefore further analysis was done to see if that occurred within this sample. It was found that general diabetes self-efficacy did moderate this relationship. The analysis suggested that for participants with type 1 diabetes those with low general diet behaviour only had high negative emotional representations when they also had low general diabetes self-efficacy. There were no significant correlations between negative emotional representations and general diet behaviour when participants had high general diabetes self-efficacy. Through correlation analysis it is not possible to establish causal links therefore it can only be suggested that either those participants with low general diet behaviour and low general diabetes self-efficacy therefore have high levels of negative emotional representations, or that having high levels of negative emotional representations led to low general diet behaviour moderated by low general diabetes self-efficacy. Assuming the relationships described by the CSM are correct and that illness representations impact on self-care behaviour with a moderating influence from the self-system (in this case self-efficacy) (Brownlee et al 2000) then it is the former explanation which fits. Participants with type 1 diabetes who reported feeling negative emotional representations about their diabetes and also felt they had low self-efficacy for performing general diabetes behaviours therefore performed less general dietary behaviours. However, the lack of correlation between general diabetes self-efficacy and general diet behaviour when the participants reported low negative emotional representations suggests that self-efficacy only had a moderating influence when participants felt negatively about their diabetes and that when participants had low levels of negative emotional representations or felt positively about their diabetes, factors other than self-efficacy had a greater impact on dietary self-care behaviour.

352

For the participants with type 1 diabetes specific diet behaviour was positively associated with general diabetes self-efficacy, flexible diabetes self-efficacy and negatively associated with consequences of diabetes. The correlation between consequences of diabetes and specific diet behaviour is interesting as it might be expected that it would be those who feel diabetes has more serious consequences who would perform more specific diabetes diet behaviours. However, the questions asked in the IPQ-R referred to financial consequences and consequences on lifestyle rather than potential diabetes complications. The correlations between consequences of diabetes and flexible diabetes self-efficacy ensured this was analysed in more detail. The analysis demonstrated that the correlation between consequences of diabetes and specific diet behaviour was significant only in those with low flexible diabetes self-efficacy. There was no correlation between these two variables in those with high flexible diabetes self-efficacy. This indicated that by having high levels of flexible diabetes self-efficacy the relationship between consequences of diabetes and specific diet behaviour was negated. It may be those who had high flexible diabetes self-efficacy felt that despite performing specific diabetes diet behaviours this had little consequence on their life.

The correlations between specific diet behaviour and the two self-efficacy variables, in those with type 1 diabetes, again supported the literature on self-efficacy which suggests that there is a cyclical process, where having self-efficacy increases the likelihood of performing a (self-care) behaviour and the more that the behaviour is performed successfully the greater the self-efficacy belief (Maddux 1995). It is likely that flexible diabetes self-efficacy was correlated with specific diet behaviour and not general diet behaviour because of the nature of the questions for general and specific diet behaviour. General diet behaviour covered aspects of diet such as eating low fat, high fibre foods

whereas specific diet was more concerned with diabetes specific aspects of diet including spacing carbohydrate throughout the day. In order to perform these specific diet behaviours it may be that more flexibility was needed than for the general diet behaviours. This would provide an explanation firstly, for the difference in relationships between general and specific diet behaviour and the other variables, such as negative emotional representations and consequences of diabetes, and secondly, the fact that flexible diabetes self-efficacy was correlated with specific diet behaviour and not general diet behaviour. Although general and specific diet behaviour were highly correlated for participants with all types of diabetes it is for this reason that they were analysed as separate self-care behaviours.

For participants with tablet treated type 2 diabetes, general diet behaviour was correlated with other self-care behaviours (specific diet behaviour, exercise and foot care). However, the only correlation with non-self-care variables observed was between general diet behaviour and general diabetes self-efficacy. Specific diet behaviour was only correlated with other self-care behaviours, and general diabetes self-efficacy, general social self-efficacy and rebellious self-efficacy. For the participants with tablet treated type 2 diabetes there were no correlations between general or specific diet behaviour and any illness representations such as consequences of diabetes or negative emotional representations, unlike participants with type 1 or insulin treated type 2 diabetes. This may reflect the comparative importance of diet in the care of tablet treated type 2 diabetes. Taking insulin provides an increase in flexibility in terms of what can be eaten and when, due to the ability to alter insulin doses depending on what is eaten. The relative inflexibility of tablet doses means that for participants with type 2 diabetes diet is an integral part of controlling their diabetes which may reflect why no illness representations were correlated with

diet behaviour. The correlations observed between general social self-efficacy and rebellious self-efficacy and specific diet behaviour but not general diet behaviour may again reflect the difference in the type of dietary behaviour being considered. Kelleher (1988) suggests that keeping to the diabetes regime may have an impact on social activities and this may be reflected in the correlation found between social self-efficacy and specific diabetes diet behaviours. The rebellious self-efficacy variable concerned deviating from the prescribed diabetes regime so again this is likely to have more relevance for the stricter diabetes specific diet behaviours than more general healthy eating aspects of general diet behaviour.

It was interesting that for participants with insulin treated type 2 diabetes flexible diabetes self-efficacy was associated with general diet behaviour rather than specific diet behaviour and that no illness representations or self-efficacy variables were associated with specific diet behaviour. As already discussed for participants with tablet treated type 2 diabetes, the lack of correlations with dietary behaviour, general or specific, may reflect the intrinsic importance of diet for those with type 2 diabetes. It is likely that the majority of participants with insulin treated type 2 diabetes would have treated their diabetes with tablets and diet when first diagnosed and then progressed to insulin. Diet is a significant part of maintaining lower blood sugar levels when diabetes is treated with oral hypoglycaemics. It may be that although these participants were now taking insulin and so had a greater degree of flexibility in their diet if they chose to alter their insulin doses the habits and dietary patterns formed when first diagnosed had remained and so were unaffected by other factors. Alternatively, due to the possible differences in diabetes education between those with type 1 and type 2 diabetes, as discussed earlier and in the interviews, the capability to do this was not there for these participants.

Blood testing behaviour

The correlations between blood testing behaviour and the other variables, such as personal responsibility causes, identity, HbA1c and negative emotional representations, were particularly note-worthy. For those with type 1 diabetes higher levels of blood testing was associated with higher personal responsibility cause beliefs, lower levels of symptoms attributed to diabetes (identity), lower HbA1c levels and fewer negative emotional representations. Following previous research that more frequent blood tests leads to better metabolic control (Schwedes et al. 2002; Welschen et al. 2005) the relationship between blood testing, lower HbA1c levels and lower identity is to be expected. Better metabolic control is suggested by lower HbA1c levels and by an absence of symptoms, such as fatigue and loss of strength. The fewer negative emotional representations could be explained in a variety of ways. The interview data suggests that interviewees linked how they felt emotionally to their blood sugar levels:

"if you're going down hypo wise and you don't catch it before you go you and turn.... but you can turn slightly nasty."
Mr D, type 1, low self-care

It could be argued that more blood testing leads to better metabolic control which in turn leads to fewer negative emotional representations or that less blood testing leads to poorer metabolic control which in turn leads to more negative emotional representations. It may be that participants felt more positive about their diabetes as a result of blood testing either because they felt they were looking after themselves well or because they had lower HbA1c levels. There is also the possibility that if individuals felt less negative towards

their diabetes and had fewer negative emotional representations they were more likely to perform self-care behaviours including blood testing behaviour. This follows the connection between affective state and the performance of behaviours suggested by Social Cognitive Theory (Bandura, 1977). The positive correlation between blood testing and personal responsibility causes, for those with type 1 diabetes, is interesting as type 1 diabetes is not commonly associated with being caused by factors within an individual's control. It may be that this association is due to those who do feel responsible for their diabetes looking after themselves better by doing more blood tests or, alternatively that those who feel less responsible for their diabetes felt aspects of their diabetes were out of their hands and therefore performed less blood tests. It is interesting to note that for all participants, whether with type 1 diabetes, tablet treated or insulin treated type 2 diabetes, no self-efficacy beliefs were correlated with the performance of blood tests. For participants with tablet treated type 2 diabetes only illness coherence was (positively) correlated with blood testing behaviour. This suggests that the more individuals felt they had an understanding of their condition the more blood tests they did. This is to be expected, particularly as this correlation was observed for participants with tablet treated type 2 diabetes. Blood testing is an essential part of adjusting insulin levels and avoiding hypoglycaemia for those treated by insulin; however, the general recommendation that blood testing is less essential for those treated by tablets (www.nice.org.uk) combined with the less direct effect blood testing has on their diabetes control supports the idea that it is those individuals who understand their diabetes to a greater extent who perform more blood tests.

Medication taking behaviour

The correlations found between medication taking behaviour and other variables, such as illness representations and self-efficacy, were limited. For participants with type 1 diabetes, medication taking was positively associated with general diabetes self-efficacy and negatively associated with negative emotional representations. This suggests that those participants who regularly took their medication had fewer negative emotional representations and more general diabetes self-efficacy. Again it is difficult to say whether taking their medication made the participants feel less negative towards their diabetes (directly or indirectly) or if feeling less negative emotional representations led to an increase in self-care behaviour. The only other correlation was for participants with tablet treated type 2 diabetes – higher levels of medication taking was associated with higher levels of blood testing behaviour. There were no correlations for insulin treated type 2 diabetes. Self-efficacy beliefs were not correlated with medication taking for participants with either tablet treated or insulin treated type 2 diabetes. The lack of relationships evident for medication taking may be for a variety of reasons. As seen in the interview analysis, medication taking was generally performed to a high level – nearly everybody reported that they took their medication every day and at recommended amounts. In the interview analysis medication taking was seen as something that was not optional but was something which had to be done to survive and the lack of interaction with other variables may reflect this. In addition, as discussed in more detail later on, the medication taking scale did not ask about different types of medication and the interview analysis suggested that participants assumed it to be the medication directly associated to their diabetes (insulin or oral hypoglycaemics).

Exercise behaviour

The lack of correlations between exercise behaviour and other variables for participants with type 1 diabetes is striking. Similarly, for participants with tablet treated type 2 diabetes, there were no correlations between exercise behaviour and illness representations or self-efficacy, other than with other self-care behaviours. In contrast, for the participants with insulin treated type 2 diabetes, higher levels of exercise behaviour were associated with older age, higher altered immunity causal beliefs, general diabetes self-efficacy, stopping hypos self-efficacy and lower levels of negative emotional representations. The connection between low negative emotional representations could be explained by several pathways: exercise is suggested to have a physiological effect on mood and emotions (Ekkekakis et al. 2000), those who feel better about themselves are more likely to exercise or being able to exercise encourages people to feel better about themselves. The positive association between exercise and stopping hypos self-efficacy is of interest. Exercise is one of the factors that can change blood glucose levels and produce hypoglycaemia so the self-efficacy to manage hypoglycaemia being linked to exercise is logical. Either experiencing hypos during or after exercise may have increased self-efficacy about stopping hypos or the participants who were more confident about stopping hypos felt that they were more able to exercise because they could deal with any hypoglycaemic consequences.

The relationship between exercise and stopping hypos was only seen in those participants with insulin treated type 2 diabetes. It may be that this relationship was not seen in those with tablet treated type 2 diabetes because, depending on the type of oral hypoglcaemics taken, these participants were unlikely to have a hypo because of exercise. The participants with type 1

diabetes, overall had a much longer duration of diabetes, and therefore would have had much more experience with managing their insulin and diet during exercise therefore making having a hypo in relation to exercise less important for those participants.

Foot care behaviour

For the participants with type 1 diabetes higher levels of foot care behaviour was correlated with a longer duration of diabetes, being unemployed, altered immunity causes and external causes (such as the belief that diabetes was caused by pollution or poor medical care). The relationship between foot care and duration may have been as a result of the physiological mechanism of neuropathy and other diabetes complications. The longer an individual has had diabetes the more likely they are to develop neuropathy and foot ulcers (Leymarie et al. 2005; Tamer et al. 2006). One of the main functions of foot care (such as checking feet regularly and care with shoes) is to detect foot problems because of neuropathy. Although there was no correlation with foot complications it may be that participants are checking their feet with more regularity if they have had diabetes for a longer period of time. The negative correlations between foot care and altered immunity and external causes are unexpected and may only be a co-occurrence rather than a correlation as there are no rational explanations for this. For participants with tablet treated type 2 diabetes the correlations were both similar and different to those participants with type 1 diabetes. Older participants with tablet treated type 2 diabetes reported more foot care behaviours which is comparable to the correlation between duration and foot care for type 1 participants. However, altered immunity causes was positively correlated with foot care which may again be

an example of a co-occurrence rather than a correlation. The participants with insulin treated type 2 diabetes reported only correlations with other self-care behaviours.

Smoking

There were no correlations between the number of cigarettes smoked and illness representations, self-efficacy or self-care behaviour for those participants with type 1 diabetes. For the participants with tablet treated type 2 diabetes there were correlations between smoking and responsibility causes and general social self-efficacy. The positive relationship between smoking and personal responsibility causes may be explained by the idea that the individuals who felt more personally responsible for their diabetes may also be those who have had an unhealthy lifestyle in the past and this may have included smoking. It may be that despite being diagnosed with diabetes these participants had not stopped smoking. There were negative correlations between the number of cigarettes smoked and altered immunity cause and blood testing behaviour for the participants with insulin treated type 2 diabetes.

HbA1c levels

The correlations between higher HbA1c levels and kidney complications for participants with type 1 diabetes and eye complications for insulin treated type 2 diabetes were expected due to the previous literature suggesting that complications develop as a result of high blood glucose levels and that lower HbA1c levels reduce the risk of complications (DCCT 1993). The lack of correlations for participants with tablet treated type 2 diabetes and with the

other complications such as foot or cardio-vascular complications may be because of the small sample sizes with tablet treated type 2 diabetes and complications in general. It is also interesting that for participants with type 1 diabetes, higher HbA1c levels were associated with less blood testing behaviour as this again supports previous literature in that higher self-care behaviour is related to better metabolic control (Schwedes et al. 2002; Welschen et al. 2005). For participants with type 1 diabetes higher HbA1c levels were also associated with higher negative emotional representations, lower chance causes, higher accident or illness causes and lower general diabetes self-efficacy. As correlations cannot establish causal links it is difficult to say whether higher HbA1c levels caused more negative emotions, perhaps due to a physiological response to higher blood glucose as described by some of the interviewees. An alternative explanation would be that individuals felt more negative about their diabetes when their HbA1c levels were higher because they were not managing to control it as well as they would like. It is also difficult to establish whether negative emotional representations had a direct or indirect impact on HbA1c. For example, if the individual was stressed or upset this may have a physiological impact on their metabolic control or an indirect effect due to a reduction in self-care behaviours (Lloyd et al. 1999).

This issue of causal direction is also relevant for the relationship between general diabetes self-efficacy and HbA1c levels. It may be that those individuals who had less self-efficacy regarding their diabetes therefore behaved in ways which led to poorer blood glucose levels and therefore raised their HbA1c levels or that higher HbA1c levels resulted in the individual feeling that they were unable to do what was necessary to control their diabetes and so had lower self-efficacy. The relationship observed between HbA1c level and chance or illness causes suggested that those who believed their diabetes was caused by

362

an accident or illness had higher levels of HbA1c. This is related to one theory in the literature that external causal attribution reduces the changes an individual will make to their lifestyle as they do not feel responsible for their condition (Weinman et al. 2000; Jessop and Rutter 2003). If this explanation of external causal attribution were applicable, those who attributed their diabetes to chance (as an external cause) would therefore also have higher HbA1c levels. However, from the interview data it was shown that those interviewees with beliefs in the role of chance did not necessarily perform lower levels of self-care behaviour or have higher HbA1cs. It may be that those participants who believed their diabetes was caused by chance still felt they were able to control their diabetes now they had the condition.

In contrast to the participants with type 1 diabetes, there was no correlation between HbA1c and self-efficacy for the participants with tablet treated type 2 diabetes; however, there were significant correlations between HbA1c and identity, timeline cyclical, emotional representations and chance causes. The relationships between chance causes and emotional representations were the same as for participants with type 1 diabetes so the same explanations may apply. It was interesting to note the relationship between HbA1c and identity. This is a logical relationship as higher HbA1c levels may lead to more symptoms being perceived and therefore connected to their diabetes. The illness representation variable timeline cyclical measures how diabetes control moves in a circle with periods where it is controllable and others where it is not. This would also logically be linked to HbA1c as HbA1c is an 'average' measure of metabolic control over six to eight weeks which may have included periods where the individuals' diabetes was slightly more difficult to control and therefore had higher blood glucose levels. In contrast to participants with type 1 or tablet treated type 2 diabetes, the participants with

insulin treated type 2 diabetes had few correlations with HbA1c – only eye complications and foot care behaviour.

6.2 Interview findings

6.2.1 Causes

The interview stage of the research provided an opportunity to look at the experience of diabetes at a greater depth and level of detail and the potential to explore the reasons for levels of self-care behaviour and how these related to illness representations and self-efficacy. The first theme discussed was *causes of my diabetes*. In the literature causal attributions have been connected to self-care behaviour. Jessop and Rutter (2003) found that participants who attributed their asthma to internal factors were more likely to take their medication and Weinman et al. (2000) suggested that participants with myocardial infarction who blamed themselves for their condition were more likely to change their lifestyle to a healthier one. The causal attributions of the interviewees varied. All the women (whether with type 1 or type 2 diabetes) thought their diabetes was caused by a combination of genetic factors and an auto-immune response to a virus or illness. The men with type 1 diabetes all primarily blamed stress as the result of an accident (Lloyd et al. 2005) and acknowledged genetic factors as a contributor to their diabetes; whereas the men with type 2 diabetes (with the exception of Mr G who had reported no causal beliefs at all) felt their diabetes was caused by a combination of genetic and lifestyle factors. The causal beliefs appeared to be based on gender and type of diabetes rather than on the basis of low or high self-care behaviour. However, the two interviewees who believed

they were partially to blame for their diabetes because of lifestyle choices both had very high levels of self-care behaviour.

