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PSYCHOSOCIAL DETERMINANTS OF GLYCAEMIC CONTROL IN PEOPLE WITH TYPE TWO DIABETES

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2005

Thesis submitted in fulfilment of the requirements for Doctorate in Philosophy with the University of Dublin, Trinity College

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DECLARATION

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SUMMARY

Whilst the number of people diagnosed with type 2 diabetes continues to rise to epidemic proportions, there has been a more moderate rise in the acknowledgement of the psychosocial factors that play a role in the treatment and care of diabetes. What is evident is that psychological and social factors can improve outcomes in diabetes. Despite the potential role of family members in influencing diabetes care, they are not routinely included in its management and the lack of research in this area reflects this neglect.

The purpose of this research was to investigate the psychosocial differences between those in good and poor control of their diabetes. In order to understand how these psychosocial differences influence diabetes control, this research took an extreme groups approach – comparing those in good control of their diabetes (HbA₁c < 7) with those in poor control (HbA₁c > 8.5), along with their family members. In order to verify the appropriateness of taking this extreme groups approach and to access the untapped views of those with diabetes and their family members, a preliminary, qualitative stage research was conducted before embarking on a larger-scale quantitative study.

The qualitative stage was guided by grounded theory and four focus groups in total were conducted with those in good and poor control of their diabetes, and their family members (N=19). Analysis of these focus groups showed no discernible differences between those in good and poor control of their diabetes. The main theme to consistently emerge from all of the groups related to the lack of information and understanding about diabetes, which impacted upon people's illness perceptions and daily life. Family members perceived diabetes to be more serious and as having a greater impact on life. Those with diabetes were unaware of this heightened concern and had a more relaxed attitude to living with diabetes. The results highlighted the value in including family members and the importance of examining illness perceptions.

Based on these results the second quantitative stage also took an extreme groups approach, which included family members and the qualitative theory provided the underlying theoretical framework. The participants with diabetes were recruited from a

diabetes out-patients clinic (n=153), where they were asked to nominate a family member who received a postal questionnaire (n=74). The psychosocial factors examined were: diabetes knowledge, treatment satisfaction, illness perceptions, diabetes self-care behaviours, social support, well-being and coping.

The quantitative stage showed no differences in diabetes knowledge, treatment satisfaction, psychological well-being or social support between those in good and poor control of their diabetes. However, there were differences in illness perceptions (causal attribution, illness identity, timeline, consequences and emotional representations), dietary behaviours and coping strategies (distraction coping). Again, family members showed heightened perceptions of the consequences of diabetes and its emotional impact. When compared with those with diabetes, family members reported lower positive wellbeing, lower levels of satisfaction with support and perceived diabetes as more cyclical and controlled more by treatment than by the individual. Logistic regression showed the variables associated with good diabetes control were; being married, higher treatment satisfaction, more stable timeline for illness, fewer diabetes-related emotions, immunity as a causal attribution, greater dietary adherence, and using less distraction and palliative coping and more instrumental coping strategies.

Taking an extreme groups approach to investigate the psychosocial differences between those in good and poor control of their diabetes has highlighted important differences between these two groups. Addressing emotional, cognitive and coping factors for those in poor control of their diabetes has implications for interventions to improve glycaemic control. Understanding the determinants of glycaemic control in diabetes has benefited from including family members who are part of the social context in which the illness exists. Future research needs to consider the potential role of family members in the management and care of diabetes.

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ABBREVIATIONS

AW = Anita White (Observer of Focus Groups) CHIP = Coping with Health and Injury Problems Questionnaire DAWN = Diabetes, Attitudes, Wishes and Needs Study DCCT = Diabetes Control and Complications Trial DFG1 = Person with diabetes - focus group 1 DFG2 = Person with diabetes - focus group 2 DiSC = North Dublin Diabetes Shared Care DKQ = Diabetes Knowledge Questionnaire DTSQ = Diabetes Treatment Satisfaction Questionnaire EC = Eimear Cunningham (Research Assistant for Data Collection) FFG1 = Family Member - focus group 1 FFG2 = Family Member - focus group 2 $HbA_{1c} = Haemoglobin A_{1c}$ IPQ-R = Illness Perceptions Questionnaire – Revised I-QR = inter-quartile rangeMdn = medianMO'L = Martina O' Leary (Research Nurse and Facilitator of Two Focus Groups) p = probabilityPMDI = Personal Models of Diabetes Interview PW = Patricia White RCT = randomised controlled trial RO'L = Ros O' Loughlin (Observer of Focus Groups) SD = standard deviationSDSCA = Summary of Diabetes Self-care Activities Questionnaire SSQ-6 = Short Form Social Support Questionnaire T = t-test WBQ-12 = Well-Being Questionnaire (12 items)

[] in quotes from focus groups indicates where spoke over each other

UKPDS = United Kingdom Prospective Diabetes Study

U = Mann-Whitney test

LIST OF PUBLICATIONS/ FUNDING/ PRESENTATIONS ARISING FROM THE RESEARCH

White, P., Smith, S.M., & O'Dowd, T. (in press). The role of the family in adult chronic illness: A review of the literature on type 2 diabetes. *Irish Journal of Psychology*.

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White, P., & Byrne, M. (2002, November). *Behaviour change and chronic illness: Can health psychology help?* Paper presented in the symposium 'Psychology and the Health Strategy. A healthy relationship? Annual conference of the Psychological Society of Ireland, Waterford, Ireland.

White, P., Smith, S.M, & O'Dowd, T. (2002, September). *Adults with diabetes. A family perspective*. Poster session presented at the Annual conference of the European Health Psychology Society, Lisbon, Portugal.

CHAPTER ONE – INTRODUCTION

It has been less than three decades since Engel (1977) first called for a move from a biomedical to a biopsychosocial approach to health and illness and in that time, there has been a major expansion and research in behavioural medicine and health psychology (Nichols, 2005). Significant advances have been made in understanding peoples' health cognitions and behaviours, through models such as the Health Belief Model (Becker & Rosenstock, 1984), Stages of Change Theory (Prochaska & DiClemente, 1984), Theory of Reasoned Action (Ajzen & Fishbein, 1980) and the Self-regulatory Model of Illness Representations (Leventhal, Nerenz & Steele, 1984). However, the area of chronic illness, lacks an overriding, holistic model of care to guide research and practice.

One of the major chronic illnesses of our time is diabetes, in particular type 2 diabetes, which is currently reaching epidemic proportions in both developed and developing countries (Wild, Roglic, Green, Sicree & King, 2004). There are two main types of diabetes. Type 1 diabetes (or insulin-dependent diabetes), which is usually diagnosed in childhood and requires insulin injections because the person is unable to produce insulin. Type 2 diabetes (non-insulin dependent diabetes) is typically diagnosed in people over 40 years of age (although current obesity levels have led to type 2 diabetes being diagnosed in children), and people can still produce insulin but often in insufficient amounts or with impaired functioning. The current escalation of type 2 diabetes and the growing recognition of the contribution that psychology and behavioural medicine can make to type 2 diabetes care provides the context for the current research study.

Diabetes is a chronic multi-system disorder that requires biomedical control through patient self-management and adherence to treatment recommendations. However, many patients do not optimally manage their illness and poor control can lead to blindness, amputation, renal failure and cardiovascular disease. Understanding the psychosocial determinants of good glycaemic control is the subject of this research. Unlike previous research in this area, which often

examines relationships amongst psychological and behavioural factors, the focus of this research is on taking a clinically important outcome of diabetes (Haemoglobin A_{1c}) and exploring it from a psychosocial perspective. This is not to imply that glycaemic control is the most important aspect of diabetes, but from a clinical and patient management perspective it is the goal if treatment. Haemoglobin A_{1c} (hereafter HbA_{1c}), is commonly used in diabetes research as it is a reliable biomedical indicator of blood glucose control and is important in the management of diabetes and in the prevention of long-term complications. It has now been established that when combined with blood pressure control, that a 0.9% absolute reduction in one of these indicators, HbA_{1c}, is associated with a 37% decrease in microvascular complications and a 21% risk reduction in any end point or death related to diabetes (Stratton et al., 2000, UKPDS 35). Such differences highlight the importance of improvements in glycaemic control and a reduction of cardiovascular risk factors such as blood pressure. Medications, eating patterns, food choices, blood glucose testing and exercise all influence glycaemic control and these in turn can all be influenced by psychosocial variables. There are also national and internationally accepted guidelines which identify what is good and what is poor glycaemic control, and these are clinically recognised as two distinct groups (St. Vincent Declaration, 1999).

Parallel to the growing awareness of psychosocial factors in health and illness has been a change in the very nature of illness. The illnesses of the twenty first century in the Western world are chronic in nature and the emphasis of health care is on disease management, the prevention of long-term complications and improved quality of life. There is a growing body of literature that demonstrates the central role of psychological factors in diabetes management (Delamater et al., 2001) and its relationship to improved diabetes outcomes (Glasgow et al., 2001). However, this has not translated into the routine inclusion of psychological care in the management of diabetes. This may be due partly to the lack of a comprehensive chronic illness model for diabetes care (Glasgow et al., 2001). Much of the research on psychological factors in diabetes has focused on specific psychological variables (e.g. social support, health beliefs, stress, personality) within a diabetes population and does not examine them from a glycaemic control perspective (Vallis, 1998). Given the importance of

maintaining good glycaemic control and understanding reasons for adherence and non-adherence, it is surprising that only two studies have been identified as taking this perspective (Peyrot & McMurray, 1985; Vallis, 1998). These studies took an extreme groups approach and examined differences in psychosocial factors of those in good control and poor control of their diabetes. They found distinct psychosocial factors (e.g. cognitive, emotional and coping) that discriminated between those in good and poor control of their diabetes. An extreme groups approach in psychological research is not common. It leads to the dichotomisation of an important variable which in turn, leads to a loss of power and sensitivity. However, this thesis deals with diabetes, which is a complex illness and in turn the relevant psychological literature is complex and confusing. It takes an original approach to examine what is most important in the treatment of diabetes from a patient and health care professional perspective – glycaemic control. Glycaemic control is both an *important* (if it increases the patient does not feel well and complications are more likely) and reliable (it is a biomedical indicator of blood glucose control over the previous three months and it has recognised guidelines and cut-off points) measure. Therefore in a bid to answer the clinically important question 'what is the difference between those in good and poor control?', an extreme groups approach was used. The advantages of taking this approach are that in a complex area of research, a direct and focused research question can be posed which is clinically applicable and acknowledges the goal of diabetes care.

In the pursuit to understand these individual differences, the social context within which people develop cognitions and behaviours needs to be considered. There is growing awareness that illnesses cannot be understood without taking account of literature on type 1 diabetes there is a recognition of the burden and impact of diabetes on the family (Delameter et al., 2001). This has not translated into the research on type 2 diabetes where little attention has been given to the family of adults with diabetes (Hixenbaugh & Warren, 1998). Research on adults with diabetes has largely been conducted in isolation from their family and social environments.

The aim of this research is to examine the psychosocial differences between those in good control and poor control of their diabetes. The terms 'good' and 'poor' control are used in this research to describe glycaemic control, more specifically HbA_{1c}. In this thesis, common guidelines for diabetes care have been followed and good control refers to people with diabetes who have a HbA_{1c} below 7% and poor control to those whose HbA_{1c} is over 8.5% (St. Vincent Declaration, 1999). Although the terms 'good' and 'poor' are far from ideal as a form of labelling people, they are used solely as a method of distinguishing between the two groups of blood glucose control.

Triangulation of methods (qualitative and quantitative) and participants (people with Type 2 diabetes and their family members) was used. This study took a two-stage approach and will be described accordingly. The first stage was a qualitative exploration of the psychosocial factors of diabetes using a grounded theory framework. The themes and theories gained from this first stage were used to further develop the research question and determine the most appropriate variables to measure.

The research is presented in chronological order. Chapter two details diabetes, its management and issues in diabetes care, and gives a brief review of the literature on chronic illness, diabetes and families. This evidence highlighted the need for a preliminary exploratory phase of the research. Using qualitative methods the illness beliefs of those with diabetes and their family members were explored. The results of this stage provided the information to develop a larger quantitative study. Chapter three describes the relevant literature and introduces the theory from the qualitative analysis as the theoretical framework for the second phase of the research. One aspect within this theory, illness cognitions, proved to be of particular importance in the first exploratory phase and is addressed in detail using Leventhal, Meyer and Nerenz's (1980) Self-Regulatory Model. Chapter four presents the hypotheses for the quantitative study and its methodology is outlined in chapter five. The results of the quantitative research are detailed in chapter six and are discussed along with the qualitative results in chapter seven in light of previous research and future implications.

The results of this study contribute to the understanding of the psychosocial variables that impact on diabetes management. The combination of qualitative and quantitative methodologies have complemented each other to allow a truer picture of the psychological aspects of diabetes to emerge. The inclusion of family members provides a unique insight into the contextual variables that influence the management of diabetes.

CHAPTER TWO - EXPLORATORY PHASE

2.1 Introduction

There is increasing recognition of the crucial role that families play in the adaptation to a chronic illness (Barth, 2000). In the case of diabetes, family members play a direct (e.g. through daily activities such as shopping and cooking) and an indirect role (e.g. through lack of support of lifestyle changes) in the adherence to recommended regimes. This central role, coupled with the recognised hereditary component of diabetes (two-to-fourfold risk increase) (Pierce, Keen & Bradley, 1995) places the family in a crucial position for understanding how people cope with diabetes. However, little is known about what family members think and feel about type 2 diabetes (Hixenbaugh & Warren, 1998).

This stage of the research was exploratory in nature and so, a full discussion of the literature on the psychosocial factors in diabetes is not presented at this point. Rather, the literature review reflects the investigative and early stage of the research, where a briefer review of the literature took place. This chapter begins with an overview of diabetes, detailing types of diabetes, risk factors and possible complications. In order to understand the current context of diabetes research, diabetes management, current guidelines for diabetes care and the role of diabetes in the health services are detailed. This is followed by a brief description of the psychological factors which play a role in the control of diabetes, focusing specifically on the role of the family in diabetes management. The use of qualitative research in diabetes is reviewed and the exploratory qualitative research that was conducted detailed. Finally, the results are presented and a discussion of how the results of this research lead to the development and refinement of the research question.

2.2 Overview of Diabetes Mellitus

2.2.1 Definition and extent of illness

Diabetes is a chronic, progressive, multi-system illness, with complications that are largely preventable. It results from insufficient insulin production or the presence of factors that oppose the action of insulin. The result of this is an increase in the blood

glucose concentration (Watkins, 2003). Diabetes is not a new illness and references to it have been found in ancient Egyptian papyrus but it is an illness whose worldwide rise is now being referred to as 'exploding' and 'epidemic' (Hopkins Tanne 2001; King, Aubert & Herman, 1998; Kopelman & Hitman, 1998). The World Health Organisation (2002) have estimated that in 2000, the number of people world-wide with diabetes was 177 million – this is set to rise to over 300 million by 2025. It is now considered to be a major public health problem (Amos, McCarthy & Jimmet, 1997; Venkat Narayan, Gregg, Fagot-Campagna, Engelgau & Vinicor, 2000). The alarming rise in diabetes, in particular type 2 diabetes, is attributed to genetic predisposition, ageing populations and to lifestyle changes which have increased obesity levels and decreased physical activity (Kopelman & Hitman, 1998). Calculating accurate prevalence rates for diabetes is difficult considering the number of undiagnosed cases that exist at any given time. Figures from the United Kingdom estimate that more than three per cent of the total population have diabetes and that a further three per cent are undiagnosed. This figure is considerably higher for those over 65 years and for Afro-Caribbean and Asian people (Watkins, 2003).

Currently in Ireland there are approximately 200,000 people with diabetes, and a further 200,000 who are undiagnosed. (Diabetes Federation of Ireland, Diabetes Care Report, 2002). The continued escalation of new diabetes cases poses a serious threat to the health of individuals and the demands placed upon health care services. The International Diabetes Federation (2004) predicted that diabetes will be one of the world's biggest environmental disasters of this century.

2.2.2 Diagnosis

A patient's clinical presentation before diagnosis can include symptoms such as tiredness, thirst, weight loss, deteriorating vision or painful neuropathy. Such varied and often vague symptoms mean that diagnosis can often be missed and must be confirmed by blood glucose measurements. Guidelines for establishing such a diagnosis have been established e.g. WHO Report (1997).

2.2.3 Types of diabetes

There are two main types of diabetes. Type 1 accounts for only 5-15% of all diabetes, it is usually diagnosed in childhood and insulin injection is necessary for control as the person

is unable to produce any insulin. With type 2 (which is also known as late-onset or non-insulin dependent diabetes), people tend to produce insulin but in insufficient amounts or with impaired functioning. People who develop type 2 diabetes tend to be over 40 years of age (although there are increasing reports of type 2 diabetes in children (Fagot-Campagna, Narayan & Imperatore, 2001)), and can be overweight and/or have a family history of diabetes. It is the exponential rise in this type of diabetes that is the main cause for concern. Its relationship with increasing obesity levels and sedentary lifestyles means that behavioural aspects of type 2 diabetes play an important role in both its onset and management.

2.2.4 Risk factors

Watkins (2003) estimates that as many as 98% of people with diabetes have had no specific cause of their diabetes identified. Several contributory risk factors have been established. A summary of risk factors from several organisations (American Diabetes Association, Diabetes UK and the Irish College of General Practitioners) is presented below:

- (i) Overweight. Obesity is the most common cause of insulin resistance
- (ii) Physical inactivity
- (iii) Increasing age
- (iv) Hereditary
- (v) Of Asian or African-Caribbean ethnic origin
- (vi) History of gestational diabetes
- (vii) History of baby over four kilos
- (viii) Impaired Glucose Tolerance

2.2.5 Diabetes and obesity

The link between the rise in obesity the rise in diabetes has been brought to the forefront, not only within the realm of scientific research but through the media, public health policies and government reports and the term 'diabesity' has emerged. Obesity is strongly and causally linked to type 2 diabetes (Pinkney, 2002). It is ironic that in a time of societal obsession with health, food and diet, that there have never been higher levels of obesity and diabetes. In Ireland, results from the Irish Health Promotion Unit's Slán

survey (2003), show that 41.9% of men are overweight and a further 14.4% are obese. The figures are slightly lower for women with 26.5% overweight and 11.8% obese. Since the previous Slán survey in 1998, levels of obesity have increased for males and females, in all social classes and across all social class groupings. A report from 2001 stated that "obesity levels increased by 67 per cent between 1990 and 2000, and more than 20 per cent of men and 16 per cent of women are now obese" (Irish Universities Nutrition Alliance, 2001)

What is particularly alarming about the rise in obesity and the subsequent rise in type 2 diabetes is that a disease that was classified as 'mature-onset' is now being diagnosed in children. There are some United States prevalence statistics, estimating that type 2 diabetes accounts for 8%-45% of newly diagnosed diabetes in children and adolescents. (Fagot-Campagna et al., 2001). However, without epidemiological data, these figures are thought to be an underestimate. There is a need for international, multi-centre research to establish standardised protocols and increase epidemiological knowledge to provide optimal care for this new patient group (Fagot-Campagna et al., 2001).

This impending epidemic is preventable (Venkat-Narayan et al., 2000). The key to controlling it is through lifestyle changes and weight loss (Pinkney, 2002). Several population studies have demonstrated that lifestyle change and weight loss for those at risk of developing diabetes can dramatically reduce the chances (by up to 58%) of developing diabetes (Diabetes Prevention Program Research Group, 2002; Tuomilehto et al., 2001). These large scale population studies are however rare and greater efforts to understand the determinants and ways of intervening are needed if the potential numbers developing diabetes is to decrease (Crawford, 2002).

2.2.6 Complications

The importance of stemming the rise in diabetes becomes apparent on examination of the complications that arise from poor control of the illness. Not only are people with diabetes at a five-fold increased risk of heart disease and a three-fold increase of stroke compared to those without the illness, diabetes is the main cause of end-stage renal disease and in people of working age, diabetes is the leading cause of blindness. These complications are preventable. The United Kingdom Prospective Diabetes Study (Stratton et al., UKPDS, 2000) has demonstrated that intensive control of type 2 diabetes and blood

pressure results in fewer diabetes related deaths, lower incidence of myocardial infarction and a substantial decrease in microvascular complications. They conclude that any reduction in HbA_{1c} is likely to be associated with a reduction in the risk of complications (Stratton et al., 2000, UKPDS). Currently in Ireland, fifty nine per cent of the health budget allocated to diabetes goes on treating these complications (Diabetes Federation of Ireland, 2002).

2.2.6.1 Macrovascular

'The major complications of diabetes are heart attack and stroke, not retinopathy, nephropathy and neuropathy' (Ginsberg, 2001, p. 194). It is estimated that between 50% to 75% of deaths in patients with diabetes are cardiovascular deaths (Hopkins Tanne, 2001). People with diabetes have a two-to four-fold risk of coronary, cerebrovascular and peripheral vascular disease compared with people who do not have the illness (Cardiovascular Health Strategy Group 1999). This increased risk is caused directly because hyperglycaemia is an independent risk factor for cardiovascular disease and indirectly because diabetes and cardiovascular disease share many of the same lifestyle risk factors. The effective management of blood pressure has been shown to reduce the risk of heart failure, strokes and related mortality (UKPDS, 1988). Such is the increased risk of cardiovascular disease that people with diabetes are now considered to be an important group for risk factor modification (Cardiovascular Health Strategy Group 1999).

2.2.6.2 *Microvascular – retinopathy, nephropathy and neuropathy*

As Watkins (2003) noted, blindness is one of the most feared complications but also one of the most preventable complications of diabetes. Unfortunately, by the time Type 2 diabetes is diagnosed, approximately twenty five percent of patients will have established background retinopathy. Kidney disease is a major complication of diabetes and the number of people with diabetic nephropathy is rising (Harvey, 2002). It is recognised in the United States and the United Kingdom as the most common cause of end stage renal failure (National Health Service Centre for Reviews and Dissemination, Effective Health Care, 2000). Damage to the peripheral nerves is a result of continued high blood glucose levels. It can effect sensation, automatic body functions and mobility. The feet in particular become susceptible to ulceration and infection, which can lead to amputation.

Diabetes mellitus is a complex illness. It is a chronic metabolic disorder that can lead to both macrovascular and microvascular complications. Diabetes care therefore ranges from monitoring blood glucose levels and diet to regular eye, blood pressure, foot and weight examination.

2.3 Patient Management of Diabetes

Managing diabetes means adapting to a complex set of long-term behaviours. Once diagnosed, the patient will quickly have to take on many of the self-care behaviours of diabetes management. They will learn how to take their own capillary samples by finger prick and interpret the results, along with new knowledge on diet, exercise, smoking, alcohol intake and medication. Hunt, Pugh and Valenzuela (1998) reported in their qualitative study of people with type 2 diabetes that self-care behaviours are not based on a single discrete set of decisions but are customised on an ongoing basis depending on priorities, social and family responsibilities, resources and level of autonomy. This means that optimal diabetes care must take cognisance of contextual and fluctuating nature of diabetes management.

The diabetes treatment regimen for most people with type 2 diabetes includes:

1) Diet

Current guidelines for a diabetes diet are normal healthy eating with an emphasis on the elimination of sugar, glucose and sucrose and the promotion of fibre, fresh fruit and vegetables and lower fat foods. As Watkins (2003) asserts, 'healthy eating is the cornerstone of diabetic treatment' (p. 11).

2) Exercise

Exercise is dependent upon the patient's age and ability but in general follows the guidelines of regular exercise consisting of mild exercise four or more times per week and/or moderate exercise three or more times per week and/or strenuous exercise three or more times per week (Health Promotion Unit, National Health & Lifestyles Survey, 2003).

3) Blood glucose monitoring

One of the new skills that a person with diabetes must master is self-monitoring of blood glucose levels. The correct monitoring, profiling and interpretation of results can give the patient and their health care professionals valuable feedback on blood glucose control.

4) Insulin injections and medication

All people with type 1 diabetes must inject insulin on a regular basis. For those with type 2 diabetes, the first level of intervention is by diet and lifestyle change alone, if this does not produce satisfactory results after a period of approximately three months then oral hypoglycaemic agents are given. Every year, approximately six percent of non-obese and two per cent of obese type 2 patients will need to start insulin as their diabetes control is sufficiently poor. Approximately 30% of all type 2 diabetes patients are treated with insulin.

2.3.1 Developments in patient self-management

Since Lorig and Holman's (1989) initial study with arthritis patients, there has been a change in the approach to patient care to what is termed a 'patient empowerment' approach. Lorig & Holman's (1989) research moved away from traditional models of educating patients with arthritis and through trained lay people, taught patients skills to manage their chronic illness on a daily basis. The user-led Chronic Disease Self-Managemement Programme (CDSMP) that they developed included: cognitive symptom management, exercise, nutrition, problem solving and communicating with health professionals. This approach sees the patient as the expert on their illness and they are considered an important member of the health care team. No longer is the patient considered a passive recipient of care – they are now viewed as experts on their condition and can become active participants in decisions about their treatment. This move towards patient involvement is reflected in the approach now taken in the United Kingdom (UK) towards chronic disease management. In the UK, a Department of Health document entitled 'The Expert Patient' (2001) acknowledges that the patient themselves have been an untapped resource for too long and acknowledge the benefits of patient inclusion and self-management. It has heralded a move away from more the more traditional biomedical approach with the patient as a passive recipient of care, to one where the patient is the expert on their condition and empowered by health care professionals to manage the demands of their illness. The importance given to this patient self-management approach cannot be over-emphasised. In the UK, the National Service Framework for Diabetes Standards has referred to self-management as the cornerstone of effective diabetes care. The information that patients were given about their illness as part of their clinical care has evolved into more structured patient self-management programmes including both skills and information. This reflects a change in responsibility for the daily management

of chronic illness from the health care professional to the individual with the illness (Newman, Mulligan & Steed, 2001).

The International Diabetes Federation also uses the term 'patient empowerment'. They define it as having three elements: knowledge, behavioural skills and self-responsibility. They refer to empowerment as being in command of one's life and as a continuing, dynamic process, which is acquired through education. This move towards patient empowerment in the management of diabetes has been extensively researched and developed in America (e.g. Anderson, Funnell, Barr, Dedrick & Davis, 1991; Anderson et al. 1995). It has been shown through an RCT of a patient empowerment programme that not only is patient empowerment a successful method of delivering self-management education and addressing psychosocial issues of diabetes but it also led to a significant reduction in glycated haemoglobin levels (Anderson et al., 1995). In fact, Norris, Lau, Jay Smith, Schmid, and Engelgau (2002) in their meta-analysis of 31 studies on the effect of self-management education on glycaemic control found that those receiving selfmanagement education had improved glycaemic control in the short-term. Those who received follow-up support had better glycaemic control in the long-term and the more contact the patient had during the intervention the more significant the improvement, showing the importance self-management training and ongoing support on glycaemic control. Given the positive outcomes of patient education programmes, the key characteristics of an effective diabetes management programme are summarised in Table 2.1

The last two decades have seen the development of many interventions to improve patients' management of their diabetes in order to avoid or delay the onset of diabetes-related complications (Steed, Cooke & Newman, 2003). The extent to which interventions lead to improvements in self-management and well-being is unclear, with many studies reporting conflicting results. Whilst some interventions have shown improvements in psychological well-being (Griva, Myers & Newman, 2000), glycaemic control (Norris, Engelgau, & Narayan, 2001) and lifestyle behaviours (Clark, Hampson, Avery & Simpson, 2004), several systematic reviews of psychological interventions in diabetes (Hampson et al., 2001; Ismail, Winkley & Rabe-Hesketh, 2004; Steed et al., 2003), have highlighted variance in the findings and methodological inconsistencies.

Table 2.1. Key Characteristics of an Effective Diabetes Management Programme (Glasgow et al. 2001)

- 1 Use a population based systems approach
- 2 Involve proactive contacts, surveillance and reminders
- Incorporate the patient as an active participant and use patient-centres collaborative goal setting
- 4 Implement consistent follow-up procedures
- 5 Assign large responsibilities to non-physican team members
- 6 Plan office visits and focus on outcomes and outcome-related processes
- 7 Use clinical information systems, such as diabetes registers and electronic medical records to improve quality of care

Some of the difficulties in interpreting the results from the self-management interventions are due to the lack of clearly specified theoretical frameworks, the lack of sufficient power and some studies are not controlled, the variety of interventions used to improve 'self-management' and the lack of any information on the components of interventions of the research, making it difficult for other researchers to replicate (see Box 2.1).

Box 2.1 Variations in Details of Interventions to Improve Diabetes Self-management

Type: Individual or Group

Style: Didactic or Collaborative Number of Contact Hours: 1-28

Location: Clinic-based, Home visits, Telephone, Computer programmes

Content: information about diet, weight-loss programme, group support, goal setting,

problem solving, cognitive-behaviour therapy, psychotherapy

2.4 Diabetes Care

2.4.1 Guidelines and recommendations

2.4.1.1International and European

One of the guiding influences on global diabetes policy and strategies is the St. Vincent Declaration of 1989. This is a document that was unanimously agreed by major stakeholders in diabetes, representing the World Health Organisation Regional Office for

Europe, and the International Diabetes Federation, European Region. It is a programme for strategic action to reduce the human and economic burden of diabetes in Europe (see Box 2.2).

Box 2.2 Ten Target Areas of the St. Vincent Declaration (1989)

- 1. Improving the detection and control of diabetes;
- 2. Raising public awareness of the opportunities of preventing diabetes and its complications;
- 3. Promoting self-care for people with diabetes;
- 4. Ensuring that care of children with diabetes is provided by specialist teams, and that their families are given the necessary support;
- 5. Supporting centres of excellence in diabetes care, education and research;
- 6. Promoting the independence of people with diabetes;
- 7. Removing discrimination against people with diabetes;
- 8. Reducing diabetes complications such as blindness, kidney disease and amputations;
- 9. Setting up information systems to enable health services to monitor and control the quality of healthcare
- 10. Promoting international collaboration.

2.4.1.2 United Kingdom

More recently in the United Kingdom, diabetes care has been incorporated in a National Service Framework. The first part of this strategy set out twelve new standards for improved diabetes care and takes a patient focused approach to diabetes care. There has been a follow-up publication of a delivery strategy describing how these standards are to be put in place. These documents have been developed to ensure that diabetes is prioritised, that best practice becomes the norm and that a comprehensive plan for the future of diabetes care is put in place. Reflected within this is the NHS's 'expert patient' approach (Department of Health, UK, 2001) which is highlighted in Standard Three 'empowering people with diabetes'.

2.4.1.3 Ireland

In Ireland, there are national guidelines from the Irish College of General Practitioners for the provision of care to people with diabetes. The most recent health strategy (Department of Health and Children, 2001) has just one mention of diabetes within the context of chronic disease management. It states that:

"the continuous and co-ordinated care to address the needs of people with particular chronic diseases such as asthma and diabetes is best provided within the primary care system. Patients with chronic illness must be supported and facilitated to participate in planned regular interactions with health-care providers and assisted in becoming the ultimate managers of their own health" (p. 71).

Despite the government recognition that diabetes is an important public health problem (Department of Health's Health Promotion Strategy, 1995), there has been no attempt to substantially improve the quality of life for those with diabetes. The report coordinated by the Diabetes Federation of Ireland and compiled by representatives of health professionals working in the diabetes field, has documented the severity of the current situation and the expenditure and services that need to be put in place to allow all of those with diabetes to have access to a quality health service (Diabetes Federation of Ireland, 2002). There is a need for a nationwide strategy on the prevention and optimal management of diabetes. In March 2004, a taskforce on obesity was set up in Ireland to address the impact of current obesity trends, and to set out a strategic framework for decreasing obesity levels in Ireland. Diabetes is indirectly included in this as one of the diseases associated with obesity.

2.4.2 Diabetes and the health services

This lack of such a comprehensive strategy means that diabetes care has developed in a piecemeal fashion with few areas providing shared care schemes and other areas having the advantage of specialist diabetes centres nearby. This geographical variation in the level of service provision at both secondary and primary care level, means that there is an important minority of people with diabetes in Ireland, who receive neither generalist nor specialist diabetes care. A further feature of health care in Ireland is its two-tier health system. The Irish health care system has both public and private institutions and funders (O'Hara, 1998). Nationally, 29.6% of the population are members of the General Medical Scheme, based on means-testing of income and have all of their health services free of charge (Report of General Medical Services Payments Board, 2003). The rest of the population have the option of public health care in hospitals but must pay for their primary care needs. This means that that patients without medical cards must pay for continuous and preventative health care thus providing a disincentive for primary diabetes care management.

As previously mentioned, the Health Strategy (2001) recognises primary care as the setting most suited to the long-term care of those with chronic illness. The research in this area has focused on improving organisational factors (such as structured patient care, audits and practice characteristics), improving the doctor-patient relationship (through patient-centred care and communication techniques) or both. The importance of organisational factors was shown in Pringle et al.'s (1993) descriptive study of the influences on glycaemic control. They analysed a number of patient, doctor, practice and delivery of care factors and found that control of diabetes was related to the organisation and process of care, with larger, better equipped practices with dietetic support significantly related to better glycaemic control. Improved care for diabetes was found to be based in larger practices and those where a good team climate was reported (Campbell et al., 2001) but there were large variations reported in the quality of clinical care. This was a retrospective study with a low patient response rate (38%) and does not inform us of the key variables that can influence diabetes care. A reduction in diabetes risk factors was found in a Danish RCT of structured personal care (de Fine Olivarius, Beck-Nielsen, Helms Andreasen, Horder & Pedersen, 2001). Characteristics of this intervention were that patients in the intervention group received regular follow-up and individualised goal setting from diagnosis until a six year follow-up. A meta-analysis of RCT's (Griffin, 1998), identified structured care as a key variable in improved diabetes care. Practices with a computerised central recall system achieved standards of care equal to or better than hospital care.

It is difficult to assess how much of the reported improvements in diabetes care are due to the changed organisational factors and how much is due to the doctor's own style. One way of addressing this is to examine the type of patient care that is delivered. Pill, Stott, Rollnick and Rees (1998) carried out a randomised control trial of 252 patients with type 2 diabetes to evaluate the effect of training in a patient-centred intervention for General Practitioners and practice nurses on clinical and psychological outcomes. The intervention proved acceptable to professionals who adopted it initially but there were no significant clinical improvements for the patients in the experimental group. This study highlighted a recurring theme within diabetes care, that of sustaining behaviour change. However, in this study it was the behaviour change of the health care professionals delivering the service that was not maintained, as two years later, only 19% of professionals were

continuing with the system and detailed follow-up analyses of changes in outcomes were not possible. Alongside this, patient-centredness was not measured, making it difficult to accurately assess the success of the intervention. The complexities of improving patient care in diabetes was highlighted in the results of Kinmonth, Woodcock, Griffin, Spiegal & Campbell's (1998) RCT of patient centred care. They measured both physiological and psychological outcomes and found that patients in the intervention group reported improved well-being, treatment satisfaction and communication. There was no decrease in glycaemic control but cardiovascular risk factors and weight was higher in intervention patients who also had less knowledge about their diabetes. The authors conclude that focusing attention on delivering patient-centred care may shift attention away from other illness management factors. Similar findings were also found in an RCT of shared care where significant improvements were found in psychosocial outcomes for patients but there was no improvement in biological outcomes (Smith et al., 2003). A systematic review of interventions to improve diabetes management found that complex interventions and organisational factors, while effective in improving patient care, do not appear to effect patient outcomes (Renders et al., 2001). However, they reported that combining these elements with patient education and including nurses in patient care did lead to improved patient outcomes.

The inconsistencies often found in research on patient-centred care were reviewed in an effort to understand if there are different concepts of patient-centredness being used and how they impact on illness outcomes (Michie, Miles & Weinman, 2002). They identified 30 studies of patient-centred care, which fell into two categories. Firstly, patient-centredness where the health professional takes the patient's perspective and patients belief's are discussed, and secondly a more active approach where the patient is encouraged to take control of the management of their illness. It is this second approach that was found to be associated with improved health outcomes. This review suggests that different types of communication lead to different patient outcomes. For example, the authors postulate that working from the patient's perspective may increase patient satisfaction but not adherence, quality of life or health outcomes, as these may be influenced by other factors such as anxiety and material circumstances. Interestingly, they also note that self-reported health and quality of life may not change due to differences in how people assess their health when they feel more in control (Michie et al., 2002). Given that many interventions do not define or measure patient-centredness, it is difficult to

conclude which elements of patient care will have the greatest influence on patient outcomes.

2.4.3 Future of diabetes care

Looking to the future of diabetes care, there are consistent findings that well-structured primary care is an effective way of delivering diabetes care (Griffin, 1998). There is also a recognition of the complexities of diabetes care and the need to address psychosocial factors and behaviour change (Griffin, 2001; Kinmonth, 1993). There has been a call to move beyond an emphasis on registration, recall and regular review to take a broader perspective when addressing diabetes care and include patient, practitioner and service factors (Griffin, 2001).

Gonder-Frederick, Cox & Ritterband, (2002) not only recognise the importance of psychosocial and behavioural factors in diabetes care (e.g. personal health beliefs, coping, personality, distress, social support, interactions with health care professionals and cultural factors) but state that they have become the cornerstone to successful diabetes treatment. Many of the problems that currently exist in diabetes care are not due to patient or health care provider factors (Brown, 2002; Glasgow et al., 2001). They conclude that these problems exist because of the current acute illness model of care and will persist unless there is a move to a chronic disease model and the treatment of diabetes as an illness with psychological, social and behavioural factors as well as medical outcomes. The issue of an acute/chronic model of care in diabetes has not been addressed in detail in the literature. What needs to be determined is the appropriate care model to improve both biological and psychosocial outcomes (Smith et al., 2003).

2.5 Complexity of Diabetes Research

It can be concluded that diabetes mellitus is a complex illness. For the person with diabetes, its management involves the adaptation to and adoption of different behaviours from testing blood sugar levels, changing diet, keeping regular appointments with health care professionals to adherence to medication. In engaging in behavioural diabetes research this complex illness is coupled with the inherent difficulties of behavioural research, (Peyrot, 2003) such as individual differences, changing behaviours and a lack of consistency within health behaviours. Given the complexity in behavioural diabetes

research it becomes increasingly challenging to determine the factors that influence glycaemic control relationships among these factors.

2.6 Psychological Factors and Control of Diabetes

The importance of behaviour change to improve outcomes in diabetes has led to the growing recognition of the contribution that psychology and behavioural medicine can make to diabetes care. Psychological consequences of a diagnosis of diabetes have been well researched and documented (Gonder-Frederick et al., 2002) and the evidence that now exists demonstrates that psychosocial factors are central to diabetes management (Delamater et al., 2001). For example, there is a consistent finding that those diagnosed with diabetes have increased levels of depression when compared to those without the illness (DeGroot, Anderson, Freedland, Clouse & Lustman, 2001). Understanding how the psychosocial and behavioural factors influence self-care has become the key to successful diabetes treatment (Gonder-Frederick et al., 2002).

2.6.1 Families and Diabetes

The management of diabetes permeates its way into all dimensions of life (e.g. work, social, relationships), affecting the people who exist within these dimensions. More recently in type 2 diabetes research, a socio-ecological approach has been taken by some researchers (e.g. Fisher et al., 2002) and it has been recognised that the successful management of diabetes depends not only on the person with the illness but on their family, friends, work colleagues and society (DAWN Study 2002; Glasgow et al., 2001). However, little attention has been given to the importance of the family in adult diabetes (Hixenbaugh & Warren, 1998) and research on families and diabetes management is limited (Fisher et al., 1998; Gonder-Frederick et al., 2002). As Anderson and Robins (1998) stated, the choices people make can be better understood if we know the characteristics of the environment they live in such as the people in their lives who are affected by the diagnosis of diabetes. It is important therefore, that the people close to the person with diabetes are accurately informed and supported so that they can support them. In 2001, Hiscock, Legard and Snape, conducted a large-scale qualitative study of NHS

diabetes service users to help inform the Diabetes National Service Framework¹. One of their findings was that people with diabetes look for information for their partners and those caring for them because "the adjustments related to living with diabetes affect(ed) both those with diabetes and the people with whom they share their lives" (p. 40).

The importance of social support for family members has been well documented in the research with children and adolescents with type 1 diabetes (Glasgow, 1994). There has been substantially less research on the role of family social support for adults with type 2 diabetes (Hixenbaugh & Warren, 1998). Preliminary data indicate that the diabetesspecific measures of family support are stronger predictors of diabetes self-care than are the more global measures of family functioning and that positive supportive family behaviours and negative non-supportive family behaviours are separate dimensions (Glasgow & Toobert, 1988). In their research with 127 adults with type 2 diabetes, Glasgow and Toobert (1988) consistently found that measuring regimen specific family support (i.e. in relation to diet, exercise, medication and blood glucose monitoring), differentiated those who were low, medium or high adherers to their regimen than using global support measures. These researchers in 1988 were discussing the usefulness of investigating the social context in which diabetes care takes place. The research in this area has tended to focus on factors such as family functioning and interactions with type 1 patients (Schaefer, McCaul & Glasgow, 1986). Ell (1996) proposes taking this interactional, family systems approach to guiding research on social support in chronic illness. By understanding the intra-family processes and interactions that take place when a family member has a chronic illness, the support needs of each individual within the family are highlighted and the impact of the illness can be addressed. What also needs to be established however is the type (instrumental, emotional, informational) and level of support that is required by those family members/partners to encourage the effective management of illness. Cox and Gonder-Frederick (1992) go further to state that support from non-family members of one's social network has seldom been investigated. It is unclear what role friends and work colleagues play in supporting the person with diabetes. More recently, the importance of the support of family members has been acknowledged in findings from a large international psychosocial diabetes research study

¹ Department of Health in United Kingdom set up the National Standards Framework to identify key interventions for a defined service or care group, and to put strategies in place to support their implementation

(Diabetes Attitudes, Wishes and Needs (DAWN) Study, 2002). These findings, from more than 5,000 adults with type 1 and type 2 diabetes highlighted the importance of family members (as well as friends and colleagues) in improving the patient's sense of well-being. The study also emphasised the importance of family social support in the achievement of effective self-management. This was crucial in helping with dietary demands, reminders to take medication and keep appointments, and support in continuing exercise programmes. However, there are currently few studies that have investigated the relationship of the family environment for adults with diabetes (Trief, Grant, Elbert & Weinstock, 1998).

2.6.2 Theories of family and illness

The Biopsychosocial Model (Engel, 1977), although not formally a model, has become accepted and embedded within health psychology literature (Stam, 2004). It does however, provide a framework for understanding the processes that underpin health and illness (McDermott, 2002). As Nicasso & Smith (1996) state, "the biopsychosocial model provides a broad conceptual framework – rather than a unifying theory – for understanding chronic illness and its management" (p. 5).

Incorporating general systems theory, the biopsychosocial model is organised in a hierarchy of subsystems of increasing complexity (see Figure 2.1). As in systems theory each subsystem can exert influence upwards or downwards and equally be influenced by those units. The theory stems from the biological sciences and incorporates the principles of organisation and interrelatedness. Drawing on Hoffman's (1981) work, Kazak (1989) explains that the central beliefs about systems theory are that: (a) the systems are composed of interrelated parts, (b) change in one part is associated with change in the all others, (c) systems maintain a regular state of homeostasis and (d) systems maintain a balance of periods of change and stability. Just as diabetes or any chronic illness brings about changes at a physiological level within the individual, it also exerts an influence on the relationships of that individual and their interactions with their environment. The usefulness of adapting the systems model to families where a member has a chronic illness has been demonstrated (Kazak, 1989). Although Kazak's overview of the model describes chronically ill children, the principles of systems theory still hold for adults and their families. The illness occurs within a hierarchy of systems, not only is the family affected by the illness but their responses (which may all differ) in turn effect the person with the illness and in many cases the course of the illness itself (Patterson, 1991; Peyrot,

McMurray & Hedges, 1988). As Patterson and Garwick (1994) assert 'chronic illness happens to a family...not just an individual'. When families are well-adapted, they can achieve a balance through the use of their resources and coping behaviours to adapt to the changing demands of the illness. When these illness needs are balanced with other family needs, there is a more successful adjustment to the illness (Kazak, 1989; Patterson & Garwick, 1994).

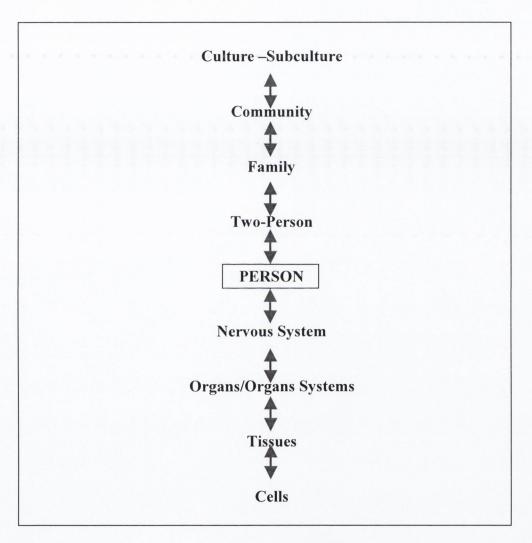


Figure 2.1. Schema of the interactional nature of systems.

From 'Clinical Application of the Biopsychosocial Model' by G.L. Engel 1980, American Journal of Psychiatry, 137, p537. Copyright 1980 by the American Psychiatric Association.

Problems in diabetes care attributed to patient self-management or health professionals are rarely caused at such an individual level. Such problems need to be addressed at a systems level (Glasgow et al., 2001). Understanding health-related behaviour is best achieved from a context and situational point of view and using a framework from the outset that embodies this, such as systems theory, allows for the inclusion of social

processes, such as the impact on families (Eiser, 1996; Roberts, Towell & Golding, 2001).

2.6.3 Marital relationships

There has been little attention given to the impact of type 2 diabetes on marital relationships (Peyrot et al., 1988; Trief, Himes, Orendorff & Weinstock, 2001). One exception is Trief et al.'s (2001) research, which indicated a relationship between marital quality and adaptation to diabetes. Their research explored the relationship between the marital relationship domains of intimacy and adjustment, glycemic control and psychosocial adaptation to diabetes. More specifically, they found that better marital satisfaction was associated with less impact of diabetes, higher satisfaction and better quality of life for the individual with diabetes. Higher levels of marital intimacy were associated with better quality of life in general and in relation to diabetes. Trief et al. (2001) state that the marital relationship may be more powerful than general family support in terms of its impact on glycaemic control. This study was based on insulintreated adults with both type 1 and type 2 diabetes, which the authors acknowledge provides unique challenges to couples, however it does not allow for the results to be generalised to the majority of those with type 2 diabetes, who do not take insulin. Similarly, Peyrot et al. (1988) investigated marital adjustment in insulin-treated adults. Using qualitative and quantitative methods, they found that patient and spouse illness perceptions were not as closely related as expected, highlighting the different responses to adjustment to an illness. There were differences in perceived severity, with spouses focusing on possible/actual complications rather than level of diabetes control. Spouse's knowledge was negatively related to diabetes adjustment because of its association with being more involved in the treatment – marital satisfaction was higher when spouse's involvement in diabetes care was lower. The findings of this study highlighted the complexity of the family's response to chronic illness and the importance of understanding the interpersonal processes that take place within a family (Peyrot et al., 1998). From her experience as a couple and family psychotherapist, Josse (2003) identified nine key areas that impact on couples when one has diabetes. They are: ownership of the problem, boundary issues, patient-caregiver roles, togethernessseparateness, pace of adaptation, gender, sexuality, belief systems and life cycle developments. This data was presented at a workshop (Diabetes UK, Psychosocial

Conference, 2003) and demonstrates the wide-ranging impact that a diagnosis of diabetes can have on a couple's relationship.

2.7 Qualitative Research and Chronic Illness

Alongside this growing realisation of the importance of understanding chronic illness from the patient's perspective is the concomitant rise in qualitative research.

Although health psychology has been one of the last disciplines to join the field of qualitative health research, it has made considerable strides over the past decade (Murray & Chamberlain, 1998). For example, qualitative methods have been used to explore symptom perceptions, adjustment to chronic illness and the barriers to uptake of services (Gallagher & MacLachlan, 2001; Tod et al. 2001). What is common from these and other qualitative studies with people with chronic illness is the depth of understanding of having a chronic illness that is gained. The results of these studies can make an important contribution to improving existing services and practice as they give a true insight into life with a chronic illness.

2.7.1 Qualitative Research and Diabetes

Anderson and Robins (1998) acknowledged that in their attempts to investigate the perceptions of people with diabetes from a solely quantitative survey method approach they lost out on capturing the richness and understanding of the patient's experience. This reflects the difficulties in general of research the complexities of adapting to chronic illness. Qualitative research has been shown to be advantageous, particularly when cultural and contextual variables play a role, as is often the case with diabetes control (e.g. Greenhalgh, Helman & Chowdhury 1998; Maillet, D'Eramo Melkus & Spollet (1996); Sissons Joshi (1995) Thompson & Gifford (2000)). Each of these studies highlights the value of taking a qualitative approach to understanding the meanings and explanations that different cultural groups attribute to their diabetes. They also contribute to the development of culturally appropriate patient education and health promotion programmes. In Greenhalgh et al.'s (1998) study, diabetes health beliefs and behaviours specific to the Bangladeshi culture were identified such as the importance given to structural and material factors in improving health, the high regard for lay opinions on diabetes and the perception that exercise could exacerbate illness. Thompson and Gifford's (2000) work with an urban Aboriginal community, applied an ethnographic

approach to epidemiology. This resulted in understanding the framework that Aborigines use to understand diabetes. They view the onset of diabetes as the result of living a life out of balance, in this case, the move away from traditional Aboriginal living to one removed from the land and family connections. This group viewed susceptibility to diabetes and all illness from three levels: (a) family, (b) community and (c) society. The authors of this study believe that having such an insight into the importance of family and community connections for health beliefs has enormous potential because public health interventions can then be targeted at the right level. The importance of family connections was also found in Sisson Joshi (1995) interviews with outpatients in India and England. One of her findings highlighted the important role of food in family and social events and the cultural expectations placed upon the person with diabetes to partake of the food. It is findings such as these that remind us of the importance of using qualitative research to reach the contextual and environmental influences on diabetes beliefs and behaviours.

One example of how qualitative research can help address and understand the complexities of diabetes control is Murphy and Kinmonth's (1995) in-depth interviews exploring how adults with type 2 diabetes interpret and manage their illness. These interviews gave a picture of how patients oriented their understanding and subsequent control, either from a focus on controlling symptoms or by avoiding long-term complications. They gleaned an insight into the participants perceived severity of their diabetes. It also provided an insight into how people rationalise their non-compliant behaviour such as believing that diabetes is a serious illness but not for them personally, or that they can control it. By having these insights into illness perceptions, it helps not only in understanding behaviour but has much wider implications in improving the management of diabetes and informing interventions.

Unfortunately, despite the increased awareness of the potential future 'explosion' of diabetes and the large-scale randomised controlled trials that have taken place (e.g. DCCT, UKPDS), the increase in qualitative research has not been mirrored. This has led to a dearth of information on people with diabetes' lived experiences, attitudes, beliefs and illness representations. With the growth and acceptance of qualitative methods in social and medical sciences this situation is changing (Appleton, 1995; Murray & Chamberlain, 1998). Smith et al.'s (2003) qualitative investigation of patient views is an example of this. Their inclusion of qualitative research as part of a larger randomised

controlled trial of the effectiveness of shared care provided new insights into patients' views regarding, their lack of awareness of cardiovascular risk, their low levels of satisfaction with care and their service delivery needs. Another example was the recent adoption of the Diabetes National Service Framework of a qualitative approach. They needed an account of service users' and carers views' of the NHS diabetes service, and conducted focus groups and in-depth interviews with 52 service users and nine carers (Hiscock et al., 2001). Qualitative methods in diabetes research have also been used to explore unknown attitudes and beliefs of health care professionals (Whitford, Lamont & Crosland, 2003). In their qualitative study of general practitioners and practice nurses, Whitford et al. (2003) found that positive attitudes to screening for diabetes were not based on the evidence for screening but on a more complex set of beliefs about patient desires, previous experience, received wisdom and evidence from other resources. This nascent qualitative field has much to contribute to understanding the effects of diabetes on the individual, the family and service delivery. The use of qualitative methods to tap into unexplored research areas such as the contextual setting of diabetes management that is the focus of this exploratory phase of the research.

2.8 Aims and Objectives

The aim off this research is to explore the beliefs, attitudes and perceptions of diabetes control.

The objectives are to achieve this by conducting focus groups with (i) people in good control and poor control of their diabetes and (ii) the family members of people with diabetes.

2.9 Methodology

2.9.1 Design

As this exploratory phase of the research examined the personal views and meanings of diabetes in a relatively under-researched group, a qualitative approach was deemed to be appropriate. Qualitative researchers aim to "study things in their natural setting, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them" (Denzin & Lincoln, 2000). There has been a move in health care and

health services research to using qualitative methods (Mays & Pope, 2000). Relying solely on quantitative survey research methods to investigate and understand the health and illness perceptions of people has its limitations. Despite the obvious gains in terms of data reduction, analysis and generalisations when using quantitative methods, this must be balanced against the loss of understanding (Anderson and Robins, 1998). Mays and Pope (2000) assert that the philosophy of both quantitative and qualitative researchers should be one of 'subtle realism' – an attempt to represent that reality rather than to attain 'the truth'. This research aimed to achieve a greater understanding of the reality of living with diabetes rather than reducing many different lived experiences to one 'truth'. To do such would be to ignore the varied and individual life that each person with diabetes experiences. This was an exploratory phase and the results informed the next stage of the research; a larger scale investigation into the psychological differences between those in good control and those in poor control of their diabetes and their family members. Grounded theory provided the theoretical background to this phase of the research and focus groups were the chosen method of investigation. Both of these are discussed in the following sections.

2.9.1.1 Why grounded theory?

Grounded theory is an inductive and deductive process of identifying analytical categories as they emerge from the data and using the data to construct a theory. It develops hypotheses from the ground up (Pope, Ziebland & Mays, 2000). The principles associated with grounded theory were developed by the sociologists Glaser and Strauss in 1967 while exploring the institutional care of the terminally ill. The methods place an emphasis on the participant's own accounts of events and the social context in which they occur. These accounts lead to the generation of a theory that is grounded in the participant's interpretations of their world. It is not a straightforward linear process but one that relies on the constant comparison of similarities and differences at all levels of analysis until a theory emerges. As Keddy, Sims and Stern (1996) state: "doing grounded theory, rather than a tidy process, is as messy as preparing a gourmet meal, where all the parts need to come together at the end" (p. 450). It does however contain the following characteristics: the inter-relation of sampling, data collection and analysis, saturation of theory development, the constant comparative method and the use of multiple data sources e.g. social context in developing a theory. Strauss and Corbin (1990) suggest four criteria for evaluating if a theory fits the data it has come from:

- Theory derived from diversity of data and represents everyday reality of phenomena
- Theory should provide understanding
- Theory should provide generality
- Theory should clarify the conditions in which its applicable and provide a basis for action in the area.

One advantage of the grounded theory approach is the focus on theory as the end result of analysis means that the researcher must move beyond providing a descriptive account (Chamberlain, 2000).

2.9.2 Focus Groups

2.9.2.1 Background

Ever since Ford motor company named there latest car 'focus' as a result of conducting focus groups with members of the public, the term 'focus group', although previously known outside of research, has now become a ubiquitous term. Market researchers have widely used focus groups since the 1950's as a pragmatic and cost-effective way of keeping in touch with consumers. The technique was first developed in the 1930's by social scientists who were exploring strategies for conducting interviews that gave the respondents a more active and less limited role than individual interviews. Although it was used during World War II, it has only been since the 1980's that it has found its way back into the fields of sociology, psychology and medicine. Certainly the last decade has seen a substantial increase in the use of focus group methodology (Wilkinson, 2004). The employment of focus groups for this research is in line with Kruegar and Casey's (2000) assertion that focus group interviews should be considered when you are trying to understand differences in perspectives between groups or categories of people. As Kitzinger (1995) writes "this method is particularly useful for exploring people's knowledge and experiences and can be used to examine not only what people think but how they think and why" (p. 299).

2.9.2.2 Definition

There does not appear to be a consistent definition for focus groups in the literature. Kruegar and Casey (2000) get around this by presenting the typical characteristics of a focus group as relating to 'people who possess certain characteristics and provide qualitative data in a focussed discussion to help understand the topic of interest' (p. 10).

Kitzinger (1994) also mentions that 'crucially, focus groups are distinguished from the broader category of group interviews by the *explicit use of the group interaction* as research data'.

2.9.2.3 Advantages and disadvantages

As with all qualitative research, focus groups go beyond the knowledge and attitudes that can be captured in quantitative research to explore why and how people think in such a way. What differentiates focus groups from other interview methods is its inherent group process. It is this group process that helps to explore sensitive issues in ways that would not be possible in an individual interview setting. Rather than inhibiting discussion, the group setting has been shown to facilitate the discussion of sensitive topics and personal disclosures (Wilkinson, 2004). The more passive role of the researcher in focus groups means that less control is exerted over the participants and discussion can evolve more naturally. The discussion is more likely to lead to the issues that are important to the group, unlike more structured interviews, which have a predetermined list of questions. The communication that takes place in focus groups allows the researcher to hear the language used by respondents and gives an insight into the vocabulary they use. A further advantage of focus groups is that they can include those who can't read or write. There are however disadvantages to having such a group process involved in research – the group has to work. The group may not engage or several members may be very vocal, making quieter members feeling excluded. Another disadvantage is that group norms may dominate, silencing individual voices of dissent (Kitzinger, 1995). This can usually be overcome through experienced facilitation and the use of negative case analysis. Ensuring confidentiality to participants also becomes more complex in a group setting. Many of these disadvantages can be overcome by careful planning and being aware of the many practical considerations of conducting focus groups.

2.9.2.4 Practical considerations

One of the first tasks in running a focus group is carefully choosing appropriate participants. They should have some shared characteristic that brings them together and allows them to identify as a group. Overcoming many of the potential group problems, is the necessity of having an experienced facilitator. They should have a knowledge of group dynamics, be skilled to intervene to include everyone in the discussion, yet allow the discussion to develop naturally. It is important that confidentiality and group rules are

agreed upon by the group before any discussion takes place. A short debrief should also be included at the end. There are many other considerations which include: the venue, recoding equipment, refreshments and payment/incentives. These all need to be planned, while constantly balancing the best research design with the resources available.

2.9.2.5 Importance of interaction

There is a tendency in focus group research to report the content of the discussion rather than the interaction and this practice is beginning to receive some criticism (Chamerlain, 2004). Kitzinger (1994, 1995) is highly critical of research that purports to have been conducted using focus group but completely neglects to address the notion that any interaction took place. In her 1994 article, she goes as far as to say that on reading such research "it is hard to believe that there was more than one person in the room at the same time" (p. 104). She argues for the "overt exploitation and exploration of interactions in focus group discussion" (p. 116).

2.9.3 Participants

2.9.3.1 Sampling

Theoretical sampling was used for this study (Mays & Pope, 2000). It has been defined by Strauss & Corbin (1998) as:

'data gathering driven by concepts derived from the evolving theory and based on the concept of "making comparisons," whose purpose is to go to places, people, or events that will maximise opportunities to discover variations among concepts and to densify categories in terms of their properties and dimensions'.

The factors underpinning this research are: the systems approach of the biopsychosocial model and the lack of understanding of psychological determinants of good and poor control. The systems approach led us to go beyond the impact of diabetes on the individual, to examine how such an event has a wider effect. To address this, family members of those with diabetes were also invited to take part in the research. It was decided to differentiate the psychological determinants of glycaemic control by examining it from 'an extreme groups approach' (Vallis, 1998) – those in good control and those in poor control. The sampling therefore had to include a group in good control and a group in poor control of their diabetes and their family members also had to be invited to participate. For this research, we have taken good control to refer to people with diabetes who have a HbA_{1c} below 7% and poor control to those whose HbA_{1c} is over

8.5% (St. Vincent Declaration, 1999). There were two different levels to this sampling – (i) control of diabetes and (ii) patient or family member and this has been referred to as a double-layer design (Kreugar & Casey, 2000) (see Table 2.1).

Various figures are given as to the number needed for effective focus groups depending on the sensitivity of the topic being discussed, the purpose of the research and the skills of the facilitator. The numbers can be as little as four (Kitzinger 1995) or up to 15. On average there are between six-ten participants in each group (Macintosh, 1993). To achieve this number, 20 participants were randomly chosen from a larger research sample (North Dublin Diabetes Shared Care (DiSC) project² (N=183). This population was divided into those with poor glycaemic control (HbA₁c >8.5) and those with good glycaemic control (HbA₁c <7). Using a stratified random sample, 10 participants in good control and 10 in poor control were randomly selected. Crossley (2002) suggests recruiting ten participants in order to reach the target of between six and eight. Snowball sampling was used, and all potential participants were asked to nominate a family member to attend a parallel focus group. This is a technique often used in qualitative research, where key individuals are identified and are in turn asked to identify further key contacts (Coolican, 2004).

2.9.3.2 Ensuring Rigour

Issues of reliability and validity always emerge in the debate on the quality of qualitative research and health psychology is no exception, with its 'over-ardent concern with methodology' (Chamberlain, 2000). However, it is because of psychology's concern with methodological standards that it can contribute to scientific research. Nevertheless, applying the terminology and methods of quantitative research to qualitative research simply does not work. As Dingwall (1992) stated:

"one of the greatest methodological fallacies of the last century in social research is the belief that science is a particular set of techniques; it is, rather, a state of mind, or attitude and the organisational conditions which allow that attitude to be expressed".

² The DiSC Study was a cluster randomised controlled trial involving 30 general practices in North Dublin. It aimed to assess the effectiveness of a new structured diabetes shared care service, incorporating qualitative and economic analyses (Smith *et al.* 2004).

Chamberlain (2000) argues that the debate on methods and terminology needs to be moved on and instead the focus should be on issues of conducting good research. The emphasis for all research should be the appropriateness of the research question and analysis, and the skills and judgement of the researcher. Historically, the emphasis in psychology, as with most disciplines, has been on objectivity, testing and measurement and it has been difficult for psychologists to abandon these characteristics in the move to qualitative inquiry. To ensure that this research was conducted in a systematic, self-conscious and professional manner, the issues of credibility, transferability, consistency and neutrality were considered.

- (a) Credibility: this is also referred to as the 'truth value' and is concerned with how accurate or truthful the analysis is, of what was said. One of the strengths of qualitative research lies in its closeness to the reality as perceived by the participants. This study ensured credibility by including all facilitators and observers interpretations of the main themes and by validating the analysis with them and with the participants (see Appendix A)
- (b) Transferability: this ensures that the analysis fits the data. Interpretation of the data can become subject to elite bias (where one or two respondents views dominate) or holistic fallacy (which occurs when a researcher feels conclusions they make are correct). However, the constant comparison technique of grounded theory means that emerging themes and theories are constantly referred back to the data and earlier analyses. The use of negative case analysis allows for minority views to be identified and examined and person triangulation facilitates the inclusion of views from different family members and people with diabetes.
- (c) Consistency: the repeatability of a study is guaranteed through systematic auditing and keeping a decision trail. For this study to be conducted, numerous documents were prepared; letters to participants, consent forms, notes for facilitators and observers, standardised interview guide, report forms, notes and memos on ongoing analysis and a decision trail for codes, categories and themes (see Appendices B H).
- (d) Neutrality: maintaining a neutral standpoint in the research process is difficult to achieve. Working closely with a highly rich data set on a topic of considerable interest to the researcher brings it own challenges of objectivity. By addressing credibility, transferability and consistency, a certain amount of subjective bias will be eliminated. However, it remains essential that the researcher is aware of their

perspective and the theoretical frameworks that shape their interpretations. Once again, by constantly returning to the transcriptions, rather than the analysis, and maintaining a systematic approach to data collection and analysis, the final results are truly embedded in what people said.

2.9.4 Ethical Issues

Ethical approval was awarded by the Irish College of General Practitioners. To ensure that the research was conducted in an ethical manner, full information was given to the participants before the focus group and during a phone-call with the research nurse where the opportunity to ask questions was offered. Participation was entirely voluntary and participants were free to leave at any stage. Consent forms (Appendix C) were signed to confirm both a willingness to participate and an understanding of the research. The importance of confidentiality within the group was emphasised. It was also explained that the data would remain anonymous, that no individual would be identifiable from any written reports and that the tapes would be destroyed after transcription. Finally, participants were encouraged to seek advice from their doctor or nurse if any issues from the discussion needed clarification.

2.9.5 Procedure

Participants were first contacted by letter (see Appendix B). This was a letter of invitation and introduction to the study. It mentioned that an 'informal meeting would take place', that the research nurse would be in telephone contact and it listed a telephone number if contact wanted to be made beforehand. An incentive of €10 was provided to cover travel costs. The use of incentives is common in focus groups and recommended by Kreugar (2000). He states that incentives are needed, as it takes an amount of effort to participate in a focus group, in fact they "are unique from other data-gathering processes in terms of the investment that must be made by the individual" (p. 90). As the focus groups were being conducted in a local venue, it was felt that €10 would more than adequately cover any travel expenses that may incur. The letter was signed by the research nurse (MO'L) who had met with the participants during the DiSC study. This was followed by a phonecall a week later from the same nurse (see Figure 2.2 representations of the timeline for conducting focus groups). For the purposes of maximising participation, it was felt that the first introduction to the study should come from a familiar researcher, who could then introduce the purpose of the focus group and the principal researcher (PW). Phone-calls

were used as they are more personal, they do not discriminate against those who cannot read, they allow for questions to be asked and queries can be immediately clarified. The use of telephones can discriminate against those who do not own one e.g. for financial reasons. However, in this study, all of the randomly selected participants had provided a telephone number. During the phone-call, potential participants were encouraged to nominate a family member to attend a parallel meeting.

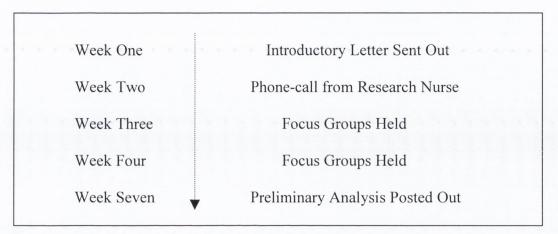


Figure 2.2. Timeline of procedure for conducting focus groups.

Both the patient and family member focus groups were held on the same evening in a local community centre to minimise inconvenience. The community centre was familiar to most participants and is one which is well used by all ages for sports, educational and social events. When participants first arrived, light refreshments were offered, the purpose of the study explained and the opportunity to ask questions given. Family members were then invited to go to another room as their focus group would be held separately. Each focus group consisted of the participants, the facilitator (PW or MO'L) and an assistant facilitator/observer (AW & RO'L). Kreuger (2000) advises the use of an assistant facilitator when conducting focus groups. It increases the amount of information gathered and helps to add to the validity of the analysis. The role of the assistant facilitator as stated by Kreugar (2000), is to take comprehensive notes, operate the tape recorder, manage the environmental conditions and logistics (e.g. refreshments, heating, seating) and to respond to unexpected interruptions (see Appendix D). Their presence proved most worthwhile as they contributed significantly both to the smooth running of the focus groups and in its analysis. Although the rooms differed in terms of size and purpose (one was a small room used for a playgroup, the other, a larger, multifunction room), the set-up for all four focus groups was the same. The participants and the

facilitator sat in a circle with a small coffee table in the middle. The assistant facilitators sat behind the circle, facing on so they could see who was talking but far enough away to remain separate from the discussion.

Each focus group began with a more detailed explanation of the study, bringing attention to the confidentiality of the research and the need for consent forms. Once the consent forms were signed and there were no other queries, the first question was posed. At the end of each focus group, the facilitator summarised the main points and looked for clarification of these points from the group. The travel expenses were then circulated (in note form in a sealed envelope) and the participants departed. Immediately after the focus groups the facilitator and assistant facilitator wrote up a focus group report (see Appendix G) to capture their immediate thoughts and reactions to the process.