6.2.2 Consequences

The interview data and the theme *consequences* provided support for the Commonsense Model (Leventhal et al. 2003). The influence of the consequences of diabetes, whether potential complications or more practical consequences, on the performance of self-care behaviour demonstrated the relationship between illness representations and the action plans or self-care behaviours performed. The main reason reported by the interviewees for looking after their diabetes was in order to avoid diabetes complications. Interestingly it was vicarious experience of diabetes complications which emerged as having the biggest motivating force. Nine of the eleven interviewees had vicarious experience of complications and all of them cited this as a reason for looking after themselves. Six of the interviewees also had personal experience of diabetes complications. Three had more serious diabetes complications (Mr B, Mr G and Mr K – neuropathy and amputation) although it was only two of the interviewees with severe complications (Mr B and Mr K) who described their personal experience of complications as a motivating factor for looking after their diabetes. For the other three interviewees with less severe diabetes complications (Ms E, Mr F and Ms M) it was vicarious experience which had a stronger impact. The two interviewees who appeared to ascribe their self-care behaviour the least to avoiding diabetes complications were Mr G and Mr H. Mr G reported being unaware of diabetes complications or the connection between high self-care behaviour and avoiding

them. He had existing complications (neuropathy) but seemed unaware of other potential diabetes complications. Mr H, in contrast, was aware of complications (although he did not have any) but did not cite them as a reason for performing self-care behaviours. Both these interviewees were men with low self-care behaviour who had no vicarious experience of diabetes complications.

The ability to avoid complications was questioned by five of the interviewees. Ms C, Mr D, Ms E, Ms M and Mr K all reported believing that although they tried their best to look after their diabetes, chance or luck would be partially responsible for developing or not developing diabetes complications. Four of these interviewees had type 1 and one had type 2 diabetes and they had a range of levels of self-care behaviour. Lange and Piette (2006) found that *seriousness* was a good indicator of blood sugar control except where participants were fatalistic and similar results were suggested here. For some of the interviewees (Ms C, Ms E and in particular Mr D who talked about the role of chance and luck on numerous occasions) although they knew the seriousness of diabetes and wanted to avoid complications, the fact that they believed the outcome was down to luck to a certain extent may have been a factor in their lower level of self-care behaviour. This provides support for Social Cognitive Theory (Bandura 1977) as although these interviewees had beliefs about the consequences of diabetes, they lacked the self-efficacy that they could prevent complications from occurring. They may, as a result, have performed lower levels of self-care behaviour than other interviewees who had similar beliefs about the consequences of diabetes but believed they were able to influence the possibility of developing complications by their behaviour. For the other interviewees (Ms M and Mr K), even if they believed developing complications may be down to luck, they also recognised that there were other benefits to high levels of self-care behaviour,

for example Ms M described her belief that she had other health problems in her family which she wanted to minimise the risk of developing. This interaction of beliefs about the seriousness of diabetes (the chances of developing and the severity of complications) and the beliefs about the benefits of performing self-care behaviour was also found by Bond et al. (1992). They found that beliefs about the severity of diabetes and its complications was not independently associated with "good compliance" but depended on beliefs about the costs and benefits of performing the self-care behaviour. Those who had the highest levels of self-care behaviour had the lowest "Threat" beliefs (beliefs about severity and susceptibility) and the highest cost/benefit beliefs. Those with high "Threat" beliefs and low cost/benefit beliefs had the lowest self-care levels. One important point which was raised by several of the interviewees was the belief that type 1 diabetes (or in the case of Mr F insulin treated diabetes whether type 1 or type 2 diabetes, which he thought was called type 1 diabetes) had greater consequences than tablet treated type 2 diabetes. This supports previous research which suggests that taking insulin is connected with an increase in the perceived seriousness of the condition (Hampson et al. 1990).

The other *consequences* of diabetes described by the interviewees included practical consequences, such as career limitations, practical consequences caused by the self-care regime, such as planning and lack of spontaneity, and positive consequences. It was interesting to note that in general it was the men who were interviewed who mentioned career, financial and driving consequences. There may be several reasons for the differences in consequences of diabetes on the careers of the interviewees for men and women. It may have been because of the differing importance of a working role for men and women with the women having multiple roles (as wife, mother and so on) while the men adopt the traditional 'breadwinner' role (Charmaz 1994).

367

However, it may be simply that the men interviewed in this study were in or wanted to work in a career sector in which it is not possible for people with diabetes to be employed such as the armed forces and HGV driving. The practical consequences of the self-care regime reflect what has been shown in previous literature (for example Kelleher 1988, Bury 1982) in terms of lack of spontaneity and loss of control. The need for continual vigilance and planning had an impact on the lives of the interviewees. Mr F and Mr B demonstrated classic examples of the impact diabetes had on their control and spontaneity, although aspects of this were found in all of the interviews. Mr B and Mr F described in detail how their diet in particular was extremely organised because of their diabetes and they discussed the implications of this on their lifestyle. Charmaz (1983) suggested that loss of control and spontaneity can lead to social isolation and this was seen in Mr G who, as a result of his diabetes either directly or indirectly, reported he no longer socialised to the same extent.

6.2.3 Myself and my diabetes

The majority of the interviewees described feeling that they were 'normal' despite having diabetes. This supports previous research by Koch et al. (2000) who found that the men they interviewed described their diabetes as not being an illness but "it's a part of life". *Normalisation* is regarded as the most common strategy for dealing with a long-term condition (Taylor and Field 1997) and involves minimising the impact of self-care behaviours on lifestyle and acting as normally as possible. Interestingly, in this research both men and women described how they were 'normal' which was in contrast to Koch et al. who found that the women they interviewed did not normalise their diabetes and

368

were very conscious of the restrictions caused by their diabetes. Kelleher (1988b) found in his research that more women than men were 'worriers' and did not normalise their diabetes. The three exceptions to "normalisation" in this research were the men with type 2 diabetes – Mr B, Mr F and Mr G. It emerged from the data analysis that these interviewees felt their diabetes marked them as 'different' from the rest of the population. All three of these interviewees placed their 'diabetes self' as a central role within their lives. In contrast, the other interviewees described being a parent, partner and worker as more important than being 'someone with diabetes'. It is important to note that both Mr B and Mr G were medically retired; however Mr F was still employed and working regularly. Their diabetes provided Mr B, Mr F and Mr G with status and an identity. Mr B and Mr F enjoyed the social consequences of having diabetes by meeting and talking to other people with diabetes and using it as a bonding experience. Both Mr B and Mr F had high levels of self-care behaviour. In contrast Mr G (with low levels of self-care behaviour) found his diabetes a socially isolating experience. He described a full and active life prior to his diagnosis with diabetes and heart problems. He reported that his diabetes now meant he was in financially reduced circumstances and his diabetes was so unpredictable he found it difficult to plan to go out or do other activities.

All three men with type 2 diabetes showed clear examples of how long-term illness had caused 'biographical disruption' (Bury 1982). An example of this is the redefinition of self and identity due to diagnosis with diabetes, as mentioned above. Another aspect of biographical disruption described by Bury is mobilisation of resources and each of these three interviewees had experienced this in a slightly different way. Mr B was single and had family that did not live nearby so he had mobilised social resources such as his membership of groups within his community, for example the church, where he

regularly talked to others with diabetes. He was very interested and active in Diabetes UK through written communication with the Diabetes UK magazine and through the internet. Because of his past employment he was also familiar with the hospital and staff who worked there so he made full use of the diabetes clinic resources as and when needed. Mr F's main social resource was his partner who provided support for the practical and emotional aspects of diabetes care. In addition to this, Mr F had a number of colleagues and friends with diabetes and reported forming an informal diabetes 'support group'. Mr G was an example of the negative side of biographical disruption. As mentioned earlier, his social circle had reduced because of lack of financial resources and the lack of spontaneity (as discussed by Kelleher 1988) resulting from his diabetes. Although the relationship with his wife was not discussed specifically, through the interview there were suggestions of certain strains on the relationship, particularly around her working outside the home. This relates to Bury's assertion that long-term illness can strain relationships as it changes the dynamics of the relationship from 'mutual dependence' to a more uneven relationship with one partner caring for the other – which was the case with Mr G and his wife.

Mr G fitted the model of biographical disruption as suggested by Bury (1982) but he also demonstrated characteristics of an earlier theory - the *sick-role* (Parsons 1951). Mr G fitted each of the criteria for Parsons' *sick-role*: 1) He felt himself to be exempt from 'normal' responsibilities and this was legitimised by his frequent admissions to hospital and receiving disability benefits; 2) He felt he had the right to be cared for and this was legitimised by his receipt of a carer's allowance; 3) He reported wanting to get better; 4) He felt that he co-operated with the medical profession, attending appointments and taking his medication. This theory has often been criticised for being too rigid and

unsuitable for long-term conditions (Lubkin and Larsen 2002). However, it was clearly appropriate for describing one of the interviewees. Mr G was different from the other interviewees (who did not fit the *sick-role*) in that he appeared to have abdicated all responsibility and ownership of his diabetes to the health care professionals who were treating him. This maintained the doctor-patient hierarchy which is the antithesis of collaborative care (Funnell and Anderson 2004). The self-care activities he described were all centred on dealing with events or crises as and when they happened in an almost acute medical model sense. A clear example of this was his treatment of his current neuropathy while showing no indication of behaviour to prevent further complications. The aspects of diabetes care concerned with preventing difficulties before they happened or detecting complications at the earliest stages (such as foot care behaviour and retinal screening) appeared to be missing from how Mr G looked after himself, possibly because of his reliance on the health care professionals and lack of ownership of his condition. This may have been why Mr G fitted the *sick-role* which is based on an acute medical model.

Mr G was also the interviewee at the most extreme end of the self-care spectrum which may be why he fitted the sick-role model and the other interviewees did not. However, the *impairment role* (Gordon 1966) which was an adaptation of the *sick-role* for long-term conditions, did fit, to a certain extent, with the experiences of the other interviewees. The impairment role suggests that normal responsibilities should not be relinquished and individuals are expected to behave as normally as possible as allowed by the long-term condition experienced. There is no requirement to 'want to get well', as required in the *sick-role*, as this is not possible, but the person should be encouraged to make the most of their life despite their long-term condition (Lubkin and Larsen 2002). The *impairment role* therefore suggests people should adapt their lives

to manage their illness and achieve 'maximization of wellness' (Lubkin and Larsen 2002) whilst maintaining additional roles that are more associated with a 'normal' life. Bury (1982) suggests that people with long-term conditions can adopt the *impairment role* whilst still being able to return to the traditional *sick-role* during periods when their symptoms are exacerbated or during specific events such as surgery. An example of this was when Mr B described returning to the *sick role* on occasions when his diabetes was uncontrollable due to catching another illness.

The *impairment role* was clearly demonstrated by all of the other interviewees who had, to a lesser or greater extent, adapted their lives and their diabetes regime to fit together to enable them to lead 'normal' lives as much as possible. The extent to which lifestyle or diabetes regime were altered and how the balance was found between the two depended on the individual. Three of the interviewees (with type 2 diabetes – Mr B, Ms J and Ms L) described making an active decision to control their diabetes and so prioritised looking after their diabetes to a certain extent. Four of the interviewees (with type 1 diabetes – Ms E, Ms M, Mr K and Mr D) reported finding a balance between their diabetes and lifestyle and integrating their diabetes into their lives. However, the balance was different for each individual. Mr D (with low self-care behaviour) reported making few alterations to his lifestyle because of his diabetes but instead had found a diabetes regime which kept his blood glucose levels reasonably controlled and fitted within his lifestyle. Other aspects of the diabetes self-care regime, such as diet and exercise, were secondary considerations for him and he did not consider them essential for his health so were not a focus of his life. In direct contrast was Ms M (with high self-care behaviour) who had also integrated diabetes into her lifestyle but had also shaped her lifestyle around her diabetes, for example finding time for exercise

and eating a healthy diet. There were no explicit reasons for why the balances these interviewees had found were different. It is suggested that the differences came from different priorities within the individual's life which led to different accommodations being made to the diabetes regime. This is further supported by looking at Ms C and Mr H who both described circumstances in which their working lives prevented them from carrying out the diabetes self-care behaviours they would like to. For these interviewees their working life was a priority over their diabetes care. The impact of working life on diabetes self-management was investigated by Weijman et al. (2005) who found that employees with a high workload were more likely to perceive insulin injecting as a burden, which corresponds with Mr H's views on performing insulin injections and blood tests whilst at work. At the other end of the spectrum, although in a different way from Mr G, diabetes and the performance of very high levels of self-care behaviour controlled the lives of Mr B and Mr F. The priority for these individuals was their diabetes above any other lifestyle considerations.

Although much of the previous discussion of this theme focuses on the sociological literature such as Bury's Biographical Disruption and theories about identity the *myself and my diabetes* theme is also supportive of the Commonsense Model (Leventhal et al. 2003) and Social Cognitive Theory (Bandura 1977). Both of these theories recognise the way in which personal and environmental factors interact with the self-care behaviours performed. The CSM suggests that socio-cultural context and the self-system interact with the relationship between illness and emotional representations and self-care behaviour. Leventhal (2003) also suggests that socio-cultural context and self-system may interact directly with aspects of the model such as the stimuli attended to, illness and emotional representations and the self-care behaviours performed. As described previously, the interviewees who considered that their

diabetes made them 'different' appeared to behave in a way which reflected this belief, for example Mr B's strict dietary behaviours. In addition, these beliefs and subsequent self-care behaviour appeared to have an impact on the behaviour and beliefs of the people around them, within their socio-cultural context. This in turn may have affected their self-care behaviour and reinforced the belief that they were 'different' as a result of their diabetes. This is seen in the descriptions by Mr B of the interactions with his family and the way in which they responded to his diabetes. Similarly, Social Cognitive Theory suggests that internal personal factors, such as cognitive beliefs, have a direct association with behaviour. This is clearly demonstrated by Ms J's role as a nurse. Ms J had professional knowledge about diabetes and strong beliefs about the importance of performing self-care behaviour for her own health, but also because of her desire to be an example for her patients with diabetes. Because of these beliefs Ms J reported a very high level of self-care behaviour. This is also an example of 'triad reciprocality' with her cognitive beliefs interacting with her behaviour, and her environment, in terms of her work, interacting with her cognitive beliefs and her behaviour.

6.2.4 Emotional experience

The emotional experiences of the interviewees varied from individual to individual; however, patterns did emerge from the data. Nine out of the eleven interviewees described the shock, fear, anger and sometimes relief at being diagnosed. The exceptions were the two women who had been diagnosed as children (Ms E and Ms M) who reported that they could not remember much about how they felt around the time of their diagnosis or how their lives had changed after being diagnosed with diabetes. This is a clear demonstration of

374

the difficulties inherent in asking about events which happened not only years ago but about a stage in life where comparisons between *before* and *after* are extremely difficult. All of the interviewees described experiencing symptoms prior to being diagnosed with diabetes, although some reported having symptoms that were more severe than others. Mr F (with type 2 diabetes) expressed relief at being diagnosed. He had been unwell for a long period of time and despite visiting his GP on several occasions it had taken months to receive a diagnosis. Mr F's relief was accentuated by the reasons suggested by his GP for his symptoms prior to his diagnosis with diabetes. It was suggested to him that he had 'yuppie flu', which he felt was regarded as a psychosomatic or even an imaginary illness, so his final diagnosis with diabetes not only enabled him to be treated and so feel well again but also justified his previous visits to the GP and legitimised his illness. The onset of fear and shock at diagnosis described by the other interviewees, and the relief felt by Mr F, have been discussed in previous literature. Charmaz (1994) describes the diagnosis with a long-term condition as an "awakening to death" in that individuals are confronted with their mortality possibly for the first time. As a consequence she suggests that shock, fear and grief may result from the threat to identity experienced. Bury's (1982) theory of *biographical disruption* also describes the consequences of diagnosis with a long-term condition and how strong emotions may be experienced, as assumptions about life and identity are challenged and uncertainty about the future develops. Kelleher (1988) looked at diabetes and how shock may be felt if the diagnosis was sudden or relief if symptoms had been felt for a period of time before diagnosis.

The CSM suggests that emotional representations are related to action plans or self-care behaviour in a parallel process to cognitive illness representations. The scope of this research means it is difficult to examine how

these initial emotional reactions to diagnosis related to self-care behaviour at the time of diagnosis. However, the emotions experienced at diagnosis appeared to still be strong in a number of the interviewees and therefore may have had a relationship with the current self-care behaviours performed by those individuals. As mentioned previously, Mr F felt great relief at his diagnosis with diabetes and subsequently described very high levels of self-care behaviour. In contrast to this, Mr G described feeling fear and confusion at his diagnosis with diabetes and subsequently had low levels of self-care behaviour. However, emotional experiences at diagnosis were clearly not associated with future self-care behaviour in all interviewees as a number of them reported having experienced fear at diagnosis but also had high levels of self-care behaviour, for example Mr B. Leventhal et al. (2003) suggest that emotional representations, like illness representations, contain past and present sources and therefore it is the combination of the emotional experience at diagnosis and subsequent emotional experiences that are related to self-care behaviour.

Following a diagnosis with diabetes the next part of the emotional experience discussed by the interviewees was the active decision to take control of their diabetes and accept it into their lives. This has been discussed earlier but the emotional relevance of the decision is also worth mentioning. Mr B, Mr D, Ms J and Ms L all felt that the point at which they decided to take control and accept how things were was when they were able to replace the fear, uncertainty, and for Mr D anger, with more practical coping strategies to deal with their diabetes. This was described in previous research by Hernandez (1995) who found that the 'expert patients' she interviewed described a 'turning point' where a decision was made to integrate their diabetes into their lives instead of striving for 'normalcy' and that this resulted in finding a way to live with diabetes with the focus on living without harming diabetes management.

376

Although this process was only described explicitly by four interviewees it is an important example of the interaction between emotional representations, coping strategies and self-care behaviours as suggested by the Commonsense Model (Leventhal et al. 2003).