2.9.6 Interview Guide for the Focus Groups

In order to achieve an understanding of participants' beliefs, attitudes and perceptions of diabetes control, the interview guide needed to be guided by a relevant theory of illness cognitions. Several cognition models of health and illness behaviour prevail in health psychology. The Health Belief Model (Becker & Rosenstock, 1984) was the first such model to attempt to understand health behaviours and whilst several reviews report generally favourable results (Harrison, Mullen & Green, 1992: Sheeran & Abraham, 1996), it is more concerned with preventative health behaviours rather than illness cognitions. The Theory of Reasoned Action (Azjen & Fishbein, 1980) and the subsequent more developed Theory of Planned Behaviour (Azjen, 1991) have specified components whose relationships can be tested and verified. It has been empirically validated (de Wit & Stroebe, 2000), in particular its concept of intention, which has shown to have a strong relationship to actual behaviour (Sheeran, Abraham & Orbell, 1999). The Theory of Planned Behaviour however is more suited to understanding intentions to perform a health behaviour rather than the illness cognitions that underlie the For the purpose of guiding questions for the focus groups, Leventhal et behaviours. al.'s, (1984) Self-Regulatory Model of Illness Representations was used. In particular, the five key illness dimensions of illness perceptions. These dimensions examine the cognitions that people have about the cause, identity, timeline, consequences and curability/controllability of their illness. A recent meta-analysis (Hagger & Orbell, 2003) of empirical studies using the Self-Regulatory Model of Illness Representations has

provided support for how these illness dimensions relate to the coping and outcomes in illness. By addressing these key dimensions of illness cognitions, it was hoped to tap into the illness beliefs of the participants. (Appendix F)

2.9.7 Analysis

Using the principles of grounded theory, notes and transcripts were read and reread by PW to identify and index themes and categories (Morse & Field, 1995). The analysis, used content and context analysis, coding, constant comparison, memoing, negative case analysis and member checking. All data relevant to each category was checked through constant comparison. Large numbers of categories resulted, which reflected as many of the nuances in the data as possible. The basis of coding was constantly reviewed to determine relevance. Then, particular categories showing relatedness were selected for further investigation, this stage can be referred to as analytical induction (Appendix H). The emerging themes were also constantly reviewed and comparisons made with existing literature until saturation of the analysis was reached and a theoretical understanding of the data was achieved. The four focus groups were tape-recorded, transcribed verbatim and entered into QSR NUD*IST Vivo, version 1.3. This is a qualitative software package which allows for handling rich text data and visually coding it (Richards, 2000). The preliminary analysis was summarised and sent out to all participants and fellow research personnel who were present, asking them to comment on whether they thought:

- (a) the summary was an accurate reflection of the discussion held
- (b) there was anything inaccurately reported
- (c) there was anything else that should be included
- (d) any other comments.

2.10 Results

2.10.1 Introduction

From a potential 40 participants, 19 took part (see Table 2.2). The participant characteristics are represented in Table 2.3 (a) and (b). Overall, the average age for those with diabetes was 70.5 years. The mean duration of diabetes was eight and a half years and two thirds were treated by diet and medication. All participants were diagnosed for at

least one year, as per the eligibility requirements for the DiSC study. Wives were most frequent attenders in the family group (five in total), followed by daughters (three) and one son took part. In presenting the quotes from the focus groups, some quotes are included as isolated text, while others are presented as short extracts from the focus group, to highlight the context in which they were said. In all cases, quotes have been referenced by the person who said them and their focus group. Names have been changed to protect the identity of the participants.

Table 2.2 Illustration of the Double-layer Design for Focus Groups (adapted from Kreugar & Casey, 2000)

LAYER 1	LAYER 2	FOCUS GROUP	NUMBER OF PARTICIPANTS
1. Good Control	(i) Patients	1	4
	(ii) Family Members	1	4
2. Poor Control	(i) Patients	1	5
	(ii) Family Members	1	6
TOTAL		4	19

No discernable differences in attitudes between those in poor and good control were noted by the researcher. There were however, some differences between family members and those with diabetes; family members had less information and greater concerns, they tended to perceive diabetes as more serious and as having a greater impact on daily living than those who actually have the illness.

Table 2.3 (a) and (b)(a) Characteristics of Participants with Diabetes by Control

Characteristic	Mean	Median	Range
Age (in years)	70.5	68.5	60-79
Good control	74	75	
Poor control	67	67	
Duration of diabetes (in years)	11.75	8.5	6-32
Good control	15.5	11	
Poor control	8	8	

(b) Gender and Treatment Characteristics of All Participants with Diabetes

Characteristic	Number	
Gender		
Male	3	
Female	6	
Treatment Type		
Diet only	1	
Diet medication	6	
Diet and insulin	2	

2.10.2 Interaction

The interaction proved positive in all four focus groups and despite occasional disagreements, particularly in one of the family groups regarding the level of severity, there was no evidence of conflict. Most participants spoke freely and listened well to each other. There appeared to be an amicable atmosphere in all the groups with humour in evidence.

C I'd say I'm the only one in this room that doubled his weight in marriage ... I got married at nine stone seven. and I went from nine seven to nineteen seven D. (There it is), get rid of the wife All break out laughing

Participants enjoyed the opportunity to compare adherence and non-adherence techniques. In many of the groups they began to speak as a collective 'we', demonstrating a sense of identity as a group. The dynamics with the family focus groups were slightly different, with members turning frequently to the facilitator for information and clarification. It is unclear if this is a reflection of the lack of information that family members have or if they saw the facilitator in the role of 'expert'. (The facilitator for the family groups was a research nurse who would have visited their house once in the previous year and once two years previously in relation to the DiSC study). Many of the participants remembered her and may have seen her within a 'clinical nurse' role rather than a research role. It was evident from early on in the analysis, that there were similarities amongst the four focus groups and three overriding themes consistent with each group emerged. In presenting the results I will give details of each of the four groups and then present the three themes common to all groups.

2.10.3 Focus Group 1 – Good control of diabetes (DFG1)

This group seemed relaxed together and got on well. Some members had a tendency to speak about other aspects of their lives and it proved difficult at times to get straight answers. As a group, they spoke of their diabetes with a sense of indifference. Although they were the group with better control of their diabetes, none of the members had a full understanding of their diabetes and its treatment. This lack of understanding and the sense of indifference can be seen in some of the following quotes:

'But we don't know enough about it, we really don't but then I think it's very hard for people to explain' (L)

'Now as I said I didn't go by the rules, I didn't go on the diet, and (still) take me couple of drinks...' (J)

'...we're all thinking the same, well we don't..., we treat it with a little bit of contempt, we don't really do what we're supposed to do'(L)

2.10.4 Focus Group 2 – Poor control of diabetes (DFG2)

This group spoke openly about their condition, used humour and were excellent at listening to each other, apologising when cutting across another person speaking.

C., I have one of the pens, the Novo pens, supposed to be great J. Yeah

C. But the one that she (diabetes nurse) has, she just (imitates pinprick on finger) and ptsssh and - it was grand. If I had one of them I'd have no problems taking tests.

All laugh

D. Not cutting across you there but if you go up she'd give you one.

There was a tendency for the conversation to steer towards food and symptoms. As this group were in poorer control of their diabetes they may have had more experience of its consequences through episodes of hyperglycaemia. They certainly spoke more about the symptoms they experienced before diagnosis such as thirst, deteriorating eyesight, and changes in weight.

Overall, this group spoke strongly on the need for education and information. People's health beliefs and behaviours were not clear cut and there were contradictions in what the participants were saying.

2.10.5 Focus Group 3 – Family members of those in good control (FFG1)

There were two more dominant members of this group who disagreed on the severity of diabetes but all four members did contribute and the group worked well. There was a need for prompting from the facilitator as the group had the impression that they were there to learn from the researchers rather than the researchers learn from them. Although all of their family members were in good control of their diabetes, they showed no knowledge of this. None of their family members were on insulin, three took medication and one was on diet alone. This influenced their perception of the severity of diabetes and three of the members did feel that diabetes was not a matter for serious concern.

'well there's not really much wrong with him..., he doesn't complain, just takes his tablets' M

2.10.6 Focus Group 4 – Family member of those in poor control (FFG2)

There were six participants in this group, two of whom were sisters who came together. This was a livelier group and all members participated. One member spoke only when directly questioned but all other participants spoke freely. There was a sense of positive interaction with group members checking with each other if they concurred with their viewpoint

'and do you feel that to?'

The focus group was seen as a form of support.

'I think these types of meetings are very helpful' P

This group spoke more about the emotional consequences of living with diabetes on themselves and their family member 'I feel very angry for me Ma that she has to go through this' M P 'It most definitely has changed his moods'

2.10.7 Themes

There were three themes that consistently emerged from the discussions of each of the four focus group: (1) Understanding, (2) Personal Perceptions and (3) Impact on Daily Life. These are represented with possible causal links in Figure 2.3.

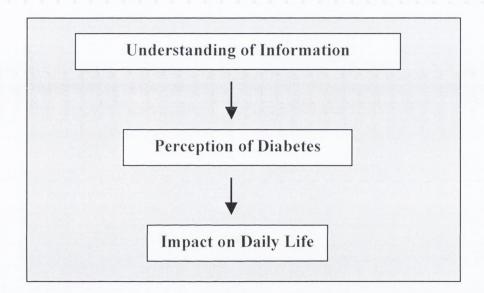


Figure 2.3. Representation of the three themes.

(1) Theme one - Understanding - '...put it in layman's language' (FFG 1)

The overriding theme that was evident in all four focus groups was the lack of understanding that people had about diabetes and its management. The issues here are: the perceived lack of available information from the family's perspective and the inability to understand the information that is available. The second pervasive aspect of this theme relates to peoples' understanding of food and diet changes. This theme of understanding relates to more than the information that is provided to how that knowledge is understood by those with diabetes and their family members.

(a) Information

Although information is readily available, particularly for those with diabetes, it is presented in a way that is difficult for the lay person to understand as the following quotes demonstrate.

'Well I think the medical language can be intimidating and you close the book' 'Well Jesus you know, as Joe says, put it in layman's language and we can understand it' (FFG1)

The lack of understanding is highlighted in this excerpt from the focus group with people in good control of their diabetes

L Truthfully I'll ask the question there now I don't know what diabetes even is, I do have no explanation for it, I don't know-

S. I think it's to do with your blood isn't it

M Yeah

- L. I know it's to do with your blood but I don't know what it's from
- J. Well you're not producing enough of blood isn't that it
- L I don't know, it's to do with something more than that..well it has to do with eh..
- S. Too much sugar..it's put down to too much sugar, you're supposed to go on wholemeal bread and all this sort of stuff, you get fed up with that wholemeal bread and all, you do
- J. Emm (in agreement)
- S. You do
- L. I don't know what diabetes is

M. They're (children) now asking which they've never done before, they're asking now you know why, and as I said to them, sorry lads I can't answer, you know why does it happen Ma, why does your sugar go like, or your blood go like that and I can't, that's what I said I can't,

The lack of understanding has led some of those with diabetes to stop asking questions altogether

- L. 'I don't ask questions about it anymore'
- S. 'I don't either'
- M. 'No, no' (in agreement)

The recommendation most frequently mentioned by all groups was for more accessible and understandable information

J. 'well I'd be the same, get the information in plain language and not be using any big words or that sort of thing (FFGI)

C. I think if you could, if they could produce something that would tell you the consequences of what to do if they do go wrong
M. Yeah

J. Yeah

C. And it would probably put you know, the fear of God into you in the first place but also it would help (DFG 2)

It's interesting to note that just one participant didn't want his father to have too much information in case it made him worry more

T. ... well I think he doesn't understand it. Not well I don't understand it either but he doesn't understand it, all he was told was take a tablet keep an your sugar and away he goes and that's it! I think that's the, as much as they need to know to be honest Facilitator: Do you feel that?

T. Yea because the more you tell them the more they worry about it, (FFG1)

(b) Food/diet

This was the topic most frequently discussed and was a continuous source of confusion and contradictions.

- J. 'The frying pan has gone out the window'
- C. 'I look forward to me fry on a Monday' (DFG2)
- L. You're told one thing and they're telling you to eat fruit, then don't eat fruit
- S. You can eat fruit and you know the tinned fruit, you can eat the tinned fruit sugar free, you can buy it and you can buy loads of food in the supermarket for diabetes and that's what I do go for
- J. Is there not sugar in the[
- S. No], there's none
- J. I was always a good fruit eater
- S. [Done in own juice
- J. Is, is] there not sugar in apples
- S. Yeah
- J. I think there is
- S. Maybe there is in ordinary apples, in the fruit you buy in the cans
- J. Umm
- S. You know the (?) it says on the tin sugar free (DFG1)

M. Now this is what has me baffled, they eh, the nurse ran off and she was talking to a doctor so she came back to Maria and she says get as many sandwiches into her as you can and I said 'sandwiches, last week you told me I wasn't to have sandwiches'

All laugh

D. This is the problem, you see there's contradictions in there from time to time and they're saying there's incidences where you need your sambos and there's certain incidences where you can't eat sambos but you've got to know the difference between the two times

M. Yeah

D. And that's what we don't know (DFG2)

It was interesting to see the influence that family can have on food and diet.

- S. ...and you know the cocktail sausages, he(husband) loves them, he has me taking cocktail sausages when I shouldn't be taking sausages but I do. I don't bother that much about me diet, you know.(DFG1)
- J. Now she was told not to take any chocolate, she was also told not to take any drink, I give her a glass of stout (FFG1)
- N. He'll eat whatever is in front of him so we use diet food and there's no problem' (FFG2)
- C. It's the diet..., the only reason that I say I'm still surviving today is the fact that she wife) is brilliant with a diet 'cause she's conscious of what we're eating. (DFG2)

(2) Theme Two - Personal Perceptions

Moving beyond the understanding that people have about diabetes, examining their personal perceptions provides a deeper understanding of how people think and feel about the illness. These personal perceptions were particularly expressed in relation to possible causes of diabetes (causal attributions) and how serious they felt diabetes was (perceived seriousness).

(a) Causal Attributions;

When asked what caused diabetes, most participants reacted with comments such as 'I wouldn't know', 'I wouldn't even hazard a guess'

'I think the one thing coming across from everybody also is the fact that everyone of us would love to know what causes it (DFG 2)

All participants were asked to make out a list together of the possible causes of diabetes. Although the participants perceived that they had little knowledge of the causes of diabetes, they then went on to name all but one of the possible causes, missing out on insulin resistance. The lists they made consisted of; sugar and too many sweet things, overweight, 'in the blood', hereditary, age, diet, lifestyle and the pancreas not producing

enough insulin. It was interesting that the only group to mention about the pancreas and the production of insulin was the group in poorer control of their diabetes. This lack of understanding regarding the cause of diabetes has led to people developing their own causal attributions based on their own personal experience. It also meant that they were less open to accepting other possible causes. This is clearly demonstrated in how easily people refuted possible causes suggested by other participants when they had no personal experience of it.

C 'I presume it's a balance of eh sugar....

J. No, no because if it did I should have it because I put nearly five sugars in me tea!'(FFG2)

- H. I'd also say that it was hereditary...well I've often heard that
- J. Well now it never affects me (FFG1)
- L. Some people say it's hereditary but I wouldn't say it because well in my family there's no one that has it (DFG1)
- T. Would age be a factor?
- J. Ah no cause you get young people that have it too(FFG1)

The lack of discussion about family screening for diabetes was evident. Only one participant with diabetes mentioned how he would like his children to be screened. For family members, the possible implications of the hereditary aspect of diabetes had not been realised. As one son of a participant with diabetes said:

T: To be honest I wouldn't worry, I mean in my case I'll watch for heart disease because me Dad had a triple by-pass'

(b) Perceived Seriousness

There were differences in perceptions of severity in all four focus groups with some believing diabetes to be a serious illness while others felt it wasn't 'well, it's not a killer disease'

It was interesting to see that participants used tangible indictors such as; number of hospital appointments, amount of blood tests and medication, and whether on insulin or not, as markers of severity.

T. My Dad's more so on a diet eh eh diabetic than, like he's on one tablet a day he's not on insulin he doesn't take any so it's not at the stage to the extent where its serious enough to take insulin. (FFG1)

'There's no illness' 'we're just on tablets' (DFG1)

J: Tis after reminding me, she must be improving because Sarah doesn't, Sarah doesn't have the testers now, she used to get the testers but she doesn't get them now. So she must be improving, has to be....(FFG1)

Family members did have a heightened perception of the severity of diabetes which in turn heightened the concern they had over the illness and it's management (see figure 2.3)

T: You know it fluctuates like that and you think is it wrong or is it right? Should I keep an eye on him every single day (FFG1)

C. 'It's the first question in the morning' (FFG2)

J. He does control his well, but I'm always thinking about it (FFG2)

P. I put a lot into his care, without nagging as much as possible. But I'm still worried....' (FFG2)

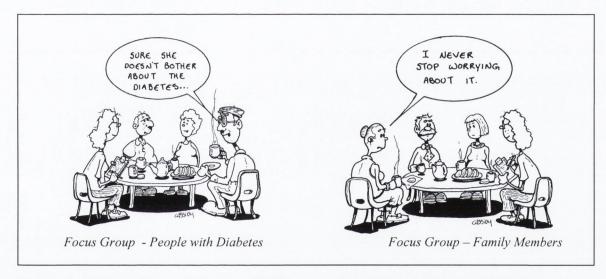


Figure 2.4. Pictorial representation of differences in perceived impact of diabetes. Note. Quotes taken directly from the focus group with people with diabetes (DFG1) and the focus group with family members (FFG2).

(3) Theme Three - Impact on Daily Life

This was an interesting theme because when speaking directly about the impact of diabetes on daily life many said there wasn't really any influence but then went on to talk about and describe just how it did impact on their lives.

M. He doesn't suffer much you know, so I wouldn't know much really about it, cause he never complains or anything...' (FFG1)

It may be that the changes are subtle, or perhaps they become incorporated into one's normal daily life. As one wife of a person with diabetes said 'you change your life without even realising it'. Several family members spoke of the changes they noticed in mood swings.

C. She gets very moody and touchy

P. It most definitely has changed his moods. He gets irritable over the slightest thing but we have learned to live with it (FFG2)

Particularly in the second family focus group, they all agreed that they always have diabetes at the back of their mind e.g. when cooking, shopping, going out together. One daughter mentioned the terrible feeling of guilt she now feels when she has to leave her mother alone during the day-time. Some family members noted that not all of their concerns were because of diabetes but partly due to the age their spouse/parent is.

H. It would (impact on our lives) but I have to say not all because of the diabetes, it's just the fact that she's on her own (FFG1)

J. She feels out of sorts sometimes but I put it down to old age, she's getting old like meself!' (FFG1)

(a) Diet

Despite the overall feeling of just getting on with life, the influence of diabetes on food choices was inescapable.

S. 'I thought the diet was a terrible thing to go on, so I done the best I could with the diet with an odd bit of this here and an odd bit of this there' (DFG1)

L. I try me best, I don't take sweets, I don't take sugar, I like to eat, I like white bread but I try to stick to the brown bread.

S. It's terrible now, I miss that white bread (DFG1)

(b) Control

There was a sense of having some control over diabetes but adherence for most was summed up by the quote 'you stick to it and you don't stick to it'.

The majority of those with diabetes had a relaxed almost laissez-faire attitude to controlling their diabetes. The sense of control was subjective and inconsistent. 'and say right, I'm not going to do this, I'm not going to do that but then of course like human beings you will go off the rails'

'you might break it from day to day but hopefully you keep within the guidelines with your blood'

'when you're feeling good you just keep doing what you're doing'

Family members varied in how they felt diabetes was controlled.

T: I think that he pretty well controls it, it's a disease that is very controllable (FFG1)

C: She doesn't control her diabetes, her diabetes controls her'(FFG2)

They felt that it was up to the person with diabetes to control their illness but that didn't mean that the notion of control does not impact on them also.

J 'He does control his well but I'm always aware and thinking of it' (FFG2)

Participants in general were positive about the service they receive from their general practitioner and hospital. They were most satisfied with the diabetes nurse specialist and least satisfied with dieticians. It is difficult to have a true reflection on satisfaction with care because participants were reluctant to mention anything negative about the service they receive as this quote demonstrates

J. They tell you nothing

D. They don't give you[nothing, they don't

MNo

D They don't give you practical information at all Now, I,I can't fault them up in (the hospital)

The impact of diabetes as perceived by those with the illness is summed up in these two quotes which describe diabetes as having an affect on one's life but it is an illness you can live with.

'when I say diabetes doesn't bother me, in the back of your mind it does bother you, it bothers you a lot'

'but you can live with it' [need to check who says these]

2.10.8 Feedback from Participants

All participants were sent a copy of the preliminary analysis and asked to rate how accurate a reflection it was of the meeting (see Appendix A). There was a 58% response rate (11/19). All participants who responded were in agreement with the analysis that was sent to them and no one said that there was anything inaccurately reported. In fact, just

over one third asked for further similar meetings to be held. Additional remarks were made by one male participant and his wife, regarding the lack of any discussion/questions on sexual functioning. This is an interesting point considering the fact that over 50 % of people over 50 years of age with diabetes experience difficulties with sexual functioning (Diabetes Update, 2003), it was not a topic that was discussed or even mentioned by anyone. This may reflect more on the age and dynamics of the group, that they may not have felt comfortable discussing sexual functioning in this setting rather than the absence of the problem.

2.10.9 Theory

The diagram featured in Figure 2.3 depicts the theory that is grounded in the data and consists of the three themes. Underlying and influencing all aspects of successful diabetes management is the level of information, understanding and knowledge that people have. This informs the personal perceptions of diabetes in relation to causal attributions and perceived severity. How this effects behaviour will determine the impact of diabetes on daily life. By using the grounded theory approach to analysing the data, it became evident that the thoughts and behaviours in relation to diabetes were grounded in the personal understanding that people had of diabetes. Through constant comparison of the data, the importance of this understanding theme quickly became apparent.

2.11 Discussion

Although each group differed in its style of interaction and dynamics, the same common themes were evident in all four groups. Overwhelmingly what has emerged is the lack of understanding about what diabetes is and how it is best managed. This lack of understanding underpins all aspects of diabetes from what causes it, how serious it is perceived to be, what is known about appropriate diet, to ultimately how it is controlled and impacts on daily life. The drawing together of these themes into a theory of understanding diabetes is by no means conclusive. Instead it clarifies what questions need to be asked—it is not know exactly what people with diabetes and their family members know and understand about diabetes, how this impacts on daily life and psychological well-being. How people with diabetes perceive their illness, their actual adherence to their regimen, and the role of family support is also unknown.

A potential limitation of the analysis of the qualitative data was the small number of focus groups that were conducted. If the aim of this stage of the research were to provide definitive answers, further focus groups would be necessary to ensure saturation of new information. However, this research aimed to explore the potential beliefs, attitudes and feelings of those with diabetes and their family members and its purpose was to generate ideas for the subsequent larger scale study. A characteristic which permeated through the focus groups was that of inconsistency – there were inconsistencies in people's knowledge and in their adherence behaviours. Further focus groups may have provided more insights into the reasons for this or perhaps it is simply a reflection of the complex nature of diabetes itself. It is an illness with many microvascular and macrovasular complications and requires the adaptation to numerous treatment demands. In discussing inconsistencies in their findings on illness beliefs in older Irish adults, MacFarlane & Kelleher (2002) note that their results are similar to previous research which found the nature of lay health beliefs to be both complex and contradictory.

Throughout the focus groups with those with diabetes there was a sense of treating diabetes with indifference, or as one participant said, 'with contempt' (*L. DFG1*). These participants had stopped asking for information about their illness and appeared ambivalent about the control of diabetes. This may be explained by a sense of unrealistic optimism (Weinstein, 1982) about their condition or perhaps reflects learned helplessness behaviours (Seligman, 1975). It may simply be a reflection of a coping style or it may reflect the characteristics of these groups; they are an elderly population with co-existing morbidities for whom diabetes may not be a priority. The lack of importance put on good adherence to diabetes management recommendations is in line with Miller and Rollnicks' (1991) understanding of behaviour change, where behaviour can only be changed if it is (a) deemed important to change and (b) the individual feels confident enough to change it.

The lack of understanding found in this study was echoed in Hiscock et al.'s (2001) qualitative report for the Diabetes National Service Framework. They provide methods for improving information provision as suggested by the users of the diabetes services. This included not providing large chunks of information immediately post-diagnosis but rather to provide it in an ongoing and incremental way through a variety of means e.g. written information, telephone contacts and audio/video taped material. Lack of knowledge was not an underlying theme from Smith et al.'s study (2003); nevertheless,

they did report on participants lack of awareness of macrovascular complications and there was a lack of knowledge regarding current dietetic guidelines, e.g. there was conflicting reports of dietary advice regarding 'diabetic' labelled food. Participants also spoke of their difficulties in understanding treatment advice and changes in blood sugar levels. Participants in Smith et al.'s study did report similar themes to this study regarding the causes of diabetes. Neither Smith et al.'s now Hiscock et al.'s study directly examined knowledge or understanding of a spouse or carer. What the current research highlights is the need for appropriate, practical information that is accessible to both those with diabetes and their families.

Understanding type 2 diabetes from a family perspective is a useful model to adopt. Diabetes is a family illness – it can impact on the daily functioning of a family through changes in food, mealtimes, daily routines, work and holidays. From this research it can be seen that family members have concerns about diabetes and that these concerns are often not voiced. They can positively or negatively influence food choices and dietary behaviours ('...she was told not to have a drink. I give her a glass of stout'; 'the only reason I'm still surviving today is because she (wife) is brilliant with the diet'). Diabetes can impact on their daily lives from shopping trips to social occasions to a constant concern for the person with diabetes. As Pierce, Ridout, Harding, Keen and Bradley (2000) have shown, the inclusion of family members in research and services does not increase their anxiety levels. Their study involved providing an education programme to adult offspring of patients with type 2 diabetes. They found that including family members in an education programme increased their perception of risk and caused no psychological harm as assessed by anxiety levels. Cardiac research in particular realise the importance of spouses and families and their potential impact on the patient's wellbeing (Weinman et al., 2003). The literature on recovery from myocardial infarction has widely acknowledged the role of the spouse, particularly in relation to the consequences on the psychological well-being of the spouse and the marital relationship (Figueiras & Weinman, 2003). More recently the illness perceptions of the spouse and patient have been examined and Figueiras & Weinman (2003) found that in couples with similar positive perceptions of the identity and consequences of the heart attack, the patient had better psychological, physical and social functioning than couples with dissimilar perceptions. The need for including relevant family members in diabetes care is essential and has the potential to impact on psychosocial and clinical outcomes.

There is a complex relationship between illness perceptions of diabetes and its subsequent control. By using Leventhal's five illness dimensions in constructing the interview guide and guiding the focus groups, there was the potential for the discussion to be limited to cognitive aspects of living with diabetes. However, by using these dimensions, it made it possible to understand diabetes from the individual's perspective. One example of the value of examining personal perceptions was that participants perceived that they had a low level of knowledge about the causes of diabetes but when directly asked, they were able to produce a comprehensive and accurate list. Despite the benefits of using illness perceptions as a guide for the focus groups, it specifically examines illness from a cognitive perspective. Other possible determinants of glycaemic control that were mentioned in the focus groups: such as social support, treatment satisfaction, knowledge and adherence behaviours are therefore not directly included. From this research there were no discernible differences between those in good and poor control of their diabetes. A more detailed quantitative study is needed to examine whether there is a difference in knowledge and illness perceptions of those in good and poor control of their diabetes, or if control is merely a matter of chance or determined by past behaviours, treatment adherence or service delivery.

For many participants, alongside the lack of understanding about diabetes runs a lack of understanding of what having a chronic illness means. Because the signs and symptoms of diabetes are not always obvious and its control is for long-term well-being, many find it difficult to associate daily behaviours with long-term gains. Understanding the control of diabetes must be from a chronic illness approach. The next stage of this research uses this theory which encompasses these findings of understanding, impact on life and perceptions of illness. It has also included the role of the family and incorporated the behavioural and emotional demands of diabetes.

The next chapter addresses this by first outlining theories of chronic illness. The psychological factors that influence glycaemic control will then be discussed. These factors will be presented within the framework of the theory from this stage of the research.

2.12 Conclusion

To conclude, this exploratory study has confirmed the benefits of including family members in understanding the impact of diabetes. The participants in this research showed a lack of understanding of diabetes. What has emerged is the need for further investigation into people's understanding and perceptions of diabetes and how this impacts on its control.

CHAPTER THREE - LITERATURE REVIEW

"The great error of our day, that physicians separate the soul from the body. The cure of the part should not be attempted without the treatment of the whole"

Plato

3.1 Introduction

This quote may have come from ancient Greece over two thousand years ago but it captures the current dilemma and paradigm shift within modern medicine from a biomedical model of care to one which incorporates psychological and social factors. The rapid technological and societal changes of the last one hundred years in the developed world has meant that not only are we living very differently but we are surviving illness and living longer. Gone are the dietary and acute infectious diseases that eradicated whole populations. Improvements in sanitation, housing and nutrition alongside medical advances have led to a shift in the causes of mortality. According to Health Statistics 2002 (Department of Health and Children, 2003), the principal causes of death in Ireland are diseases of the circulatory system and cancer. This represents a trend in most developed countries, where the major health burden and principal causes of death are long-term chronic diseases. Similar trends in developing countries mean that by 2020, 80% of their disease burden will be from chronic conditions (World Health Organisation (WHO), 2002).

These changes in health and illness have brought to the surface the question of body-mind interactions. The view that what happened in the body was separate to the workings of the mind has prevailed from some of the ancient Greece philosophers to modern medicine and was strongly influenced by Cartesian dualism. It has led to a mechanistic understanding and treatment of the human body with the disease being treated as a part to be fixed (McClelland, 1985). Often labelled the biomedical approach to medicine, it has provided enormous gains in the understanding and treatment of disease. What it has failed to do however, is to address the psychological and social factors that play such a large role in the development and management of chronic illness.

In 1946, the World Health Organisation adopted a definition of health that was entered into force in two years later. It states that "health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity". This all-

encompassing definition of health has not changed since 1948 but healthcare delivery and beliefs about health and illness have. In his landmark paper in 1977, Engel argued that the existing biomedical model was insufficient in:

"understanding the determinants of disease and arriving at rational treatments and patterns of health care. We are now faced with the necessity and the challenge to broaden the approach to disease to include the psychosocial without sacrificing the enormous advantages of the biomedical approach". (p. 131)

He argued that psychological, behavioural and social factors must be taken into account if a patient's illness is to be truly understood. This newer biopsychosocial model is particularly relevant in a time where lifestyle behaviours are amongst the main risk factors for morbidity and mortality. This broader perspective is also particularly suited to chronic illness whereby the patient and their families make permanent behavioural, social and emotional adjustments (Sarafino, 1998).

3.2 Theories of Chronic Illness

There is no one accepted definition of what is meant by chronic illness. There is agreement however that a chronic illness is one which is long-lasting, with a progressive course and no known cure (De Ridder, 2004). It is acknowledged in the literature on chronic illness that no overriding or guiding model exists (Wright & Kirby, 1999). The research on diabetes is no exception but the enormous gains in research cannot be effectively transferred into improved care for people with diabetes without the move towards a chronic disease model of diabetes (Glasgow et al., 2001). It has long been recognised that there is a need for a multifactoral and integrated framework for diabetes research based on the biopsychosocial model (Peyrot & McMurray, 1985). Given the breath of research within psychology on chronic illness it will be presented as (i) psychological responses and consequences of chronic illness, which include: reactions, coping, loss, personal control, self-efficacy and causal attributions, and (ii) transactional models of chronic illness.

3.2.1 Psychological responses and consequences

The initial response to a diagnosis of a chronic illness has been described by Shontz (1975) as consisting of a sequence of reactions.

- (a) Shock: this is characterised by being stunned or bewildered, behaving in an automated fashion and feeling a sense of detachment from the situation. The sense of shock is usually short-term but can persist for weeks. This type of reaction has been captured in the title of an article by Brown (2002), when he wrote "Inside every chronic patient is an acute patient wondering what happened".
- (b) Encounter: during this stage the person becomes overwhelmed and experiences feelings of loss, despair, grief and a sense of disorganised thoughts
- (c) Retreat: it is at this stage that the reality of the situation begins to sink in and strategies such as denial or avoidance used.

Not everyone will respond in this way and stage theories such as this, are not as popular in psychology as they once were due to the lack of supportive evidence for them (Weinstein, Rothman & Sutton, 1998). Nevertheless, Shontz's theory does provide a useful starting point for understanding initial reactions to a diagnosis.

Other researchers have focused on the coping mechanisms that people employ, e.g. active coping, avoidant coping, emotion-focused or problem-focused. Pinder (1990), has specifically looked at how people use information as a coping strategy. Some patients actively source information and try to gain as much knowledge as possible as a way of coping (seekers). Others (avoiders) don't want to know anything more than they have to and leave it to others e.g. spouse, doctor to worry about the details. A final group (weavers) use both strategies and in effect hear what they want to hear. Coping strategies are discussed in detail in section 3.9.1.

Regardless of the specific process or etiology of the chronic illness, loss is a pervasive factor in the adjustment to the diagnosis, particularly for those under 65 years of age (Sidell, 1997; Williams & Koocher, 1998). The onset of a chronic illness is filled with uncertainties about prognosis, progression of the illness, treatment demands and future abilities. It is this uncertainty and sense of the unknown which leads to a sense of loss and disrupts personal control (Williams & Koocher, 1998). Charmaz (1983) takes a medical sociological approach and sees the consequences of chronic illness as a 'loss of self'. She has described four factors which contribute to the mal-adaptation of people to their illness: leading restricted lives, experiencing social isolation, being discredited and burdening others.

Loss in chronic illness has been studied in terms of loss of personal control and has been studied using health locus of control. Personal control was first described by Rotter (1954) when he hypothesised that people learn general ways of thinking that events are either due to external factors over which they have no influence (external locus of control), or due to their own efforts that they can exert (internal locus of control). A large body of literature has developed around this concept and in general they confirm that those with an external locus of control use more maladaptive coping strategies when confronted with stressors (Folkman, 1984). The development of the Health Locus of Control Scale reflected the division of health locus of control into three scales: internal (where the person has control over their health), powerful others (where health is believed to be controlled by other people e.g. doctor) and chance (where health is controlled by luck or fate) (Wallston, Wallston & DeValliss, 1978). Some chronic illnesses are very unpredictable (e.g. multiple sclerosis), leaving the patient with few opportunities to influence their illness (De Ridder, 2004). What is important therefore, is the patients perceived control rather than their actual control and it is these perceptions of control that can influence adjustment to chronic illness. In general, it has been found that those with a high internal locus of control are more likely to adjust to their illness and take on the behaviours recommended to control the illness. They are also more likely to adhere to the demands of the illness regime. However, the relationship is not straightforward, it depends upon mediating variables such as the context of the situation and the individual's dynamics (Williams & Koocher, 1998). Christensen, Turner, Smith, Holman & Gregory (1991), illustrated this in their study with end-stage renal disease patients. Although patients with high internal control displayed lower levels of depression, when these patients had unsuccessful kidney transplants their depression levels were higher than those with external control. This study demonstrates the importance of contextual factors and how high internal control can have a negative effect in highly uncontrollable situations.

In order for a person to successfully manage their chronic illness, not only do they have to believe that they can play a role in its management (internal control) but also that they have the ability to carry out the tasks/behaviours (self-efficacy). This concept of self-efficacy is closely related to perceived control. It was first put forward by Bandura (1977) and is the belief that one has the skills and knowledge to perform certain behaviours and carry out tasks. Examining the role of self-efficacy in illness adjustment has found that

higher perceptions of self-efficacy are associated with higher levels of motivation and higher intentions to perform behaviours, but there are mixed results as to whether they change actual behaviour (De Ridder, 2004). This may partly be due to the multi-faceted nature of behaviour change itself.

A key variable in understanding how people respond to their illness is centred on their beliefs about what caused the illness. Causal attributions have been extensively studied over the past decade and have been shown to have an effect on outcomes (French, Marteau, Senior & Weinman, 2002). The most widely cited finding is that blaming others for the cause of illness is associated with poor physical and emotional outcomes (Wright & Kirby, 1999). Causal beliefs are complex and it is important to examine how they relate to each other (French et al., 2002).

3.2.2 Transactional Models

The vast array of variables that impact on chronic illness make it difficult to segregate any one and examine it in isolation. Therefore theories which are more inclusive and holistic are better suited to chronic illness. These theories examine the transactions that occur within an individual and between the individual and their environment. An obvious example detailed earlier is the biopsychosocial model (Engel, 1977). One such theory applied to illness is that of Encapsulation Theory (Birenbaum 1990), which is attempts to understand how people integrate their illness with their life. It postulates that those who 'encapsulate' their illness and do not let it take over their lives, leaving part of their life 'disease-free' have a more successful adaptation to their illness. This theory was developed within paediatric psychology and as yet has not been examined in the literature on adult health psychology. These models do not focus on one particular psychological construct but rather view chronic illness in terms of its effects on the individual and their lives.

3.2.2.1 Moos and Schaefer's Crisis Theory of Adjustment

This theory was first put forward by Moos (1982) to explain cognitive adaptation to life transitions and crises. The historical development of this theory includes such varied sources as Darwin's theory of Evolution, psychoanalytic concepts and Eriksons's (1963) developmental life-cycle approach. Central to these theories is how people cope, develop

and evolve in crises. Crisis theory itself examines how a stressful event disrupts a person's physiological, psychological and social equilibrium and how new cognitive and personal skills must be developed in order for effective adaptation to occur (Moos & Schaefer, 1986). How a person copes depends upon three sets of factors (Figure 3.1):

- (i) Illness-related factors: the extent of a threat that the illness poses is related to how a person copes. The more disfiguring, disabling, painful or lifethreatening an illness is, the harder it is to successfully cope (Cohen & Lazarus, 1979).
- (ii) Background and Personal Factors: demographic and personality factors also influence the coping process. Those with a hardy personality tend to cope with illness more positively (Kobasa, 1979). Age and developmental stage also play a role e.g. it is well accepted within the literature on type 1 diabetes that adolescence is a particularly vulnerable stage with a decrease in the management of diabetes and a deterioration in its glycaemic control (Hampson, et al., 2000).
- (iii) Physical and Social Environmental Factors: not only does a patient have to learn to adapt to their illness but they must also adapt to how their physical environment and social community accommodates them. Many physical features of our society disable those with illness by not providing adequate resources. However the social support that many patients receive from family, friends, neighbours and medical staff has a positive affect on how people cope with their illness.

These three sets of factors are the first stage of adaptation and how they relate to each other influences the next phase – *the coping process*.

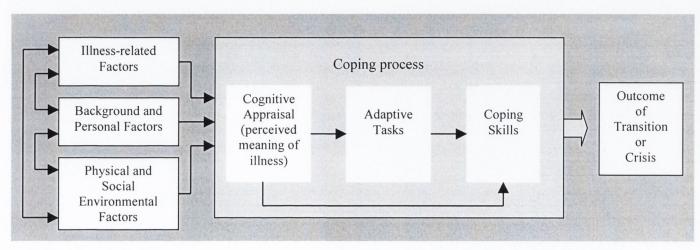


Figure 3.1. A conceptual model for understanding life crises and transitions (Moos & Schaefer, 1986).

The coping process stage has three inter-related components. It begins with the cognitive appraisal of the illness that refers to the perceptions, meanings and beliefs that the person holds about their illness (this will be discussed in more detail later in the chapter, section 3.5). This cognitive appraisal will influence how a person takes on the adaptive tasks of coping. Moos and Schaefer (1986) describe five tasks (see Table 3.1) they believe are encountered in every illness or life event. However, the relative importance and weighting given to each one will depend upon the individual.

Table 3.1 Major Sets of Adaptive Tasks

- 1. Establish the meaning and understand the personal significance of the situation
- 2. Confront reality and respond to the requirements of the external situation
- 3. Sustain relationships with family members and friends
- 4. Maintain a reasonable emotional balance
- 5. Preserve a satisfactory self-image and maintain a sense of competence and mastery

Note. From "Life Transitions and Crises" (Moos & Schaefer) in Moos, R.H. (ed) (1986), Coping with Life Crises: An integrated approach. New York: Plenum Press.

The coping skills that a person employs depends upon their cognitive appraisal and resolution of the adaptive tasks. Whether the person is appraisal-focused, problem-focused or emotion-focused determines the type of coping used. Moos and Schaefer (1986) acknowledge that different coping strategies are neither inherently adaptive nor maladapative, it depends upon the situation and the extent to which the strategy is used. Each strategy can be employed individually or in combination with other strategies.

This theory identifies the key components of coping with a life event or chronic illness and the contributory factors to that coping process. It is the successful resolution of these elements that lead to a positive adaptation to the crisis. Although this model provides a useful framework for understanding the transitions that occur when adapting to a chronic illness, it has not been extensively used within chronic illness research and the relationships between the components have not been empirically tested.

3.3 Overview of Psychological Factors that Influence Control of Diabetes

Twenty two years ago, one of the first reviews of psychological factors in diabetes was published (Fisher, Delameter, Bertelson & Kirkley, 1982). Its acknowledgement of the complexity and vastness of this field was accurate and its emphasis on adjustment to illness, family dynamics and improving diabetes management are contemporary concerns. Ten years later in 1992, Cox and Gonder-Frederick detailed the empirical advancements in behavioural diabetes research. They encouraged a move towards interventions and treatment outcome studies and the inclusion of multidisciplinary sites to improve quality of life for patients with diabetes. The evidence that now exists demonstrates that psychosocial factors (e.g. well-being, quality of life, patient satisfaction, behaviour change, social support, coping) are central to diabetes management (Bradley & Gamsu, 1994; Delamater et al., 2001; Gonder-Frederick et al., 2002). However, the routine inclusion of psychological care within diabetes management has not yet transpired and interventions that do occur have tended to use small sample sizes and single sites (Delamater et al., 2001). Nevertheless, advancements that have been made in the field over the past two decades must not go unnoticed. There has been a move away from the earlier pursuit of identifying personality variables that play a role in the control of diabetes. Much of the research in this area was with children (Johnson, 1980) and older adults (Gordon et al., 1993) with type 1 diabetes. The lack of consistent findings and methodological problems in this research (such as sampling and experimenter biases, poor or unknown inter-rater reliability, lack of appropriate control groups and lack of reliable objective measures) (Fisher et al., 1982), stemmed the potential tide of research in the 1980's into personality and diabetes control.

The relationship between stress and diabetes has also been the focus of research in the past. Studies have examined the role of stress directly and indirectly on diabetes, from the stress of the onset of diabetes, the role in its onset, the physiological affects on glucose levels and stress management (Bradley, 1988). It is not surprising that given the many possible influences of stress on such a complex illness that there have been inconsistent findings in this field. What has been recognised is that every individual with diabetes has their own way of responding to their illness, to stress and to stress management - it is this individuality that needs to be incorporated into diabetes care and research (Bradley, 1994).

In order to integrate the diverse literature from psychology on diabetes, the theory derived from the qualitative stage of the research will be used as a framework (see figure 3.2). The first theme, 'Understanding' will explore people's knowledge and understanding of the illness and introduces two important consequences of diabetes that did not emerge from the first stage of the research. Secondly, 'Personal Perceptions' will discuss in more detail the literature on illness cognitions, in particular the self-regulatory model. Finally, the 'Impact on Daily Life' theme will examine adherence, social support, psychosocial adaptation and coping with diabetes.

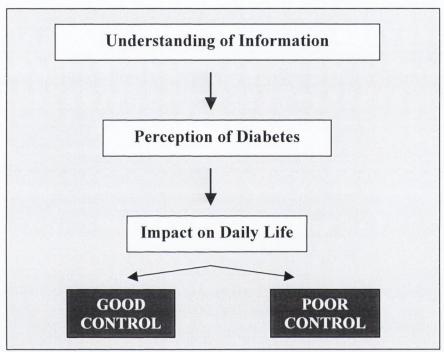


Figure 3.2. Using Qualitative Theory as theoretical framework for current research

Figure 3.2 represents the evidence from the qualitative stage of the research which established the importance of examining concepts such as: knowledge, family involvement, adherence and illness cognitions. The outcome in this research is diabetes control as measured by glycaemic control. However, before discussing each element of this theory in detail, a brief overview of psychology and diabetes research is presented.

3.4 'Understanding'

People with diabetes can only make the necessary changes to their lives if they have been informed of their condition and its management. An earlier approach to interventions

from the 1980's was to educate the patient about their illness. This often happened in a didactic, class-room manner and was a precursor to the patient-centred/self-management approach of the 1990's. There are conflicting results regarding the effect of knowledge on glycaemic control and with different educational interventions and outcome measures characterising much of the earlier work in this field, it can be concluded only that patient education has the potential to increase knowledge and improve glycaemic control (Coates & Boore, 1996). Despite the education that people receive, it has been found that people with diabetes still have a need for information about their illness (Hiscock et al., 2001). Participants in the qualitative study at the earlier stage of this current research, suggested that their partners should also be given opportunities to learn more about diabetes, as they too had to make adjustments related to the diagnosis of diabetes. Knowledge is often included as an outcome measure in trials but there is a need for the consistent use of reliable and valid measures.

3.4.1 Consequences of diabetes

Amongst the possible physical and medical consequences of diabetes detailed earlier (see section 2.2.6) are two complications that can have a substantial impact on psychosocial functioning and quality of life. Problems of sexual functioning and declining cognitive functioning deserve specific attention.

3.4.1.1 Sexual functioning

Although acknowledged as a common consequence of diabetes, psychological research on sexual functioning in diabetes is still in its infancy. With the exception of De Beradis et al.'s cross-sectional study (2002), there has been little attention given to the effects of sexual dysfunction on psychological well-being and quality of life. In their study of almost three thousand men with type 2 diabetes, 34 % reported erectile dysfunction frequently and a further 24% reported it as occurring occasionally. Their study linked erectile dysfunction to significantly higher levels of stress and poorer psychological adaptation to diabetes. Approximately thirty five per cent of men with diabetes will develop problems of sexual functioning and this figures increases to fifty per cent for men over fifty years of age with diabetes (Diabetes Update, 2003). The causes of these problems in men are mainly related to neuropathy complications and/or peripheral vascular disease (Watkins, 2003). For women, the relationship has not been examined to the same extent (Enzlin, Mathieu & Demytteanere, 2003) but it appears to have a strong

relationship with psychological factors (Thomas & LoPicciolo, 1994). Different treatments are available from psychosexual therapy (which is recommended for all patients with problems of sexual functioning), to oral medications and surgical treatment, Treatment is highly successful with psychosexual therapy alone responsible for success in 50% to 80% of motivated diabetes patients (Watkins, 2003).

3.4.1.2 Cognitive impairment

Since the 1970's the effect of diabetes control on cognitive functioning has received attention in the literature. However, there has only been a small number of studies addressing this topic and the findings are inconsistent (Asimakoupoulou & Hampson, 2002). This field of inquiry is fraught with methodological difficulties with the majority of studies being either case control or epidemiological (Asimakoupoulou & Hampson, 2002). There is also a lack of consensus on the measures to be used, Areosa Sastre and Grimley Evans (2002) mention that over 60 are in use in research. Other problems include small participant numbers and often the lack of suitable controls (Cosway, Strachan, Dougall, Frier, & Deary, 2001). In their Cochrane Review on treatment for cognitive impairment in diabetes patients, Areora Sastre and Grimley Evans (2002) could not find any studies that were suitable for inclusion. The evidence that exists from prospective and longitudinal studies confirms the association between diabetes and a decline in cognitive functioning (Gregg, Engelgau & Narayan, 2002) and points to a two-fold increase in the risk of cognitive impairment or dementia in people with diabetes when compared with the general population. This risk is influenced by age, duration of diabetes, glycemic control and other co-morbid illnesses (e.g. hypertension, depression and neuropathy) (Asimakoupoulou & Hampson, 2002). Given that the research points to the more complex aspects of cognitive functioning being affected, in particular verbal memory (Cosway et al., 2001), it is surprising that only one review has looked specifically at the affects of impaired cognitive functioning on diabetes self-management (Asimakoupoulou & Hampson, 2002). They concluded that cognitive impairment is not likely to affect self-management for those with type 2 diabetes. However, given the lack of consensus in this area, there is a need for an extensive study of the effects of diabetes on cognitive functioning.

3.5 'Personal Perceptions'

3.5.1 Illness cognitions

Illness cognitions have been defined as "any mental activity (e.g. appraisal, interpretation, recall) undertaken by an individual who believes himself or herself to be ill, regarding the state of his or her health and its possible remedies" (p. 32) (Croyle & Ditto, 1990). How a person thinks about their illness has a direct effect on their illness and treatment behaviours. The research on illness cognitions and representations has gained momentum over the past decade but earlier studies from social and cognitive psychology cannot be ignored for the lasting contributions they have made.

Many theories in health psychology have origins in social psychology. One such example is Festinger's Social Comparison Theory (1954) which has been used as a method of explaining peoples' evaluations of their illnesses and symptoms (Pennebaker, 1982). The original theory asserts that as humans we evaluate our opinions and abilities by comparing them to others who we feel are better off than ourselves (upward comparison) or worse off (downward comparison). Croyle and Barger (1993) support the view that experiencing a physical illness is conducive to downward comparison, thereby increasing subjective well-being.

Jenkins, in 1966 was one of the first to analyse illness representations in a systematic way. His factor analysis of 16 questions relating to illness representations led to three dimensions believed to represent illness: those of personal involvement, human mastery and social desirability (Croyle & Barger, 1993). His use of single items to measure complex constructs has been criticised and researchers using other approaches began to dominate the field. It was in 1980 when Leventhal, Meyer and Nerenz published their paper on 'The common-sense model of illness danger' that health psychology began to contribute to and develop the study of illness cognitions. Previous to this it was a topic most likely to be examined from a medical anthropological or sociological perspective. Leventhal et al.'s 1980 paper provided an alternative cognitive model to the other behavioural models of the time (e.g. Health Belief Model (Becker & Rosenstock, 1984), Self-efficacy (Bandura, 1977), and the Theory of Planned Behaviour (Azjen & Fishbein, 1980)) and was the first to present empirical data explaining the structure and process of patients' illness schemata (Skelton & Croyle, 1991). It differs from these models because

it doesn't presume rational, knowledge-based reasoning by the patient, instead this illness cognitions model acknowledges that reasoning, stemming from beliefs about the illness can influence behaviour (De Ridder, 2004).

3.5.2 Self-regulatory Model of Illness Representations

Leventhal et al.'s (1980) model was further developed in 1984 (Leventhal, Nerenz and Steele) to become the Self-Regulatory Model of Illness Representations (see Figure 3.3). Bishop (1991) succinctly describes this as a model that "views health-related behaviour as the result of an iterative process by which the person integrates both internal and external stimulus information with existing cognitive structures to give meaning to the person's experience" (p. 33). In other words, it identifies how a patient processes information about their illness and how these cognitions influence coping and outcomes (e.g. disease management, psychological well-being and social functioning). This model attempts to capture the important aspects of behavioural self-regulation such as emotional processes, the dynamic nature of behavioural decisions and the appraisal process (Cameron & Leventhal, 2003). The theory of self-regulation has been described as 'ideally suited to understanding and improving patients' management of chronic illness' (Petrie, Broadbent & Meechan, 2003, p. 257). Patients need to be able to constantly feedback information about their condition to make behavioural changes and because of its flexible nature, the Self-Regulatory Model facilitates this.

A particular strength of this approach is that it starts with the patients experience and *their* model of *their* illness (Weinman & Petrie, 1997). The inclusion of the patient's perspective means that they play an active role in processing their experience (Bishop, 1991). Other unique features of this model are that it uses illness representations to understand the coping mechanisms that people employ. It is also one of the few models within health psychology that draws on the important sub-fields of persuasion, motivation and emotions, partly due to Leventhal's research background in these areas (Skelton & Croyle, 1991).

This model involves many different factors operating on different levels and influencing each other to achieve self-regulation. Therefore, it seems appropriate that a systems approach is taken to understand these dynamic interactions that take place (Bishop, 1991).

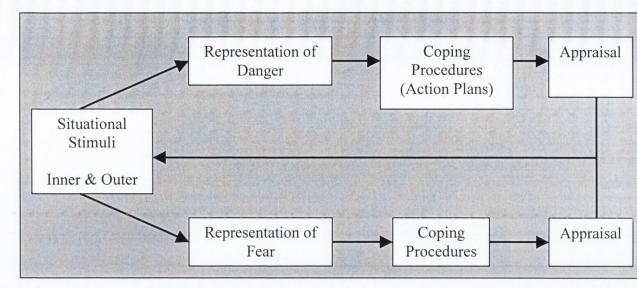


Figure 3.3. Parallel process model of the self-regulatory model (Leventhal et al., 1984).

The first stage of the Self-Regulatory Model of Illness Representations begins with people creating cognitions about their illness based on their 'lay' information of the illness, information they have received from perceived significant others (e.g. spouse, doctor) and the symptoms they are currently experiencing. People interpret these concrete and abstract sources of information in a way that helps them manage and make sense of their illness (Leventhal et al., 1984). The next stage of the model has been referred to by Leventhal as a parallel processing model, where emotional representations (representation of fear) and cognitive representations (representations of danger) are simultaneously developed. It is the cognitive representations that have received most attention in the research and from extensive open-ended interviews (Meyer, Leventhal & Gutman, 1985) four dimensions of illness emerged:

- (1) Identity beliefs about the illness's label and the symptoms being experienced. Different researchers use different methodologies for measuring identity, some use statements regarding identity beliefs, knowledge of symptoms or lists of illness-related symptoms experienced (Hagger & Orbell, 2003).
- (2) Cause beliefs people have about what caused their illness e.g. environmental, psychological or genetic. There are many different approaches and interpretations used in studies of illness causal attributions and the subsequent inconsistencies prevent accurate understandings to develop of how people think about the causes of their illness (Shiloh, Rashuk-Rosenthal & Benyamini, 2002). When these researchers

- examined the illness cognitions literature for causes of illness, they found 140 different causes listed, demonstrating the potential breadth of this area.
- (3) Timeline beliefs about the course the illness will take and the timescale of its symptoms
- (4) Consequences beliefs about the impact that the illness will have on daily life Research by Lau and Hartman (1983) led to a fifth dimension being added:
- (5) Cure/controllability beliefs about whether the illness can be cured and the sense of control over coping behaviours and/or treatment.

Hagger and Orbell (2003) conducted a meta-analysis of 45 empirical studies that used the Self-Regulatory Model of illness representations (also referred to as the Common-Sense Model of Illness Representations). Their analysis has provided further support for the construct and discriminant validity of these five illness dimensions across different illness types. The intercorrelations amongst the illness dimensions have not only been shown to be strong and significant (e.g. Weinman, Petrie, Moss-Morris & Horne, 1996) but they also demonstrate a systematic and logical pattern of relations. Such is the support and acceptance of these five illness dimensions, that Heijmans & De Ridder (1998) referred to them "as the basic building blocks of illness representations" (p. 486). Nevertheless, there is a lack of research that tests the specific components of the model in relation to preventative behaviours (Walsh, Lynch, Murphy & Daly, 2004).

The first four illness dimensions have positive interrelationships (Hagger & Orbell, 2003). A higher score on the identity dimension or a strong illness identity, is related to a more chronic timeline and more serious consequences (Weinman et al., 1996). Timeline is also associated with more serious consequences, meaning that those who view their illness as lasting a longer time also view it as having more consequences on their life. The last dimension of curability/controllability has negative relationships with the other illness dimensions. Those who perceive themselves to have a higher degree of control over their illness also believe that they will suffer fewer serious consequences of their illness. The illness dimensions that people develop may not be in accordance with medical knowledge or advice, but they are the cognitions that people use to make judgements about and manage their illness (De Ridder, 2004).

Simultaneous to the development of these illness representations exists the emotional representations that people make. These are the emotional responses that people have in relation to their illness that affect their coping strategies. For example fear of pain may lead to avoidance behaviours or anxiety about symptoms may result in a person seeking treatment. The rise in research on the illness dimensions in the Self-Regulatory Model over the past decade has dominated, and there has been a neglect of the emotional representations component of the model. The inclusion of a five-item scale of emotional representations within the Revised Illness Perception Questionnaire (IPQ-R) is a welcome addition (Moss-Morris, Weinman, Petrie, Horne, Cameron & Buick, 2002). As it is a new component, the relationships between emotional representations, coping and outcomes have yet to be understood.

The final part of the Self-Regulatory Model of illness representations presents how coping impacts on the health outcomes of disease state, social, role and physical functioning, psychological well-being, vitality and emotional distress. One of the first studies to show the impact of illness representations on disease management and behaviour, Meyer et al. (1985) found that patients most likely to adhere to their recommended treatment were newly diagnosed, rather than patients who had the illness for a long time and had a chronic timeline. Research has shown how health outcomes have a negative relationship with serious consequences, strong identity and a chronic timeline (Heijmans & De Ridder, 1998; Scharloo et al., 1998). With the exception of disease status they have also been shown to have a positive relationship with a high sense of control (Moss-Morris, Petrie & Weinman, 1996). The effects of these dimensions on the management of illness and illness behaviours will vary according to the illness (Leventhal & Benyamini, 1997). In their work with cardiac patients, Petrie, Weinman, Sharpe and Buckley (1996) found that several outcomes were related to illness representations. Participation in cardiac rehabilitation was significantly related to a strong cure/control belief at admission, those who returned to work earlier had a shorter timeline perception and lower consequences, higher consequences were significantly related to later disability, and a strong illness identity was related to greater sexual dysfunction.

A key element of the Self-Regulatory Model is the feedback loop that allows for the appraisal of success or failure of coping, which in turn leads to revised goals or strategies (Cameron & Leventhal, 2003). A problem with this, as Bennett (2000) states is that

'most researchers have not explored the complexities of a recursive system and have focussed instead on the relationship between coping strategies and a single outcome at one point in time' (p. 75). Two of the original researchers (Nerenz & Leventhal 1983), pointed out that there is a generic underlying structure to illness representations but they are not well integrated and may not always all be present (Bennett, 2000). Stam (2004) in his analysis of theory in health psychology is critical of the relatively simple theories that exist in the discipline. He quotes Leventhal (1996) in his American Psychological Association presidential column as saying that 'many of our theories are little more than broad themes that guide but do not constrain our thinking; they are frames of reference rather than theories'. Despite the enormous gains in illness representations research, there has been a lack of theoretical testing of the Self-Regulatory Model itself. Whilst the illness dimensions have been supported by research, there is a need to investigate all of its elements, in particular the appraisal process, and for formal testing of the model (Hagger & Orbell, 2003).

It is also interesting to note that the move from general models of illness representations to disease specific models has not received adequate attention in the literature. There are advantages to both approaches. A disease specific model would ensure that the nuances of each illness would be captured, whereas a general model would develop more general principles that would be more flexible and inclusive (Schiaffo, Shawaryn & Blum 1998). Heijmans and De Ridder (1998) report that there is no structure that is common to all illnesses, instead illness dimensions tend to merge together depending on the illness under investigation. Whereas Schiaffo, Shawaryn & Blum (1998) argue that despite different illnesses, patients often have similar knowledge and difficulties. This warrants further discussion to ensure consistency and continuity in future research.

Another issue within the literature on illness representations is that it largely based on cross-sectional data. In their early research, Nerenz and Leventhal (1983) mention that a crucial step in coping with chronic illness is in acknowledging that the illness *is* a chronic one. It seems paradoxical then that given a few exceptions (e.g. Petrie et al 1996), there is a dearth of longitudinal research on chronic illness representations. We do not have an understanding of how illness representations change over time or differ at various points in the illness. There is a need for longitudinal research examining these changes (Hagger & Orbell, 2003).

The publication of the first intervention to specifically target changing illness representations to improve outcomes (Petrie, Cameron, Ellis, Buick & Weinman, 2002) has heralded a move from assessment-type research to interventions. This is not an entirely new departure given that interventions to improve outcomes have previously incorporated illness cognitions. For example, in diabetes, interventions that include illness representations have been shown to improve the self-management of diabetes with clinically significant results (Petrie et al., 2003). However, these studies have mainly included patients with type 1 diabetes (e.g. Snoek et al., 2001) and tend to be more successful when the effects are immediate and measurable e.g. a reduction in blood pressure. Petrie et al.'s (2002) intervention aimed to improve the time it took myocardial infarction patients to return to work by changing inaccurate and negative illness perceptions they held to more accurate and positive perceptions. The intervention was a brief cognitive-based one that took place over three sessions while the patient was still in hospital. Not only was it successful in bringing about positive changes in patients' illness cognitions but it significantly improved the rate at which patients returned to work compared with routine care.

As promising as these results are, Hampson (1997) cautions against the use of illness representations solely as a basis for interventions in diabetes. Improvements in self-management and glycaemic control result from the complex intertwining of psychological, social and biomedical factors. It is these relationships that have yet to be understood.

3.5.3 Illness representations and diabetes

Diabetes has been shown to be the most studied illness within the literature on illness representations (Hagger & Orbell, 2003). Diabetes itself is an illness that requires self-regulation (Petrie et al., 2003). Patients must constantly attend to their symptoms, self-monitor their blood glucose levels and remain vigilant about their diet and exercise in order to achieve good glycaemic control and prevent long-term complications.

Understanding diabetes from a self-regulatory perspective has allowed researchers to understand how patients, in particular those with type 1 diabetes, arrive at their daily self-treatment decisions and achieve long-term control (Gonder-Frederick & Cox, 1991; Wing, Epstein, Nowalk & Lamparski, 1986). The literature on illness representations and the self-management of diabetes incorporates studies which examine constructs closely

associated with the Self-Regulatory Model (e.g. control, causal attributions) and those which explicitly use Leventhal's model (Hampson, 1997). Although diabetes is the most studied illness in this field, the number of studies is still limited (Griva et al., 2000). From the research that does exist, there is a weighting towards type 1 diabetes research. In their meta-analysis of 45 illness representations studies, Hagger & Orbell (2003) included only three studies which exclusively examined type 2 diabetes. A further four studies included both type 1 and type 2 diabetes within the same study. Despite the limited amount of research, there is support for the Self-Regulatory Model in diabetes (Hampson, 1997).

3.5.3.1 Illness representations and outcomes in diabetes

One of the characteristics of type 2 diabetes is that it can be asymptomatic before diagnosis and during the illness. The majority of studies of symptom awareness have been with type 1 diabetes and the research conducted with type 2 diabetes has tended to show that although people detect hyperglycaemia better than hypoglycaemia, their estimates of blood glucose levels are inaccurate (Hampson, 1997). It is important that patients monitor their symptoms and take appropriate action for the daily and long-term management of their illness. Murphy & Kinmonth (1995) found that people with type 2 diabetes don't interpret their symptoms in terms of short-term and long-term diabetes management. Their qualitative exploration of patients understanding of their illness, found that patients oriented themselves either towards the avoidance of short-term symptoms or toward the avoidance of long-term complications. Those who took a longerterm view of diabetes self-management also perceived it as a more serious illness. Another illness dimension, control has been associated with greater involvement in diabetes self-care behaviours. Griva et al. (2000) also found in their study of 64 young adults and adolescents with type 1 diabetes that control beliefs were consistently related to self-reported adherence. Along with self-efficacy, they found that consequences and illness identity accounted for 40.6% of the variance in HbA_{1c}. This study again shows the link between illness cognitions with diabetes outcomes and although preliminary in nature, it does provide an opportunity for future longitudinal and intervention studies.

Hampson and colleagues developed their own method of investigating people's personal models of their diabetes through structured interviews and more recently, questionnaires. Their first study (Hampson, Glasgow & Toobert, 1990) investigated the relationship between the personal models of diabetes and self-care activities. A comprehensive

Personal Models of Diabetes Interview (PMDI) was conducted with 46 females with type 2 diabetes. This interview was based on the illness dimensions of the Self-regulatory Model and led to four composite indicators of personal-models; cause, symptoms, treatment and seriousness. Dietary self-management could be significantly predicted and exercise behaviour only marginally predicted from the personal models. These findings have been replicated in a larger study (n=78) including both males and females with type 2 diabetes (Hampson, Glasgow & Foster, 1995). Another study focusing on adolescents with type 1 diabetes, provides further support for the use of illness beliefs and personal models in understanding self-management behaviours (Skinner & Hampson, 2001).

3.5.3.2 Context of diabetes illness representations

Baumann (2003) wrote that "self-regulation mechanisms arise from both individual and collective experiences" (p. 250). Therefore, a key influence on the development of illness representations is the environment a person lives in. A true understanding of how people think about their illness can only be reached by placing their illness representations within the context that they have been developed in. This has led to studies examining the health beliefs of people with diabetes from different cultural and ethnic backgrounds (Greenhalgh, Helman & Chowdhury, 1998; Maillet et al., 1996 and Sunday & Eyles, 2001). A number of studies have specifically addressed illness representations of diabetes within a cultural context. Sissons Joshi (1995) explored causal attributions of diabetes in England and India and found that a much higher percentage of Indian patients gave diet or their own eating as a cause of diabetes than the English patients did. The important social role of food within Hindu society meant that for some separating their social obligations from their needs as a person with diabetes proved difficult. For English patients, having a causal theory for their diabetes was connected to their subsequent adjustment to the illness. Thompson & Gifford (2000) ethnographic research has provided insights into the meaning of diabetes for an urban Aboriginal community. The lack of balance that many experience in the management of their 'sugar diabetes' is seen as intertwined with the lack of balance in daily life. For this group, the symptoms of diabetes are not recognised prior to diagnosis and often attributed to other life events so that when the diagnosis comes it's perceived as sudden. This impacts on the perceived timeline of diabetes and its subsequent control. Diabetes is seen as an illness consisting of a series of acute episodes rather than as a long-term chronic disorder. Even the language used when talking about

diabetes is the same language for acute infectious illnesses. Again, the central role of the family and food within this culture means that adherence to diet has additional pressures.

These studies highlight the impact of cultural environment on the development of illness representations and self-management behaviours. Two further studies have specifically examined the Self-regulatory Model from a cultural perspective (Barnes, Moss-Morris & Kaufusi, 2004; Jayne & Rankin, 2001). Again, these studies highlight the benefits for diabetes care of understanding illness representations within a cultural context and taking cognisance of factors such as people's religious beliefs, their experiences with the health services, beliefs about modern medicine and the stigma attached to certain illnesses.

3.5.3.3 Family and illness representations

One factor common to all cultures is that illness takes place within a family context. It is within the family where the earliest illness representations are formed as symptoms acquire labels and meanings, and behaviours are learned (Leventhal & Benyamini, 1997). This was recognised early on in the development of models on illness representations "every component of the illness control system from the representation of disease through the development and execution of coping to appraisal is heavily influenced by interaction with the family and by its impact on the family unit" (Leventhal, Leventhal & van Nguyen, 1986, p. 116). Leventhal, Leventhal and Contrada (1998), discuss two ways in which social and cultural factors influence illness representations: firstly through the cultural information that exists regarding illness and its labels and secondly, through more direct social encounters which influence decision making and illness management behaviours. As Weinman et al., (2003) note, this influence of social environment is more pronounced now, given that most chronic illnesses are managed at home, yet family context has been neglected in the research on illness representations. Despite social context being recognised from the outset as constantly influencing every component of the self-regulation system (Leventhal, Brissette & Leventhal, 2003), there has been a lack of research on understanding how such processes work and how they influence selfregulation. Several studies have been conducted with patients and their spouses with chronic fatigue syndrome and Addison's disease (Heijmans, De Ridder & Bensing, 1999) and with those recovering from a myocardial infarction (Figueiras & Weinman, 2003). What these studies have shown is the considerable differences that couples have about illness representations. Those with more congruent representations had better illness and

psychological outcomes. There has also been an extension of illness perceptions from its previous confinement to physical illness to mental health (Barrowclough, Lobban, Hatton & Quinn, 2001). Further research needs to examine the level of congruence amongst patients and spouses, its effects on outcomes and its relationship to social support. The inclusion of the social context in more recent research on illness representations has begun to address one of its criticisms that it remains largely concerned with internal, individual processes while ignoring the external and social influences (Ogden, 1995).

3.5.4 Measuring illness cognitions

A key contributory factor to the increase in research on illness representations, particularly over the past decade has been the availability and accessibility of measurement tools. In particular, the Personal Models of Diabetes Interview (PMDI) (Hampson et al., 1990), the Illness Perception Questionnaire (IPQ) and more recently, the Revised Illness Perception Questionnaire (IPQ-R) (Moss-Morris et al., 2002; Weinman et al., 1996). The original Illness Perceptions Questionnaire was developed as a method of assessing illness representations. Its scales were derived from the five illness dimensions of the Self-Regulatory Model and based on data from seven different illness groups: myocardial infarction, chronic fatigue syndrome, rheumatoid arthritis, diabetes, pain, renal and asthma. Although originally devised as a generic assessment tool, diseasespecific versions were later developed. The questionnaire was revised to address some minor psychometric problems but more importantly to include a scale on emotional representations and illness coherence. The inclusion of emotions is welcomed, as the original IPQ assessed only the cognitive aspects of patients' representations and in doing so limited our understanding of how people respond to illness. However, the development of the IPQ-R is based on one study of cross-sectional data and is a relatively recently addition to the field of illness representations. Further prospective studies will confirm the associations across time for different illnesses. Nevertheless, the expansion within illness representations research to include other aspects of the Self-regulatory Model such as social context and emotions may preclude it from relying solely on the five illness dimensions to become as Hampson (1997) warned "a collection of variables and not a truly integrated theory".