Although, as mentioned earlier, Ms E and Ms M were unable to describe the emotions experienced at diagnosis to a great extent because they were diagnosed as children, this also meant that they had had diabetes and that it had had an emotional impact on aspects of parts of their lives which the other interviewees had not experienced. The interviewees were not asked about emotional experience throughout their life course, instead the questions concentrated on diagnosis and how they experienced diabetes currently; however, Ms E and Ms M introduced into their interviews how their diabetes had affected their pregnancies and how this had had an impact on them emotionally. This demonstrated firstly, how great an impact diabetes had on their pregnancies in a physical and emotional sense. It also highlighted aspects of these interviewees' lives which were important, both as a specific event but also in terms of an ongoing role as a mother which remained an important consideration when dealing with their diabetes.

The two main aspects of everyday life with diabetes that emerged as causing the most worry and anxiety for the interviewees were the possibility of diabetes complications and the occurrence of hypos. The fear and worry about complications were emotions that the interviewees lived with and dealt with in their individual ways. As discussed earlier, this was intertwined with beliefs about how much the interviewee could prevent complications and how much depended on chance rather than the performance of self-care behaviours. The relationship between emotions and consequences of diabetes has been shown

in previous literature, for example Hampson et al. (1990) found that questions asking about participants' emotional response to their diabetes were part of the *seriousness* variable (very similar to the *consequences* variable) showing how related emotions and consequences were. In contrast, hypos were a much more immediate possibility than complications and so had a more direct impact on the interviewees' lives. They were also seen as more preventable by self-care behaviour. The interviewees had developed coping strategies for when they had a hypo or in case they were unable to help themselves because of a hypo. For example Mr B had an alarm and Mr D checked his blood sugar before driving to make sure he did not have a hypo whilst behind the wheel.

The gender difference in terms of reported emotional experience was clear from the interview data. One example was the anger described by the men about how their diabetes had limited their lives in terms of HGV driving or their career, which was largely missing from the interviews with the women. In addition to this, only the women expressed positive emotions in relation to their diabetes, for example Ms L feeling pride over her blood sugars when they were in the range she was aiming for. The men expressed few positive emotions about aspects of their diabetes, but several did report feeling jealous of other people who did not have diabetes, in particular those who they considered to have the same or greater risk factors for diabetes than themselves. For example, Mr F discussed his neighbours who led a sedentary lifestyle and were very overweight and how he felt it was not fair that they did not have diabetes and yet he did. This corresponds with the findings of Charmaz (1994) who interviewed men about their experiences of long-term conditions. She found that the men described being betrayed by their own bodies and that this produced anger, self-pity and also "envy of the healthy", which was not found in women. The differences between men and women also demonstrated the

interaction of the socio-cultural system and self-system, of which gender is a clear example, with emotional representations and self-care behaviour as suggested by the CSM.

The overall pattern described in the interview analysis was one of an emotional journey from diagnosis, through acceptance of diabetes to the everyday emotional experiences of diabetes. Although analysis of the emotional experience was limited because the interviews did not cover the whole life history of the interviewees, a picture was gained of how diabetes had affected the interviewees at different stages of their lives and how it affected them at the time of their interviews. The exception to the emotional journey was Mr G. Although he was diagnosed eight years previously the emotions he described seemed more appropriate to someone who had just been diagnosed, for example anger, frustration, despair, confusion and fear. It may be that this was related to his perceived lack of knowledge about diabetes, his adoption of the sick-role or his lack of motivation to find out about diabetes for himself. Charmaz (1994) describes how men may become depressed when "lessons in chronicity" challenge their assumptions about aspects of the male identity such as mastery and competence. This was seen for Mr G who described how his life now contrasted with his life before his diagnosis with diabetes in terms of his working life and his lack of ability to do the things he used to do. This may have developed into a sense of helplessness when dealing with his diabetes. The experience of Mr G was a good example of the relationship between emotional representations, illness representations, socio-cultural context, self-system and self-care behaviour described by the CSM. Mr G's emotional representations, as described previously, appeared to be associated with his emotions at diagnosis – fear, anxiety, confusion, despair – and this may have interacted with certain aspects of his socio-cultural context and self-system, such as his

adoption of the sick-role, his reported lack of motivation to expand his diabetes knowledge and coping strategies, to result in his low level of self-care behaviour.

6.2.5 Self-efficacy

Self-efficacy was found to develop in seven main ways which corresponded with the four sources of self-efficacy suggested by Bandura (1977): *personal experience* (including *continuous routine* and *lack of choices*), *social persuasion* (including *personal research and knowledge*), *vicarious experience* and *affective states*. Personal experience emerged as the primary way in which the interviewees developed self-efficacy, followed by *social persuasion* and *vicarious experiences.* This is very similar to the suggestions of Bandura (1977). He describes performance experiences (or personal experiences) as the strongest influence on self-efficacy. This is supported by the interview data as all of the interviewees gained most self-efficacy from personal experience. One form of performance experience emerged from six of the interviewees describing the continuous diabetes regime as reinforcing their self-efficacy. Each time the regular self-care behaviour was performed successfully self-efficacy for that behaviour increased. All of the interviewees described feeling they had no choice but to perform some of the self-care behaviours, for example taking insulin injections. Bandura (1997) describes this as *routinization* where once a behaviour is performed to a necessary level and has been practiced to a sufficient extent it becomes routinized and therefore no longer requires a 'higher cognitive control'.

The self-efficacy beliefs of the interviewees were somewhat intertwined with another construct similar to self-efficacy – *outcome expectancy*. Bandura states that self-efficacy beliefs are thought to have an impact on outcome expectancies but how much depends on the amount to which outcome expectancy depends on the quality of performance (Bandura 1977). The administering of insulin injections is an important example of this within this research. The outcome expectancy that failing to perform medication taking behaviours will lead to ill health, complications and potentially death means that the quality (in terms of frequency and appropriate doses) of the performance of injections needs to be high to avoid (or achieve) the outcome expectancy. Because the interviewees have successfully avoided falling ill by taking their injections and by performing high levels of medication taking behaviour their self-efficacy for this is high. This is contrasted with other medication taking behaviour, for example by Mr D. He reported that he did not believe that the tablets prescribed by his doctor for his cholesterol levels or blood pressure had any impact on his health and therefore he did not have outcome expectancies relying on the performance of this tablet taking self-care behaviour. This meant that he did not perform those behaviours. Although the tablets for cholesterol and blood pressure Mr D was prescribed were important for his diabetes care from a medical point of view, they had no direct impact on his blood sugar levels and therefore he considered them to be unimportant. This supports previous research by Murphy and Kinmonth (1995) who found that some of their interviewees with type 2 diabetes believed that if a behaviour did not raise their blood sugar levels then it did not have an impact on their risk of complications.

Bandura's second most influential source of self-efficacy is vicarious experience followed by verbal or social persuasion. Interestingly, for the

interviewees verbal persuasion appeared to be more influential than vicarious experience; however, Bandura was describing a generic model of self-efficacy and in a health care environment the influence of health care professionals providing advice and treatment plans could be expected to be of a greater influence.

Another aspect of self-efficacy which emerged from the interview analysis was the involvement of partners in looking after two of the interviewees' diabetes and how this impacted on their self-care behaviour. Both Mr F and Mr K described the extent to which their partners assisted with the care of their diabetes. Mr K attributed much of his high self-care to the influence of his wife who was a nurse. Mr F reported how his partner controlled what he ate, was the person who had done research on diabetes when he was first diagnosed and how she told him what to do to look after his diabetes. Both Mr F and Mr K described high self-efficacy about most of the self-care activities (with the exception of exercise); however, both men suggested that without the input and influence of their partners they were not sure that they would perform the self-care behaviours to the same extent. In chapter four it was suggested that it may have been the partners of these men who had the self-efficacy regarding certain self-care behaviours, such as diet, rather than the men themselves. Interestingly, none of the women reported similar relationships with their partners regarding their diabetes. In general the men often used terms such as 'we' or 'our' when talking about their diabetes and the self-care behaviours they performed; whereas the women all used 'I'. In the sample there were only two interviewees who did not have a current partner (one man and one woman); however the women with partners still used 'I' when talking about their diabetes. This was discussed by Charmaz (1994) who interviewed men about long-term illness and identity and found that for the men she interviewed who were

married or with a partner, their long-term illness was a positive opportunity in terms of strengthening their roles within their household as husband and/or father and allowed their partner to strengthen their role as care-giver. This is clearly seen in the cases of Mr F and Mr K. Charmaz (1994) also suggests that for women this did not happen and that women tended to cope with long-term illness primarily on their own which was also supported by the interview data. The differences in partner involvement in the interviewees' diabetes management for men and women which emerged from the interview data is also supported by Nouwen et al. (1997). They found that, in their analysis of individuals with type 1 or type 2 diabetes, more men than women were classed as belonging to a 'spousal overinvolvement' group. Participants in this group reported high levels of positive reinforcement behaviour from their spouses but also high levels of "misguided support behaviours". More women than men were classed as belonging to a 'low support-low involvement' group with regards to their diabetes self-care. Participants in this group reported that their spouses did not provide much support in regards to their diabetes and also reported low levels of reinforcing behaviours from their spouse or significant others.

Social Cognitive Theory suggests that affective state can influence self-efficacy beliefs (Maddux 1995). If negative affective states are experienced during the performance of a behaviour it is suggested that low self-efficacy beliefs may be developed for that behaviour and vice versa. This was seen within the data for both negative and positive affective states. Mr G demonstrated this through his report of the negative emotions he experienced because of blood testing and how as a result he had low self-efficacy about how to respond to his blood test results and so did not perform them regularly any more. The negative emotions that Mr G reported feeling in relation to his

diabetes may have had a negative impact on his self-efficacy beliefs about his ability to control his blood sugar levels which in turn may have increased his feelings of depression (as described by Mr G himself) becoming a negative feedback loop of low self-efficacy and negative affective state. The relationship between positive affect and self-efficacy was shown by Ms L when she described feeling positive emotions, such as pride and happiness, about how her self-care behaviour had resulted in well controlled blood glucose levels. This supports the idea that self-efficacy is influenced by affective state but also that there is a relationship between emotions and self-care behaviour, possibly moderated by self-efficacy.

6.3 Combining the questionnaire and interview findings

The combination of the questionnaire and interview data provided the opportunity to consider the same questions from a different perspective. The questionnaire data allowed direct analysis of illness representations, self-efficacy and their relationship with self-care behaviour. The interview stage allowed a more in-depth exploration of the relationships between illness representations, self-efficacy, self-care behaviour and other factors which may have been important in explaining self-care behaviour but which were not measured at the questionnaire stage.

The differences found in the questionnaire analysis for illness coherence between length of duration of diabetes, for chance causes between type of diabetes for the men and for timeline cyclical between gender were all supported by the interview analysis. Other differences found between illness

representations and self-efficacy for marital status, education status and for tablet treated type 2 diabetes compared to type 1 and insulin treated type 2 diabetes, could not be compared with the interview analysis because of the demographic characteristics of the interviewees.

In chapter five, the details of the relationships between illness representations, self-efficacy and self-care for type of diabetes and gender were described and discussed. In the questionnaire analysis the relationships between illness representations, self-efficacy and self-care behaviours for type of diabetes were investigated; however, as a consequence of comparing the questionnaire and interview data it was decided to look at the relationships between the questionnaire variables for gender, as gender emerged as being important in the interview analysis. There were striking differences between the significant correlations found for men and women. In particular, the importance of general diabetes, flexible diabetes and rebellious self-efficacy for women when explaining general diet behaviour and the multiple correlations between external causes, general diabetes self-efficacy, HbA1c, identity and emotional representations with blood testing behaviour. This was in contrast to the relative lack of correlations between illness representations and self-efficacy with general diet behaviour and blood testing behaviour for men. There were also a larger number of illness representations associated with HbA1c (higher HbA1c levels were correlated with more symptoms attributed to diabetes, more consequences of diabetes, a higher score for the timeline cyclical which measured whether diabetes changed over time, more negative emotional representations, and lower attribution of diabetes to hereditary causes and general diabetes self-efficacy) for women. For the men higher HbA1c levels were only correlated with higher curing diabetes beliefs and assertiveness self-efficacy. The lack of correlations seen for the men may be because the

variables measured did not have an impact on self-care behaviour; however, another explanation may be that when completing the questionnaires men may have found it more difficult to report aspects of their diabetes such as feelings and self-efficacy beliefs. From the interview data it was clear that the men had an equally complicated set of beliefs about their condition, self-efficacy and why they performed self-care behaviours which suggests that the lack of correlations may be due to reporting differences produced as a result of the data collection methods used. Previous research has suggested that men and women differ in the way they express emotion or report behaviour and symptoms (Ashmore 1990; Gross and John 1995; Hebert et al. 1997; Gross and John 1998; Kroenke and Spitzer 1998). This is discussed in more detail in the methodological issues section of this chapter (p. 398).

The variance in self-care behaviour explained by illness representations and self-efficacy in the questionnaire analysis was relatively low; however, the interview analysis provided an opportunity to ascertain if this was due to measurement issues, other factors, or the inappropriate nature of the CSM as a theoretical model. The majority of the correlations found in the questionnaire analysis for individuals with type 1, type 2 diabetes and men and women were supported by the interview data (as discussed in more detail in chapter five). The interview analysis also suggested that the CSM, as a theoretical model, was representative of the relationships between self-care behaviour, illness representations and self-efficacy. There were certain measurement issues which may have explained the lack of variance explained by the questionnaire analysis. This will be discussed in more detail later on (p. 392). The interview analysis demonstrated the importance of the socio-cultural context and self-system (for example identity, self-efficacy and coping strategies) for explaining self-care behaviour. The only aspect of these systems addressed in the

questionnaire stage of the research was self-efficacy and there were certain issues raised about the scope of the measurement of self-efficacy provided by the questionnaire. Aspects of the socio-cultural system and self-system such as identity and priorities in life were not addressed in the questionnaire stage; however they were found to have be associated with the performance of self-care behaviour in the interview data and may therefore have explained more of the variance if they had been measured in the questionnaire stage of the research.

6.4 How the findings fit the Commonsense Model of the Self-Regulation of Health & Illness (CSM)

The CSM suggests a self-regulatory process where input (internal and external) develops illness representations of the condition (or 'health threat') which, moderated by the self-system and socio-cultural context, influences the choice of action plan or self-care behaviour which is then evaluated against a comparator value and feeds back into the inner and outer stimuli of the input (Leventhal et al. 2003) (a diagram of this model can be found in chapter one p. 70). This research has explored the relationships between stimuli, illness representations, socio-cultural and self-system factors and self-care behaviour and how this related to the CSM. Although some of the relationships suggested by the CSM were found in the questionnaire analysis, overall the variance in self-care behaviour explained by illness representations and self-efficacy was low. In addition to this there were relationships between illness representations, self-efficacy and self-care behaviour that, on the basis of previous literature and the CSM, would have been expected and were not found in the questionnaire

analysis. This contrasted with the interview stage of this research which provided substantial evidence for the CSM. The lack of variance explained and the lack of correlations in the questionnaire stage compared with the interview findings may be explained by a number of methodological issues which relate to the sample size used in the questionnaire stage, the individual questionnaires used and other aspects of the methodology. These issues are discussed in more detail in the next section of this chapter (p. 392).

Substantial support for the CSM emerged from the interview stage of this research. Illness representations were found to be related to inner and outer stimuli such as existing lay beliefs, advice of friends, guidance from health care professionals and the experience of symptoms. These illness representations were associated with self-care behaviour, for example the consequences of diabetes was a strong motivating factor for self-care behaviour. Other socio-cultural/self-system factors such as those found in the *myself and my diabetes* theme, were also shown to have an impact on the choice of self-care behaviour. The interview data demonstrated how the 'success' of the self-care behaviour was appraised using various techniques such as symptoms and blood tests and these were fed back into the illness representations of the individuals.

One of the ways in which it is suggested that the socio-cultural and self-system impact on the CSM is by moderating the relationship between illness representations and self-care behaviour (Cameron and Leventhal 2003). In the questionnaire analysis self-efficacy was found to moderate only two of the correlations between illness representations and self-care. For the participants with type 1 diabetes, general diabetes self-efficacy moderated the relationship between emotional representations and general diet behaviour and flexible

diabetes self-efficacy moderated the relationship between consequences of diabetes and specific diet behaviour. These results may have been as a consequence of the methodological and measurement issues referred to earlier and discussed in more detail in the next section of this chapter. However, the interview analysis indicated that the influence of self-efficacy and other socio-cultural/self-system factors extended beyond moderating the relationship between illness representations and self-care behaviours. The stimuli (inner and outer) from which the illness representations of the individuals developed were influenced by socio-cultural/self-system factors. The extent to which interviewees listened to the advice of health care professionals and friends and colleagues about their diabetes depended on factors such as their trust in medical authority, past experience of health issues and their identity and self (for example Ms J and Ms M's professional identities as nurses and Mr G's sick role). Illness and emotional representations were also influenced directly by socio-cultural/self-system factors. The consequences of diabetes, such as diabetes complications, and beliefs about the ability to avoid complications were dependent on socio-cultural beliefs about chance, fate, and luck and integrated with identity and self. The different methods used by the interviewees to appraise the success of the self-care behaviours employed also suggested a socio-cultural/self-system effect. Men and women tended to differ in which methods they used, with women using tangible measurements such as blood tests whereas men used more varied methods such as how often they had a diabetes appointment and how they felt in themselves in terms of symptoms and emotional states. This gender difference found throughout the CSM was a clear indication of the importance of socio-cultural/self-system factors. Gender is a construct which could be said to be a product of socio-cultural and self-system factors which appeared to influence all aspects of the CSM from the data analysis of this research.

In addition to the impact of the socio-cultural/self-system on the other aspects of the CSM, illness and emotional representations, the self-care behaviours performed and the outcome of the appraisals of the 'success' of the self-care behaviours also had an impact on the socio-cultural context and self-system. Mr G's sick-role identity was perpetuated by the negative appraisals that he made of his condition and how he was looking after himself. Mr B's identity as an 'expert patient' was reinforced by the 'success' of his strict diabetes regime of self-care behaviours. This supports the assertions of Brownlee et al. (2000) and Leventhal et al. (2004) who suggest that socio-cultural context and the self-system have an impact on illness representations and vice versa. This thesis indicates that the impact of the socio-cultural and self system moves beyond illness representations and moderating the relationship between illness representations and self-care behaviour, and is important in all aspects of the CSM including the appraisal in the feedback loop and the original inner and outer stimuli which feed into the self-regulation system.