The use of the IPQ alongside the PMDI with type 1 diabetes patients has found generally consistent results (Lawson, Bundy, Lyne & Harvey, 2004). There are other standardised

measures of illness representations which are used in the research (e.g. Implicit Models of Illness Questionnaire; Turk, Rudy and Salovey, 1986) alongside other non-generic measures and qualitative methodologies. Little is known about the advantages and disadvantages of each method (Heijmans & De Ridder, 1998) and what is now needed are comparison studies to identify the strengths and weaknesses of the different methods (Moss-Morris et al., 2002).

3.6 'Impact on Daily Life'

3.6.1 Adherence to treatment

Patient non-adherence was described in 1979 as one of the most serious problems facing the health profession (Dunbar & Stunkard, 1979). Little has changed in the intervening years and in the United States, the financial burden of patient non-compliance has been estimated to be 100 million dollars each year (Haynes, McKibbon, Kanani, Brouwers & Oliver, 1997). One of the first problems in the research on adherence is the lack of a standardised definition. There has also been a change in terminology, from patient compliance to adherence to concordance. The term compliance has been considered to have negative connotations and implies that the power lies with the health professional. Concordance however implies that the patient is a more active participant in their health care. The term adherence includes the partnership approach from concordance and is more widely used in the literature. It is this term that will be used throughout this thesis and corresponds with the adopted definition from the World Health Organisation Adherence meeting (2001) that adherence to a long-term therapy is:

'the extent to which a person's behaviour – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider'.

The research on adherence is fraught with difficulties, researchers use different terms and definitions of adherence, the methodologies used are varied both in nature and quality and the assessment of adherence has been conducted by objective, subjective, standardised and unstandardised methods. One persistent and consistent finding is that people with chronic conditions have difficulty adhering to their long-term treatment recommendations (Vermeire, Hearnshaw, Van Royen & Denekens, 2001; WHO 2001)

3.6.1.1 Issues in assessing adherence

Two of the main issues in assessing adherence are the different types of assessment tools used and the different reasons for non-adherence. Measurements of adherence vary from pill counts, self-monitoring diaries and observation to biomedical indicators such as blood and urine tests. However, the most frequently used method is patient self-report, which has a tendency to overestimate adherence rates (Ley, 1997). Patients often feel threatened when reporting adherence levels to health care professionals and Warren and Hixenbaugh (1998) found in their study of 324 adults with diabetes that 43% of patients regularly and 20% occasionally do not tell the truth about adherence to health care professionals. The reasons given were that they wanted the health care professional to believe that they thought their diabetes was serious and that they didn't want them to become angry. Such figures emphasise the importance of ensuring reliability when using self-report measures, for example by making the data anonymous.

There are many different reasons why patients do not adhere to their recommended treatments but they can be broadly divided in two categories.

- (1) Non-intentional whereby the patient does not intend to be non-adherent but through lapse of memory or lack of understanding, behaviours aren't adhered to
- (2) Intentional, also referred to as intelligent non-adherence as the patient makes their own decisions as to which elements of the treatment regimen will fit in best with their desired lifestyle.

3.6.1.2 Adherence and diabetes

In diabetes, there is the potential for numerous adherence problems, given the behavioural complexity and number of regimen demands placed upon the patient (i.e. diet, exercise, blood glucose monitoring and exercise). The literature on adherence to treatment for diabetes reflects the problems in adherence research: there is a lack of explicit standards for adherence, the complexity of long-term treatments (Johnson, 1993), the lack of clear concepts, the absence of theory-based research and the lack of differentiation between adherence, self-care behaviour and metabolic control (Glasgow et al., 1989). In addition there are inconsistencies in the literature due to the lack of methodological rigour in research designs, sampling frames, selection of measures, sample size and the lack of control of confounding variables (WHO, 2001).

For some people with diabetes, finding the motivation to adhere is difficult as the complications that result from non-adherence only become evident in the long term. Therefore, there are often no immediate disadvantages of non-adherence. Of the research that has taken place, the majority has been conducted with children and adolescents, and little is known about adherence for adults with diabetes (Warren & Hixenbaugh, 1998). One estimate from the American Diabetes Association was that less than 2% of adults with diabetes fully adherence to all aspects of their treatment regime (Beckles et al., 1998). It is also important to remember that many people with diabetes also have comorbidities such as hypertension, obesity and depression. These co-existing illnesses not only add to the complexity of adhering to treatments but increase the likelihood of poorer outcomes (Ciechanowski, Katon & Russo, 2000). A further complication of adherence rates from the research is that they simply convey that the behaviour took place, they do not indicate that the behaviour was correctly performed. Taylor (1999) describes studies that found that 80% of those taking insulin, do so incorrectly, 58% administer the wrong dosage and 77% test the sugar content of their urine incorrectly.

There are also no consistent findings regarding adherence to treatment regimen and subsequent glycaemic control. Those that have found such a link, tended to use global measures of adherence, cross-sectional designs and were unable to determine the direction of causality (Warren & Hixenbaugh, 1998). A further complication in the literature on adherence in diabetes is the lack of consistency across the demands of diabetes treatment (Orme & Binik, 1989). These researchers demonstrated that adherence to one component of the diabetes regimen is relatively independent of adherence to the other components and warned against the use of global measures of adherence in diabetes.

With these issues in mind, adherence rates for each of the four components of the diabetes regimen have been examined. Levels of adherence to diet vary greatly across studies. Anderson & Gustafson (1998) found 70% of participants had good-to-excellent adherence to their recommended diabetes diet whereas an earlier study reported that up to 75% of those with diabetes did not adhere to their diet (Christensen, Terry et al., 1983). Figures for adherence to exercise are difficult to find. However, given the consensus that adherence rates to changing lifestyle behaviours are low (Taylor, 1999), it can be

expected that exercise behaviours will be less well adhered to than other aspects of the regimen. Blood glucose monitoring works in a different way and many people with diabetes rely on how their blood glucose levels 'feel', rather than on actual readings, similar to hypertension patients (Hampson et al., 1990). It is common practice for people with diabetes to keep a diary of their blood glucose recordings; however not all patients monitor and record their blood glucose levels in a systematic way. Studies have shown that between 40% and 80% of patients under record their blood glucose levels on at least half of their recordings in order to make them look more favourable (Warren & Hixenbaugh, 1998). Taking medication and insulin injections are the most frequently adhered to components of diabetes treatment (Warren & Hixenbaugh, 1998). In general, adherence to the lifestyle aspects of diabetes treatment (diet and exercise) is lower than adherence to medication or insulin injections (Orme & Binik, 1989). Overall, approximately only 15% of patients appear to adhere to all of their treatment recommendations (Taylor, 1999).

The move to more patient centred care and examining the illness from the patient's perspective has the potential to improve adherence rates and influence this area of research. Based on the correlates of adherence in diabetes (WHO report, 2001), future investigations should acknowledge: treatment and disease characteristics (e.g. the duration of diabetes, particular milestones within diabetes such as the move to medication or insulin and its potential effects on adherence), intra-personal factors (e.g. the age, gender, self-esteem, stress levels of the patient), inter-personal factors (e.g. patient-provider relationship and social support), and environmental factors (e.g. the influence of culture and environment on adherence).

3.6.2 Social Support

"It is important to recognise that family members and friends are directly or indirectly affected by an event, encounter the same or closely related adaptive tasks, and use the same kinds of coping" (Moos & Schaefer, 1986, p. 10).

While taking a family approach for improving the management and outcomes of diabetes has become the norm for children and adolescents with diabetes, adults with diabetes are often considered in isolation from their social context (Warren & Hixenbaugh, 1998). Little attention has been given to the importance of the family in adult diabetes (Hixenbaugh & Warren, 1998) and unsurprisingly, research on families and diabetes

management is limited (Fisher et al., 1998). A review of diabetes and behavioural medicine goes as far as to say that in the literature on adult diabetes, family factors have been 'virtually ignored' (Gonder-Frederick et al., 2002). Recently, a more socioecological approach has been taken (Fisher et al., 2002) which has recognised that the successful management of diabetes depends not only on the person with the illness but on their family, friends, work colleagues and community (Glasgow et al., 2001).

One way of examining the role that family play in the management of diabetes is through the concept of social support. There is extensive empirical evidence that people with strong networks of support live longer and enjoy better health than more isolated individuals (Uchino, Cacioppo, & Kiecolt-Glaser, 1996). What is still unknown is how this causal relationship works. It is thought that having strong networks of support proveides a buffering effect against stress. However, there is little agreement on how to conceptualise social support, and a lack of guiding theoretical frameworks in this area has meant that much of the research is descriptive in nature.

From diabetes research with children and adolescents it has been found that increased parental involvement is associated with increased blood-glucose monitoring (Anderson et al., 1997). Both family and friends' support is important to the adolescent (Skinner, John and Hampson, 2000) in terms of general emotional support and diabetes-specific support. As previously mentioned (section 2.6.1), research with people with type 2 diabetes indicates that diabetes-specific measures of family support are stronger predictors of diabetes self-care than are the more global measures of family functioning (Glasgow & Toobert, 1988). Studies in general have shown a relationship between poor social support and poor self-management of diabetes (Belgrave & Moorman, 1994; Schlundt et al., 1994). Not only is it important to look at social support at a diabetes-specific level but because of the lack of consistency of behaviour across regimen demands (Orme & Binik, 1989), it is recommended that supportive relationships in diabetes should be examined at a regimen specific level (Skinner and Hampson, 1998).

3.6.3 Psychosocial adaptation

3.6.3.1 Psychological well-being

Psychological and physical well-being are interdependent in the management of diabetes and according to Bradley & Gamsu (1994) 'psychological well-being is, in its own right,

an important goal of diabetes management'. Because of the broad nature of the term 'psychological well-being', studies often examine elements of psychological well-being such as depression, anxiety, stress or self-esteem. Lower well-being for those with type 2 diabetes has been found to be associated with a greater number of illness complications (Eiser, Riazi, Eiser, Hammersly & Tooke, 2001), although the patients in this study were from a hospital clinic sample which may have included those experiencing more complications than the general diabetes population. This study also found no relationship between glycaemic control and psychological well-being. This lack of a relationship between glycemic control and psychological well-being was found in a randomised controlled trial set up to examine the effects of including psychological well-being in patient care (Pouwer, Snoek, van der Ploeg, Ader & Heine, 2001). Although it resulted in more positive well-being, the intervention did not influence HbA_{1c}. Similar results have been found in other randomised controlled trials (e.g. Kinmonth et al., 1998; Smith et al. 2003), and understanding the relationship between psychological and physical outcomes remains.

3.6.3.2 Depression

Psychological well-being is often thought of in terms of depression. This is of particular importance in diabetes because higher rates of depression have been associated with people with diabetes. When compared with people without a chronic illness, those with diabetes are two-three times more likely to have depression (Anderson, Freedland, Clouse & Lustman, 2001; Nichols & Brown, 2003). Prevalence figures suggest that between 30% to more than 40% of people with diabetes suffer from depression (Anderson et al., 2001; Peyrot & Rubin, 1997). Although depression in diabetes has been shown to respond to non-medical treatments such as coping skills training (Peyrot & Rubin, 1999) and cognitive behaviour therapy (Lustman, Griffith, Freedland, Kissel & Clouse, 1998), it is often undiagnosed in diabetes patients (Peyrot, 2003). The consequences of this can have an impact on diabetes management and glycaemic control. Higher levels of both anxiety and depression have been found in separate meta-analyses to be associated with hyperglycaemia (Anderson et al., 2002; Lustman et al., 2000). Following on from this is the finding from a meta-analysis of 27 studies, that depression is significantly and consistently associated with diabetes complications (De Groot et al., 2001). What is not yet understood is the mechanisms by which depression and diabetes are associated or the causal direction – it is unknown whether people are more depressed because of their

complications or if their depression lead to less effective management and subsequent complications. Further longitudinal investigations and interventions are needed to understand depression and its causal relationship in diabetes.

3.6.4 Coping

Coping can play a key role in the adjustment to an illness and its subsequent management (Macrodimitris & Endler, 2001; Maes, Leventhal & De Ridder, 1996). There are two broad approaches to coping that have been identified in the literature. Firstly, dispositional coping focuses on an individual's usual coping strategies or coping style. Because people do not use new coping strategies each time they encounter a stressful situation, they rely on their coping disposition or style (Carver, Scheier & Weintraub, 1989). Secondly, situational coping examines whether different situations need different strategies. Coping is not seen as static but as a process of appraisal and has been defined by the early researchers in this field (Lazarus & Folkman, 1984) as:

'constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person' (p. 141).

Lazarus and Folkman (1984) describe a two-stage appraisal of stress. Firstly, the situation itself is appraised as harmful or beneficial and secondly, if it is appraised as harmful, the coping resources needed to reduce stress are appraised. This sense of a changing process where events and outcomes are appraised and the results acted upon is similar to the mechanisms of the Self-Regulatory Model of illness representations, where appraisal of outcomes provides feedback for how the situation is interpreted. Some of the research in relation to illness representations and coping has been previously discussed (section 3.5.2).

3.6.4.1 Coping strategies

There are two main coping strategies that were identified by Lazarus and Folkman (1984):

(1) Problem-focused coping, which uses cognitions and behaviours to manage the problem, e.g. finding out information, planning, seeking practical social support and learning new skills.

(2) Emotion-focused coping relies on regulating emotions in relation to the stressor, e.g. distraction, seeking emotional social support and changing cognitions about the meaning of stressful events.

These two strategies are not independent and can be used together (Myers, Newman & Enomoto, 2004). A third coping strategy has been added by Endler and Parker (2000) which they termed avoidance coping. This coping strategy refers to methods that people use to escape from the stressful situation, e.g. focusing on other unrelated priorities, being in the company of other people,

In general, with chronic illness, it has been found that problem-focused coping is related to better adjustment. (Myers et al., 2004). It does however, depend upon the situation, as problem-focused coping is more suited to controllable situations, whereas emotion-focused coping is better in uncontrollable situations, such as terminal cancer (Endler, Parker & Summerfelt, 1993). The research has found more favourable outcomes in diabetes with the use of problem-focused coping (Rose, Fliege, Hildebrandt, Schirop & Klapp, 2002), but the majority of this research has been with type 1 diabetes and little is known about coping for those with type 2 diabetes (Macrodimitris & Endler, 2001; Karlsen & Bru, 2002; Maes et al., 1996). The reason why problem-focused coping is a more favourable strategy in diabetes is because of the many tasks related to controlling diabetes and it is only through active coping that people with diabetes can effectively manage their illness (Maes, et al. 1996). However, this does not mean that people with diabetes do use problem-focused coping. Karlsen and Bru (2002) used two coping measures with type 1 and 2 diabetes patients and found low levels of active, task-oriented coping, particularly amongst type 2 patients.

3.6.4.2 Coping measures

The research on coping is 'plagued' by methodological weaknesses (Endler et al., 1993). There is a lack of reliable and valid measures, a lack of empirical evidence for existing measures, a lack of attention to age and gender differences (Endler et al., 1993), a lack of disease-specific measures (Macrodimitris & Endler, 2001) and a lack of hypothesis driven coping research (Coyne & Gottleib, 1996). Endler et al. (1993), are critical of the lack of attention given to assessment issues in health psychology in general, and coping strategies in particular. The result is a lack of progress in understanding coping in health and illness

and there is yet to be the development of a stable body of knowledge in this area (Coyne & Gottleib 1996).

One example of an attempt to overcome some of the existing problems is Endler and Parker's (2000), Coping with Health, Injuries and Problems Scale (CHIP). These researchers differentiate between an 'interindividual' approach (dispositional/general coping) and an 'intraindividual' approach (situational coping). Taking an intraindividual approach, this measure includes four coping dimensions; distraction, palliative, instrumental and negative coping. It also provides norms for different age groups by gender, in an attempt to address some of the methodological problems in this area.

Overall, it can be concluded that 'coping research is undergoing somewhat of a crisis' (Myers et al., 2004, p. 154). What are needed are measures, theoretically driven with acceptable psychometric properties. There are other possibilities for this area of research, such as taking a broader perspective by including dispositional and situational aspects of coping, and using qualitative methods of inquiry (Myers et al., 2004).

3.7 Characteristics of the Psychology and Diabetes Research Literature

There are several characteristics of the research on psychology and type 2 diabetes which impact on the body of literature that exists:

a) Lack of type 2 research.

This literature review draws heavily on research conducted with those who have type 2 diabetes. However, much of the body of literature that exists on psychological factors and diabetes has come from children and adolescents with type 1 diabetes (Hixenbaugh & Warren, 1998). With the rapidly rising numbers of people diagnosed with type 2 diabetes and the recognition of psychological and behavioural factors in its management, it is important that this illness is understood separately (Macrodimitris & Endler, 2001).

b) Lack of longitudinal studies.

Type 2 diabetes is not a new area of inquiry, nevertheless there is a dearth of longitudinal research. Given the chronic and long term nature of diabetes, this is particularly noteworthy and several authors have recognised the need for well-controlled long-term research (Delamater et al. 2001; Hixenbaugh & Warren, 1998).

c) Measurement issues.

A methodological issue that pertains to much of this research is the variety of measurement and assessment tools used. Some researchers use general measures suitable for all patient groups while others rely on disease-specific measures. Such a divergence of measures makes the comparison and combination of research a formidable task. Clare Bradley has carried out extensive work in this area and has brought together a number of diabetes-specific measures examining knowledge, well-being, quality of life, attitudes and beliefs, self-management and satisfaction (Bradley, 1994). As comprehensive as this work is, it reflects only a small minority of the diabetes measures that are used. As an example of this, Garratt, Schmidt and Fitzpatrick (2001), reviewed the literature and found nine different diabetes-specific measures of health-related quality of life. Only five of these measures provided sufficient evidence for reliability and validity.

d) Gap between knowledge and practice

There is now a sufficient body of knowledge which supports the integral role that psychosocial factors play in the management of diabetes (Delamater et al., 2001). However, the move to integrate this knowledge into successful and sustainable diabetes care interventions has not yet happened (Delamater et al., 2001; Glasgow et al., 1999). This is not particular to diabetes and may reflect a wider problem within health psychology. Nichols (2005) argues that despite twenty years of research in health psychology, there has been (in the UK) "a failure to develop psychological care as part of the thinking, culture and routines of general hospitals and health centres" (p26).

e) Lack of a comprehensive model

As previously discussed (section 3.2), there is a lack of an overriding model of chronic illness, both in general (Wright & Kirby, 1999) and specific to diabetes (Glasgow et al., 2001). The effect of this on research has led to studies being conducted with differing theoretical frameworks or in some cases, none at all.

3.8 Summary

Based on the results of the exploratory phase of the research, a more comprehensive literature review of the psychosocial factors that play a role in diabetes control was

undertaken. The staring point for this was to investigate the existing theoretical models that underpin chronic illness. There is a lack of guiding behavioural science models not only in diabetes (Glasgow et al., 2001) but in chronic illness in general (Wright & Kirby, 1999). Much of the research that does exist tends to focus on particular psychological constructs such as personal control, self-efficacy and coping rather than taking a holistic, biopsychosocial approach to the factors that effect a person living with a chronic illness. In light of the absence of an integrated model in diabetes research, the theory generated from the focus groups of the first stage of this research was used to underpin the subsequent research and literature review. This theory provides a framework for understanding many of the factors that influence how a person adapts to a chronic illness.

The last two decades has seen a growth in the literature on psychology and diabetes. What can be concluded is that psychosocial factors (e.g. psychological well-being, patient satisfaction, behaviour change, social support and coping) influence the management of diabetes (Bradley & Gamsu, 1994; Delameter et al., 2001; Gonder-Frederick et al., 2002). Despite the growing recognition that type 2 diabetes - as with other adult chronic illness, is a family illness (Hixenbaugh & Warren, 1998), the regular inclusion of spouses and other family members in the research has yet to take place (Fisher et al., 1998). The literature on illness representations has also recognised the neglect of the family context (Ogden, 1995; Weinman et al., 2003) and several studies have now included spouses (Barrowclough et al., 2001; Figueiras & Weinman, 2003; Heijmans et al, 1999). Theses studies have shown the different illness perceptions that couples can have and how these differences impact on illness and psychological outcomes. Including family members in illness representations also acknowledges the origins of the model and its early recognition of the importance of social factors in illness representations (Leventhal et al., 1986, 1998, 2003). There now appears to be adequate evidence to support the illness dimensions of the Self-Regulatory model (Hagger & Orbell, 2003; Heijmans & DeRidder, 1998; Moss-Morris et al., 2002; Weinman et al., 1996).

Despite the wealth of data that now exists in the psychological research on diabetes, it is still unknown how these psychosocial factors impact on glycaemic control and exactly how those in good control of their diabetes differ psychosocially from those in poor control. The exclusion of family members from the research has meant that little is known about the impact of diabetes on its social environment. The next chapter addresses the

aims and objectives of the current research based on the literature presented in this chapter and the results of the first exploratory stage of the research.

CHAPTER FOUR - AIMS AND HYPOTHESES

4.1 Theoretical Background

The review of the literature has highlighted the importance of understanding the psychosocial determinants of control in type 2 diabetes. In the absence of a guiding theory both within chronic illness and the psychological care and research of diabetes, this research has generated its own theory, grounded in the focus groups with people with diabetes and their family members. This study examines diabetes management from two viewpoints; those with diabetes and their family members. Figure 4.1 presents how the various factors within the theory will be measured and how they are related. This study is examining how psychosocial factors influence the physical and psychological outcomes of diabetes. This research begins with the outcome of good and poor glycaemic control and uses these endpoints as a basis for examining the potential predictors of diabetes control.

4.2 Aim

The primary aim of this study is to examine the psychosocial differences between those in good control and poor control glycaemic control of their type 2 diabetes.

A secondary aim is to explore the psychosocial factors of people with diabetes and their family members.

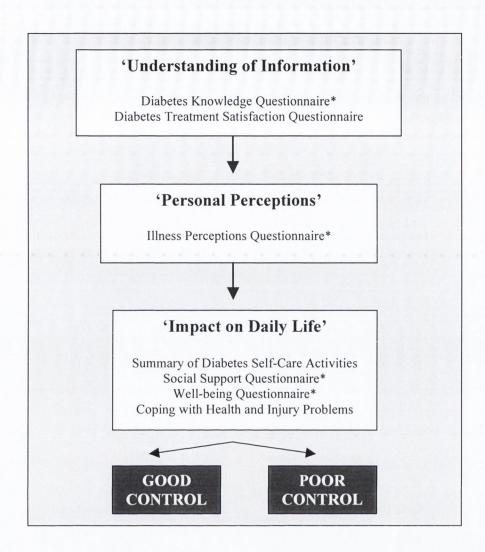


Figure 4.1. Measures used in application of factors from the qualitative theory to current research.

Note * denotes measure for family members

4.3 Hypotheses

Independent variables or predictors in this research are; illness representation, social support, family, coping, psychological well-being, diabetes knowledge, diabetes self-care activities. The dependent variable is diabetes control as measured by HbA_{1c} .

Hypothesis I That there is a difference between those in good control and poor control of their diabetes on the following psychosocial dimensions:

- Illness representations
- Coping
- Psychological well-being

- Daily self-care activities
- Social support
- Diabetes treatment satisfaction
- Knowledge of diabetes

Hypotheses II That there is a difference between the family members of those in good and poor control of their diabetes on the following psychosocial dimensions:

- Illness representations
- Psychological well-being
- Social support
- Knowledge of diabetes

Hypotheses III That there is a positive relationship between family members and those with diabetes on the psychosocial dimensions of:

- Illness representations
- Psychological well-being
- Social support
- Knowledge of diabetes

Due to the large number of variables (see Table 4.1), each measure will be described separately in relation to glycaemic control.

Hypothesis (i) - Illness Representations

That those in good control of their diabetes and their family members will have higher levels of perceived personal and treatment control, weaker illness identity, lower perceived consequences and a less chronic timeline than those in poor control of their diabetes and their family members.

Hypothesis (ii) – Social Support

That those in good control of their diabetes and their family members will have a larger support network and a higher level of satisfaction

with support than those in poor control of their diabetes and their family members.

Hypothesis (iii) – Coping

That those in good control of their diabetes will use higher levels of instrumental coping and lower levels of emotional preoccupation than those in poor control of their diabetes.

Hypothesis (iv) – Psychological Well-being

That those in good control of their diabetes and their family members will have higher levels of energy and overall positive well-being and lower levels of anxiety and depression than those in poor control of their diabetes and their family members.

Hypothesis (v) – Treatment satisfaction

That those in good control of their diabetes will have higher levels of treatment satisfaction than those in poor control of their diabetes.

Hypothesis (vi) – Daily Self-care Activities

That those in good control of their diabetes will adhere better to their recommended treatment than those in poor control of their diabetes.

Hypothesis (vii) – Diabetes Knowledge

That those in good control of their diabetes and their family members will have better knowledge of diabetes than those in poor control of their diabetes and their family members.

Table 4.1. List of Variables Included in Current Study

	Variable Name	Measurement Tool
1	Illness Identity	IPQ-R
2	Timeline (acute/chronic)	IPQ-R
3	Timeline (cyclical)	IPQ-R
4	Personal Control	IPQ-R
5	Treatment Control	IPQ-R
6	Illness Coherence	IPQ-R
7	Consequences	IPQ-R
8	Emotional Representations	IPQ-R
9	Cause	IPQ-R
10	Number Support	SSQ-6
11	Level Satisfaction with Support	SSQ-6
12	Distraction Coping	CHIP
13	Palliative Coping	CHIP
14	Instrumental Coping	CHIP
15	Emotional Preoccupation	CHIP
16	Depression	Well-being Q
17	Anxiety	Well-being Q
18	Energy	Well-being Q
19	Positive Well-being	Well-being Q
20	Satisfaction with Treatment	DTSQ
21	Diet	SDSCA
22	Exercise	SDSCA
23	Glucose Testing	SDSCA
24	Medication	SDSCA
25	Knowledge	DKQ
26-	Others; treatment type, duration, age, gender, SES,	
35	GMS, education, other illnesses, related consequences,	
36	HbA1c	

CHAPTER FIVE - METHOD

5.1 Introduction

This chapter describes the methods used to test the hypotheses of the previous chapter. It details the design, sample selection and measures used in the research. A detailed account of the procedure is given, followed by results from the pilot study.

5.2 Design

This is a cross-sectional study. It takes an extreme groups approach, whereby variables for those in good control of their diabetes will be compared with those in poor control. There is also a second level of participants where a family member of those in good and poor control will be included.

5.3 Sample

5.3.1 Clinic selection

An outpatient's clinic in the diabetes day care centre of a large suburban teaching hospital was selected as the setting for the data collection. This clinic provides outpatient care to adults with diabetes in Tallaght and the surrounding area. The total population of this clinic is approximately 4,600, which includes paediatric patients and all types of diabetes, although approximately 90% are patients with type 2 diabetes. This number reflects only those who have chosen to attend a hospital clinic and does not include patients receiving their care exclusively in a primary care setting, privately or those who receive no care. Patients are seen at three/six/twelve monthly intervals, depending on their needs. The clinic provides medical, nursing, dietician and podiatrist support. On average 40 patients attend the selected outpatients clinic every week.

5.3.2 Sample size

One of the problems with research in this area is the lack of detail given in published studies to help determine sample size. The potential number of participants needed was estimated in a number of ways. Firstly, power calculations using the Well-being

Questionnaire (Bradley, 1994) were calculated. This variable was chosen recent Irish data using this questionnaire was available. Using STATA power calculations with 90% power to detect a five point difference in well-being which corresponds with a significant absolute change in glycaemic control, a total of 90 participants in each group was needed. Initial consultations with statisticians confirmed the need for this number and a final figure of 100 in each group was decided upon.

Once data collection had commenced it became evident that there were not equal numbers of people attending the clinic from each group. Furthermore, time constraints of the clinic (three hours once a week), meant that it was only possible to meet with two-three participants during each clinic. The period of data collection was extended by ten weeks to attain a revised total number of 150 participants. This revised number, was deemed large enough to detect a five point difference in well-being with 80% power.

5.3.3 Patient selection

Participants were selected on a weekly basis from the outpatient list. Before each clinic the medical records of all patients were examined and those meeting the criteria were selected either by the principal researcher (PW) or research assistant (EC) . The selection criteria was:

- Person with type 2 diabetes
- Diagnosed for more than 1 year
- HbA_{1c} level less than 7% or more than 8.5% (recognised values for good and poor metabolic control of diabetes St Vincent Declaration 1999)
- Physically well enough to take part
- An ability to give informed consent

At each clinic, ten patients were random selected from the total eligible sample of patients who met the criteria. However, after four weeks of data collection it became evident that this method of patient selection was not practical for two reasons. Firstly, there were not always ten patients who met the criteria and secondly, patients who were eligible and selected may not be available (did not attend or with nurse/doctor/dietician/podiatrist), whereas those who were eligible and not part of the random selection were available to participate. This meant that there were times when no data could be collected despite the presence of eligible participants. It was decided to move from a random procedure of selection to a non-random criterion-based selection

procedure. This procedure is one that is commonly used in health settings (Smithson, 2000).

5.3.4 Family member selection

A snowball sampling technique was used to recruit family members. All participants who took part in the research were invited to nominate a family member who would be interested in completing a shorter set of measures and posting them back in the provided stamped and addressed envelope. This technique provided a method of recruiting family members who normally would not be accessible. The disadvantage of this method is that it includes only members of a specific network and is therefore self-selecting (Bowling, 1998).

5.3.5 Data Retrieval

Patient Records

The following information was noted from participants' charts:

- Demographic and socio-economic characteristics; name, age, gender, date of birth, marital status, address, medical card holder, occupation
- Medical details; type of diabetes, duration of diabetes, type of treatment, diabetes complications and other illnesses (see Appendix I).

Computer Databases

The hospital database (Key) was accessed for HbA_{1c} scores. HbA_{1c} was taken as the most recent entered value for each patient (all HbA_{1c} measures were DCCT compliant). Ten months into the study a local diabetes clinical database (DIAMOND) began to operate in the diabetes day centre. Although it did not contain complete records for all patients, it was used in conjunction with patient charts for the retrieval of data.

Further Information

Information regarding the participant's educational level was unavailable from medical records and was asked verbally at the start of the interview. This information was important in giving a fuller picture of the participant's background. Other missing demographic information from the patient's charts was also completed at this time.

5.4 Measures

- 5.4.1 Participant with Diabetes
 - (a) Diabetes Knowledge Questionnaire (DKQ) (Garcia, Villagomez, Brown, Kouzekanani & Hanis, 2001)

The DKQ is a 24-item measure of diabetes knowledge. It is derived from the original 60 item questionnaire which was developed for use in both Spanish and English as part of an education study with people with diabetes and their family members/friend. The authors took into account the low education and literacy levels of the potential respondents and items were written in simple language with a three possible response choices (1) yes, (2) no and (3) I don't know (Appendix J). The measure was developed in Mexico and several items were altered to allow for differences in blood glucose measurements used in Ireland and to replace the word 'diabetic' with the term 'person with diabetes'. Research from 502 respondents has shown a reliability coefficient of .78 and adequate construct validity as measured by sensitivity to the education intervention (Garcia et al., 2001).

- (b) Diabetes Treatment Satisfaction Questionnaire (DTSQ) (Bradley, 1994)

 This measure was developed to specifically measure satisfaction with diabetes treatment regimens (Bradley, 1994). It has a total eight items which respondents are asked to rate on a seven-point scale. Six of the items are answered in relation to satisfaction with treatment (e.g. from very satisfied to very dissatisfied, very convenient to very inconvenient, very flexible to very inflexible) and are summed to give a total for treatment satisfaction. The remaining two items measure patient satisfaction with treatment control and concern the perceived frequency of hyperglycaemia and hypoglycaemia respectively (see Appendix K). These two individual items are answered on a scale ranging from most of the time to none of the time. Results from international studies report an alpha coefficient from .79 to .86, with good construct validity and sensitivity to change (Hirsch, Bartholomae & Volmer, 2000; Nicolucci et al., 2004; Westaway & Seager, 2004).
- (c) Illness Perception Questionnaire-Revised (IPQ-R)(Moss-Morris et al., 2002) The Illness Perceptions Questionnaire- Revised (IPQ-R) (Moss-Morris et al., 2002) consists of nine subscales that measures how the patient thinks about:
- (i) the symptoms they experience that are associated with the illness (Identity)

- (ii) how long the illness will last (Acute/Chronic Timeline)
- (iii) how cyclical the illness is (Cyclical Timeline)
- (iv) the expected outcomes and effects (Consequences)
- (v) the amount of control patient has over their illness (Personal Control)
- (vi) how effective they think their treatment is (Treatment Control)
- (vii) how much the patient understands their illness (Illness Coherence)
- (viii) the emotional impact of the illness (Emotional Representations)
- (ix) what may have caused the onset of the illness (Cause)

The IPQ-R has three separate sections. In each section, the participant is advised to answer the questions in relation to their own personal beliefs and not to be influenced by what other people (lay and medical) may think. The first section addresses identity beliefs. It lists 14 symptoms and asks the participant whether they have experienced each symptom and if so, whether it was related to their diabetes. The second section has 38 items and addresses the subscales of timeline, consequences, control, illness coherence and emotional representations. Participants are presented with statements in relation to these scales and asked to rate their level of agreement on a five point scale ranging from strongly agree to strongly disagree. The third section contains 18 suggested causes of diabetes, and participants are again asked to rate their level of agreement on a five point scale. Finally, they are asked to list the three most important causes for them of their diabetes (see Appendix L).

This questionnaire is a revised version of the original Illness Perceptions

Questionnaire (IPQ) first developed by Weinman et al. in 1996. The original IPQ

measured the five components of illness representations (identity, consequences,
timeline, control/cure and cause) from Leventhal's Self-Regulatory Model of Illness

Representations (Leventhal et al., 1984). Since its development is has been used in
research with many different illnesses and has provided evidence for the use of illness
representations in understanding adaptation to illness (Heijmans & De Ridder, 1998;
Petrie et al., 1996; Weinman et al., 2003). However, this measure had sometimes
shown low internal reliability on the cure/control subscale and that the timeline
subscale did not assess cyclical beliefs. Furthermore, the IPQ did not include the
important emotional representations dimension of illness perceptions, nor did it have
any measure of how well the patient felt they understood their illness. All of these

shortcomings have been addressed in the IPQ-R: the cure/control subscale has been divided into two separate components – personal control and treatment control, and subscales measuring cyclical timeline beliefs, emotional representations and illness coherence have all been added. Analysis of 711 patients from eight different patient groups has demonstrated good internal reliability on the subscales, ranging from .79 to .89 and good test retest reliability up to six months. The IPQ-R has also demonstrated discriminant and predictive validity.

(d) Summary of Diabetes Self-Care Activities Questionnaire (SDSCA) (Toobert & Glasgow, 1994)

This is a standardised questionnaire which measures self-care behaviours, it is not explicitly a measure of diabetes adherence – rather it measures recommended behaviours from four dimensions of diabetes self-care.

This questionnaire has four subscales which assess the main aspects of diabetes self-care: diet amount (2 items), diet type (3 items), exercise (3 items), blood glucose testing (2 items) and medication adherence (2 items) (Appendix M). Participants are asked to think back on their self-care activities over the previous seven days when answering each item. Each component of diabetes care is separate and it has been shown that adherence to one area of care does not automatically relate to adherence to other areas (Orme & Binik, 1989). Therefore, the subscales on this measure remain separate and are not combined into an overall self-care score.

This measure was developed to address some of the issues in assessing self-care such as the different components of the diabetes regimen, distinguishing between accidental and voluntary non-adherence and comparing actual behaviour to recommended behaviour, which can vary between patients and health care providers. This last point is dealt with by asking respondents the percentage of a recommended activity they engage along with the actual amount. This is advantageous as different guidelines are given / perceived and it does not assume that all participants in a study will have exactly the same guidelines, rather it is their perceived adherence that is measured (Warren & Hixenbaugh, 1998). Reliability has been shown for this measure based on 307 participants with either type 1 or type 2 diabetes from three separate studies (Toobert & Glasgow, 1994). Inter-item correlations exceeded .5 for the majority of the subscales. This measure has also demonstrated face and content validity (Toobert & Glasgow, 1994).

(e) Social Support Questionnaire-6 (SSQ6) (Sarason, Sarason, Shearin & Pierce, 1987)

This questionnaire contains a measure of the number of people available for support and satisfaction with support. It has one quasi-structural measure of support and one global functional measure of support. There are six questions in total and participants are asked to indicate the number of supports they have (from 0-9) and the satisfaction they have with that support (ranging from 1- very dissatisfied with support to 6 –very satisfied) (see Appendix N). Sarason et al. (1987) report high internal consistency for both subscales (alpha .9 - .93) and high test-retest reliability. The validity of the scale has also been adequately demonstrated by the authors, indicating that the SSQ6 shows similarities with a number of related measures. For this research, a seventh question was added to the measure, asking specifically about diabetes-related support.

(f) The 12-item Well-Being Questionnaire (W-BQ12) (Bradley, 2000; Pouwer, van der Ploeg, Ader, Heine & Snoek, 1999)

The original Well-Being Questionnaire was developed in 1982 to measure depressed mood, anxiety and positive well-being in people with diabetes. Since then the 22 item questionnaire has been extensively used in studies examining the effects of new treatments and interventions (Bradley, 2003). It is also recommended by the World Health Organisation and the International Diabetes Federation as an appropriate measure to assess psychological outcomes of diabetes care (Bradley & Gamsu, 1994). The more recently developed 12-item measure is a shorter, more balanced version of the original and although developed to be suitable for people with diabetes, it is not diabetes-specific (Bradley, 2003). The W-BQ12 contains 12 items that assess three aspects of well-being: negative well-being, energy and positive well-being. The scores from these three subscales are combined to give a total general well-being score, with a higher score indicating greater well-being. Respondents are asked to indicate on a four point scale (all the time – not at all), how often they have experienced the feelings described in each statement over the past few weeks e.g. 'I get upset easily or feel panicky' 'I have been waking up feeling fresh and rested' (see Appendix O). The W-BQ-12 has been examined across diabetes type and gender for each subscale, and a high level of internal consistency reliability has been found (Cronbach's alpha 0.73-0.87). For General Well-being the reliability is even higher (Cronbach's alpha

0.88-0.91). Convergent and discriminant validity has also been demonstrated with this measure (Mitchell & Bradley, 2001; Pouwer et al., 1999).

(g) Coping with Health and Injury Problems (CHIP) (Endler & Parker, 2000) The CHIP is a self-report measure of coping with illness. It consists of 32 items and assesses four different coping styles. Endler & Parker (2000) describe these coping styles as (a) Distraction Coping - the extent to which people use thoughts and behaviours aimed at avoiding preoccupation with the health problem, (b) Palliative Coping – the various 'self-help' responses used to alleviate the unpleasantness of the situation and to make oneself feel better, (c) Instrumental Coping – task-oriented/ problem focused strategies to deal with the illness and (d) Emotional Preoccupation – the extent to which the respondent focuses on the emotional consequences of the illness. This measure also has an inconsistency index, which measures how consistently an individual has completed the measure. Participants rate on a five point scale (not at all – very much), the extent to which they engage in particular coping strategies in relation to their illness (Appendix P). The CHIP form generates raw scores for each of the four coping scales and standard T-scores with a mean of 50 and a standard deviation of 10, with a score of 45-55 representing an average score. Normative data is provided from 2,358 participants of different ages, gender and health status. The authors acknowledge that age and gender effect CHIP results and provide separate normative data for males and females aged 18-29 years, 30-49 years and 50 or over for each of the coping scales. Moderate to high internal reliability has been demonstrated for these different sample (alphas .70 - .88) and it has excellent test-retest reliability. Factor analysis has confirmed the four coping scales and good construct validity has been shown.

5.4.2 Family members

(a) Diabetes Knowledge Questionnaire

This measure was originally developed for use both with those with diabetes and their family members/friends without any modifications (Garcia et al. 2001) and was included in the measures for family members (Appendix J).

(b) Illness Perception Questionnaire-Revised (modified for relatives) This was the only measure that had to be adapted for use with family members. Previous studies have examined the illness perceptions of carers and spouses (Barrowclough et al., 2001; Figueiras & Weinman, 2003; Heijmans et al., 1999). The latter two studies used only slightly reworded versions of the IPQ-R and then went on to directly compare patients' and spouses' scores. However, Barrowclough et al.'s (2001) study further modified the IPQ-R to examine where possible illness representations not only from the family member's perspective but also from how they thought the person with diabetes perceived their illness. For example the original item from the IPQ-R 'my illness has major consequences on my life' was changed to (a) 'their illness has major consequences on their life' and (b) 'their illness has major consequences on my life'. This study took Barrowclough et al.'s (2001) approach to examining family members illness representations. For the identity, timeline acute/chronic, timeline cyclical and cure-control scales, the words 'my diabetes' were simply replaced by 'their diabetes'. The individual changes on the other scales can be seen in Appendix Q and the full modified questionnaire in Appendix R.

Barrowclough et al.'s (2001) research used the IPQ measure rather than the IPQ-R and reported psychometric properties are based on the earlier IPQ. Internal consistency (with the exception of the timeline subscales), inter-item correlation and test-retest reliability were all within acceptable ranges in their research and evidence for concurrent validity with elements of carer functioning, patient functioning and the carer-patient relationship was shown. This analysis however was conducted with a small sample (N=47), in relation to a mental health problem that has known negative effects on the well-being of carers. In this regard it is different to type 2 diabetes, and the current study is the first one of its kind to use this modified IPQ-R measure.

(c) Social Support Questionnaire-6

There were no changes made to this questionnaire. It has been previously used with different populations and is not illness-specific. As previously, a seventh question was added relating to diabetes-specific support (see Appendix N).

(d) Well-being Questionnaire

Although this measure is appropriate for use with those with diabetes, it is also suitable without any changes for those without the illness (Bradley, 2003). Therefore it was used in the same format with family members of those with diabetes (Appendix O).

5.4.3 Order of Questionnaires

It was decided that the questionnaires would be presented in a random order to minimise fatigue eliminate any potential order effects. Following the pilot, this system was not found to be effective. The measures are of different lengths and require different levels of concentration and ability. When the more complex questionnaires were all presented first, respondents became more frustrated and fatigued with the process. An optimal order of questionnaires was finalised for the study, in terms of minimising fatigue and every participant received the measures in this manner (Table 5.1). This order proved successful, with the first two questionnaires being short, relatively easy to complete and introducing the topic of diabetes. The following questionnaires interspersed the more complex questionnaires (IPQ-R and CHIP) with shorter, less demanding measures.

Table 5.1 Order of Administration of Questionnaires

Order	Measure				
1 st	Diabetes Treatment Satisfaction Questionnaire				
2 nd	Summary of Diabetes Self-Care Activities Questionnaire				
3 rd	Illness Perceptions Questionnaire – Revised				
4 th	Social Support Questionnaire-6				
5 th	Well-Being Questionnaire				
6 th	Coping with Health and Injury Problems				
7 th	Diabetes Knowledge Questionnaire				

5.5 Procedure

5.5.1 Clinic

Before the start of every clinic, all eligible patients were clearly marked (by PW or EC) on the master clinic list used by the nurses. Patients were seen first by a member of the

nursing staff and clinical observations were performed such as height, weight, blood pressure, blood glucose levels. They then returned to the waiting area and waited to be called by one of the doctors. Occasionally, this waiting time is used to see one of the diabetes nurse specialists or the dietician. However, for most there can be a significant waiting period of over one hour. It is during this waiting time that patients were first approached by the one of the nurses and the nature of the research briefly explained. If they agreed to participate they were then brought to one of the consultation rooms within the clinic and introduced to the researcher (PW or EC). The measures were interviewer-administered.

The research was then explained verbally in greater detail and a written version of the information sheet was made available (see Appendix S). Once the participant had agreed verbally to participate, they were invited to complete the Informed Consent Form (see Appendix T). The anonymity of the participants and the confidentiality of the research were reiterated. It was emphasised that participation was entirely voluntary, that they were free to leave at any point and most importantly that they would not be delayed any more than their normal waiting time.

Personal and demographic details from the patient and their chart (age, marital status, occupation, medical card recipient, education level) were first noted Participants were then given the option of either filling out the questionnaires themselves or for the researcher to complete the questionnaires by reading through them with the participants. Given that this, in general, was an older population being asked to complete a large number of potentially complex measures and that 25% of the Irish population have been found to be at the lowest level of literacy (Binkley, Matheson & Williams, 1997), it was felt that all participants should have the option of completing the measures in the manner that most suits them. Indeed, more than three-quarters of participants asked for the researcher to help complete the questionnaire. On average, it took 30-40 minutes to complete the measures

5.5.2 Postal Questionnaire

The family part of the research was briefly mentioned at the outset of the meeting and once the questionnaires had been completed, the participant was then asked if they would consider bringing home a similar but smaller questionnaire folder to an appropriate person at home. Included with the measures as listed above were; a letter of introduction,

an invitation to sign that consent is given, short questionnaire on demographic details, a final blank page for the participant to write any further comments and a stamped addressed envelope (see Appendix U). A reminder and a copy of the questionnaires were sent out to non-responders after three weeks. A final follow-up reminder and questionnaires were posted out after another three weeks had elapsed. The use of reminders in postal questionnaires is important given the relatively low response rate associated with this method. In this study, reminders also included a copy of the original questionnaires and a stamped addressed envelope, which have been found to increase the likelihood of participants returning their questionnaires (Edwards et al., 2002). Participants who did not wish to fill out the measures had the option of posting them back blank and no further reminders would be sent.

5.6 Ethical Approval

Ethical approval was awarded by the St James's Hospital and Federated Dublin Voluntary Hospitals Joint Research Ethics Committee in December 2002. Both researchers collecting the data are members of the Psychological Society of Ireland and as such operate under their Code of Professional Ethics. This code consists of the following four principles:

1) Respect for the rights and dignity of the person.

The dignity, moral and cultural values of each participant was respected. All information obtained was treated as confidential and every effort made to ensure that the participant understood the nature of the research before giving consent to participate.

2) Competence

It was essential that the researchers understood their function within the research and acknowledge that this role is limited.

3) Responsibility

This principle refers to the trustworthy, accountable and reputable manner in which psychologists must act towards participants. Of most relevance, is the avoidance of harm to participants by appropriate screening and debriefing. The nursing staff played an integral role in this as they were able to inform the researchers if selected participants were not suitable for health reasons and were a source of referral for participants looking for further information and/or support.

4) Integrity

The researchers are obliged to be honest and accurate in all of their dealings. They must treat others in a fair, open and straightforward manner. All participants were informed of the purpose and nature of the research and given every opportunity to ask questions and/or withdraw from the research.

5.7 Pilot Study

The pilot study consisted of two clinic sessions with a total of seven people with diabetes and three family members participating. It was decided that these sessions had uncovered any potential flaws in the procedure and choice of measures and to begin the study on the third week. Following the pilot study three main changes were made. Firstly, the original chosen coping measure was the COPE (Carver et al., 1989). It was soon evident that the CHIP (Endler & Parker, 2000) would be a more appropriate choice given its more general questions. The COPE identifies coping strategies in relation to a particular event/stressor (e.g. 'I say to myself "this isn't real"'; 'I think about how I might best handle the problem'; 'I sleep more than usual') and given that many people did not view their diabetes in such terms, it was difficult for them to answer the questions. The second change has been previously mentioned in this chapter and refers to the move from a random order of questionnaires to a set sequence. The final change did not become evident until several weeks into the data collection when there was a change in the selection procedure from randomly selecting ten participants from the eligibility list to including all potentially eligible participants. This change has been previously discussed (section 5.3.3 Patient selection).

5.8 Statistical Analysis

All of the data from the measures was entered into and analysed in the statistical package SPSS 12.0 for Windows. Descriptive analyses were carried out on the demographic data and each of the individual measures and means and standard deviations or medians and inter-quartile ranges presented. The internal reliability of each of the scales was calculated using Cronbach's alpha and where possible principal component analysis conducted on the measures. Differences between those in good control and poor control of their diabetes were examined using either t-tests or Mann-Whitney tests depending on the

distribution of the data. Finally differences in scores between those with diabetes and their family members were also calculated using either t-tests or Mann-Whitney tests.

Logistic regression was selected in order to understand the contribution of each variable to the difference between good control and poor control of diabetes. It was particularly applicable to this research as it can be used with a broader range of research situations than for example, discriminant analysis. Given the mix of normal and skewed distributions in this data and the different levels of measurement, the less restrictive assumptions of logistic regression were more appropriate to the data. Logistic regression therefore, was used to estimate the probability of the dependent variables (good and poor control) being predicted by the independent variables. It is suited to models where the dependent variable is dichotomous, as in this case.

Based upon the theory from the qualitative research (as outlined in Chapter Three), the outcome - in this case diabetes, is influenced by understanding, (Diabetes Knowledge Questionnaire, Diabetes Treatment Satisfaction Questionnaire), personal perceptions (Illness Perception Questionnaire – Revised). These factors in turn influence the adaptation and coping process which consists of, adaptive tasks (Summary of Diabetes Self-care Activities Measure), social support (Short form Social Support Questionnaire), well-being (Well-Being Questionnaire) and coping (Coping with Health and Injury Problems). This theory links together all of the factors that were measured in this research in a meaningful way. It provides a framework for understanding the variables that influence the control of diabetes and determines how these will be included in a model for logistic regression.

Hosmer and Lemeshow (1990) explain that the goal of logistic regression is to find the best fitting model to describe the relationship between an outcome (dependent variable) and a set of predictor (independent) variables. It differs from linear regression in that its outcome variable is binary or dichotomous, as opposed to continuous. It is particularly suited to this data, as the dependent variable is dichotomous ('good control' or 'poor control'). Logistic regression computes the odds that a particular outcome will occur based on the independent variables. It does this by using maximum likelihood estimation to transform the dependent into a logit variable. A pseudo R² is used to indicate the strength of the relationship, a goodness-of-fit test measures the agreement between the

observed and predicted outcomes, the Wald statistic tests the significance of the individual logistic regression coefficient for each independent variable and the odds ratios (Exp (B)) and their 95% confidence intervals give the probability of the outcome occurring/probability of the outcome not occurring:

(odds ratio = [odds (A/l)/odds (A/m)], where A = event, l = group 1, and m = group 2). The closer the odds ratio value is to one, the more independent the two possible outcomes are – there's a 50/50 chance of a particular outcome if there is a small change in the independent variable. If the odds ratio is greater than one (e.g. 1.8), then the outcome (e.g. good control of diabetes) is 1.8 times more likely to occur with a unit change in the independent variable, holding the other variables constant. If it is below one, then the outcome is less likely to occur with a unit change in the independent variable holding the other variables constant. Odds ratios are usually interpreted alongside 95% confidence intervals and if the 95% confidence interval includes one, it can be quickly interpreted that there is no statistical significance between the two possible outcomes.

The following chapter details the results of each of these analyses.

CHAPTER SIX – RESULTS

6.1 Introduction

This chapter contains the descriptive, univariate and multivariate analysis of the data. The results for each measure will be discussed in accordance with the factors they represent on the qualitative theory (Chapter Three, Figure 3.1). Therefore the demographic details and medical details will be described, followed by diabetes knowledge and satisfaction with treatment. Personal perceptions will be discussed from the results of the Illness Perceptions Questionnaire. The summary of diabetes self-care activities and social support will be reported upon followed by psychological well-being and finally the coping measure. Each section will begin with the analysis for differences between those in good and poor control, followed by the general descriptive results for the total sample. The results from each of the measures for the participants with diabetes will be presented followed by the results for family members, where comparisons will be made with participants with diabetes. Finally, logistic regression will be used to assess the variables most likely to predict good control of diabetes.

The data was entered into SPSS 12.0.1 for windows and screened for data inaccuracies. Any missing data was checked and where possible retrieved, otherwise coded as missing. Data was then checked for normal distribution and outliers. On inspection, there were a high number of skewed distributions (skewness determined by skewness statistic ≥ (2)(Std. Error)), and median and inter-quartile ranges have been provided for variables where this occurs. Consequently, differences between those in good and poor control, in many cases were examined by using the Mann-Whitney U test. Alpha was set at .05, so that there was a 5% chance of making a Type 1 error when the null hypothesis is true.

6.2 Data Collection Results

6.2.1 Setting details

There were two groups of participants: (i) those with diabetes and (ii) their family members. Participants with diabetes were recruited from a weekly diabetes outpatients clinic and data collection took place over 53 weeks. On average, 40 patients were scheduled to attend each of these weekly clinics. On the morning of each clinic, the chart

for each patient was examined by the researcher to verify that they met the selection criteria of; having type 2 diabetes and diagnosed for more than one year. Their most recent HbA1c result was retrieved from the hospital's computerised database (KEY). Approximately halfway through the study the patients' records became available on a diabetes-specific database (DIAMOND). The data on this system was incomplete and was used in conjunction with the patients' charts. In total 595 patients were deemed eligible for inclusion in the study. Of this total, 345 patients (58%) attended the outpatients clinic (see Figure 6.1). During the clinic, eligible patients were first approached by one of the clinic nurses and invited to participate.

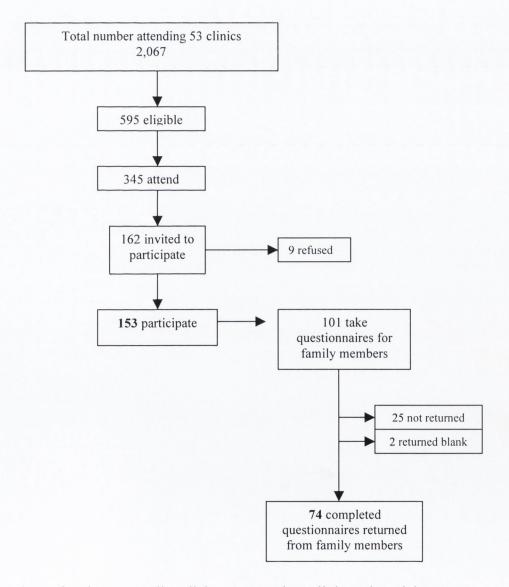


Figure 6.1. Flowchart of patients attending diabetes outpatient clinic and participants.

6.2.2 Non-participants

There were only nine patients who refused to participate. Of note, the majority (89%) of those who refused were in good control of their diabetes (see Table 6.1). Of the 153 participants who did take part, 101 (66%) identified an eligible family member to take a questionnaire home to. Within two weeks of the clinic appointment, 53 (52.5%) of family members had returned their questionnaires. After the first reminder was sent to all non-respondents, 10 (9.9%) questionnaires were returned, and a further 13 (12.9%) were returned following a second reminder. Two questionnaires were returned blank, leaving a total of 74 (73%) questionnaires from family members that were completed and returned. In comparison to the interview administered questionnaires, the postal questionnaires were more incomplete, with data missing and at times entire measures not filled in. This will be addressed when discussing the results of each questionnaire.

Table 6.1 Demographic Details of Non-participants

	Number	Percentage
Gender		
Male	4	44%
Female	5	56%
Control of diabetes		
Good	8	89%
Poor	1	11%
Reasons given		
No reason given	5	56%
Impact on waiting time	2	22%
Taken part in research before	1	11%
Feeling unwell	1	11%

6.3 Participants with Diabetes

6.3.1 Demographic details

Of the total 153 participants, 94 (61.4%) were in good control of their diabetes and 59 (38.6%) were in poor control. Although there is not an equal divide between the two groups, it does give a reflection of the numbers of people with a HbA1c under 7 and over

8.5. In order to get a sense of this distribution for all patients, a random sample of 100 patients with type 2 diabetes was selected from the Diamond database. This showed that 73.7% of patients had a HbA1c under 7 and 26.3% had a HbA1c over 8.5. This trend towards more people in good control was also demonstrated when results of all HbA1c tests in the hospital over a three month period were examined (82.7% under 7 and 17.3% over 8.5), although these figures also included paediatric patients and people with type 1 diabetes.

Whilst there was a large range of ages for all participants with type 2 diabetes (28 - 84)years), the median age was 58 years with an inter-quartile range (I-QR) of 52 years to 68 years. The mean age for all participants with diabetes was 59.1 years (S.D. 11.99) (see Table 6.2). The majority of participants were married (71.2%) and only 2.7% had no formal education. It should be noted however that a further 38.7% had been educated to only a primary school level. The number of participants who were members of the General Medical Scheme was 46.3%, higher than the national average of 29.6% (General Medical Scheme, 2003). The socio-economic status (SES) of participants was determined by their type of employment. The classifications are those used for by the Central Statistics Office for census purposes. For a number of participants (42.5%) there was no information regarding type of employment and these were given separate categories of 'retired', 'housewife', or 'unemployed'. Having no SES for more than twofifths of the participants means that any subsequent analysis using SES must be interpreted with caution. There was only one significant difference between the groups on any of the demographic measures, with significantly more family members of those in good control participating than those in poor control (χ 2=6.27, df = 1, p=0.012).

Table 6.2. Demographic Details of People with Diabetes

	Total Participants with Diabetes	Participant with Diabetes <7	Participant with Diabetes >8.5
N	153	94 (61.4%)	59 (38.6%)
Gender		()	(2 2 2 2 2)
% Male	56.2%	56.4%	55.9%
Age			
Mean (S.D.)	59.1 (11.99)	59.9 (11.96)	57.8 (12.03)
Marital Status			
Married	71.2%	74.5%	66.1%
Single	12.4%	10.6%	15.3%
Widowed	11.1%	11.7%	10.2%
Separated/			
Divorced	5.2%	3.2%	8.5%
Education			
No formal	2.7%	2.2%	3.4%
Primary	38.7%	38.5%	39.0%
Junior Cert	16.0%	18.7%	11.9%
Leaving Cert	24.0%	18.7%	32.2%
Undergraduate	16.0%	18.7%	11.9%
Post-graduate	2.7%	3.3%	1.7%
SES [§]			
I	3.3%	3.2%	3.4%
II	18.3%	21.3%	13.6%
III	11.1%	8.5%	15.3%
IV	14.4%	10.6%	20.3%
V	9.8%	13.8%	3.4%
VI	0.7%	1.1%	0%
Housewife	26.8%	26.6%	27.1%
Retired	10.5%	8.5%	13.6%
Unemployed	5.2%	6.4%	3.4%
GMS			
% Yes	46.3%	47.3%	44.6%
Family Member			
% Participated	48.4%	56.4%	35.6%

[§] I=Professional, II=Managerial and Technical, III=Non-manual, IV=Skilled, V=Semi-skilled, VI=Unskilled

6.3.2 Medical details

The mean duration of diabetes was 5.58 years (S.D. 4.94). The duration of diabetes is not normally distributed (see Figure 6.2). The median is 4 years and the I-QR, 2-7 years. As can be seen from figure 6.3, this differs for those in good and poor control, with those in poorer control having diabetes for a significantly longer time (t = -3.692, df = 147, p < 0.001) (see Table 6.3).

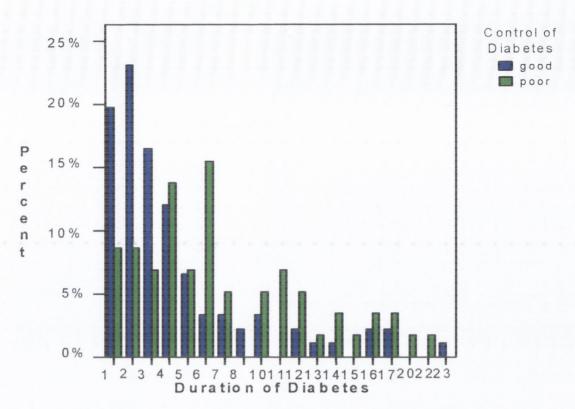


Figure 6.2. Duration (in years) of diabetes for participants in good control and poor control of diabetes.

Table 6.3. Medical Details of Participants with Diabetes

	Total Participants with Diabetes	Participant with Diabetes <7	Participant with Diabetes >8.5	p
Duration of Diabetes				.000***
Mean (S.D.)	5.58 (4.94)	4.44 (4.37)	7.38 (5.26)	
Type of Treatment				$.000***(\chi)$
% Diet Only	13.1%	18.1%	5.1%	
% Diet and Medication	71.2%	80.9%	55.9%	
% Insulin	15.7%	1.1%	39.0%	
Number of Other				
Illnesses - Mean (SD)				
Co-morbidities	1.71 (1.3)	1.64 (1.18)	1.82 (1.5)	.399 (t-test)
Vascular Disease	0.92 (.85)	0.90 (0.83)	0.95 (0.89)	.764 (t-test)
Diabetes Complications	0.19 (.56)	0.14 (0.47)	0.26(0.67)	.184 (t-test)

Note. χ2 result refers to all three treatment types. ***p<.001

Overall, the majority of people are on a diet and medication regime for their diabetes. Again, this differs according to their level of control and as to be expected, significantly more people in poor control (39%) are on insulin than those in good control (1.1%) (χ 2 = 41.073, df = 2, p = 0.00). The number of other illnesses was taken from patient charts

and the clinic database. Those in poor control had higher average numbers of other illnesses for each of these categories (Table 6.3), although this difference is not statistically significant. Although the trends shown here are for those in poor control to have a higher percentage of co-morbidities, vascular disease and diabetes-related complications, no significant difference was found between the two groups (t = -0.847, df = 149, p = 0.3999; t = -.03, df = 149, p = 0.764 and t = -1.335, df = 149, p = 0.184 respectively). Overall, this is an older population with 50% having diabetes between 2-7 years. As expected those in poor control are more likely to be taking insulin. There are however, no significant differences between control of diabetes and number of other illnesses.

6.4 Family Members

6.4.1 Demographic details

Of the 74 family members who returned their questionnaires, 71.6% were from those whose family member was in good control of their diabetes. Demographic details are presented in Table 6.4. There was a significant difference between participation in the research and diabetes control (χ 2=6.27, df = 1, p=0.012) (Table 6.2), showing a relationship between participation in the research and the control of diabetes.

Table 6.4. Demographic Details of Family Members

	Family Member	Family Member	Total Family
	<7	>8.5	Members
N	53	21	74
Gender % Male	34.6%	9.5%	27.4%
Age			
Mean (S.D.)	53.1(15.5)	48.5(18.4)	51.8(16.4)
Median (I-QR)	56(43-64)	48(34-64)	54(42-64)
Education			
No formal	0.0%	0.0%	0.0%
Primary	20.4%	30.0%	23.2%
Junior Cert	20.4%	15.0%	18.8%
Leaving Cert	36.7%	40.0%	37.7%
Undergraduate	16.3%	15.5%	15.9%
Post-graduate	6.1%	0.0%	4.3%

Family members age ranged from 17 years to 83 years of age, reflecting the different types of family members who participated. Given the distribution of ages, it is more accurate to consider the median age (54 years) and the inter-quartile range (42-64 years). There was no significant difference in ages between those in good and poor control (Mann-Whitney U = 432, p = 0.318).

Family members education level did not differ between the two groups ($\chi 2=2.138$, df=5, p=.83). As can be seen from Figure 6.3 and Table 6.5, participants' wives made up the largest group of family members who responded. There were no significant differences in the control of diabetes and the relationship to family member ($\chi 2=12.96$, df=7, p=0.073). There were far more female respondents (65.4%), particularly for family members of those in poor control (90.5%) than male respondents and no husbands of those in poor control responded to the questionnaires. This gender difference and control of diabetes was found to be significant ($\chi 2=4.735$, df=1, p=0.041).

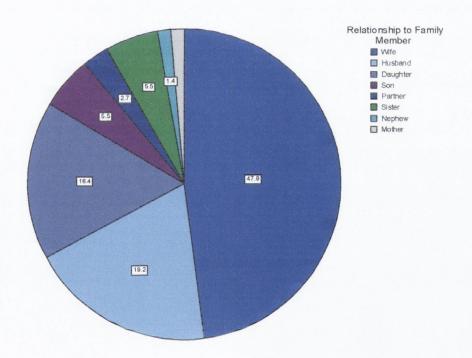


Figure 6.3. Relationship of family members to person with diabetes; percentage within each category.

Table 6.5 Relationship of Family Member to Person with Diabetes

Relationship	Good Control		Poor Control		Total	
	N	(%)	N	(%)	N	(%)
Wife	23 (4	14.2%)	12	(57.1%)	35	(47.9%)
Husband	14 (2	26.9%)	0	(0.0%)	14	(19.2%)
Partner	0 (0	0.0%)	2	(9.5%)	2	(2.7%)
Daughter	8 (1	5.4%)	4	(19.0%)	12	(16.4%)
Son	3 (:	5.8%)	1	(4.8%)	4	(5.5%)
Sister	2 (3.8%)	2	(9.5%)	4	(5.5%)
Nephew	1 (.9%)	0	(0.0%)	1	(1.1%)
Mother	1 (.9%)	0	(0.0%)	1	(1.1%)

6.5 Diabetes Knowledge Questionnaire (DKQ) (Participants with Diabetes)

The Starr County diabetes knowledge questionnaire (Garcia et al., 2001) was adapted for use in this study. It consists of 24 questions scored as either 'yes' or 'no', giving a total possible score of 24. From the 148 participants who completed this measure, the mean score was 16.15. This means that on average, participants got 67% of the questions correct.

Dividing the sample into those in poor and good control of their diabetes, there was no significant difference in knowledge scores (t = -0.741, df = 145, p = 0.460). Further analysis of each question found that there were no significant differences between those in good and poor control on any aspects of diabetes knowledge.

Table 6.6 lists in descending order the questions that were correctly answered by the total sample. The questions most people answered correctly related to diabetes foot care (Q16), the different types of diabetes (Q11), blood sugar levels (Q5), cause of diabetes (Q2) and some of the consequences of diabetes (Q20, Q14). In contrast, the questions that were the least well answered related to cleaning cuts (Q17), causes of diabetes (Q1, Q3) and the signs of high and low blood sugar levels (Q21, Q22). Question twelve relating to an insulin reaction was poorly answered. This question was considered vague and not well understood by many of the participants, 60% of whom do not take insulin to

control their diabetes. The different scores show inconsistencies in peoples' knowledge. For example, 93.4% of participants correctly agreed that the usual cause of diabetes is the lack of effective insulin in the body, however, 68.9% of people said that the kidneys caused this.

Other results worth noting are that 73.5% correctly answered that diabetes could not be cured (Q7), this does however mean that just over a quarter of this sample believe that their diabetes can be cured. Looking at some of the lifestyle questions shows that approximately two thirds of participants correctly disagreed that medication is more important than diet and exercise in controlling diabetes (Q13), leaving one third who believe that medication is the most important aspect of their diabetes regimen. Newer diet guidelines, which promote normal healthy eating and advise against the use of specialist 'diabetic foods' have not reached all those with diabetes in this sample, with 39.7% agreeing that a diabetes diet consists mainly of special foods (Q24). Nevertheless, questions regarding other aspects of diet, such as the importance of how foods are cooked were well answered (Q18).

Table 6.6 Percentage of Correctly Answered Questions on the Diabetes Knowledge Questionnaire

Question	Percentage who
	answered correctly
Q16. People with diabetes should take extra care when cutting their toenails	96.7%
Q11. There are two main types of diabetes: type 1 (insulin-dependent) and type 2	
(non-insulin dependent)	95.4%
Q5. In untreated diabetes, the amount of sugar in the blood usually increases	95.3%
Q2. The usual cause of diabetes is lack of effective insulin in the body	93.4%
Q20. Diabetes can cause loss of feeling in the hands, fingers and feet	92.0%
Q15. Cuts and abrasions on people with diabetes heal more slowly	88.7%
Q14. Diabetes often causes poor circulation	88.6%
Q18. The way people with diabetes prepare their food is as important as the food	
they eat.	87.3%
Q19. Diabetes can damage your kidneys	86.0%
Q6. If I have diabetes, my children have a higher chance of having diabetes	81.3%
Q8. A fasting blood sugar level of 9 is too high	80.8%
Q7. Diabetes can be cured	73.5%
Q10. Regular exercise will increase the need for insulin and other diabetes	
medication	72.7%
Q13. Medication is more important than diet and exercise to control diabetes	65.6%
Q9. The best way to check diabetes is by urine testing	64.0%
Q24. A diabetes diet consists mainly of special foods	60.3%
Q4. Kidneys produce insulin	58.0%
Q23. Tight socks or tights are not bad for people with diabetes	57.0%
Q22. Frequent urination and thirst are signs of low blood sugar	51.0%
Q12. An insulin reaction is caused by too much food	35.6%
Q21.Shaking and sweating are signs of high blood sugar	32.5%
Q3. Diabetes is caused by the failure of the kidneys to keep sugar out of the urine	31.1%
Q1. Eating too much sugar and other sweet foods is a cause of diabetes	15.8%
Q17. A person with diabetes should cleanse a cut with extra care	4.0%

6.6 Diabetes Treatment Satisfaction Questionnaire (DTSQ) (Participants with Diabetes)

This measure (Bradley, 1994) yields a total satisfaction score and separate frequency of hyperglycaemia and hypoglycaemia scores. The six questions which make up the total score each have a six point scale, meaning a maximum total score for this questionnaire is 36. The results of this study were negatively skewed towards high satisfaction, as can be seen in Figure 6.4. The median for the total sample was 32, the inter-quartile range was 29-32.