The significant involvement of socio-cultural context and self-system factors in the decision making processes about self-care behaviours shown by this research supports the empowerment approach to diabetes care (Anderson 1985). This approach suggests that collaborative care between health care professionals and individuals with diabetes should replace the didactic medical acute-care model (Glasgow and Anderson 1999). The empowerment approach emphasises the responsibility of the person with diabetes for their diabetes care and the outcomes and consequences of their diabetes (Glasgow and Anderson 1999). This responsibility means that people with diabetes are able to make informed decisions about their diabetes care and their self-care behaviour with

reference to what is important to them and how their diabetes fits within their lives.

Three of the interviewees described making active decisions to take control of their diabetes and four of the others described the integration of diabetes into their lives. Ten out of eleven of the interviewees discussed their relationships with their health care professionals and for six of them their relationships could have been improved in ways which are suggested in the empowerment literature (Glasgow and Anderson 1999). For example Ms C described being treated in a child-like way by the health care professionals she saw at the hospital, which has also been discussed by Broom and Whittaker (2004). Mr D, Ms M, Mr K and Ms L all disagreed with their consultant or diabetes nurse on advice they were given that they felt did not work for them or correspond with how they had experienced their diabetes. Instead they chose to follow their own judgements made on the basis of their personal experience of their own diabetes. The importance of socio-cultural context and the self-system for the interviewees and the desire for these considerations to be taken into account when discussing their self-care behaviour with their health care professionals demonstrates how vital it is that diabetes care takes account of and uses aspects other than physiological measurements and didactic diabetes education when developing self-care plans for those with diabetes.

6.5 Methodological issues

As mentioned previously there were certain methodological issues which may explain the limited support for the CSM found in the questionnaire stage of this research and further discussion is needed concerning the adoption of a mixed methods approach. Both aspects of the study, quantitative and qualitative, had strengths and weaknesses that had an impact on the data collected and the analysis subsequently carried out. As mentioned previously, the number of participants who took part in the questionnaire stage of the research was small, particularly for some of the statistical analyses, such as the correlations for those with tablet treated type 2 diabetes and when investigating the complex relationship between duration, type of diabetes and illness coherence. This restricted the type of analyses that could be performed and means that the results should be interpreted with caution. It is also important to note that this was a cross-sectional study and so was unable to reflect any changes in beliefs over time and what impact that may have had on self-care behaviour. The questionnaire analysis and findings were also affected by the limitations of the questionnaires used for data collection. The advantage of conducting a mixed method approach was that in the interview stage of the study there was the opportunity to discuss the completion of the questionnaires and therefore gain an insight into the difficulties and different interpretations made by the participants whilst completing the questionnaire stage.

The Revised Illness Perception Questionnaire (IPQ-R) and the Summary of Diabetes Self-Care Activities scale (SDSCA) were both pre-validated

questionnaires which have been used to look at illness representations and diabetes self-care behaviours in numerous studies (Scharloo et al. 1999; Steed et al. 1999; Glasgow et al. 2000; Wagner et al. 2000). However, even these two questionnaires were found to have limitations and implications for the findings of this study. For the IPQ-R two main specific issues came to light. Firstly there was the inclusion of an item asking if the respondent thought diabetes was curable. This was removed from the scoring of the scale as it was so incongruent with the answers for the rest of the questions asking about time-line. The other main issue was the sole concentration on negative emotional representations. It emerged from the interviews that there were positive emotional experiences which had an impact on self-care but these were not addressed in the IPQ-R.

The SDSCA was also found to have difficulties with its construction which may have impacted on how it was completed. Self-report behaviour questionnaires are notoriously difficult to develop and the utilisation of questions about 'how many times in the last 7 days...' appeared to be relatively easy to answer and provide more information than simply asking if a specific behaviour was performed. The majority of the respondents completed the medication aspect of the scale by indicating a very high level of self-care behaviour. This may have been an accurate representation of the medication taking behaviour of this population or, as emerged in the interviews, it may be that many of the participants of this research took multiple medications – multiple insulin injections and tablets for a range of conditions associated with their diabetes – and that these medications were not necessarily taken to the same extent. This kind of detail was not addressed in the SDSCA and it may be that the variation in medication taking found in the interviews but not the

questionnaire responses may reflect this. Toobert et al. (2000) suggested that the specific diet scale was the weakest part of the SDSCA and was the scale with the least internal reliability. This does not appear to have had an overt impact on the results of this research; however, it should be taken into consideration. The participants were all treated at the same diabetes outpatient clinic so could be assumed to have received similar advice regarding specific diet; however, there is no guarantee that this was the case and so this may have had an impact on the diet aspect of the scale.

The self-efficacy scale used in this study was an adapted version of an existing scale by Grossman et al. (1987). There were several limitations to this scale. The original scale was designed for adolescent Americans and, although every attempt was made to adapt the scale for adult British participants, there was some suggestion from the interview data that this was not entirely successful. Added to which the questionnaire was developed 20 years ago which meant that diabetes care recommendations may have changed. For example, 'Sneak food not on my diet without getting caught' caused significant discussions about how interviewees may feel able to 'sneak food' but they either did not as that would make them ill or they did not have a strict diet to follow so it was not really a question of having to 'sneak food':

"Sneak food not on my diet without getting caught [laughs] Right, so what do I put? Go in the middle, don't know? Maybe I can? I don't... Can I leave it blank or would that confuse you?"

Ms L, type 2, medium self-care

394

In addition to various wording issues, the self-efficacy scale was not particularly comprehensive in measuring all aspects of self-efficacy as suggested by Social Cognitive Theory. Bandura (1977) suggests that there are three dimensions to self-efficacy: *magnitude, strength* and *generality*. In common with most self-efficacy measurements, this self-efficacy scale asked about situations in which the respondent had self-efficacy but failed to ask about the more complicated aspects such as the three dimensions of self-efficacy. The decision to use this self-efficacy questionnaire was taken with a view to the limited time available to conduct this research. At the time of selection the researcher was aware of no other questionnaires which measured all aspects of self-efficacy, as suggested by Bandura. As developing a new measure of self-efficacy was beyond the scope of this study it was decided to use an existing questionnaire and accept the implications and limitations. The self-efficacy questionnaire had been adapted and used in previous research with different populations (Havermans and Eiser 1991; Griva et al. 2000; Aalto et al. 2000; Howells et al. 2002; Pinar et al. 2003) and, as a diabetes specific rather than a generic measure, it followed Bandura's recommendations for task specific questions relating to self-efficacy (Bandura 1997). The issues surrounding wording of the questionnaire, mentioned earlier, also provided the opportunity in the interviews for discussion of the methods used in this thesis and self-efficacy relating to specific diabetes self-care behaviours.

As well as the individual questionnaire-specific issues there were also general aspects of data collection which affected all of the questionnaires used in this study. Although wording has been mentioned in relation to specific questions above it is important to address this issue for the questionnaires as a whole. Despite the questionnaire being piloted there was still room for different

interpretations of the questions asked. This was particularly the case for the self-efficacy questionnaire but there was also evidence from the interview data that the IPQ-R and SDSCA were sometimes interpreted in different ways. For example, Mr H answered the IPQ-R question 'My diabetes has serious financial consequences' by thinking about how diabetes affected the NHS and so indicated that he strongly agreed that it had, despite feeling that his diabetes had no financial consequences for himself:

"I thought about that when I was asked the first questionnaire it was it was just personally which I don't really, I generally the same as the rest of the family so we don't buy special stuff for myself and then I thought well there is a consequence to the NHS and that that provide all the stuff for me, you know how much it costs so there is a consequence there somewhere but not personally, so the first questionnaire I was thinking about myself and on the second..."

Mr H, type 1, low self-care

This was completely different from Mr F who also indicated he strongly agreed with the statement but considered that for him personally diabetes did have strong financial implications:

"when I was lorry driving last year I was on £500 a week no problem and er then all of a sudden that day I was diagnosed on insulin ..... that's it, that's the end of your licence now to go from £500 a week to nothing and there's no help out there for diabetics for this..."

Mr F, type 2, high self-care

The wording used in the IPQ-R around emotions experienced may also have had an impact on the answers given. Throughout the questionnaire

analysis emotional representations appeared to have few correlations, and therefore no relationship with, most of the self-care behaviours. However, this was in contrast to the findings from the interview data. The wording of the IPQ-R asks if the respondent was depressed or anxious or upset *about* their diabetes. (For example, 'When I think about my diabetes I get upset'). The negative emotions experienced by the interviewees directly *about* their diabetes were mostly felt at diagnosis and as the interviewees had all had diabetes for at least five years, the majority of interviewees felt these emotions had passed. However, they did experience negative emotions as a *consequence* of their diabetes, for example because of the career or financial limitations, the reaction of others to their diabetes and so on. Although this may sound like sophistry the interpretation of the questions may have played an important part in why emotional representations were less prolific than in the interviews or than might have been expected.

There were several aspects of the relationship between illness representations, self-efficacy and self-care which emerged from the interview data and yet were not found in the questionnaire analysis. As mentioned previously, there were few correlations with emotional representations. Several reasons have already been suggested for this but there were also the different data collection methods to consider. The interview setting allowed time and space to expand on issues relating to diabetes which were important for the interviewee. Emotions are a very individual and personal experience and the interview situation, involving two people talking rather than one person with a pen and paper with set responses mapped out, was inherently more suitable for discussing difficult issues, personal thoughts and feelings and therefore emotions. Added to which, the researcher had the ability to interpret cues other

than purely verbal ones enabling difficult concepts to measure, such as emotions and self-efficacy, to be explored. Key examples of this were the anger of Mr D about his diagnosis and the consequences on his career, and Mr B's excitement and enjoyment of changing recipes to suit his low sugar requirements. Both were portrayed by facial expressions, body language and tone of voice in addition to specific things that were said.

The use of interview methods allowed access to cues to emotional representations that were not measured by the questionnaires. This is particularly important with regard to the way in which men and women respond to questionnaires. Hebert et al. (1997) found that, on a dietary self-report measure, men had a tendency to report a high level of behaviour due to a bias towards the desire for social approval. They also found that women had a tendency to report diet in a "defensive" way as a response to a bias towards social desirability. These differences resulted in different reporting of dietary behaviour. Gross and John (1995) found that participants reported higher levels of positive expressivity of emotion than negative expressivity and that women were generally more emotionally expressive than men. They suggest that the preferential reporting of positive expressivity may be related to social desirability. If, as suggested by Hebert et al. (1997), there are differences between men and women in terms of biases towards social approval and social desirability this may lead to differences in reporting of emotions for men and women. Gross and John (1998) found that men reported "masking" their emotions more than the women did. They suggest that this may be because of cultural factors, such as the differences in what is acceptable in society for men and women in terms of display of emotions, or due to socialization processes which result in "sex differences not just in emotional expression but in emotional

experience." (p. 177). The potential differences in reporting of men and women may have led to differential reporting in the questionnaire stage of certain aspects, such as emotional representations. Although these differences may have also been present during the interviews, the data suggests that the male interviewees felt comfortable in the interview situation discussing their emotions. The additional non-verbal cues, such as tone of voice and facial expression, enabled access to emotions beyond the content of what was being said.

The advantages of using interview methods for examining emotional experiences are important. By interviewing participants it was also possible to record beliefs about other aspects of the diabetes experience, such as self-efficacy, particularly in light of the limitations associated with the self-efficacy questionnaire discussed previously. Although accessing the data about the interviewees' self-efficacy beliefs was not straightforward, as much of the data was in non-verbal cues or the way in which specific behaviours were discussed, the interview situation did allow a more in depth analysis of the different dimensions of self-efficacy and how self-efficacy beliefs developed. In addition, the interviews provided the opportunity to gain a fuller picture of how the participants looked after themselves and performed self-care behaviour under different circumstances. This was neatly illustrated in Mr H's questionnaire responses, where it was not possible to differentiate between his low levels of self-care behaviour when at work and his higher levels of self-care behaviour when not working; however, it was possible to examine this more fully in his interview.

The obvious limitation of questionnaires, that only the questions asked can be answered, was also shown to be important by the interview data analysis. Out of various aspects of the self-system and socio-cultural context, only self-efficacy was measured in the questionnaire stage; however, the interview analysis demonstrated that other aspects were vital for the interviewees in explaining how they looked after their diabetes. If other aspects of the self-system and socio-cultural context were included in the questionnaire stage it may be that more variance in self-care behaviour could have been explained.

So far the limitations of the questionnaire stage have been discussed but it was also the case that there were issues surrounding the interview stage of the study, such as the self-selecting nature of conducting interviews. There were two main things to consider in terms of self-selection: were the interviewees all very interested in diabetes and therefore were motivated to participate and did they have the time to be interviewed as a consequence of their diabetes (for example being medically retired) and were therefore atypical of the diabetes population? Only three of the interviewees (all with high levels of self-care behaviour) suggested that they felt it was important for them to participate in research to do with diabetes. This may have been influenced by various factors. Mr B was very interested in finding out all he could about diabetes and was very active in the diabetes community and Ms J and Ms M were health care professionals. The other interviewees had a range of levels of self-care behaviour and interest in diabetes which suggests this was not an issue that introduced bias. The other important factor to be considered was having the time available to be interviewed. Two of the interviewees were medically retired; however, the remaining nine interviewees were all employed

which demonstrates that overall the sample of interviewees was not just those who were retired or unemployed. The main obstacle that was found for the interviews was in finding women with low self-care behaviour to agree to be interviewed. Three women with low self-care were approached, two agreed but later cancelled the interview appointment and the third showed no interest. An attempt was made to ascertain why these women did not want to be interviewed but no clear reasons were given. Women with medium self-care levels were interviewed but the lack of women with low self-care available for interview may have had an impact on this part of the data analysis.

Despite the contrast between quantitative and qualitative methods, the use of both and the different data collection techniques was a considerable strength for this piece of research. It allowed a deeper and more comprehensive exploration of how personal experience relates to self-care behaviour through the development of illness representations and self-efficacy beliefs.

Conclusion

The aims of this research were: to investigate if there were differences between the personal experience of diabetes for individuals with type 1 and type 2 diabetes; to determine whether the personal experience of diabetes and its relationship to self-care behaviour could be described using the Commonsense Model of the Self-Regulation of Health and Illness (CSM) (Leventhal et al. 2003); and to investigate if individuals with type 1 and type 2 diabetes had different illness representations, self-efficacy beliefs and self-care behaviours and relationships between them.

The findings indicate that there were differences between the personal experiences of individuals with type 1, tablet treated and insulin treated type 2 diabetes. These differences were found for causal attribution, consequences of diabetes and blood testing behaviour. There were also differences in the patterns of emotional experience for those with type 1 and type 2 diabetes, possibly as a consequence of the different ages of diagnosis inherent for the two conditions. Those with type 1 diabetes, particularly when diagnosed at a young age, had experienced a greater part of their lives with diabetes and so their condition had impacted on events which were not a consideration for those with type 2 diabetes. In contrast, those with type 2 diabetes described more intense emotions at their diagnosis and, particularly for the men, their diagnosis with diabetes appeared to have had a larger impact on their identity and self. It was found that gender and duration of diabetes had an impact on the experience of diabetes. Different factors emerged as being important for men and women when explaining self-care behaviour and illness representations for their diabetes. Duration of diabetes was related to differences in flexible

diabetes self-efficacy. In addition, duration and type of diabetes were related to the participants' understanding of their diabetes. Untangling this relationship between type of diabetes and duration was beyond the scope of this study.

The Commonsense Model of the Self-Regulation of Health and Illness (CSM) provided a useful way of conceptualising the personal experience of diabetes and the data analysis suggested that the links between illness and emotional representations, self-care behaviour and the socio-cultural context and self-system were applicable to the personal experiences of diabetes for this sample of people with diabetes. The complexity of the relationships between these factors was revealed through the use of a mixed methods approach. The importance of socio-cultural context and the self-system for explaining the self-care behaviour of the participants and why they made certain choices supports the collaborative approach to diabetes care where the person with diabetes becomes empowered, takes responsibility for their diabetes and in doing so makes the appropriate self-care behaviour choices for them.

This study has raised a number of issues which warrant further investigation. The impact of socio-cultural context and the self-system, in particular with regard to gender and identity, has been somewhat under-researched in past literature using the CSM. From this study it can be seen that these aspects of the model are very important in explaining the choices that people with diabetes make about their self-care behaviour. Further research should develop the socio-cultural context and self-system components of the model beyond the current theoretical positioning. Future empirical research could provide more details in a similar way to how illness representations have been developed and theorised. Gender has been shown to be important not only in this thesis but also in previous research (Hampson et al. 1995). There

were striking differences between men and women in terms of the relationship between their experience of diabetes and identity and self. There were also differences in the causal beliefs, consequences of diabetes and emotional experiences of the male and female interviewees.

Leventhal et al. (2003) have suggested that socio-cultural context and the self-system interact with other aspects of the CSM in a variety of ways. These include moderating the relationship between illness representations and self-care behaviours, influencing the interpretation of the stimuli attended to, affecting the choice of goals and coping strategies made. They may be targets for change within the model themselves (Brownlee et al. 2000). Previous research suggests that within the self-system there are representations in a similar form to the illness representations: identities, timelines, causes and consequences (Leventhal et al. 2004). This thesis has shown that the impact of socio-cultural factors and self-system extends to influence the stimuli attended to, the formation of illness representations, the choice of potential self-care behaviours and the evaluation of the effectiveness of the self-care behaviours. Suggestions have been made about the theoretical structure and impact of the socio-cultural context and self-system in previous research; however, future research should explore this area in greater depth to clarify the relationships between the socio-cultural context and self-system and the rest of the CSM.

This thesis has also raised issues about the use of certain methodologies. The CSM has largely been researched using quantitative methods and this study has shown there to be a number of limitations in the use of established questionnaires designed for this purpose. Additionally the difficulty in studying self-efficacy via questionnaires and interviews has been explored and doubts cast on the currently predominant methods for this area of research.