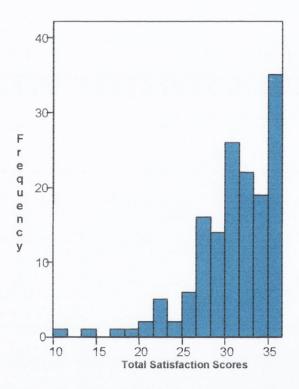


Figure 6.4. Distribution of scores for total satisfaction on the Diabetes Treatment Satisfaction Questionnaire.

There was little variance on the questions that made up the total score and their medians are represented in Figure 6.5. When examining differences between those in good control (median = 32, I-QR = 29-35) and poor control (median = 31, I-QR = 28-33) of their diabetes, there was a trend towards those in poor control being less satisfied with their diabetes treatment. Statistical analysis showed no differences on any individual questions and the results for total satisfaction were also not significant (U=2164, $N_1 = 96$, $N_2=55$, p=0.064).

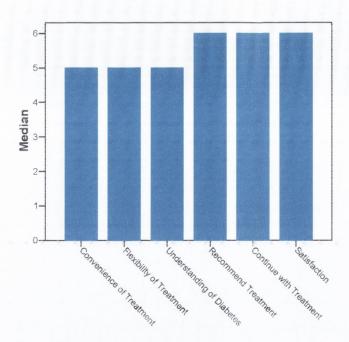


Figure 6.5. Medians of components of total score on the Diabetes Satisfaction Questionnaire (N=153).

The perceived frequency of high and low blood glucose levels also ranged in score from 0-6. Hypoglycaemic events were rarely experienced by this sample (median = 1, I-QR = 0-1). Hyperglycaemic events were more frequent (median =2, I-QR = 0.75-3) and there was a significant difference between those in good control (median =1, I-QR = 0-2) and poor control (median = 3, IQR= 2-5) of their diabetes (U=1426, N_1 =94, N_2 =56, p<0.001, two-tailed). Those in poor control of their diabetes experienced significantly more hyperglycaemic episodes than those in good control of their diabetes.

6.7 Illness Perceptions Questionnaire – Revised (IPQ-R) (Participants with Diabetes)

There are three separate sections to the IPQ-R: (a) the causal dimension (which contains 18 causal attributions for diabetes), (b) the identity dimension (which is the sum of diabetes-related symptoms experienced), and (c) the timeline, consequences, control, coherence and emotional dimensions. The results will be discussed for each section and correlations amongst the different dimensions analysed. First, reliability of the questionnaire is addressed to assess for consistency across scales.

6.7.1 Reliability

Reliability analysis on the Illness Perceptions Questionnaire was assessed using Cronbach's alpha. From Table 6.7 it can be seen that with the exception of treatment control, all of the scales perform well. The alpha value for treatment control was 0.43, indicating a low level of reliability. It should be noted that participants had difficulty with the wording on three of the five items that make up this scale. Further analysis of the Illness Perceptions Questionnaire takes these reliability values into consideration.

Table 6.7 Reliability Values for the Illness Perceptions Questionnaire

Scale	Cronbach's
	Alpha
Timeline (acute/chronic)	0.85
Timeline (cyclical)	0.89
Consequences	0.72
Personal Control	0.69
Treatment Control	0.43
Illness Coherence	0.83
Emotional Representation	0.84

6.7.2 Causal Beliefs

Causal beliefs for diabetes are measured by the IPQ-R in a different manner to the other variables and will be reported first. Participants were asked to indicate their level of agreement on a five-point scale to 18 possible causes of diabetes. As suggested by Moss-

Morris et al. (2002), these 18 attributions have been categorised into four broad causal attributions (psychological attributions, risk factor attributions, immune attributions and chance attributions), which allows for a more meaningful interpretation. They are then asked to report what they perceived to be the three most important causes of their diabetes. The results for the first part are summarised as percentages for all participants in Table 6.8.

There was one significant difference between cause of diabetes and control - that was in relation to hereditary (t=1,235, df=147, p=0.024). Those in poor control of their diabetes had a stronger perception that hereditary was a cause of their diabetes (mean = 3.67), than those in good control of their diabetes (mean = 3.12).

There were only four causes that 50% or more of all participants agreed or strongly agreed were causes of their diabetes. They were: hereditary, diet, their own behaviour and ageing.

Table 6.8 Causal Attributions of all Participants with Diabetes (N=148)

Cause	Strongly Disagree (%)	Disagree (%)	Neither Agree nor Disagree (%)	Agree (%)	Strongly Agree (%)
Stress or worry	9.5	30.4	14.9	32.4	12.8
Hereditary^	12.1	25.5	10.1	22.1	30.2
Germ or virus	23.6	50.0	23.0	3.4	0.0
Diet^	4.0	15.4	9.4	45.6	25.5
Chance or bad luck	17.4	38.3	8.7	27.5	8.1
Poor medical care	24.2	54.4	6.7	12.8	2.0
Pollution	21.5	52.3	18.1	7.4	0.7
Own behaviour^	8.7	36.2	6.0	40.9	8.1
Mental attitude	21.5	57.7	6.0	12.1	2.7
Family problems	12.1	49.7	10.1	24.2	4.0
Overwork	14.8	51.7	8.1	20.8	4.7
Emotional state	16.8	47.0	8.1	24.2	4.0
Ageing^	10.1	30.2	9.4	43.0	7.4*
Alcohol	28.2	44.3	8.7	16.1	2.7
Smoking	19.5	53.7	7.4	16.1	3.4
Accident or injury	28.2	64.4	1.3	3.4	2.7
Personality	22.1	62.4	9.4	6.0	0.0
Altered immunity	12.1	51.7	13.4	18.8	4.0

 $Note. \ ^{\circ}$ indicates causes that 50% or more participants agreed or strongly agreed this item was a cause of their diabetes

These 18 items were then categorised into the four causal attributions of: psychological attributions, risk factors, immune attributions and chance. Analyses revealed no significant differences between the two groups in relation to causal attributions.

One hundred and forty seven participants gave at least one perceived cause for their diabetes, 94 gave two causes and only 53 of the total sample listed three causes. The fact that many participants only gave one or two causes and some gave similar causes that would have been coded the same, means that the responses could not be condensed any further. The responses in relation to the three perceived causes of diabetes were coded into 21 codes. The five most frequently reported causes for all participants were; hereditary, diet/eating habits, stress/worry, weight and having another illness (e.g. stroke, heart attack, gestational diabetes). Table 6.9 shows the breakdown of all causes by control of diabetes and priority. Overall, the top five causes are similar for those in good and poor control. A higher percentage of those in poor control reported that they didn't know the cause of their diabetes (8.9%) than those in good control (1.1%). Over the three causes, those in poor control report ageing more frequently (5.4%, 14.7% and 5.3% respectively) as a cause than those in good control (1.1%, 1.7% and 2.9% respectively). For both groups, causes such as lifestyle, smoking, drinking, mental attitude and a germ/virus occur more frequently as a second or third cause, rather than as a primary cause of diabetes.

Table 6.9 Percentage of Responses for each Cause of Diabetes Reported

Codes	First (Cause	Second	l Cause	Third Cause		
	Good	Poor	Good	Poor	Good	Poor	
	(n=91)	(n=56)	(n=60)	(n=34)	(n=34)	(n=19)	
Diet/eating habits	20.9%	16.1%	20.0%	23.5%	11.8%	15.8%	
Hereditary	18.7	30.4%	13.3%	14.7%	11.8%	5.3%	
Stress/worry	16.5%	10.7%	16.7%	17.6%	17.6%	10.5%	
Specific illness	14.3%	5.4%	10.0%	5.9%	2.9%	5.3%	
Weight	13.2%	8.9%	15.0%	8.8%	2.9%	5.3%	
Eating sweet things	3.3%	-	3.3%	<u> -</u>		5.3%	
Lack exercise/lifestyle	3.3%	-	5.0%	2.9%	11.8%	10.5%	
Work	2.2%	1.8%	1.7%	-	5.9%	5.3%	
Soft Drinks	1.1%	1.8%	-	-	-	-	
Don't know	1.1%	8.9%	-	-	-	-	
Ageing	1.1%	5.4%	1.7%	14.7%	2.9%	5.3%	
Menopause	1.1%	3.6%	1.7%	-	-	-	
Medication	1.1%	1.8%	-	-	-	-	
Chance/bad luck	1.1%	-	-	-	2.9%	-	
Lack knowledge	1.1%	-	-	-	-	-	
Smoking	-	3.6%	5.0%	2.9%	2.9%	10.5%	
Alcohol	-	1.8%	5.0%	2.9%	17.6%	10.5%	
Myself	-	-	1.7%	-	-	-	
Mental attitude/emotions	-		-	-	5.9%	5.3%	
Germ/virus	-		-	-	2.9%	5.3%	
Environment	-		-	2.9%	-	-	

6.7.3 Identity

The identity scale examines the patient's ideas about the label, the nature of their condition (related symptoms) and the links between them (Weinman et al. 1996). It is the only dimension on the IPQ-R that is not scored along a five-point agreement scale. The score for identity is calculated by the number of diabetes-related symptoms identified from a given list of fourteen symptoms. Both the mean and standard deviation scores, and the median and inter-quartile range for illness identity, alongside the other

dimensions are detailed in Table 6.10. Distribution on five of the eight subscales on the IPQ-R was skewed, therefore medians and inter-quartile ranges are provided. Participants in good control reported experiencing a mean of 2.8 diabetes-related symptoms, while those in poor control reported a mean of 4.5 diabetes-related symptoms and this difference was found to be significant (U=1835.000, N_1 =92, N_2 =57, p=0.002, two-tailed) (Table 6.11).

Table 6.10 Descriptive Statistics for Dimensions on the Illness Perception Questionnaire

Good Control (n=94)					Poc	r Con	trol (n=59)	
Scale	Mean	SD	Median	I-QR	Mean	SD	Median	I-QR
Illness identity	2.8	2.6	3	1-4	4.5	3.3	4	2-7
Timeline	23.9	3.8	24	22-27	24.2	5.0	26	22-28
acute/chronic								
Timeline cyclical	3.2	0.3	8	8-12	11.1	4.1	10	8-16
Consequences	16.1	4.1	16	13-19	18.4	4.5	18	15-22
Personal control	24.5	2.8	24	23-26	24.4	3.5	24	22-27
Treatment control	17.9	2.2	18	17-20	17.5	3.0	18	15-20
Emotional	14.2	3.7	19	16-20	16.6	5.4	20	16-2-
representations								
Illness coherence	18.1	3.8	14	12-16	18.12	4.1	14	12-20

6.7.4 Timeline, consequences, control, illness coherence and emotional representations Examining the descriptive statistics for the scales on the IPQ-R for those in good and poor control shows the similarity between the groups on personal control, treatment control and illness coherence. Analysing the groups for differences reveals that people in poorer control of their diabetes are significantly more likely to perceive their illness as occurring in a cyclical fashion than those in good control (U=1879.000, p=0.007) (Table 6.11). This difference in perception of timeline did not hold for the acute/chronic timeline dimension, and there was no significant difference between those in good and poor control, with most perceiving diabetes as a chronic illness (total median score = 24, I-QR 22-27).

Those in poor control perceived their illness as having significantly more consequences on their lives than those in good control (U= 1763.000, p=0.003). There were no differences between the two groups on the control dimensions (although it is not possible to comment on treatment control, given its low reliability) or on how well they felt they understood their illness. There was a difference however on the emotional representations dimension, with those in poor control reporting that they experience significantly more negative emotions in relation to their diabetes, than those in good control (U=1861.500, p=0.006).

Table 6.11 Differences between Good Control and Poor Control Groups on the Illness Perceptions Questionnaire

	N ₁	N ₂	Mann-Whitney U	p (two-tailed)
Identity	92	57	1835.000	0.002**
Timeline acute/chronic	89	57	2250.500	0.248
Timeline cyclical	89	57	1879.000	0.007**
Consequences	89	56	1763.000	0.003**
Personal control	89	56	2488.000	0.987
Treatment control	89	56	2212.000	0.247
Illness coherence	89	57	2484.500	0.831
Emotional representations	89	57	1861.500	0.006**

^{*}*p* < .05. ***p* < .01.

6.7.5 Correlations on the IPQ-R

Correlation coefficients using Spearman's Rho were calculated to examine the intercorrelations on the IPQ-R dimensions (Table 6.12). There was a consistent positive
association between illness coherence, personal control and timeline (acute/chronic). This
shows that those who feel they have a better understanding of their illness, also have a
higher sense of personal control over their diabetes and a view that diabetes is a chronic
rather than an acute illness. Other dimensions that were all positively associated with
each other were; identity, timeline (cyclical), consequences and emotional
representations. Those with a stronger illness identity were also more distressed about
their diabetes and had a view of diabetes as a cyclical illness with more consequences.

The two control dimensions of personal and treatment control were positively associated. Illness coherence was also related to the treatment control dimension and negatively related to emotional representations.

The causal attributions of psychological attributions, risk factor attributions and immune attributions were all positively correlated with each other. Chance attributions were correlated with immune attributions only. Looking at causal attributions and the other dimensions, psychological and risk factor attributions were both positively associated with identity, consequences and emotional representations. A higher perception of psychological and risk factors as a cause of diabetes is related to a stronger illness identity, more psychological distress about diabetes and a perception that diabetes is a more serious illness. Risk factors also showed a positive relationship with the cyclical timeline dimension. It had a non-significant relationship with illness coherence, whereas the other three causal attributions of psychological, immune and risk factors were all negatively related to illness coherence.

Table 6.12 Correlation Coefficients of the IPQ-R Dimensions (N=149)

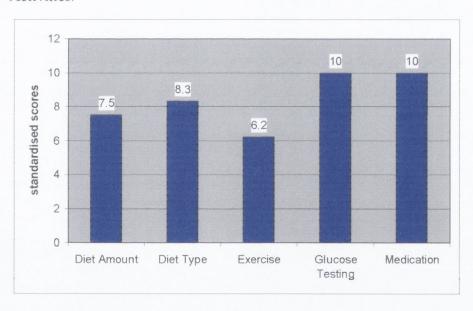
	1	2	3	4	5	6	7	8	9	10	11	12
1 Identity												
2 Timeline acute/chronic	.08											
3 Timeline cyclical	.49***	02										
4 Consequence	.38***	.15	.46***									
5 Personal control	06	.29***	16	.02								
6 Treatment control	08	17*	11	.04	.34***							
7 Illness coherence	12	.21**	16	07	.46***	.22**						
8 Emotional representat.	.28***	.01	.46***	.40***	03	.04	28**					
9 Psychological attributions	.17*	04	.14	.23**	07	.02	19*	.24**				
10 Risk Factor attributions	.26**	.06	.19*	.26**	01	.02	04	.19*	.39***			
11 Immune attributions	.16	.01	.14	.13	21**	.05	20**	.09	.28**	.23**		
12 Chance attributions	.11	13	.15	.01	19*	02	34***	.14	.14	.10	.31***	

^{*}*p*<.05. ***p* < .01. ****p*<.001

6.8 The Summary of Diabetes Self-care Activities Measure (SDSCA) (Participants with Diabetes)

There are five subscales within this measure which refer to: diet amount, diet type, exercise, glucose testing. Each scale will be individually discussed, as there is no overall score. Each question within the scales was coded and scored. The questions had several different scoring scales; some were percentages, others on differing scales of four points, five points and eight points. Every score was recoded into a standardised score from one to ten and the median standardised score for each subscale was calculated (see Figure 6.6). Moderate reliability was found with this measure and the Cronbach's alpha score was .59.

Figure 6.6. Median scores on the subscales of the Summary of Diabetes Self-care Activities.



Analysis of differences in diabetes self-care behaviours and the control of diabetes found significant differences on both diet subscales. There was a significant difference between those in good and poor control of their diabetes in how well they reported following their diet (U=2048.000, N_1 =94, N_2 =59, p=0.005, two-tailed). This means that those in poor control were less likely to follow their diet. There was also a significant difference between those in good control and those in poor control in the type of food consumed (U=2235.000, N_1 =94, N_2 =59, p=0.04, two-tailed), meaning that those in poor control were more likely to have a lower fibre, higher fat and higher sugar content to their diets. There were no significant differences on any of the other subscales.

Overall, participants reported that they were highly adherent to their recommended medication (median=10, I-QR=10-10). Of the 24 participants who reported taking insulin, 23 (95.8%) said that they took 'all of their insulin injections' in the previous week and the remaining person (4.2%) reported taking 'most of them'. Of the one hundred and twenty participants who said they take medication for their diabetes, 109 (90.8%) reported that they had taken 'all of them' in the previous week and the other 11 (9.2%) said that they had taken 'most of them'.

Glucose testing was also well adhered to (median=10, I-QR=6-10), with 58.8% reporting that they had tested their blood sugar 100% as recommended. Only 7.2% reported that they had tested their blood glucose levels 0% of the recommended times in the previous week. In relation to the type of foods people eat, sugar intake is most closely adhered to (Figure 6.7). Ninety-five participants out of 153 (62.1%) reported having no sweets or desserts as part of any of their meals during the week prior to the study. High fat foods are also consumed in moderation, with only one participant having fatty foods with all of their meals in the previous week and nine participants (5.9%) having fatty foods with 25% of their meals. Fifty-five participants (35.9%) included high fibre foods in 100% of their meals in the previous week and a further 53 (34.6%) with 75% of their meals.

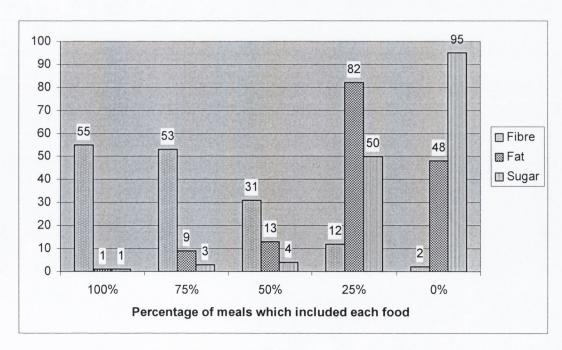


Figure 6.7. Number of people report adhering to diet recommendations for fibre, fat and sugar intake.

The 'diet amount' scale refers to how well the participant feels they followed their diet in the previous week. Figure 6.8 shows the percentage of participants who followed their diet 'always', 'usually', 'sometimes', 'rarely' and 'never'. A second question on this scale referred to how successful people were at limiting their calories in the previous week. Many participants said that they were unsure of both their recommended calorie intake and their actual calorie intake. They were advised by the researcher to think in more global terms of their food intake during the previous week rather than attempting to count calories. Of the 153 participants who answered this question, a total of 22.2% said that they successfully limited their calories 100% of the time, 39.9% successfully limited them 75% of the time, 24.8% 50% of the time and 13.1% 25%-0% of the time.

From figure 6.6, it can be seen that exercise is the diabetes self-care activity with the lowest median score (6.2). The median number of days that participants engage in at least 20 minutes physical exercise was 5 (I-QR = 3-7 days). However, when asked how often they participated in 'a specific exercise session other than what you do around the house or as part of your work' this decreases to a median of 3 days (I-QR = 0-6). Figure 6.9 illustrates this in more detail.

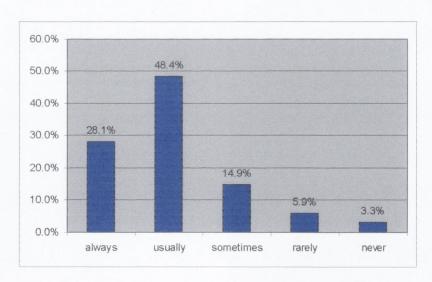


Figure 6.8. Frequency of adherence to diet.

A further question on participation in the amount of recommended exercise caused difficulties for many participants who commented that no particular amount of exercise had been recommended. For the purpose of answering the item on the questionnaire, guidelines of twenty –thirty minutes, three-four times per week were suggested yet

nineteen people were unable to answer this question. Of the 87% of participants who did answer, 45.5% had adhered 100% to the amount of exercise recommended. A further 11.9% had exercised 75% of their recommended amount, with the remaining 42.5% engaging in 50% or less of their recommended exercise.

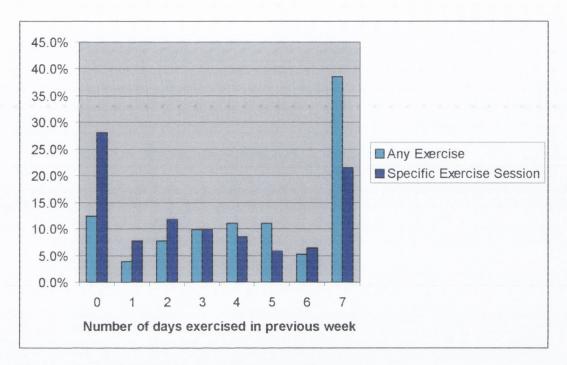


Figure 6.9. Participation in exercise over previous seven days.

This self-report measure of diabetes self-care activities has found that in this sample people with diabetes report excellent adherence to their recommended medication. The majority of participants (72.5%) had tested their blood glucose levels every day or most days in the previous week and just over three quarters (76.5%) felt that they followed their recommended diet 'usually' or 'always'. Exercise shows the lowest levels of reported adherence, with 28% of this sample having engaged in no specific exercise at all in the previous week and 47.4% had had two or less exercise sessions.

6.9 Social Support Questionnaire (SSQ-6) (Participants with Diabetes)

There were two parts to each of the seven questions on this measure (Sarason et al., 1987), the first part asked how many people (up to nine) the person had for a particular type of support and the second asked how satisfied they were with that support on a scale of one to six. The range was 0-63 and 1-42 respectively.

Statistical analysis of group differences in the control of diabetes, showed that there were no significant differences in levels of support (U=2440.00, N_1 =88, N_2 =57, p=0.78) between those in good control (median = 21, I-QR = 11-31) and those in poor control (median = 24, I-QR = 11-32) of their diabetes or in satisfaction with support (U=2205.00, N_1 =88, N_2 =57, p=0.18) between those in good control (median = 42, I-QR = 36-42) and those in poor control (median = 40, I-QR = 36-42) of their diabetes.

Overall, the results were skewed towards high satisfaction and so, medians and interquartile ranges are provided in Table 6.13. Participants have a median of three people who they can turn to for support and they are very satisfied with the support they have. Of note, question seven which asked specifically about support for diabetes, yielded the lowest score. Participants had a median of one person whom they could turn to for diabetes-related support. Most often this was a member of the diabetes outpatients' clinic, or the clinic itself. Although there is a low level of perceived support for diabetes (median = 1, I-QR = 1-4), there is a high level of satisfaction (median=6, I-QR=6).

Table 6.13 Median and I-QR for Each Question on the Short-form Social Support Questionnaire

Question	Number in Support Network median (I-QR)	Level of Satisfaction median (I-QR)
Q1. Who is there to distract you?	3 (1-4)	6 (5-6)
Q2. Who helps you to relax?	2 (1-4)	6 (5-6)
Q3. Who accepts you?	4 (1-6)	6 (6)
Q4. Who cares for you?	4 (1-6)	6 (6)
Q5. Who makes you feel better?	3 (1-5)	6 (5-6)
Q6. Who is there to console you?	2 (1-4)	6 (5-6)
Q7. Who helps you with your diabetes?	1 (1-4)	6 (6)
Total	21 (11-31)	42 (36-42)

The data was then examined for differences in support between those who had nominated a family member to participate and those who had not, presuming that those who had nominated someone had at least some support. There was no difference in the number of people for support that participants reported but there was a significant difference in their satisfaction with support (Table 6.14). Participants who had nominated a family member

for inclusion in the research were more satisfied with the support they had (U=2085.000, N_1 =144, N_2 =144, p=.03).

Table 6.14 Differences on the Social Support Questionnaire between Participants who Nominated a Family Member and Those who did not Nominate a Family Member

	Median	I-QR	U	N_1	N_2	p
Number of People for Support			2367.500	144	144	0.38
Nominated family member	21	13-32				
No nomination of family	22	8-31				
Satisfaction with Support			2085.000	144	144	0.03*
Nominated family member	42	38-42				
No nomination of family	40	35-42				

^{*}p < .05.

6.10 Well-Being Questionnaire (WBQ-12) (Participants with Diabetes)

Psychological well-being was assessed using the 12-item Well-Being Questionnaire (Bradley, 2000; Pouwer et al., 1999). This is made up of three subscales, negative well-being, positive well-being and energy, all of which are scored so that a higher score indicates greater well-being. This scale was found to be reliable with this sample and the Cronbachs alpha for this questionnaire was .85. When the sample is divided into those in good control and poor control, those in poor control show slightly lower negative well-being, equal energy, higher positive well-being and higher general well-being (see Table 6.15), however, Mann-Whitney tests revealed that none of these differences were significant.

Table 6.15 Differences in Control of Diabetes on the Well-being Questionnaire

Scale	N	Mean	SD	Median	I-QR	U	p
Negative Well-being						2595.5	0.642
Good	92	2.30	2.7	2	0-4		
Poor	59	2.73	3.1	1	0-5		
Energy						2658.0	0.830
Good	92	6.82	2.7	7	5-9		
Poor	59	6.68	3.8	7	4-10		
Positive Well-being						2656.0	0.963
Good	92	8.66	2.8	9	7-11		
Poor	58	8.62	2.8	10	7-11		
General Well-being						2643.0	0.923
Good	92	25.17	6.4	25	21-30		
Poor	58	24.57	7.9	27	21-31		

The mean score for General well-being for the total sample was 24.94 (SD 7.1). The scores for the subscales can be seen in Table 6.16, alongside means and standard deviations from a study evaluating the W-BQ12 (Pouwer et al., 1999), which separates those with complications from those without complications, and scores from a study on the impact of a diagnosis of diabetes (Adriannse et al., 2004).

Table 6.16 Means and Standard Deviations for W-BQ12 Total and Subscale Scores from Three Studies of People with Type 2 Diabetes

Scale	Current Study	12 months post- diagnosis ^a	With complications ^b	Without complications ^b
N	150	116	349	354
Negative Well-being	2.47 (2.8)	1.9 (2.6)	2.7 (2.9)	1.9 (2.4)
Energy	6.76 (3.2)	8.0 (2.8)	7.5 (3.0)	8.3 (2.8)
Positive Well-being	8.65 (2.8)	9.4 (2.5)	7.6 (2.8)	8.7 (2.7)
General Well-being	24.94 (7.1)	27.6 (6.8)	24.4 (7.2)	27.2 (6.8)

^aAdriannse et al (2004); ^bPouwer et al (1999)

General well-being in this sample is lower than in other studies and closely resembles those of Pouwer et al's group that have complications. On the subscales, the mean energy score is consistently lower than the other samples, suggesting that this group report lower levels of energy. The other two subscales do not show such a consistent pattern. Distributions on the negative well-being, positive well-being and general well-being scales were skewed, therefore medians were considered for the analysis.

6.11 Coping with Health Injury and Problems (CHIP) (Participants with Diabetes) Individual item responses on the CHIP were scored and coded into the four coping scales (distraction coping, palliative coping, instrumental coping and emotional preoccupation). Cronbach's alpha for the CHIP was .83, indicating that it was a reliable measure. Population norms for the CHIP are provided by the authors in the form of a standardised T-score (Endler & Parker, 2000). These T-scores have a mean of 50 and a standard deviation of 10. Scores between 45 and 55 are considered average and those below 40 indicate below average use of the coping approach. In line with the T-scores provided, the means and standard deviations of this sample will be considered. The T-scores provided in Table 6.17 are for those over 50 (mean age for participants in this study = 59.1 years) and where necessary the average has been taken of the male and female scores. Taking the group as a whole, the scores on all four of the coping scales are within the average population norms, showing that this total group do not show any distinctively different coping patterns. The norms for the groups when divided into levels of control again show average coping patterns. The only exception to this is the poor control group score, which was slightly above average on the distraction coping scale (Tscore=57.5). When analysed, there was a significant difference between the two groups on distraction coping (t=-2.117, df=134, p=0.036, two-tailed). Those in poor control use distraction coping more than those in good control. This was the only scale with any significant difference between the two groups.

Table 6.17 Descriptive Statistics and *T*-scores for Coping with Health Injury and Problems Measure

	Distraction Coping*	Palliative Coping	Instrumental Coping	Emotional Preoccupation
Good Control				
n	80	81	80	80
Mean (SD)	26.20 (6.3)	23.81 (5.7)	30.28 (6.0)	20.30 (7.8)
T-score	52.5	49	50	49
Poor Control				
n	56	57	57	56
Mean (SD)	28.39 (5.5)	24.98 (5.2)	28.51 (7.1)	22.20 (8.5)
<i>T</i> -score	57.5	52	47.5	52.5
Total				
N	136	138	137	136
Mean (SD)	27.10 (6.0)	24.30 (5.5)	29.54 (6.5)	21.08 (8.1)
T-score	54.5	49	50	51

^{*} significant difference between groups at .05 level

6.12 Family Members – Introduction

Seventy four (73%) of the family members invited to take part in the research completed and returned their questionnaires. The majority of these questionnaires (71.6%) were from family members of those in good control of their diabetes.

These questionnaires were filled in by family members in their own homes and posted back to the researcher, unlike the measures for those with diabetes, which were interview-administered. This led to a difference in the quality of the completed questionnaires, with the postal questionnaires containing more missing data and occasionally complete measures unanswered. The Short-form Social Support questionnaire had the least number of respondents, with total support scores available for 52 participants and total satisfaction scores for only 39 family members.

6.13 Diabetes Knowledge Questionnaire (DKQ) (Family Members)

Total scores on the DKQ are summed from the 24 questions giving a range of 0-24. The mean total score for family members was 15.27 (S.D. 3.29). This was lower than those

with diabetes whose mean total score was 16.18 (S.D. 2.89) but there was no significant difference between family members and those with diabetes on knowledge scores (t=1.766, df=192, p=0.079).

Family members showed highest knowledge scores on questions relating to: lack of effective insulin is a usual cause, the two types of diabetes, that diabetes often causes poor circulation, taking care when cutting nails and that blood sugar levels increase in untreated diabetes (see Table 6.18). Ninety seven per cent incorrectly answered that people with diabetes should cleanse a cut with extra care. The second and third lowest scoring questions related to signs of hypoglycaemia and hyperglycaemia. Only 28% of family members correctly identified the signs of low blood sugar and 16% the signs of high blood sugar. The pattern of correct answers was similar to those with diabetes. With one exception (Q14), both groups had the same five highest and lowest answers. Analysis to see if there was a correlation between family members and those with diabetes on their knowledge of diabetes, showed no significant relationship (r=-0.177, r=68, p=0,149).

When examining differences in relation to the control of diabetes and knowledge, family members of those in good control had a higher total score (mean = 15.38, S.D. = 3.43) than family members of those in poor control (mean=14.91, S.D.=2.99). This difference was not statistically significant (t=0.411, df=46, p=0.68).

Table 6.18 Percentage of Correctly Answered Questions by Family Members on the Diabetes Knowledge Questionnaire

Question	Percentage who
	answered correctly
Q2. The usual cause of diabetes is lack of effective insulin in the body	95.7%
Q11. There are two main types of diabetes: type 1 (insulin-dependent) and type 2	
(non-insulin dependent)	94.1%
Q14. Diabetes often causes poor circulation	94.1%
Q16. People with diabetes should take extra care when cutting their toenails	92.8%
Q5. In untreated diabetes, the amount of sugar in the blood usually increases	91.2%
Q20. Diabetes can cause loss of feeling in the hands, fingers and feet	88.2%
Q15. Cuts and abrasions on people with diabetes heal more slowly	89.9%
Q7. Diabetes can be cured	88.2%
Q19. Diabetes can damage your kidneys	77.3%
Q10. Regular exercise will increase the need for insulin and other diabetes	
medication	75.8%
Q6. If I have diabetes, my children have a higher chance of having diabetes	75.0%
Q8. A fasting blood sugar level of 9 is too high	73.5%
Q18. The way people with diabetes prepare their food is as important as the food	
they eat.	72.5%
Q24. A diabetes diet consists mainly of special foods	59.1%
Q4. Kidneys produce insulin	63.6%
Q12. An insulin reaction is caused by too much food	56.1%
Q13. Medication is more important than diet and exercise to control diabetes	55.2%
Q9. The best way to check diabetes is by urine testing	52.9%
Q23. Tight socks or tights are not bad for people with diabetes	41.2%
Q1. Eating too much sugar and other sweet foods is a cause of diabetes	40.6%
Q3. Diabetes is caused by the failure of the kidneys to keep sugar out of the urine	35.8%
Q22. Frequent urination and thirst are signs of low blood sugar	27.9%
Q21. Shaking and sweating are signs of high blood sugar	16.4%
Q17. A person with diabetes should cleanse a cut with extra care	2.9%

6.14 Illness Perceptions Questionnaire - Revised (IPQ-R) (Family Members)

As for those with diabetes, the results for the causes dimension will be presented first as it is scored differently to the other dimensions. Identity will then be reported as its scores are summed from the number of diabetes-related symptoms identified. The remaining seven dimensions are all scored on a five point likert scale assessing the respondents'

level of agreement with each item. Means and standard deviations only are reported for the causes dimension and medians and inter-quartile ranges are included for the other dimensions, as distribution was skewed. In this questionnaire, the dimensions of consequences, personal control, illness coherence and emotional representations were divided into those relating to what the family member perceives and those relating to what they think the person with diabetes perceives about their illness. This measure was found to be reliable with this sample and had an overall Cronbach's Alpha of .78.