Another area which may benefit from further research is the personal experiences of pregnancy with diabetes. Both interviewees who had been pregnant whilst having diabetes raised it as a very important event in their lives and both had very strong emotions and beliefs connected to the experience. With the increasingly early onset of type 2 diabetes more women with type 2 diabetes will be experiencing pregnancy. It was not within the scope of this study to examine the different experiences of pregnancy for those with type 1 and type 2 diabetes. However, it is conceivable that the differences between the personal experiences of type 1 and type 2 diabetes, in terms of illness beliefs and the differing treatment received, may have an impact on pregnancy and, in particular, the pre-conceptual care that individuals receive and therefore on the health of the mother and the pregnancy outcome.

Overall, this research found the CSM to be a useful theoretical model for investigating self-care behaviour. There are difficulties and disadvantages inherent in using a theoretical model to describe and explain such a complex and dynamic concept as self-care behaviour. However, there are also distinct advantages including the ability to compare illness experiences between individuals, measure similarities and differences and investigate explanations for behaviour which may lead to the development of improved treatment and care for individuals with the condition. This thesis has confirmed the efficacy of the CSM as a theoretical model but has also suggested areas in which further research is needed allowing the model to better represent the complexity of coping with a long-term condition in the 'real world'.

References

Aalto, A. and A. Uutela (1997). "Glycemic control, self-care behaviours and psychosocial factors among insulin treated diabetics: a test of an extended health belief model." International Journal of Behavioral Medicine 4(3): 191-214.

Aalto, A., A. Uutela et al. (2000). "Disease related distress among insulin-treated diabetic patients: Associations with health status, psychosocial factors and self-care practices." European Journal of Public Health 10(1): 68-74.

Abramson, L. Y. et al. (1978) "Learned helplessness in humans." Journal of Abnormal Psychology 87: 49-74.

Adolfsson, E. T., M. Walker-Engstrom et al. (2007). "Patient education in type 2 diabetes – a randomized controlled 1-year follow-up study" Diabetes Research and Clinical Practice 76: 341-350.

Anderson, R. M. (1985). "Is the problem of non-compliance all in our heads?" The Diabetes Educator 11(1): 31-34.

Anderson, R. M., J. T. Fitzgerald et al. (1997). "A comparison of global versus disease specific quality of life measures in patients with NIDDM." Diabetes Care 20: 299-303.

Anderson, R. M., M. M. Funnell et al. (1995). "Patient empowerment: results of a randomized controlled trial." Diabetes Care 18(7): 943-949.

Anderson, R. M. and M. M. Funnell (2005). "Patient empowerment: reflections on the challenge of fostering the adoption of a new paradigm." Patient Education and Counselling 57(7): 153-157.

Aljasem, L. I., M. Peyrot, et al. (2001). "The impact of barriers and self-efficacy on self-care behaviours in type 2 diabetes." The Diabetes Educator 27(3): 393-404.

Ajzen, I. (1985). From intention to actions: A theory of planned behaviour. Action-control: From Cognition to Behavior. J. Kuhl and J. Beckman Heidelberg: Springer: 11-39.

Arnold, M. S., P. M. Butler, et al. (1995). "Guidelines for facilitating a patient empowerment program." The Diabetes Educator 21(4): 308-312.

Ashmore, R. D. (1990). Sex, gender and the individual. Handbook of Personality: Theory and Research L. A. Pervin New York, Guilford Press: 486-526.

Bandura, A. (1977). "Self-efficacy: Towards a unifying theory of behavior change." Psychological Review 84: 191-215.

Bandura, A. (1986). Social Foundations of Thought and Action: A Social Cognitive Theory. Englewood Cliffs, NJ, Prentice-Hall.

Bandura, A. (1989). "Human agency in social cognitive theory." American Psychologist **44**(9): 1175-1184.

Bandura, A. (1995). On rectifying conceptual ecumenism. Self-Efficacy, Adaptation, and Adjustment: Theory, Research and Application. J. E. Maddux. New York, Plenum Press: 347-371.

Bandura, A. (1997). Self-Efficacy: The Exercise of Control. New York, W. H. Freeman and Company.

Barnes, L., R. Moss-Morris et al. (2004). "Illness beliefs and adherence in diabetes mellitus: a comparison between Tongan and European patients." New Zealand Medical Journal 117(1188):

Bartlett, E. (1986). "Historical glimpses of patient education in the United States." Patient Education and Counseling **8**: 135-149.

Bauman, A. E., H. J. Fardy, et al. (2003). "Getting it right: why bother with patient centred care?" Medical Journal of Australia **179**: 253-256.

Bauman, L. J., L. D. Cameron, et al. (1989). "Illness representations and matching labels with symptoms." Health Psychology **8**: 449-470.

Bauman, L. J. and H. Leventhal (1985). "I can tell when my blood pressure is up can't I?" Health Psychology **4**: 203-218.

Bernal, H., S. Woolley, et al. (2000). "Correlates of self-efficacy in diabetes self-care among Hispanic adults with diabetes." The Diabetes Educator **26**(4): 673-680.

Bishop, G. D. and S. A. Converse (1986). "Illness representations: a prototype approach." Health Psychology **5**(2): 95-114.

Bond, G. G., L. S. Aitken, et al. (1992). "The Health Belief Model and adolescents with insulin-dependent diabetes mellitus." Health Psychology **11**: 190-198.

Bradley, C. (1995). "Health beliefs and knowledge of patients and doctors in clinical practice and research." Patient Education and Counseling **26**: 99-106.

Brennan, D. P. T. et al. (2000) "Population-based adherence to prescribed medication in type 2 diabetes: a cause for concern [abstract]". Diabetic Medicine **17**: A3

Britten, N. (1995) Qualitative interviews in medical research. British Medical Journal **311**, 251-253.

Broom, D. and A. Whittaker (2004) "Controlling diabetes, controlling diabetics: moral language in the management of diabetes type 2." Social Science and Medicine **58**: 2371-2382.

Brown, S. A., R. B. Harris et al. (2000). "Gender and treatment differences in knowledge, health beliefs, and metabolic control in Mexican Americans with type 2 diabetes." The Diabetes Educator **26**(3): 425-436.

Brownlee, S., H. Leventhal, et al. (2000). Regulation, self-regulation, and construction of the self in the maintenance of physical health. Handbook of Self-Regulation. M. Boekaerts, P. R. Pintrich and M. Zeidner. San Diego, Academic Press: 369-416.

Bryman, A. (1988) Quantity and Quality in Social Research. London, Routledge.

Bury, M. (1982). "Chronic illness as Biographical Disruption." Sociology of Health and Illness 4(2).

Bury, M. (2005). Health and Illness. Cambridge, Polity Press.

Bury, M. and J. Gabe (2004). The Sociology of Health and Illness. London, Routledge.

Cameron, L. D. and H. Leventhal (2003). The Self-Regulation of Health and Illness Behaviour. London, Routledge.

Carver, C. S. and M. F. Scheier (1998). On the Self-Regulation of Behavior. New York, Cambridge University Press.

Charmaz, K. (1983). "Loss of self: a fundamental form of suffering in the chronically ill." Sociology of Health and Illness 5(2): 168-195.

Charmaz, K. (1994). "Identity dilemmas of chronically ill men." Sociological Quarterly 35(2): 269-288.

Charmaz, K. (1999). From the "Sick Role" to stories of self. Self, Social Identity and Physical Health. R. J. Contrada and R. D. Ashmore. Oxford, Oxford University Press.

Ciechanowski, P. S., W. J. Katon, et al. (2003). "The relationship of depressive symptoms to symptom reporting, self-care and glucose control in diabetes." General Hospital Psychiatry 25: 246-252.

Clark, M., S. Hampson et al. (2004). "Effects of a brief tailored intervention on the process and predictors of lifestyle behaviour change in patients with type 2 diabetes." Psychology, Health and Medicine 9(4): 440-449.

Cooley, C. H. (1972). Looking-glass self. A Reader in Social Psychology. J. G. Mannis and B. N. Meltzer. Boston, Allyn and Bacon Inc.

Cooper, A., G. Lloyd, et al. (1999). "Why patients do not attend cardiac rehabilitation: role of intentions and illness beliefs." Heart 82: 234-236.

Cox, D. J., L. Gonder-Frederick et al. (2006). "Blood glucose awareness training: What is it, where is it, and where is it going?" Diabetes Spectrum 19(1): 43-49.

Cox, K. (2003). "Assessing the quality of life of patients in phase I and II anti-cancer drug trials: interviews versus questionnaires." Social Science and Medicine 56(5): 921-931.

Croyle, R. T. and J. B. Jemmott (1991). Psychological reactions to risk factor testing. Mental Representation in Health and Illness. J. A. Skelton and R. T. Croyle. New York, Springer-Verlag: 85-107.

Cryer, P. E. (1999). "Hypoglycemia is the limiting factor in the management of diabetes." Diabetes Metabolism Research and Reviews 15: 42-46.

Curtin, M. and I. Lubkin (1995). What is chronicity? Chronic Illness: Impact and Interventions. I. Lubkin. Sudbury, MA, Jones and Bartlett: 3-25.

DAFNE Study Group (2002). "Training in flexible, intensive insulin management to enable dietary freedom in people with type 1 diabetes: Dose Adjustment For Normal Eating (DAFNE)." British Medical Journal 325: 746

Department of Health (2001). National Service Framework for Diabetes. London, Department of Health.

Diabetes Control and Complications Trial Research Group (1993) "The effects of intensive treatment of diabetes." New England Journal of Medicine. 329: 977-986.

Deci, E. L. and R. M. Ryan (1995). Human autonomy: the basis for true self-esteem. Efficacy, Agency and Self-Esteem. M. H. Kernis. New York, Plenum Press: 31-49.

DeFronzo, R. A., E. Ferrannini et al. (2004) International Textbook of Diabetes Mellitus (3rd edition) Chichester, Wiley and Sons.

Denzin, N. K. (1970). The Research Act in Sociology, Butterworths.

Denzin, N. K. (1992). Symbolic interactionism. Rethinking Psychology. J. A. Smith, R. Harre and L. V. Langenhove. London, Sage: 43-58.

Diamond, E. L., K. L. Massey, et al. (1989). "Symptom awareness and blood glucose estimation in diabetic adults." Health Psychology 8: 15-26.

Dollard, J. and N. E. Miller (1950). Personality and Psychotherapy. New York, McGraw-Hill.

Donnan, P. T. et al. (2002) "Adherence to prescribed oral hypoglycaemic medication in a population of patients with Type 2 diabetes: a retrospective cohort study." Diabetic Medicine 19: 279-284.

Easterling, D. and H. Leventhal (1989). "The contribution of concrete cognition to emotion: neutral symptoms as elicitors of worry about cancer." Journal of Applied Psychology 74: 787-796.

Edgar, K. A. and T. C. Skinner (2003). "Illness representations and coping as predictors of emotional well-being in adolescents with type 1 diabetes." Journal of Pediatric Psychology 28(7): 485-493.

Eiser, J. R., A. Riazi, et al. (2001). "Predictors of psychological well-being in types 1 and 2 diabetes." Psychology and Health 16: 99-110.

Ekkekakis, P., E. E. Hall, et al. (2000)."Walking in (affective) circles: Can short walks enhance affect?" Journal of Behavioral Medicine 23(3): 245-275.

Ellis, S. E., T. Speroff, et al. (2004). "Diabetes patient education: a meta-analysis and meta-regression." Patient Education and Counseling 52: 97-105.

Epstein, S. (1991). Cognitive-experiential self-theory: An integrative theory of personality. The Relational Self: Theoretical Convergences in Psychoanalysis and Social Psychology. R. Curtis. New York, Guildford Press: 111-137.

Ferzacca, S. (2000). ""Actually, I don't feel that bad": Managing diabetes and the clinical encounter." Medical Anthropology Quarterly 14(1): 28-50.

Field, A. (2000). Discovering Statistics using SPSS for Windows. London, Sage.

Fielding, N. and J. Fielding (1986). Linking Data. Beverly Hills, CA, Sage.

Fitzgerald, J. T., W. K. Davis et al. (1996). "Development and validation of the Diabetes Care Profile." Evaluation and the Health Professions 19(2): 208-230.

Fitzgerald, J. T., L. D. Gruppen et al. (2000) "The influence of treatment modality and ethnicity on attitudes in type 2 diabetes" Diabetes Care 23(3): 313-318.

Freshwater, D. (2005) Reading mixed methods research: Contexts for criticism. Mixed Methods in Health and Social Care, Cambridge.

Funnell, M. M. and R. M. Anderson (2004). "Empowerment and self-management of diabetes." Clinical Diabetes 22(3): 123-127.

Garber, M. et al. (2007). "HIV-infected African Americans are willing to participate in HIV treatment trials." Journal of General Internal Medicine 22(1): 17- 42.

Glasgow, R. E. and R. M. Anderson (1999). "In diabetes care, moving from compliance to adherence is not enough: something entirely different is needed." Diabetes Care 22(12): 2090-2091.

Glasgow, R. E. and E. G. Eakin (1998). Issues in diabetes self-management. Handbook of Behavior Change. S. A. Shumaker, E. B. Schron, J. K. Ockene and W. L. McBee. New York, Springer-Verlag: 435-461.

Glasgow, R. E., K. D. McCaul et al. (1987) "Self-care behaviours and glycemic control of Type 1 diabetes." Journal of Chronic Diseases 40: 399-412.

Glasgow, R.E. and D.J. Toobert. (2000). "Brief, computer assisted dietary self-management counselling: effects on behaviour, physiologic outcomes and quality of life." Medical Care 38(11): 1062-1073.

Goffman, E. (1969). The Presentation of Self in Everyday Life. Harmondsworth, Middlesex, Penguin Books.

Gonder-Frederick, L. A. and D. J. Cox (1990). Symptom perception and blood glucose feedback in the self-treatment of IDDM. Neuropsychological and

Behavioral Aspects of Diabetes. C. S. Holmes. New York, Springer-Verlag: 154-174.

Gordon, G. (1966). Role Theory and Illness. New Haven CT, College and University Press.

Griva, K., L. B. Myers, et al. (2000). "Illness perceptions and self-efficacy beliefs in adolescents and young adults with IDDM." Psychology and Health 15: 733-750.

Gross, J. J. and O. P. John (1995). "Facets of emotional expressivity: three self-report factors and their correlates." Personality and Individual Differences 19: 555-568.

Gross, J. J. and O. P. John (1998). "Mapping the domain of expressivity: multimethod evidence for a hierarchical model." Journal of Personality and Social Psychology 74(1): 170-191.

Grossman, H., S. Brink, et al. (1987). "Self-efficacy in adolescent girls and boys with IDDM." Diabetes Care 10: 324-329.

Gurin, P. et al. "Personal and ideological aspects of internal and external control." Social Psychology 41: 275-296.

Hagger, M. S. and S. Orbell (2003). "A meta-analytic review of the commonsense model of illness representations." Psychology and Health 18(2): 141-184.

Hampson, S. E. (1997). Illness representations and the self-management of diabetes. Perceptions of Health and Illness. K. J. Petrie and J. A. Weinman. Amsterdam, Harwood Academic: 323-348.

Hampson, S. E. (1997). "Personal models and the management of chronic illness: a comparison of diabetes and osteoarthritis." European Journal of Personality 11: 401-414.

Hampson, S. E., R. E. Glasgow, et al. (1995). "Personal models of diabetes among older adults: relationship to self-management and other variables." The Diabetes Educator 21(4): 300-307.

Hampson, S. E., R. E. Glasgow, et al. (1990). "Personal models of diabetes and their relations to self-care activities." Health Psychology 9: 632-646.

Harris, J. (2005). "Research is a moral duty." Journal of Medical Ethics 31: 242-248.

Harter, S. (1978) "Effectance motivation reconsidered: Towards a developmental model." Human Development 21: 36-64.

Havermans, T. and C. Eiser (1991). "Locus of control and efficacy in healthy children and those with diabetes." Psychology and Health 5: 297-306.

Hayman, R. M. et al. (2001). "Participation in research: Informed consent, motivation and influence." Journal of Paediatrics and Child Health 37(1): 51-54.

Hebert, J. R., M. Yunsheng et al. (1997). "Gender differences in social desirability and social approval bias in dietary self-report." American Journal of Epidemiology 146: 1046-1055.

Heckhausen, H. (1977). "Achievement motivation and its constructs: A cognitive model." Motivation and Emotion 1: 283-329.

Heijmans, M. and D. deRidder (1998). "Assessing illness representations of chronic illness: explorations of their disease-specific nature." Journal of Behavioural Medicine 21(5): 485-503.

Hernandez, C. A. (1995). "The experience of living with insulin-dependent diabetes: lessons for the diabetes educator." The Diabetes Educator 21(1): 33-37.

Hillson, R. (2002) Practical Diabetes Care (2nd edition) Oxford, Oxford University Press.

Horne, R. and J. Weinman (2002). "Self-regulation and self-management in asthma: exploring the role of illness perceptions and treatment beliefs in explaining non-adherence to preventer medication." Psychology and Health 17(1): 17-32.

Hornsten, A., H. Sandstom et al. (2004). "Personal understandings of illness among people with type 2 diabetes." Journal of Advanced Nursing 47(2): 174-182.

Howell, D. C (2002) Statistical Methods for Psychology Pacific Grove, CA, Duxbury.

Howells, L. A. L. (2002). "Self-efficacy and diabetes; why is emotional 'education' important and how can it be achieved?" Hormone Research 57: 69-71.

Howells, L., A. C. Wilson et al. (2002). "A randomized control trial of the effect of negotiated telephone support on glycaemic control in young people with type 1 diabetes." Diabetic Medicine 19: 643-648.

Hurley, C. C. and C. A. Shea (1992). "Self-efficacy: strategy for enhancing diabetes self-care." The Diabetes Educator 18(2): 146-150.

Ikeda, K., F. Aoki, et al. (2003). "Association of blood glucose control with self-efficacy and rated anxiety and depression in type 2 diabetes mellitus patients." Psychological Reports 92(2): 540-544.

Janz, N. and M. H. Becker (1984). "The Health Belief Model: A decade later." Health Education Quarterly 11: 1-47.

Jessop, D. C. and D. R. Rutter (2003). "Adherence to asthma medication: the role of illness representations." Psychology and Health 18(5): 595-612.

Johnson, J. E. and H. Leventhal (1974). "The effects of accurate expectations and behavioral instructions on reactions during a noxious medical examination." Journal of Personality and Social Psychology 29: 710-718.

Johnston-Brooks, C. H., M. A. Lewis, et al. (2002). "Self-efficacy impacts self-care and HbA1c in young adults with type 1 diabetes." Psychosomatic Medicine **64**(1): 43-51.

Kahn, C. R., G. C. Weir et al. (2005). Joslin's Diabetes Mellitus (14th edition) Boston, Lippincott, Williams and Watkins.

Kaplan, R. M. and S. L. Hartwell (1987). "Differential effects of social support and social network on physiological and social outcomes in men and women with type II diabetes mellitus." Health Psychology **6**(5): 387-398.

Katon, W. J. (2003). "Clinical and health services relationships between major depression, depressive symptoms and general medical illness." Society of Biological Psychiatry **54**: 216-226.

Kavanaugh, D. J., S. Gooley, et al. (1993). "Prediction of adherence and control in diabetes." Journal of Behavioural Medicine **16**: 509-522.

Kelleher, D. (1988a). Diabetes. London, Routledge.

Kelleher, D. (1988b). Coming to terms with diabetes: coping strategies and non-compliance. Living with Chronic Illness: The Experience of Patients and their Families. R. Anderson and M. Bury. London, Unwin Hyman: 137-155.

Kelly, M. P. and L. M. Millward (2004). Identity and Illness. Identity and Health. D. Kelleher and G. Leavey. London, Routledge: 1-18.

Kingery, P. M. and R. E. Glasgow (1989). "Self-efficacy and outcome expectations in the self-regulation of non-insulin dependent diabetes mellitus." Health Education **20**(7): 13-19.

Koch, T., D. Kralik, et al. (2000). "Men living with diabetes: minimizing the intrusiveness of the disease." Journal of Clinical Nursing **9**: 247-254.

Kroenke, K. and R. L. Spitzer (1998) "Gender differences in the reporting of physical and somatoform symptoms." Psychosomatic Medicine **60**: 150-155.

Kuijer, R. G. and D. T. D. d. Ridder (2003). "Discrepancy in illness-related goals and quality of life in chronically ill patients: The role of self-efficacy." Psychology and Health **18**(3): 313-330.

Kulik, J. A. and H. I. M. Mahler (1987). "Effects of preoperative roommate assignment on preoperative anxiety and recovery from coronary-bypass surgery." Health Psychology **6**: 526-543.

Kyngas, H., M. Hentinen, et al. (1998). "Adolescents' perceptions of physicians, nurses, parents and friends: help or hindrance in compliance with diabetes self-care?" Journal of Advanced Nursing **27**: 760-769.

Lai, W. A, C. Y. Lew Ting et al. (2005). "How diabetic patients think about and manage their illness in Taiwan." Diabetic Medicine **22**(3): 286-292.

Lange, L. J. and J. D. Piette (2006). "Personal models for diabetes in context and patients' health status." Journal of Behavioural Medicine **29**(3): 239-253.

Larkin, M. (2004) Qualitative Psychology. Interpretative Phenomenological Analysis 6th Annual Conference, Nottingham.

Law, G. U., T. P. Kelly, et al. (2002). "Self-management and well-being in adolescents with diabetes mellitus: do illness representations play a regulatory role?" Journal of Adolescent Health 31: 381-385.

Lawson, V. L., C. Bundy, et al. (2004). "Using the IPQ and PMDI to predict regular diabetes care-seeking among patients with type 1 diabetes." British Journal of Health Psychology 9: 241-252.

Lawton, J, E Peel et al. (2005) "Lay perceptions of type 2 diabetes in Scotland: bringing health services back in." Social Science and Medicine 60(7): 1423-1435.

Lefcourt, H. M. (1981) Research with the locus of control construct San Diego, CA, Academic Press.

Leventhal, H. (1970). "Findings and theory in the study of fear communications." Advances in Experimental Social Psychology 5: 119-186.

Leventhal, H., I. Brissette, et al. (2003). The commonsense model of self-regulation of health and illness. The Self-Regulation of Health and Illness Behaviour. L. D. Cameron and H. Leventhal. London, Routledge: 42-65.

Leventhal, H., E. Halm, et al. (2004). Living with chronic illness: a contextualized, self-regulation approach. The SAGE Handbook of Health Psychology. S. Sutton, A. Baum and M. Johnston. London, Sage: 197-240.

Leventhal, H., D. Meyer, et al. (1980). The common sense representation of illness danger. Contributions to Medical Psychology. S. Rachman. New York, Pergamon: 7-30.

Leventhal, H. and D. R. Nerenz (1983). Self-regulation theory in chronic illness. Coping with Chronic Disease. B. G. Burish and I. A. Bradley. New York, Academic Press.

Leventhal, H., J. C. Watts, et al. (1967). "Effects of fear and instructions on how to cope with danger." Journal of Personality and Social Psychology 6: 313-321.

Leymarie, F., J. L. Richard and D. Malgrange (2005) "Factors associated with diabetic patients at high risk for foot ulceration." Diabetes and Metabolism 31(6): 603-605.

Lin, E. H. B., W. Katon, et al. (2004). "Relationship of depression and diabetes self-care, medication adherence, and preventive care." Diabetes Care 27: 2154-2160.

Lloyd, C. E., P. H. Dyer, et al. (1999). "Association between stress and glycemic control in adults with type 1 (Insulin dependent) diabetes." Diabetes Care 22(8): 1278-1283.

Lloyd, C. E., J. Smith, et al. (2005). "Stress and diabetes: a review of the links." Diabetes Spectrum 18(2): 121-127.

Lubkin, I. M. and P. D. Larsen (2002). Chronic Illness: Impact and Interventions.

Maddux, J. E. (1995). Self-efficacy theory: an introduction. Self-Efficacy, Adaptation and Adjustment: Theory, Research and Application. J. E. Maddux. New York, Plenum Press: 3-36.

Maibach, E. and D. A. Murphy (1995). "Self-efficacy in health promotion research and practice: conceptualization and measurement." Health Education Research 10(1): 37-50.

Mason, B. J. et al. (1995). "Assessment of sulfonylurea adherence and metabolic control." The Diabetes Educator 21(1): 52-57.

Mathieson, C. M. (1999). Interviewing the ill and the healthy. Qualitative Health Psychology: Theories and Methods. M. Murray and K. Chamberlain. London, Sage: 117-132.

Mayo, L. (1956). Guides to Action on Chronic Illness. New York, National Health Council.

McCaul, K. D., R. E. Glasgow, et al. (1987). "Diabetes regimen behaviors: predicting adherence." Medical Care 25(9): 868-881.

Mead, G. H. (1934). Mind, Self and Society. Chicago, University Press.

Meetoo, D. (2004). "Clinical skills: empowering people with diabetes to minimize complications." British Journal of Nursing 13(11): 644-651.

Meyer, D., H. Leventhal, et al. (1985). "Common-sense models of illness: the example of hypertension." Health Psychology 4: 115-135.

Mora, P., C. Robitaille, et al. (2002). "Trait negative affect relates to prior weak symptoms, but not to reports of illness episodes, illness symptoms and care seeking." Psychosomatic Medicine 64: 436-449.

Morgan, D. (2005) Triangulation and its discontents: developing pragmatism as an alternative justification for combining qualitative and quantitative methods. Mixed Methods in Health and Social Care, Cambridge.

Morris, A. D. et al. (1997) "Adherence to insulin treatment, glycaemic control, and ketoacidosis in insulin-dependent diabetes mellitus." Lancet 22(350): 1505-1510.

Moss-Morris, R., K. J. Petrie, et al. (1996). "Functioning in chronic fatigue syndrome: do illness perceptions play a regulatory role?" British Journal of Health Psychology 1: 15-25.

Moss-Morris, R., J. Weinman, et al. (2002). "The Revised Illness Perception Questionnaire (IPQ-R)." Psychology and Health 17: 1-16.

Murphy, E. and A. L. Kinmonth (1995). "No symptoms, no problem? Patients' understandings of non-insulin dependent diabetes". Family Practice 12:184-192.

Norris, S. L., M. M. Engelgau, et al. (2001). "Effectiveness of self-management training in type 2 diabetes: a systematic review of randomized controlled trials." Diabetes Care 24(3): 561-587.

Nouwen, A., J. Gingras et al. (1997). "The development of an empirical psychosocial taxonomy for patients with diabetes." Health Psychology 16(3): 263-271.

Orme, C. M. and Y. M. Binik (1989). "Consistency of adherence across regimen demands." Health Psychology 8: 27-43.

Padgett, D. K. (1991). "Correlates of self-efficacy beliefs among patients with non-insulin dependent diabetes mellitus in Zagreb, Yugoslavia." Patient Education and Counseling 18: 139-147.

Paes, A. H. P et al. (1997) "Impact of dosage frequency on patient compliance." Diabetes Care 20(10): 1512-1517.

Parsons, T. (1951). The Social System. London, Routledge.

Paterson, B. (2001). "Myth of empowerment in chronic illness." Journal of Advanced Nursing 34(5): 574-581.

Patton, M. (1987) How to Use Qualitative Methods in Evaluation. London, Sage.

Persell, S. D., N. L. Keating, et al. (2004). "Relationship of diabetes specific knowledge to self-management activities, ambulatory preventative care and metabolic outcomes." Preventative Medicine 39: 746-752.

Petrie, K. J., J. Weinman, et al. (1996). "Role of patients' view of their illness in predicting return to work and functioning after myocardial infarction." British Medical Journal 312: 1191-1194.

Pickup, J. C. and G. Williams (2003). Textbook of Diabetes Massachusetts, Blackwell Publishing.

Pimm, T. J. and J. Weinman (1998). "Applying Leventhal's self-regulation model to adaptation and intervention in rheumatic disease." Clinical Psychology and Psychotherapy 5: 62-75.

Pinar, R., L. Arslangolu et al. (2003). "Self-efficacy and its interrelation with family environment and metabolic control in Turkish adolescents with type 1 diabetes." Pediatric Diabetes 4(4): 164-173.

Price, M. J. (1989). "Qualitative analysis of the patient-provider interactions: the patient's perspective." The Diabetes Educator 15(2): 144-148.

Quatromoni, P. A., M. Mibauer, et al. (1994). "Use of focus groups to explore nutrition practices and health beliefs of urban Caribbean Latinos with diabetes." Diabetes Care 17: 869-873.

Radley, A. (1994). Making Sense of Illness: The Social Psychology of Health and Disease. London, Sage.

Rhee, M. K., W. Slocum et al. (2005)."Patient adherence improves glycemic control." The Diabetes Educator 31(2): 240-250.

Roethlisberger, F. J. And W. J. Dickson (1939). Management and the Worker. Cambridge Mass., Harvard University Press.

Rose, A. M. (1962). Human Behaviour and Social Process. London, Routledge and Kegan Paul.

Rosenberg, M. and R. Turner (1981). Social Psychology: Sociological Perspectives. New York, Basic Books.

Rosenstock, I. M., V. J. Strecher, et al. (1988). "Social Learning Theory and the Health Belief Model." Health Education Quarterly 15(2): 175-183.

Rubin, R. R. (2005) "Adherence to pharmacologic therapy in patients with type 2 diabetes mellitus." American Journal of Medicine 118(5A): 275-345.

Rubin, R. R., M. Peyrot, et al. (1989). "Effect of diabetes education on self-care, metabolic control and emotional well-being." Diabetes Care 12(10): 673-679.

Scharloo, M., A. A. Kaptein, et al. (1999). "Predicting functional status in patients with rheumatoid arthritis." The Journal of Rheumatology 26(8): 1686-1692.

Scharloo, M., A. A. Kaptein, et al. (2000). "Patient's illness perceptions and coping as predictors of functional status in psoriasis." British Journal of Dermatology 142: 899-907.

Scheier, M. F. and C. S. Carver (2003). Goals and confidence as self-regulatory elements underlying health and illness behaviour. The Self-Regulation of Health and Illness Behaviour. L. D. Cameron and H. Leventhal. London, Routledge: 17-41.

Schoenberg, N. E. C. H. Amey et al. (1998). "Stories of meaning: lay perspectives on the origin and management of noninsulin dependent diabetes mellitus among older women in the United States." Social Science and Medicine 47(12): 2113-2125.

Schwab, T., J. Meyer, et al. (1994). "Measuring attitudes and health beliefs among Mexican Americans with diabetes." The Diabetes Educator 20: 221-227.

Schwarzer, R. (1992) Self-efficacy: Thought control of action Hemipshere.

Schwedes, U., M. Siebolds, et al. (2002). "Meal-related structured self-monitoring of blood glucose." Diabetes Care 25(11) 1928-1932.

Silverman, D. (2005) Doing Qualitative Research: A Practical Handbook. London, Sage.

Sim, J. (2005) Problems in integrating qualitative and quantitative approaches. Mixed Methods in Health and Social Care, Cambridge.

Sissons Joshi, M. (1995). Lay explanations of the cause of diabetes in India and the UK. Representations of Health, Illness and Handicap. I. Markova and R. M. Farr. UK, Harwood Academic: 163-188.

Siguroardottir, A. K. (2005). "Self-care in diabetes: model of factors affecting self-care." Journal of Clinical Nursing 14: 301-314.

Skinner, E. A. et al. (1988). "Control, means-ends and agency beliefs: A new conceptualisation and its measurement during childhood." Journal of Personality and Social Psychology 54: 117-133.

Skinner, E. A. (1996). "A guide to contructs of control". Journal of Personality and Social Psychology 71(3): 549-570.

Skinner, T. C. et al. (2000) Diabetes During Adolescence. In Psychology in Diabetes Care. F. J. Snoek and T. C. Skinner, Chichester, John Wiley and Sons.

Skinner, T.C. and S. Cradock (2001). "Empowerment: a response" Practical Diabetes International 18(1): 26.

Skinner, T. C. and S. E. Hampson (1998). "Social support and personal models of diabetes in relation to self-care and well-being in adolescents with type 1 diabetes mellitus." Journal of Adolescence 21: 703-715.

Smith, J. A. and M. Osborn (2003). Interpretative phenomenological analysis. Qualitative Psychology: A Practical Guide to Methods. J. A. Smith. London, Sage: 51-80.

Steed, L., S. P. Newman, et al. (1999). "An examination of the self-regulation model in atrial fibrillation." British Journal of Health Psychology 4: 337-347.

Strauss, A. and J. Corbin (1998). The interplay between qualitative and quantitative in theorizing. Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory. London, Sage: 27-34.

Surwit, R., A. Scovern, et al. (1982). "The role of behaviour in diabetes care." Diabetes Care 5: 337-342.

Szacki, J. (1979). History of Sociological Thought. London, Aldwych Press Ltd.

Tamer, A., S. Yildiz, et al. (2006). "The prevalence of neuropathy and realtionship with risk factors in diabetic patients: A single-center experience." Medical Principles and Practice 15(3): 190-194

Taylor, S. and D. Field (1997) Sociology of Health and Health Care. Oxford, Blackwell Science.

Teza, S. L., W. K. Davis et al. (1988) "Patient knowledge compared with national guidelines for diabetes care." The Diabetes Educator 14: 207-211.

Thomas, J., I. Scarinci, et al. (2003). "A descriptive and comparative study of the prevalence of depressive and anxiety disorders in low-income adults with type 2 diabetes and other chronic illnesses." Diabetes Care 26: 8.

Thompson, S. T., W. F. Auslander, et al. (2001). "Influence of family structure on health among youths with diabetes." Health and Social Work 26(1): 7-14.

Thorne, S., B. Paterson, et al. (2003). "The structure of everyday self-care decision making in chronic illness." Qualitative Health Research 13(10): 1337-1352.

Toljamo, M. and M. Hentinen (2001). "Adherence to self-care and social support." Journal of Clinical Nursing 10: 618-627.

Toobert, D. J., S. E. Hampson, et al. (2000). "The Summary of Diabetes Self-Care Activities measure." Diabetes Care 23(7): 943-950.

Tunbridge, W. M. and P. D. Home (1991) Diabetes and Endocrinology in Clinical Practice. London, Edward Arnold.

Velicer, W. F., C. C. DiClemente, et al. (1990). "Relapse situations and self-efficacy: an integrative model." Addictive Behaviors 15: 271-283.

Warren, L. and P. Hixenbaugh (1998). Adherence and diabetes. Adherence to Treatment in Medical Conditions. L. B. Myers and K. Midence. Amsterdam, Harwood Academic.

Watkins, K. W., C. M. Connell, et al. (2000). "Effect of adults' self-regulation of diabetes on quality of life outcomes." Diabetes Care 23(10): 1511-1515.

Weinman, J., K. J. Petrie, et al. (1996). "The Illness Perception Questionnaire: A new method for assessing illness perceptions." Psychology and Health 11: 431-446.

Weinman, J., K. J. Petrie, et al. (2000). "Causal attributions in patients and spouses following first time myocardial infarction and subsequent lifestyle changes." British Journal of Health Psychology 5: 263-273.

Weijman, I., W. J. G. Ros et al. (2005)."The role of work-related and personal factors in diabetes self-management." Patient Education and Counseling 59: 87-96.

Welschen, L.M.C., E. Bloemendal, et al. (2005)."Self-monitoring of blood glucose in patients with type 2 diabetes who are not using insulin." Diabetes Care 28(6): 1510-1517.

Whitehead, W. E., C. Winget, et al. (1982). "Learned illness behavior in patients with irritable bowel syndrome and peptic ulcer." Digestive Diseases and Sciences 27(3): 202-208.

Wolever, T. M. S., S. Hamad et al. (1999)."Day-to-day consistency in amount and source of carbohydrate intake associated with improved blood glucose control in type 1 diabetes." Journal of the American College of Nutrition 18(3): 242-247.

Wong, M. L. et al. (2004). "Willingness to donate blood samples for genetic research: a survey from a community in Singapore." Clinical Genetics 64(1): 45-51.

Zeidner, M., M. Boekaerts, et al. (2000). Self-regulation: directions and challenges for future research. Handbook of Self-Regulation. M. Boekaerts, P. R. Pintrich and M. Zeidner. San Diego, Academic Press.

Ziebland, S. (2004) An Introduction to Qualitative Interview Analysis Training. DIPex, Oxford.

Zimmerman, B. J. (2000). Attaining self-regulation: a social cognitive perspective. Handbook of Self-Regulation. M. Boekaerts, P. R. Pintrich and M. Zeidner. San Diego, Academic Press: 13-41.

http://www.diabetes.org.uk/Guide-to-diabetes/Complications/Short_term_complications/Hypoglycaemia/ (accessed January 2007)

http://guidance.nice.org.uk/CG15 (accessed January 2007)

http://guidance.nice.org.uk/CGG (accessed January 2007)

Appendices

Appendix A – Demographic questionnaire

Some Details About You

Please could you take the time to read through these questions and answer them by ticking the correct answer where necessary. Thank you.

1) Age:

2) Sex:

Male ☐   Female ☐

3) Marital Status:

Single ☐   Married ☐   Separated/Divorced ☐

Living Together ☐

4) Highest Level of Education Reached:

O-levels/GCSEs ☐   A-levels ☐   First degree ☐

Further Degree ☐   Vocational Qualification (Please specify)

Other (Please specify)

5) Age when diagnosed with diabetes:

6) Type of diabetes:

Type 1 ☐   Type 2 ☐

7) What type of medication do you take?

8) Ethnic origin:
(Please tick all relevant)

White/European (including UK) ☐   Afro-Caribbean ☐

Asian ☐   Chinese ☐

African ☐   Other (Please specify) ☐

9) Job status:

Are you currently in paid employment? Yes ☐   No ☐

422

Appendix B – Illness Perception Questionnaire – Revised

Your views about your diabetes

Listed below are a number of symptoms that you may or may not have experienced since your diabetes. Please indicate by circling *Yes* or *No*, whether you have experienced any of these symptoms since your diabetes, and whether you believe these symptoms are related to your diabetes.

	I have experienced this symptom *since my diabetes*		This symptom is *related to my diabetes*	
Pain	Yes	No	Yes	No
Sore throat	Yes	No	Yes	No
Nausea	Yes	No	Yes	No
Breathlessness	Yes	No	Yes	No
Weight loss	Yes	No	Yes	No
Fatigue	Yes	No	Yes	No
Stiff joints	Yes	No	Yes	No
Sore eyes	Yes	No	Yes	No
Wheeziness	Yes	No	Yes	No
Headaches	Yes	No	Yes	No
Upset stomach	Yes	No	Yes	No
Sleep difficulties	Yes	No	Yes	No
Dizziness	Yes	No	Yes	No
Loss of strength	Yes	No	Yes	No

We are interested in your personal views of how you now see your current diabetes.

Please indicate how much you agree or disagree with the following statements about your diabetes by ticking the appropriate box.

	Views about your diabetes	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
1	My diabetes will last a short time.					
2	My diabetes is likely to be permanent rather than temporary.					
3	My diabetes will last for a long time.					
4	This diabetes will pass quickly.					
5	I expect to have this diabetes for the rest of my life.					

6	My diabetes is a serious condition.					
7	My diabetes has major consequences on my life.					
8	My diabetes does not have much effect on my life.					
9	My diabetes strongly affects the way others see me.					
10	My diabetes has serious financial consequences.					
11	My diabetes causes difficulties for those who are close to me.					
12	There is a lot which I can do to control my symptoms.					
13	What I do can determine whether my diabetes gets better or worse.					
14	The course of my diabetes depends on me.					
15	Nothing I do will affect my diabetes.					
16	I have the power to influence my diabetes.					
17	My actions will have no affect on the outcome of my diabetes.					
18	My diabetes will improve in time.					
19	There is very little that can be done to improve my diabetes.					
20	My treatment will be effective in curing my diabetes.					
21	The negative effects of my diabetes can be prevented (avoided) by my treatment.					

22	My treatment can control my diabetes.					
23	There is nothing which can help my condition.					
24	The symptoms of my conditions are puzzling to me.					
25	My diabetes is a mystery to me.					
26	I don't understand my diabetes.					
27	My diabetes doesn't make any sense to me.					
28	I have a clear picture or understanding of my condition.					
29	The symptoms of my diabetes change a great deal from day to day.					
30	My symptoms come and go in cycles.					
31	My diabetes is very unpredictable.					
32	I got through cycles in which my diabetes gets better and worse.					
33	I get depressed when I think about my diabetes.					
34	When I think about my diabetes I get upset.					
35	My diabetes makes me feel angry.					
36	My diabetes does not worry me.					
37	Having this diabetes makes me feel anxious.					
38	My diabetes makes me feel afraid.					

Causes of my diabetes

We are interested in what <u>you</u> consider may have been the cause of your diabetes. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that caused your diabetes rather than what others including doctors or family may have suggested to you. Below is a list of possible causes for your diabetes. Please indicate how much you agree or disagree that they were causes for you by ticking the appropriate box.

	Possible causes	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
1	Stress or worry					
2	Hereditary – it runs in my family					
3	A germ or virus					
4	Diet or eating habits					
5	Chance or bad luck					
6	Poor medical care in my past					
7	Pollution in the environment					
8	My own behaviour					
9	My mental attitude eg thinking about life negatively					
10	Family problems or worries					
11	Overwork					
12	My emotional state eg. feeling down, lonely, anxious, empty					
13	Ageing					
14	Alcohol					
15	Smoking					
16	Accident or injury					
17	My personality					
18	Altered immunity					

In the table below, please list in rank-order the three most important factors that you now believe causes <u>YOUR diabetes</u>. You may use any of the items from the box above, or you may have additional ideas of your own.

The most important causes for me:

1) _____
2) _____
3) _____

Appendix C – *Summary of Diabetes Self-Care Activities Scale*

How You Look After Yourself and Your Diabetes

The questions below ask you about your diabetes self-care activities during the past 7 days. If you were ill during the past 7 days, please think back to the last 7 days that you weren't ill. Please circle the correct number of days.

Diet

1)   How many of the last SEVEN DAYS have you followed a healthy eating plan?

2)   On average over the past month, how many DAYS PER WEEK have you followed a healthy eating plan?

3)   On how many of the last SEVEN DAYS did you eat five or more servings of fruit and vegetables?

4)   On how many of the last SEVEN DAYS did you eat high fat foods such as red meat or full fat dairy products?

5)   On how many of the last SEVEN DAYS did you space carbohydrates evenly throughout the day?

Exercise

6)   On how many of the last SEVEN DAYS did you participate in at least 30 minutes of physical activity? (Total minutes of continuous activity including walking).

7)   On how many of the last SEVEN DAYS did you participate in a specific exercise session (such as swimming, walking, biking) other than what you do around the house or   as part of your work?

Blood Sugar Testing

8)   On how many of the last SEVEN DAYS did you test your blood sugar?

9) On how many of the last SEVEN DAYS did you test your blood sugar the number of times recommended by your health care provider?

Medication

10) On how many of the last SEVEN DAYS did you take your recommended diabetes medication?

Foot Care

11) On how many of the last SEVEN DAYS did you check your feet?

12) On how many of the last SEVEN DAYS did you inspect the inside of your shoes?

13) On how many of the last SEVEN DAYS did you wash your feet?

14) On how many of the last SEVEN DAYS did you soak your feet?

15) On how many of the last SEVEN DAYS did you dry between your toes after washing?

Smoking

16) Have you smoked a cigarette – even one puff – during the past SEVEN DAYS?

Yes   No

17) If yes, how many cigarettes did you smoke on an average day?

Recommendations About How to Look After Your Diabetes

1)   *Which of the following has your health care team (doctor, nurse, dietician etc) advised you to do? Please tick all answers that apply to you.*

a)   Follow a low-fat eating plan.

b)   Follow a complex carbohydrate diet.

c)   Reduce the number of calories you eat to lose weight.

d)   Eat lots of food high in fibre.

e)   Eat lots of fruit and vegetables (at least 5 a day).

f)   Eat very few sweets (for example desserts, chocolate, cake, non-diet fizzy drinks).

g)   Other. (Please specify)

h)   I have not been given any advice about my diet from my health care team.

2)   *Which of the following has your health care team (doctor, nurse, and dietician) advised you to do? Please tick all answers that apply to you.*

a)   Get low level exercise (such as walking) on a daily basis.

b)   Exercise continuously for at least 20 minutes at least 3 times a week.

c)   Fit exercise into your daily routine (for example, walk up the stairs instead of using the lift, get off a bus stop early and walk the rest of the way).

d)   Engage in a specific amount, type, duration and level of exercise.

e)   Other. (Please specify)

f) I have not been given any advice about exercise from my health care team.

3)   *Which of the following has you health care team (doctor, nurse, dietician) advised you to do? Please tick all answers that apply to you.*

a)   Test your blood sugar using a drop of blood from your finger and a colour chart.

b)   Check your blood sugar using a machine to read the results.

c)   Test your urine for sugar.

d)   Other. (Please specify)

e)   I have not been given any advice either about testing my blood or urine sugar level by my health care team.

4)   *Which of the following medications for your diabetes has your doctor prescribed?*

a)   An insulin injection 1 or 2 times a day.

b)   An insulin injection 3 or more times a day.

c)   Diabetes tablets to control my blood sugar level.

d)   Other. (Please specify)

Appendix D – *Self-Efficacy Scale - Original*

Self-efficacy for diabetes scale (SED)

Instruction: Please read the following questions. After each question, please make a check in the circle to show how much you believe you can or cannot do what is asked *now.*

1)   Be the one in charge of giving my insulin injection to myself.

2)   Figure out my own meals and snacks at home.

3)   Figure out what foods to eat when I am away from home.

4)   Keep track of my own blood sugar levels.

5)   Watch my own sugar levels in my urine.

6)   Change the amount of time I get insulin when I get a lot of extra

         exercise.

7)   Judge the amount of food I should eat before activities.

8)   Figure out how much insulin to give myself when I am sick in bed.

9)   Prevent having reactions.

10)   Avoid or get rid of dents, swelling, or redness of my skin where I get

         my shot.

11)   Talk to my doctor myself and ask for the things I need.

12)   Suggest to my parents changes in my insulin doses.

13)   Sleep away from home on a class trip or at a friend's house where no

         one knows about my diabetes.

14)   Keep myself free of high blood sugar levels.

15)   Know how to make my urine tests look better or worse than they are.

16)   Avoid having acetones.

17)   Change my doctor if I don't like him/her.

18)   Feel able to stop a reaction when I am having one.

19)   Ask for help I need from other people when I feel sick.

20)   Tell a friend I have diabetes.

21) Play baseball or other sports that take a lot of energy.

22) Argue with my doctor if I felt he/she were not being fair.

23) Prevent blindness and other complications from my diabetes.

24) Tell my boyfriend or girlfriend I am diabetic.

25) Do things I have been told not to when I really want to do them.

26) Get as much attention from others when my diabetes is under control as when it isn't.

27) Easily talk to a group of people at a party when I don't know them.

28) Make a teacher see my point of view.

29) Show my anger to a friend when he/she has done something to upset me.

30) Take responsibility for getting my homework and chores done.

31) Regularly wear a medical alert tag or bracelet which says I have diabetes.

32) Sneak food not on my diet without getting caught.

33) Believe that I have the ability to have control over my diabetes.

34) Follow my doctor's orders for taking care of my diabetes.

35) Run my life the same as I would if I didn't have diabetes.

Appendix E – *Self-Efficacy Scale – Revised*

<u>Coping With Your Diabetes</u>

Please read the following questions. After each question please circle the answer which you feel best shows how much you believe you can or cannot do what is asked at the present time.

1)   Be in charge of giving my own injections or taking my own tablets

2)   Work out my own meals and snacks at home.

3)   Work out what foods to eat away from home.

4)   Keep track of my blood sugar levels.

5)   Change the amount of insulin or increase the amount of food I eat when I do a lot of exercise.

6)   Work out how much insulin I need to give myself or how much I need to eat if I am ill.

7)   Prevent having hypos.

8)   Talk to the doctor about my diabetes and ask for things I need.

9)   Keep myself free from high blood sugars.

10)   Avoid having ketones in my urine.

11)   Feel able to stop a hypo if I have one.

12)   Ask for help from other people if I feel ill.

13)   Tell friends and colleagues that I have diabetes.

14)   Do activities or exercises which require a lot of energy.

15)   Argue with my doctor if I feel he/she is not being fair.

16)   Prevent complications from my diabetes.

17)   Do things I have been told not to do when I really want to do them.

18)   Get as much attention from others when my diabetes is under control as when it isn't.

19)   Easily talk to a group of people at a social or work event when I don't know them.

20)   Make a work colleague, friend or family member see my point of view.

21)   Show my anger when someone has done something to upset me.

22)   Regularly wear a medical tag or bracelet which says I have diabetes.

23)   Sneak food not on my diet without getting caught.

24)   Believe that I have the ability to have control over my diabetes.

25)   Follow my doctor's recommendations for taking care of my diabetes.

26)   Run my life the same as I would if I didn't have diabetes.

Appendix F – *Complications Checklist*

What are the effects of your diabetes?

Have you ever experienced the following symptoms or been told by your doctor or nurse that you have any of the following conditions as a result of your diabetes? Please tick any that apply to you and if possible indicate when you were told (month and year – approximately is fine).

Please tick

No complications or problems due to diabetes

Problems with your feet

Neuropathy

Foot complications

Pain/ tingling in your feet

Ulcers

Amputation

Problems with your eyes which have needed treatment

Eye complications

Mild retinopathy

Background retinopathy

Small changes at the back of your eyes

Cataracts

Proliferative retinopathy

Major or severe changes at the back of your eyes

Problems with your kidneys

Kidney disease

Nephropathy

Protein in your urine due to your kidneys

Microalbumin in your urine

Problems with your circulation

Heart attack

Angina

Heart failure

Stroke

Appendix G – *Interview Topic Guide*

1) To start with could you just tell me a bit about yourself....

- Your family, what you do for a living for example...
- What type of diabetes do you have?
- How you know what type it is?
- What do you think are the differences between type 1 and type 2 diabetes?
- How do you think other people (people you know, the media etc) see diabetes
– type 1 and type 2 – in general, yours in particular?

2) Can you tell me about what treatment you have for your diabetes?

3) Can you tell me about when you found out you had diabetes?

- What happened and how you felt.
- What you knew about diabetes before being diagnosed with it and how you
knew about it eg. someone you know with diabetes, media etc.

4) What do you think caused your diabetes?

- How have you found out about what caused your diabetes?
- Eg. doctors, media, other people you know etc.
- Do you think your behaviour had any affect on developing diabetes?
- How do you feel about this?
- How do you feel when thinking about what caused your diabetes?
- Angry, regretful, resigned, frustrated, fatalistic....?

5) Are there any symptoms or differences in your body or health since your diagnosis with diabetes?

- Symptoms experienced, mental health.
- Strength and weaknesses.
- How do you feel about these differences?

6) Are there any things which are different about your life now you have diabetes?

- Physically, emotionally, financially, psychologically etc.
- Attitudes of other people.

7) What do you do to look after yourself and your diabetes?

- Diet, exercise, blood testing, medication, hospital appointments etc.

8) How do you know what you need to do to look after your diabetes?

- Where have you got your advice from?
- What advice have you been given?

9) How well do you think you look after yourself and your diabetes?

- How do you measure whether you are looking after your diabetes successfully or not?
- What aspects of looking after your diabetes are most/least important to you?
- How important is it to you to look after your diabetes?
- Do you follow the advice given to you and if not when and why not?

10) How confident do you feel about managing your diabetes?

- Do you/or have you asked for help with your diabetes?
- Who from?
- Did it/ does it help?
- Which parts of your diabetes do you feel confident about? ie diet, exercise, blood testing, taking medication, overall balance.
- Which bits don't you feel confident about? ie diet, exercise, blood testing, taking medication, overall balance.
- Complications

11) Could you talk me through your day yesterday describing in details any bits where your diabetes was involved?

- Probing for more detail at interesting bits, asking how felt about behaviours carried out, impact on day to day activities, thought processes etc.

12) Could you talk me through your last visit to the diabetes clinic?

13) How do you feel about the future?

14) Is there anything else that I haven't asked you during this interview that you feel is important for me to know?

Appendix H – *Questionnaire variables*

Questionnaire	Scale	Higher score means:
Illness Perception Questionnaire - Revised	Identity	More physical symptoms attributed to diabetes.
	Timeline	Longer lasting diabetes is believed to be.
	Consequences	More consequences of having diabetes.
	Personal Control	More personal control over diabetes.
	Treatment Control	More control the treatment has over diabetes.
	Illness Coherence	More understanding of diabetes.
	Timeline Cyclical	More cyclical illness pattern.
	Emotional Representations	More negative emotions experienced about diabetes.
	Curing Diabetes	Greater belief that diabetes is curable.
	Personal Responsibility Causes	Feeling more personally responsible for cause of diabetes.
	Mental State Causes	Greater belief that mental states caused diabetes (eg. stress, worry, depression).
	Accident or Illness Causes	Greater belief that accident or illness caused diabetes.
	External Causes	Greater belief that external factors caused diabetes (eg. pollution, environment).
	Altered Immunity Causes	Greater belief that diabetes caused by altered immunity.
	Hereditary Causes	Greater belief that diabetes caused by hereditary factors.
	Chance Causes	Greater belief that diabetes caused by chance.

Self-Efficacy Scale - Revised	General Diabetes Self-Efficacy	More self-efficacy about general diabetes self-care.
	Flexible Diabetes Self-Efficacy	More self-efficacy about caring for diabetes in flexible way.
	Assertive Diabetes Self-Efficacy	More self-efficacy about being assertive with HCPs about care needed and asking for help.
	General Social Self-Efficacy	More self-efficacy about general social situations.
	Rebellious Behaviour Self-Efficacy	More self-efficacy about not following 'rules' given by HCPs.
	Stopping Hypos Self-Efficacy	More self-efficacy about stopping hypos once they have started.
	Revealing Diabetes Self-Efficacy	More self-efficacy about telling others that they have diabetes.
	Showing Anger Self-Efficacy	More self-efficacy about showing anger to other people.
Summary of Diabetes Self-Care Activities Scale	General Diet Behaviour	More days when general dietary behaviours followed (eg. low fat, low sugar, fruit and veg).
	Specific Diet Behaviour	More days when specific dietary behaviours followed (eg. carbohydrate spread throughout the day).
	Exercise Behaviour	More days when general or specific exercise activities performed.
	Blood Testing Behaviour	More days when blood tests performed.
	Medication Taking Behaviour	More days when medication taken and timings and amounts to recommendations of HCPs.

	Foot Care Behaviour	More days when specific foot care activities performed (eg checking feet, checking shoes).
	Smoking Behaviour	Participant smokes = 2 Participant doesn't smoke = 1.

Appendix J - *Summary of significant relationships between variables for type of diabetes*

Self-care behaviour	Relationship	Type 1 diabetes	Tablet treated type 2 diabetes	Insulin treated type 2 diabetes
General diet behaviour	Positive	Duration* General Diabetes Self-Efficacy* Specific diet behaviour* Medication taking*	General diabetes self-efficacy* Exercise** Foot care* Specific diet behaviour**	Chance causes* Flexible diabetes self-efficacy* Blood testing* Exercise* Specific diet**
	Negative	Emotional Representations*	None	None
Specific diet behaviour	Positive	Education* General diabetes self-efficacy** Flexible diabetes self-efficacy* General diet behaviour* Foot care*	General diabetes self-efficacy** General social self-efficacy* Exercise* Foot care* General diet behaviour** Blood testing*	General diet behaviour** Blood testing behaviour** Exercise* Foot care*
	Negative	Consequences*	Rebellious self-efficacy*	Employment status*

Exercise	**Positive**	None	General diet behaviour** Specific diet behaviour* Foot care*	Age* Altered immunity causes* General diabetes self-efficacy** Stopping hypos self-efficacy* General diet behaviour* Specific diet behaviour* Blood testing behaviour* Foot care*
	Negative	None	None	Emotional representations*
Blood testing	**Positive**	Personal responsibility causes*	Illness coherence* Specific diet behaviour* Medication taking*	Age* General diet behaviour* Specific diet behaviour** Exercise*
	Negative	Identity** Emotional representations* HbA1c results**	None	Employment status* Smoking behaviour*
Medication taking	**Positive**	General diabetes self-efficacy* General diet behaviour*	Blood testing behaviour*	None
	Negative	Emotional representations*	None	None

Foot care	**Positive**	Duration* Specific diet behaviour*	Age** Altered immunity causes* General diet behaviour* Specific diet behaviour*	Specific diet behaviour* Exercise*
	Negative	Employment status* Altered immunity causes* External causes*	None	None
Smoking	**Positive**	Duration* Personal control* Illness coherence*	Personal responsibility causes*	Altered immunity causes*
	Negative	None	General social self-efficacy*	Blood testing behaviour*
HbA1c	**Positive**	Emotional representations* Accident/illness causes* Kidney complications*	Identity* Timeline cyclical* Emotional representations*	Eye complications*
	Negative	Chance causes* General diabetes self-efficacy* Blood testing behaviour**	Chance causes*	Foot care*

* = p < 0.05
** = p < 0.005

Appendix K – Demographic characteristics of the interviewees

Name	Type of diabetes	Age	Duration of diabetes (years)	Marital status	Occupation	Level of self-care*	Complications **
Mr B	2	50	22	Divorced (2 children)	Registered disabled	High	Yes
Ms C	2	53	22	Married (2 children)	Social worker	Medium	No
Mr D	1	48	25	Married (4 children)	Warehouse worker	Low	No
Ms E	1	51	43	Married (2 children)	Teacher	Medium	Yes
Mr F	2	50	7	Living with partner (3 children)	Warehouse worker	High	Yes
Mr G	2	47	8	Married (2 children)	Registered disabled	Low	Yes
Mr H	1	46	23	Married (2 children)	Retail Manager	Low	No
Ms J	2	43	5	Married (2 children)	Nurse	High	No
Mr K	1	48	18	Married (3 children)	Warehouse worker	High	Yes
Ms L	2	55	5	Widowed (3 children)	Decorator	Medium	No
Ms M	1	33	28	Married (1 child)	Nurse	High	Yes

* High/low/medium self-care based on composite score of responses to SDSCA

questionnaire. High > 33, Medium 30 to 33, Low < 30.

** Presence of complications based on yes/no response to whether participants had one or more of retinopathy, neuropathy, nephropathy or cardio-vascular complications.

All interviewees were taking insulin to treat their diabetes.

The experience of diabetes: how does it effect self-care behaviour?

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

Why are we doing this study.

It is important for people with diabetes to carry out different types of self-care activity to keep themselves healthy in the short term and long term. This study will look at how peoples' personal experience of their diabetes affects how they look after themselves. By looking at what affects and alters self-care we can work out how to help people with diabetes in ways which work for them. This study will last for three years over all however the maximum amount of time you will need to give is two hours.

What the study will involve and what you need to do.

We will be talking to approximately 100 people with diabetes. Half of these people will have type 1 diabetes and half will have type 2 diabetes. You have been asked to take part because you match the necessary characteristics of participants for this study in terms of age, sex and type of diabetes.

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

Your part in the study will take a maximum of two hours. You will be asked to complete a questionnaire. This can either be done in the clinic or you can take it home and post it back to us if you would prefer. We will also be interviewing ten people with diabetes. You do not have to agree to be interviewed as well as completing the questionnaire if you do not wish to. The people who are interviewed will be randomly selected from the people who agree to this part of the study. The interviews will last one hour and will take place at the clinic, either at the time of your regular appointment or on a different occasion if preferred. If a second

trip to the clinic is needed bus fares and car parking fees will be reimbursed.

As part of the study we will also look at your medical notes to get your most recent HbA1c results. No separate blood tests will be done.

How the study may affect you.

Some people may find that the information discussed is of a sensitive nature that might be found upsetting. If this is the case we will provide a list of contacts for you to talk to someone about any issues that may have arisen

We hope that providing an opportunity for you to talk about your diabetes will help you. However, this cannot be guaranteed. The information we get from this study may help us to treat people with diabetes better in the future.

In no way will taking part in this study affect or alter any aspect of the treatment you receive for your diabetes. Your G.P. will not be informed of your participation in this study and all your answers will remain strictly confidential.

If you are harmed by taking part in this research project there are no special compensation arrangements. If you are harmed due to someone's negligence then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms should be available to you.

What we will do with your information.

All information which is collected about you during the course of the research will be strictly confidential. Any information about you will have your name and address removed so that you cannot be recognised from it.

The results of the study will be used in a PhD thesis and may be published in academic journals. Information gained from the people who take part in the study will not be recognisable from the reports and all names will be removed to protect confidentiality. You can get a copy of the finished study from the researcher, however a summary sheet will be sent to everyone who takes part as a matter of course.

<u>Further Details.</u>

This study is being organised by the Open University and has been reviewed by the Milton Keynes Local Research Committee.

For any further information please feel free to contact Katherine Stothard on 01908 858 566 or email K.J.Stothard@open.ac.uk .

If you agree to take part in this study you will be given a copy of this information sheet and a copy of your signed consent form.

Thank you for reading this information and in advance for taking part in the study.

10th December 2003 V2

Patient Identification Number:

CONSENT FORM

The experience of diabetes: how does it effect self-care behaviour?

Katherine Stothard

Please Tick

1) I confirm that I have read and understood the information sheet dated 10th December 2003 for the above study and have had the opportunity to ask questions.

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

3) I understand that direct quotations may be taken from what I say however I understand that I will not be identifiable from those quotes. I give my permission for direct quotes to be used.

4) If I am selected I agree to talk to the researcher about my diabetes in a short interview.

5) I agree to take part in the above study.

Name of patient   Date   Signature

Name of person taking consent Date   Signature
(if different from researcher)

Researcher   Date   Signature

10th December 2003 V2

450

Patient Identification Number:

CONSENT FORM

The experience of diabetes: how does it effect self-care behaviour?

Katherine Stothard

Please Tick

1) I confirm that I have read and understood the information sheet dated 9th September 2005 for the above study and have had the opportunity to ask questions.

☐

2) I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected, and that any data that I have provided will be destroyed if I so request.

☐

3) I understand that the interview will be tape-recorded and transcribed.

☐

4) I understand that the interview is confidential and that only the researcher and her two supervisors will have access to the tape and transcription.

☐

5) I understand that if I wish to see the transcription I can ask the researcher.

☐

6) I understand that direct quotations may be taken from what I say however I understand that I will not be identifiable from those quotes. I give my permission for direct quotes to be used.

☐

7) I agree to take part in the interview described above.

☐

Name of patient   Date   Signature

Researcher   Date   Signature

2nd September 2005 V1

451

Appendix M - Interview Analysis Themes Overview

Page number	Theme	Sub-themes	Summary of findings
	4.2 Causes of my diabetes		1) The men with type 1 diabetes thought their diabetes was caused by stress or shock due to an accident. 2) The men with type 2 diabetes and high self-care thought obesity, poor diet, lack of exercise and hereditary factors caused their diabetes. 3) The man with type 2 diabetes and low self-care did not know what caused his diabetes. 4) All the women (with type 1 and type 2 diabetes) thought that their diabetes was caused by a virus or infection and hereditary factors. 5) Four interviewees (male, female, type 1 and type 2 diabetes) thought luck or chance was part of the cause of diabetes. 6) The interviewees found out what caused their diabetes from health care professionals, family knowledge and their own research, regardless of their gender or type of diabetes.
	4.3 Looking after myself	*4.3.1 Why I look after myself*	1) The majority of interviewees looked after their diabetes primarily in order to avoid diabetes complications. 2) Some of the interviewees looked after their diabetes to avoid dying at a younger age,

				to feel healthy on a daily basis, to prevent hypos, because of the influence of partners, to keep their driving licence, to keep healthy in order to look after their family, to provide a good example to others with diabetes and avoid becoming a burden in older age. There were no differences found between type of diabetes or gender.
			4.3.2 How I know how to look after my diabetes	3) The majority of interviewees got advice on how to look after their diabetes from health care professionals. 4) The majority of interviewees found that their personal experience of diabetes differed from the advice they were given by health care professionals and used their own personal experience to guide how they looked after their diabetes. 5) Only interviewees with type 2 diabetes mentioned getting advice about their diabetes from their GPs. 6) Four of the interviewees with high levels of self-care behaviour carried out their own research about diabetes on the internet or through Diabetes UK. 7) Only the men interviewed described getting advice or help from friends or colleagues with diabetes.
			4.3.3 How I look after myself	8) Diet, medication taking and blood testing were the most regularly carried out self-care behaviours. There were no differences on the basis of type of diabetes or gender. 9) Exercise and foot care were the least performed self-care behaviours. Those interviewees who did exercise felt that exercise was a vital part of looking after diabetes

453

			to a greater extent than those who did not. The interviewees who reported high levels of foot care either had existing foot problems or were health care professionals themselves. There were no differences on the basis of type of diabetes or gender.
		4.3.4 How I know I'm looking after myself	10) The women who were interviewed used their own blood sugar monitoring or HbA1c results to evaluate if they were looking after their diabetes successfully. 11) The men evaluated how their diabetes was being looked after by how they felt, blood test results, how often they were asked to attend the diabetes outpatient clinic or whether they had succeeded in their aims such as losing weight.
4.4 Myself and my diabetes		*4.4.1 Being 'different'/being 'normal'*	1) The majority of the interviewees considered themselves to be 'normal' despite having diabetes; however the three men with type 2 diabetes considered that their diabetes made them different from the general population and 'different'.
		4.4.2 Roles and status	2) For the majority of the interviewees their roles and status were to do with being a member of a family or their working life. In contrast the men with type 2 diabetes used diabetes as a primary role in their life and it provided status for them. 3) One of the men with type 2 diabetes had adopted the sick-role.
		4.4.3 Ownership and responsibility	4) Three of the interviewees, with type 2 diabetes, had made an active decision to take control and responsibility for their diabetes.

			5) Four of the interviewees, with type 1 diabetes, had integrated their diabetes into their everyday life.
			6) Two of the interviewees, with medium and low self-care behaviour felt that their working life stopped them from looking after their diabetes to the extent they would like to.
			7) Two of the interviewees, both men with type 2 diabetes, described how their diabetes controlled their lives.
			8) Two of the men interviewed (both with high self-care) shared responsibility for their diabetes self-care with their partners.
	4.5 Emotional experience	*4.5.1 Reaction to the diagnosis*	1) The majority of the interviewees described feeling shocked, scared, angry or relieved at their diagnosis with the exception of two women with type 1 who were diagnosed as young children and couldn't remember much detail about their reactions to their diagnoses.
		4.5.2 Acceptance of the diagnosis	2) Three interviewees, with type 2 diabetes, described making an active decision to deal with their diabetes and how this led to acceptance of their condition.
		4.5.3 Specific events causing emotional	3) The two women with type 1 who were diagnosed as children had experienced emotional upheaval due to their pregnancies.

		upheaval	
		4.5.4 Everyday emotional experiences	4) Five interviewees with medium or high levels of self-care behaviour (type 1 and type 2 diabetes, men and women) described fear and worry as a consequence of personal or vicarious experience of diabetes complications. 5) Six of the interviewees (type 1 and type 2 diabetes, men and women) reported feeling worried about having hypos. 6) Three of the men interviewed experienced anger as a consequence of how diabetes limited their lives in terms of career or driving. 7) Five interviewees (all with high levels of self-care behaviour) described feeling proud when their blood sugars were being controlled. 8) All the women who were interviewed mentioned feeling lucky and a sense of relief that they only had diabetes and that it could have been a much more serious condition. None of the men described feeling that way.
	4.6 Consequences of my diabetes	*4.6.1 Practical consequences imposed by others*	1) Four of the men interviewed (with type 1 and type 2 diabetes) felt that their diabetes had had negative consequences on their employment experiences and prospects. One woman mentioned difficulties in terms of her career caused by her diabetes. 2) Other financial consequences were mentioned by five interviewees, such as eating more expensive food, being unable to work and getting insurance. It was primarily men who found their diabetes had a negative consequence on their finances. 3) Four of the men (and no women) thought that their diabetes had a negative impact on

				driving.
			4.6.2 Practical consequences imposed by self-care regime: *- Restriction and freedom* *- Continuous routine* *- Constant planning* *- Balance*	4) Nine of the interviewees felt the food they could eat was restricted in some way. Three interviewees (all with type 2 diabetes) reported that they could only eat certain types of food and had to avoid other food they would have liked to eat. Five interviewees (with type 1 and type 2 diabetes) described having to eat when they did not want to because of their diabetes. Three of the interviewees (with type 1 and type 2 diabetes) felt able to eat what they liked and adapt their insulin to meet their requirements. The man with type 2 diabetes and low self-care who had adopted the sick-role ate what he liked but felt he did not know how to adapt his insulin or diet to look after this diabetes. 5) Four of the men interviewed (and no women) felt they had to take their insulin injections at the same time every day, regardless of type of diabetes. All of the interviewees had developed strategies for incorporating diabetes into their lives. The majority of interviewees commented on the continuous, tedious and inconvenient nature of the self-care routine. 6) All of the interviewees described the need for constant planning in order to ensure they could cope with various aspects of the self-care routine and the restrictions placed on them. For example, the need to carry round diabetes equipment, planning before holiday and looking at food labels when shopping. 7) The majority of the interviewees reported the importance of finding a balance between looking after their diabetes and maintaining a 'normal' everyday life. Individual interviewees had chosen different ways to do this depending on their lifestyles, priorities

457

			in life and individual preferences.
		4.6.3 Physical consequences	8) Physical consequences discussed by the interviewees included getting other illnesses more easily (type 1 and type 2 diabetes), being more tired and less physically able (type 2 diabetes only), erectile dysfunction and other physical ailments such as lumpy injection sites and weight gain (men with type 2 diabetes only).
		4.6.4 Future consequences	9) The majority of the interviewees talked about avoiding the potential future consequence of diabetes complications. Nine of the interviewees had vicarious experiences of complications which all of them considered to be a highly motivating factor for looking after their diabetes. Five of the interviewees had existing complications but it emerged from the interviews that seeing others with very severe complications was more motivating than experiencing complications personally, particularly when they were minor such as background retinopathy. No differences were found between type of diabetes or gender.
		4.6.5 Positive consequences	10) Only the two men with type 2 diabetes described meeting others with diabetes as a positive consequence of their diabetes. 11) Three of the women interviewed (and no men) felt a positive consequence of their diabetes was that they now led a healthier lifestyle.
	4.7 Self-efficacy	*4.7.1 How self-efficacy*	1) Eight ways that self-efficacy was influenced emerged from the data: personal experience, social persuasion, vicarious experience, personal research and knowledge,

458

		developed	continuous automated routine, no option but to do it, with the aid of partners, and affective states. 2) All of the interviewees attributed some of their self-efficacy to personal experience. 3) Five interviewees (type 1 and type 2 diabetes, men and women, high and low self-care) described enhanced self-efficacy from social persuasion from health care professionals. 4) Three interviewees (all men) felt their self-efficacy was increased by vicarious experiences. 5) Four interviewees (all with high or medium self-care behaviours) enhanced their self-efficacy through personal research and knowledge. 6) Six interviewees (type 1 and type 2 diabetes, men and women, high and low self-care behaviours) felt the continuous routine influenced their self-efficacy. 7) Two interviewees (both men) had partners who shared responsibility for their diabetes self-care and so influenced their self-efficacy.
		4.7.2 Self-efficacy beliefs held	
		4.7.3 Outcome expectations and achievement of	8) All of the interviewees felt having no option but to perform the behaviour increased their self-efficacy; however, the choice to perform the behaviour or not depended on how important the individual considered the self-care behaviour to be for their diabetes (for

		goals	example insulin injections versus exercise). 9) Only one interviewee (with the most extreme emotional reaction to his diabetes) displayed any effects of affective state on self-efficacy.