6.14.1 Correlations on the Family Members' IPQ-R

In order to examine relationships amongst the dimensions, correlations were performed on the IPQ-R data (see Table 6.19). The associations were not as clear-cut as for those with diabetes. However, there were the same correlations on two of the dimensions – symptoms and consequences.

Family members showed a positive relationship between a stronger illness identity and both their own perceptions and how person with diabetes perceived diabetes to be more cyclical, a more serious illness and displayed more serious consequences. Family members perception of diabetes as a more serious illness was also related to their cyclical timeline beliefs and higher levels of distress for themselves and the person with diabetes. Family members also shared the same consistent positive associations between symptoms, timeline (cyclical), consequences and emotional representations as those with diabetes. Illness coherence beliefs for family members were positively correlated to cyclical timeline beliefs and emotional representations for both themselves and those with diabetes. These illness coherence beliefs were negatively correlated with chronic timeline beliefs and the illness coherence beliefs they felt those with diabetes have. Control beliefs differed for family members perceptions and their perceptions of those with diabetes. Whilst family members personal control beliefs did correlate positively with how the person with diabetes perceived the consequences of the illness, most of the correlations were for how they perceived the person with diabetes related to personal control. The personal control that family members believe that those with diabetes have was positively correlated with their acute/chronic timeline, their perceptions of illness control and their illness coherence.

Table 6.19 Correlation Coefficients of the Family IPQ-R dimensions (N=62)

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	1
1																
2	.15															
3	.58**	06														
4	.41**	.16	.28*													
5	.48**	.18	.21	.42**												
6	13	05	.04	08	33**											
7	.19	.29*	03	.11	.13	09										
8	.02	02	14	06	04	.00	.40**									
9	.08	37**	.34**	.10	01	.09	19	19								
10	04	.33**	17	17	.09	14	.29*	.30*	69**							
11	.36**	08	.48**	.58**	.19	00	02	10	.46**	34**						
12	.41**	04	.46**	.52**	.22	15	04	08	.48**	43**	.58**					
13	.19	.07	.25*	.21	.13	.02	.16	.27*	.13	03	.19	.28*				
14	.22	.14	.21	.25*	.22	.08	01	.01	.16	21	.19	.30*	.35*			
15	.17	08	.18	.07	.03	.15	04	.05	.32**	20	.12	.16	.51**	.27*		
16	15	30*	.02	11	05	.15	15	14	.23	12	02	16	.21	06	.28*	

Note. 1 = identity, 2 = timeline acute/chronic, 3 = timeline cyclical, 4 = consequences for family member, 5 = consequences for person with diabetes, 6 = personal control family member, 7 = personal control person with diabetes, 8 = treatment/cure control, 9 = illness coherence family members, 10 = illness coherence person with diabetes, 11 = emotional representations family member, 12 = emotional representations person with diabetes, 13 = psychological attributions, 14 = risk factors, 15 = immunity, 16 = accident/chance.

As with the causal attribution correlations for those with diabetes, family members risk factor, psychological and immune attributions were all positively associated with each other. Chance attributions were positively related to immune attributions and negatively related to an acute/chronic timeline. Psychological attributions were positively associated with a cyclical timeline, treatment control and the perceived emotional representations of those with diabetes. Risk factors were positively correlated with family members perceived seriousness and their perceived emotional representations of those with diabetes. Immune attributions were correlated only with family members illness coherence.

6.14.2 Causal Beliefs

When asked for level of agreement from the list of eighteen possible causes of diabetes, 'diet' was the leading cause, with 81.1% of family members agreeing or strongly agreeing that diet was a cause. The second leading cause was hereditary, with 53.7% and then 'ageing' with 48.5% agreeing or strongly agreeing with these causes. Almost 40% said that 'stress or worry' was a cause of their family member's diabetes and the fifth

^{*}*p*<.05. ***p* < .01.

most common cause rated was 'their own behaviour' with just 27.5% agreeing or strongly agreeing. Means and standard deviations for the leading causes and the least likely causes are provided in Table 6.20. From this table it can be seen that an 'accident or injury' was perceived as the least likely cause of diabetes and 92.6% of family members disagreed or strongly disagreed that it was a cause. A large number also disagreed or strongly disagreed that 'a person's personality' (85.3%) or 'their mental attitude' (75.4%) could be a cause of diabetes. The majority of family members also disagreed/strongly disagreed that outside influences such as 'germs or viruses' (77.9%), 'pollution' (72.4%) and 'poor medical care in the past' (76.8%) were causes of diabetes.

When looking at responses separately for family members of those in good and poor control, there was only one cause where there was a significant difference. This was for 'chance or bad luck' (t = 2.376, df = 65, p = 0.02), which family members of those in good control perceived to be a cause of diabetes more than those in poor control. One other item, 'overwork' although not significant, was approaching significance (t = -1.932, df = 66, p = 0.058). Family members of those in poor control scored higher on this item, showing a trend to agreeing more strongly than those in good control that overwork was a cause of diabetes.

When these items were categorised into the four causal attributions of psychological attributions, risk factors, immune attributions and chance, chance attributions was still the only category to have a significant difference between those in good and poor control (t=-1.231, df=64, p=.03). Family members of those in good control had a significantly stronger belief that diabetes occurred due to chance or an accident.

Participants were also asked to list what they perceived to be the three most important causes of their family members diabetes. The total list of causes was coded and ranked. For each cause, family members of those in good control and poor control listed the same top three causes therefore, the total group results are shown in Table 6.25. The results are similar to the previous causes section with the main causes of diabetes including diet, hereditary, ageing and stress. The only new editions are 'work' and 'lifestyle' which included lack of exercise.

Table 6.20 Means and Standard Deviations for Family Members Causal Attributions of Diabetes.

Cause	Mean	S.D.
Diet	3.94	0.86
Hereditary	3.15	1.44
Ageing	3.07	1.14
Stress or worry	2.91	1.13
Own behaviour	2.71	1.13
Overwork	2.50	1.18
Family problems	2.39	1.14
Smoking	2.37	1.20
Emotional state	2.34	1.19
Altered Immunity	2.33	0.91
Chance or bad luck	2.28	1.03
Alcohol	2.25	1.22
Pollution	2.13	0.84
Poor medical care	2.13	0.97
Mental attitude	2.10	0.88
Germ or virus	1.99	0.80
Personality	1.91	0.75
Accident or injury	1.85	0.74

Table 6.21 Percentage of Family Members Responses to Perceived Causes of Diabetes

	Cause 67		nd Cause I=64		rd Cause =58
	%		%		%
Hereditary	41.8%	Diet	32.3%	Diet Ageing	17.2% 17.2%
Diet	19.4%	Hereditary	9.4%	Weight	12.1%
Stress	10.4%	Work Lifestyle	7.8% 7.8%	Stress Lifestyle	8.6% 8.6%

6.14.3 Identity

Participants reported on the number of diabetes-related symptoms that their family member experienced since their diagnosis. Identity was one of three of the eight scales on the IPQ-R that were skewed and so, medians, inter-quartile ranges and nonparametric statistics will be reported. The total group mean was 4.19 (S.D. = 3.38) and the median 4

(I-QR = 1-7). This was higher than those with diabetes (median=3, I-QR = 1-6) but this difference in identity was not significant (U=4035.000, N1=149, N2=62, p=.15).

Family members of those in poor control reported a higher mean number of diabetes-related symptoms (5.43, S.D. =3.82)) than those in good control (3.56, S.D. = 2.98). The median for family members of those in poor control was 4 (I-QR = 1-6) and for those in good control was 4, (I-QR = 3-8). Analysis showed that the difference between the medians of the two groups was not significant (U=305.500, N_1 =41, N_2 =21, p=0.061). Therefore, although there was no significant difference in control of diabetes and family members reporting of diabetes-related symptoms, there was a trend towards family members of those with poorer control having a stronger illness identity.

6.14.4 Timeline, Consequences, Control, Illness Coherence and Emotional Representation

Table 6.22 shows the differences between family members' scores and participants with diabetes scores on the IPQ-R. There were significant differences on five of the eight dimensions. For timeline acute/chronic, there was a trend towards family members having a more chronic timeline perception of diabetes than those with the illness, although this did not reach significance (U=4386.000, N_1 =146, N_2 =71, p=.07). On the timeline cyclical dimension there was a significant difference between the groups $(U=4226.500, N_1=146, N_2=71, p=.03)$, family members perceived diabetes as coming and going in cycles more than those with diabetes did. Family members perceived diabetes as having significantly more serious consequences than those with diabetes (U=3340.500, N_1 =145, N_2 =71, p=.001). There was also a highly significant difference in relation to personal control (U=492.50000, N_1 =145, N_2 =71, p<.001), where participants with diabetes perceive diabetes to be more personally controllable than their family members perceptions. The opposite was the case for treatment control and family members perceive diabetes to be more controllable by treatment than those with diabetes $(U=3969.000, N_1=145, N_2=71, p=.01)$. Family members perceive that they have significantly less understanding about diabetes than those with the illness (U=1590.500, $N_1=146$, $N_2=70$, p=.001). Finally, there was no difference in perceived levels of emotional distress between family members and those with diabetes (U=4934.000, $N_1=146, N_2=71, p=.68$).

Table 6.22 Differences between Person with Diabetes and the Family Members own Perceptions on the Illness Perceptions Questionnaire

Dimension		Family Members		icipants Diabetes	U	N ₁ , N ₂	p
	Mdn	I-QR	Mdn	I-QR			
Identity	4	1-7	3	1-6	4035.000	149, 62	0.15
Timeline acute/chronic	26	23-28	24	23-28	4386.000	146, 71	0.07
Timeline cyclical	12	8-14	9	8-14	4226.500	146, 71	0.03*
Consequences (FM)	14	12-18	16	16-20	3340.500	145, 71	0.001***
Personal control (FM)	18	14-19	24	19-24	492.500	145, 71	0.001***
Treatment control	19	18-20	18	18-20	3969.500	145, 71	0.01*
Illness coherence (FM)	12	11-15	20	16-21	1590.500	146, 70	0.001**
Emotional rep. (FM)	14	12-18	14	13-19	4934.000	146, 71	0.68

Note. (FM) corresponds to the family members own perceptions.

Family members on the IPQ-R were also asked what they felt the person with diabetes perceptions were about the consequences(e.g. 'their diabetes has major consequences on their life'), personal control (e.g. 'there is a lot which they can do to control their symptoms'), illness coherence (e.g. 'they don't understand their diabetes') and emotional representations ('their diabetes makes them feel angry') of their illness. The differences between the illness perceptions that those with diabetes reported and what their family members thought their perceptions were are presented in Table 6.23.

Table 6.23 Differences between Person with Diabetes Perceptions and the Family Members Perceptions of the Person with Diabetes' Perceptions

Dimension	Family Members		Participants with Diabetes		U	N ₁ , N ₂	p
	Mdn	I-QR	Mdn	I-QR			
Consequences	17	15-18	16	16-20	4947.500	145, 71	0.64
Personal control	24	22-26	24	19-24	5132.000	145, 71	0.97
Illness coherence	20	17-21	20	16-21	4295.500	146, 70	0.05*
Emotional representations	16	14-16	14	13-19	4012.500	146, 70	0.01**

^{*}p<.05, **p<.01

^{*}p<.05, **p<.01, ***p<.001

There were no differences in what family members reported as the perceptions of those with diabetes and what the participants with diabetes themselves reported about the consequences of diabetes and the sense of personal control over the illness. This indicates that family members have an accurate sense of the patient's perceived seriousness and how much they can do to control their illness. However, perceptions differed in relation to the understanding of the illness and the emotional distress it causes. Family members report that patients are more emotionally distressed about their diabetes than those with the illness feel they are (U=4012.500, N_1 =146, N_2 =70, p<.01). Family members also feel that those with diabetes know more about the illness than the patients themselves perceive they do (U=4295.500, N_1 =146, N_2 =70, p<.05).

Family members' responses on the IPQ-R were then analysed for differences between family members of those in good control and family members of those in poor control of their diabetes. The descriptive statistics for family members of those in good and poor control can be seen in Table 6.24. Analysis of the differences in control and dimensions on the IPQ-R showed that the two groups were very similar. There was just one dimension where family members of those in good control differed from those in poor control. This was on the timeline (acute/chronic) dimension ((U=333.000, N_1 =50, N_2 =21, p<.02) (Table 6.25). Family members of those in poor control see diabetes as more of a chronic long lasting illness than family members of those in good control.

Table 6.24 Descriptive Statistics for the Family Members' Illness Perception Questionnaire

	Good Control (n=41-50)						Poor Control (n=21)				
Scale	Mean	SD	Median	I-QR	Mean	SD	Median	I-QR			
Illness identity	3.56	2.9	4	1-6	5.43	3.8	4	3-8			
Timeline acute/chronic	24.64	3.5	25	23-27	26.30	4.7	28	25-20			
Timeline cyclical	11.19	3.9	12	8-14	11.05	3.7	10	9-15			
Treatment control	18.77	2.3	18.75	18-20	18.66	3.3	19	16-21			
Consequences FM	14.36	2.7	14	13-14	14.52	2.9	14	12-17			
Consequences D	16.92	2.1	17.5	15-18	15.97	1.8	16	15-19			
Personal control FM	17.06	3.6	18	15-20	16.73	3.8	16	13-18			
Personal control D	23.84	3.3	24	22-26	25.07	2.9	24	22-28			
Illness coherence FM	12.86	3.3	12	11-16	12.71	2.9	12	11-14			
Illness coherence D	19.66	3.3	20	18-21	19.01	4.1	20	16-23			
Emotional rep. FM	15.05	3.7	14	12-18	14.59	4.5	14	13-17			
Emotional rep. D	16.46	4.5	16	14-20	16.5	4.5	15.5	12-21			

Table 6.25 Differences between Good Control (N_1) and Poor Control (N_2) Family Member Groups on the Illness Perceptions Questionnaire

	N_1	N ₂	Mann-Whitney U	p (two-tailed)
Identity	41	21	305.500	0.06
Timeline acute/chronic	50	21	333.000	0.02*
Timeline cyclical	50	20	488.500	0.88
Treatment control	50	21	487.500	0.63
Consequences FM	50	21	474.000	0.52
Consequences D	50	21	481.000	0.58
Personal control FM	50	21	401.000	0.12
Personal control D	50	21	476.000	0.53
Illness coherence FM	50	20	465.000	0.65
Illness coherence D	50	20	490.000	0.89
Emotional rep. FM	50	20	478.000	0.77
Emotional rep. D	50	20	467.000	0.78

^{*}p < .05.

6.15 Social Support (SSQ-6) (Family Members)

The two parts to this questionnaire examined (1) how many people the person had for a particular type of support and (2) how satisfied they were with that support on a scale of one to six. Total scores are given for each section with a possible range of 0-63 and 1-42 respectively. The results from family members were skewed towards high satisfaction and so, medians and inter-quartile ranges are provided in Table 6.26.

This shows a high level of satisfaction with support but when compared with the results from participants with diabetes, family members are significantly less satisfied with the support they have (U=1899.000, N_1 =145, N_2 =39, p<.001). There was no significant difference between the two groups on the numbers in their support network (U=3730.000, N_1 =145, N_2 =52, p=.91). Those without diabetes have a similar number of people for support as those with diabetes but they are less satisfied with the support they receive.

Table 6.26 Family Members Median and I-QR for each Question on the Short-form Social Support Questionnaire

Question	Number in Support Network median (I-QR)	Level of Satisfaction median (I-QR)	
Q1. Who is there to distract you?	4 (2-6)	5 (5-6)	
Q2. Who helps you to relax?	2 (1-4)	5 (4-6)	
Q3. Who accepts you?	3 (1-5)	6 (5-6)	
Q4. Who cares for you?	3.5 (2-6)	5 (5-6)	
Q5. Who makes you feel better?	3 (1-4)	5.5 (5-6)	
Q6. Who is there to console you?	2 (1-4)	6 (5-6)	
Q7. Who helps you with diabetes?	2 (1-4)	5 (5-6)	
Total	18 (12-30)	36 (34-41)	

The results for family members were analysed for differences in relation to the control of diabetes. Table 6.27 shows that there were no differences in satisfaction levels. The median number of people for support was higher for family members of those in poor control but this did not reach significance.

Table 6.27 Differences between Family Members of those in Poor Control and Good Control on the Social Support Questionnaire

	Median	I-QR	U	N_1	N_2	p
Number of People			187.000	37	15	0.07
Good Control	16	12-28				
Poor Control	22	14-35				
Satisfaction			143.000	29	10	0.95
Good Control	38	34-42				
Poor Control	35	32-40				

6.16 Well-being Questionnaire (WBQ-12) (Family Members)

The score for General Well-being is calculated from the three subscales of negative well-being, energy and positive well-being and has a range of 0-36. Cronbach's alpha was .84 indicating that this was a reliable measure. The mean and standard deviation scores will be discussed in light of other studies, which tend to report mean scores but because of the non-normal distribution on two of the scales, analysis is based on medians and interquartile ranges. Family members in this research had a mean General Well-being score of 24.59 (S.D. = 6.26). Other studies that have used the well-being score with people without diabetes have reported mean General Well-being scores of 26.8 (Farmer, Doll, Levy & Salkovskis, 2003). This sample display lower psychological well-being than other groups without diabetes. Their well-being scores were similar to those of their family member with diabetes (means=24.59 and 24.94 respectively). Subscale analysis revealed that the family members and those with diabetes differed significantly on positive well-being scores (U=4100.500, N_1 =150, N_2 =67, p=.03) (see Table 6.28). Participants with diabetes experience higher positive well-being, although overall, General Well-being is the same for both groups.

Table 6. 28 Differences between People with Diabetes and Family Members on Well-Being Questionnaire

Scale	Participant Group	N	Median	I-QR	U	p
Negative Well-	Family	151	1	0-3	4503.00	0.09
being	Person with diabetes	69	1	0-4		
Energy	Family	151	7	5-9	4856.500	0.90
	Person with diabetes	65	7	5-9		
Positive Well-being	Family	150	8	6-10	4100.500	0.03*
	Person with diabetes	67	9	7-11		
General Well-being	Family	150	26	20-29	4533.500	0.50
	Person with diabetes	64	25	21-27		

^{*} p < .05.

Examining the results for family members, they were again divided into those from families with a member in good control of their diabetes and those whose family member was in poor control of their diabetes. Mann-Whitney U tests were performed on each of the subscales and the total (see Table 6.29). No significant differences were found between family members of those in good control and poor control on their psychological well-being on any of the scales.

Table 6.29 Control of Diabetes Differences on the Well-being Questionnaire for Family Members

Scale	Control of Diabetes	N	Median	I-QR	U	p
Negative Well-being	Good	48	0	0-3	425.000	0.27
	Poor	21	2	0-3		
Energy	Good	46	7	4-9	414.000	0.74
	Poor	19	6	5-8		
Positive Well-being	Good	47	8	6-10	418.500	0.48
	Poor	20	9	6-11		
General Well-being	Good	45	27	21-29	363.500	0.35
	Poor	19	25	19-30		

6.17 Logistic Regression

A preliminary logistic regression highlighted the high range of scores on the different scales, this meant that there was a large variability in the variables for both groups (i.e. good and poor control) which had the potential to obscure the differences between them. It was decided after consultation with a senior biostatistician to condense the scores on each variable into three categories, e.g. low, medium and high, with each category accounting for approximately one third of the scores. The grouped independent variables were then treated as if categorical and the last group served as the reference group (Hosmer & Lemeshow, 1989). Changing continuous variables to discrete categorical variables is not usual practice within the discipline of psychology, however it is frequently practiced in clinical and epidemiological research (Austin & Brunner, 2004). The disadvantages of this process are a loss of sensitivity within the data and an increased chance of a type 1 error. However, it does make the analysis and subsequent results more meaningful by reducing variability (calculating the proportion e.g. of those in good control) in each group, which preserves the underlying relationship between the variables (Bower, 2002). Because logistic regression does not assume a linear relationship within each variable, it can analyse categorical data in a useful way. Therefore, the scores for each variable, within every measure were recoded into three equal categories. This was done by examining the distribution of scores for every variable and dividing the data into three equal categories e.g. low, medium and high satisfaction.

Because the measures in this research were interview administered for those with diabetes, there was a relatively low number of missing values. On average, across all of the measures the data was 94% complete. Missing data does however become an issue when using logistic regression as it will only consider every complete case. To overcome this potential loss of data, expectation-maximisation (EM) estimations were performed. This form of missing values analysis has advantages over simply replacing missing values with the mean score as it can calculate missing values within a normal distribution, taking account of naturally occurring variances within that distribution (Schaefer & Graham, 2002).

With all of the measures in this study, there were a total of thirty one variables to be included in the logistic regression (Table 6.30). Such a high number would be unmanageable for meaningful logistic regression modelling. To address this, variables within each measure were first analysed separately using logistic regression. This meant that a separate logistic regression model was run with each variable. Those variables with a statistical significance of 0.1 or less were then retained for the model. The rationale for keeping all of those at 0.1 or less was to include variables that may have been significant, if the sample were larger. This method of selection does mean however, that variables chosen are reflective of statistical power, which is a function of sample size. Each variable is in three categories, in this logistic regression, the last category is held as the reference category and significant levels are available for the first and second ones. If either of these were significant (at 0.1 level), they were included in the final model. Table 6.31 contains all of the independent variables to be entered into the logistic regression model.

Whilst including demographic details of the patients in the logistic regression, it was not possible to include their medical details due to the high level of missing data. This was because of the lack of consistency and clarity in the recording of the medical data in patient files. Of note, duration of disease was not included in the final analysis. Although duration of disease has been found to be a predictor of glycaemic control both in cross-sectional (Blaum et al., 1997) and longitudinal studies (Benoit, Fleming, Philis-Tsimikas & Ji, 2005), this was decided upon as including duration of disease as a predictor in this model would have overshadowed the data on the psychosocial predictors of glycaemic control.

Table 6.30 All Variables examined by Measure-Specific Logistic Regression

	MEASURE	Variable
1	DEMOGRAPHICS	Gender
2		Age
3		Medical Card Holder
4		Marital Status
5		Work Status
6		Education
7	KNOWLEDGE (DKQ)	Total Diabetes Knowledge
8	TREATMENT SATISFACTION (DTSQ)	Satisfaction with Treatment
9	ILLNESS PERCEPTIONS (IPQ-R)	Symptoms
10		Timeline
11		Time – Cyclical
12		Consequences
13		Personal Control
14		Cure Control
15		Illness Coherence
16		Emotional Representations
17		Psychological Attributions
18		Risk Factors
19		Immunity
20		Accident/Chance
21	DAILY ACTIVITIES (SDSCA)	Diet Amount
22		Diet Type
23		Exercise
24		Glucose
25	SOCIAL SUPPORT (SSQ-6)	Number of Supports
26		Satisfaction with Support
27	PSYCHOLOGICAL WELL-BEING	General Well-being
28	COPING (CHIP)	Distraction
29		Palliative
30		Instrumental
31		Emotion

The dependent variable for the logistic regression was control of diabetes. A key factor in logistic regression is determining which predictor variables will be entered and in what order. Statistical significance determined the variables to be entered and the theoretical model from the qualitative research determined the order. The first block of variables entered were; knowledge, satisfaction and demographics. The second block contained those related to illness perceptions (IPQ-R), daily tasks (SDSCA) and coping

with the illness (CHIP). There were seven outliers when the logistic regression was computed, so these were all removed and the logistic regression rerun with a total of 146 cases.

Table 6.31 Significant Variables from Measure-Specific Logistic Regressions (N=153)

Measure	Variable			Signif (Wald)	
DEMOGRAPHICS	Marital status (1) Education (2)			0.11	
				0.11	
KNOWLEDGE	Diabetes Knowledge (1)			0.10	
			0.09		
TREATMENT SATISFACTION	Treatment satisfaction (1)			0.02	
			0.02		
ILLNESS PERCEPTIONS	Symptoms (1)			0.03	
	(2		0.11		
	Timeline cycl		0.14		
	Emotional Representations (1)			0.01	
			(2)	0.02	
	Immunity	(2)	, ,	0.02	
	Accident	(2)		0.12	
DAILY ACTIVITIES	Diet Amount	(1)		0.01	
		(2)		0.09	
	Diet Type	(2)		0.07	
COPING	Distraction	(1)		0.02	
		(2)		0.05	
	Palliative	(2)		0.06	
	Instrumental	(1)		0.003	
	Emotional	(1)		0.07	

Note (1) and (2) refer to the categories low and medium respectively.

Using the omnibus test, this final logistic model was significantly significant ($\chi 2=18.758$. df= 7, p < .009) for the first block of variables and this significance increased with the addition of the second block ($\chi 2=72.971$, df = 22, p<.001). This goodness-of-fit was also confirmed by the Hosmer-Lemeshow test (see Table 6.32). Cox & Snell 's and Nagelkerke's R² accounted for between 12.1% and 16.5% of the variance for the first block of variables, rising to between 46.6% and 63.7% of the variance in the second block. Overall, 64.4% of the classification of the control of diabetes is

successfully predicted with the first block of variables, with 77.2% of those in good control predicted but only 42.6% of those in poor control predicted. This changed when the variables in the second block were entered, to an overall prediction success of 82.9%, with 87.0% of those in good control correctly predicted and an improved prediction rate of 75.9% for those in poor control.

Table 6.32 Goodness-of-Fit Statistics for Final Logistic Regression (N=146)

	Hosmer & Lemeshow Test*			' R ² '		Outcome Correctly Predicted		
	X2	df	p	Snell	- Nagelkerke	Total	Good	Poor
Block I (marital status, education, knowledge, treatment satisfaction)	9.827	8	.277	.121	.165	64.4%	77.2%	42.6%
Block 2 (illness perceptions, daily adaptive tasks, coping)	6.738	8	.565	.466	.637	82.9%	87.0%	75.9%

^{*} Note –the Hosmer and Lemeshow result is a test of the null hypothesis that the model is good, a high p value indicates a good model

Table 6.33 gives coefficients, Wald statistic, degrees of freedom, probability, odds ratios and 95% confidence intervals are given for all of the significant predictors of diabetes control. It's important when interpreting the results to remember that the last category was the reference category in the analysis as otherwise, the interpretation may seem counter-intuitive. From this table it can be seen that being married, less knowledge, a higher satisfaction with treatment, less cyclical perceptions of the illness, fewer diabetes-related emotions, greater causal attribution of immunity, better adherence to diet, less distraction and palliative coping and more instrumental coping are all associated with increased odds of being in good control of diabetes. Less diabetes knowledge appears to be associated with better odds of being in good control of diabetes.

Examining the results in more detail, being married is associated with an increase in the odds of good control by a factor of 3.52. For diabetes knowledge, as levels of knowledge go from high to medium to low there is an increase in the odds of better diabetes control by a factor of 5.09 and 5.48 respectively. With lowering levels of treatment satisfaction there is a decrease in the odds of good diabetes control by factors of 0.07 and 0.09, conversely, it can then be said that higher treatment satisfaction is associated with odds

of better diabetes control. Following dietary guidelines in relation to specific foods (e.g. low fat, low sugar, high fibre) was associated with better diabetes control – the values show that lower adherence to diet was associated with a decrease in the odds of good control by a factor of 0.09. Both illness representations and coping featured in the final model, with illness representations contributing three predictor variables and three out of the four coping dimensions proved to be significant. Perceiving diabetes as less cyclical and having less emotional representations about the illness were associated with increased odds of good control, whereas having higher causal attributions of immunity was associated with good control. Emotional representations proved particularly powerful. From table 6.33, it can be seen that as emotional representations decrease from high, to medium to low levels there is an associated increase in the odds of being in good control by a factor of 23.25 and 20.8 respectively. Coping also made important contributions, with less distraction and palliative coping associated with an increase in the odds of good control, while using less instrumental coping is associated with a decrease in the odds of good control by a factor of 0.045.

With the exception of diabetes knowledge, these predictor variables were associated with diabetes control in a predicted manner. The model is a good fit of the data and confirms the approach to understanding diabetes control grounded in the patients' and family members experiences.

Table 6.33 Significant Predictors of Glycaemic Control from Logistic Regression

	B Wald		df	P	Ex(B)	95% C.I. Ex(B)	
						Lower	Upper
Marital Status (1)	1.259	4.017	1	.045*	3.521	1.03	12.02
Diabetes Knowledge (1)	1.627	4.072	1	.044*	5.090	1.48	24.72
(2)	1.713	4.275	1	.039*	5.548	1.09	28.15
Treatment Satisfaction (1)	-2.614	6.776	1	.009**	0.073	0.10	0.52
(2)	-2.385	7.617	1	.006**	0.090	0.01	0.50
Timeline Cyclical (1)	1.362	2.095	1	.148	3.904	0.62	24.69
(2)	2.080	5.172	1	.023*	8.001	1.33	48.02
Emotional Rep. (1)	3.035	9.335	1	.002**	20.80	2.98	145.44
(2)	3.147	8.978	1	.003**	23.25	2.969	182.15
Cause – Immunity (1)	-0.986	1.244	1	.265	0.373	0.66	2.11
(2)	-1.816	4.384	1	.036*	0.163	0.03	0.89
Diet Type (1)	-1.507	2.496	1	.114	0.222	0.34	1.44
(2)	-2.410	6.110	1	.013*	0.090	0.01	0.61
Distraction Coping (1)	2.764	10.97	1	.001***	15.86	3.93	82.34
(2)	2.090	7.671	1	.006**	8.101	1.84	35.60
Palliative Coping (1)	3.500	8.864	1	.003**	33.11	3.31	331.59
(2)	2.164	6.166	1	.013*	8.701	1.58	48.05
Instrumental Coping (1)	-3.013	7.970	1	.005**	0.045	0.05	0.39
(2)	1.054	1.312	1	.252	2.869	0.473	17.41

^{*}p<.05. **p<.01. ***p<.001.

6.18 Comments from Participants

Having met with all of the people with diabetes while they were completing the questionnaires, many spoke of their illness and how it affects their life. Documenting just some of these comments supplements the wealth of data gained from the quantitative information.

After explaining the purpose of the research to participants, many commented about how they feel about their diabetes. These initial comments appeared to be divided between those who immediately said they had no problems with their diabetes 'just live my life' and those who saw diabetes as a burden, 'a curse' and a 'nuisance'. One participant described diabetes as a 'slow creeping disease'.

Approximately 5% of the men in this research mentioned the impact of diabetes on their sex lives. They spoke of the lack of information available, how it had never been discussed as part of their diabetes care and of the subsequent consequences on their lives. It may seem a small minority but given the context of the discussion of a difficult topic during a first meeting with a female researcher, it is impossible to assess the importance of this issue for men with diabetes. Another comment made by a number of participants was regarding their dissatisfaction with the continuity of care in the diabetes clinic. Although overall satisfied with the quality of care, participants were unhappy about seeing different doctors on each visit and how they never got to see the consultant. A final aspect that was not captured in any of the measures was the level of other stressors that people have in their lives. Many participants had other health, personal and family problems that became apparent when people began to talk to the researcher. Diabetes is only one part of a far more complex life people lead.

6.19 Summary

This chapter analysed the data from a total number of 153 participants with diabetes and 74 of their family members. Examining demographic differences between those in good control (n=94) and poor control (n=59) showed that the two groups were very similar. As expected, those in poorer control of their diabetes had a longer illness duration and were more likely to be taking medication and insulin. There was a significant difference between diabetes control and family participation, with those in good control more likely to involve a family member in the research.

Diabetes knowledge for both control groups was similar and although people with diabetes had higher knowledge scores than their family members, the difference was not statistically significant.

Satisfaction with diabetes treatment proved to be very high, with a median score of 32/36 for those with diabetes. There was a trend in the data for those in poor control to be less satisfied but this did not reach significance.

There was also no difference between the control groups on either the subscales or the total for well-being. Family members also completed this questionnaire and they also

showed no differences on the scales in terms of control. However, when the participants with diabetes were compared with their family members, they experienced higher positive well-being than their family but overall, general well-being was similar for both samples.

Social support had two scores; the number of people available for the support and the satisfaction with the support. Both family members and those with diabetes showed no differences with regard to good and poor control, and support. When family members were compared with participants with diabetes, they were found to be less satisfied than those with diabetes with the support available to them. Further examination of differences between participants with diabetes who had nominated a family member/ those who had not and support found that those who had nominated someone were significantly more satisfied with the support they have than those who had not nominated a family member.

Adherence to the daily requirements of the diabetes regimen showed that those in good control report that they adhere significantly more to following their diet in general and to eating the correct types of food than those in poor control. There were no control differences on the other adherence behaviours.

Illness representations had several dimensions where people in good and poor control of their diabetes differed. Those in good control of diabetes report experiencing significantly less diabetes-related symptoms than those in poor control. They also see diabetes as less cyclical, having less consequences on their lives and experience less diabetes-related distress than those in poor control of their illness. Family members also had similar diabetes control differences in relation to a cyclical timeline. Family members results on the IPQ-R dimensions were compared with those with diabetes and they were found to perceive diabetes as significantly more cyclical, having more consequences, less personal control, more cure control and were more distressed about diabetes than participants with the illness.

Distraction coping was the only coping strategy that differed between those in good and poor control of their diabetes, with participants in poor control using it significantly more than those in good control.

Results from the logistic regression explained differences between those in good and poor control of their diabetes. The variables that significantly contributed to good diabetes control were; being married, having a higher satisfaction with treatment, having more stable perceptions of the illnesses timeline, having fewer diabetes-related emotions, believing immunity to be more of a cause of diabetes, adhering more to diet, and using less distraction and palliative coping and more instrumental coping strategies. With one exception – knowledge, the significant predictor variables were associated with diabetes control in the direction that had been predicted. The manner in which the predictor variables were added to the model showed a high level of prediction success (82.9%) and demonstrated the usefulness of the theory from the qualitative research. The implications of this and a discussion of the results will take place in the next chapter.

CHAPTER SEVEN – DISCUSSION

7.1 Introduction

This final chapter discusses the results of the qualitative and quantitative research and places them in the context of the relevant literature. The main results will be first discussed separately from both stages of the research and then links between them explored. The quantitative results will also be discussed in light of the original hypotheses. Similarities with existing literature and unexpected or inconsistent findings are highlighted. Limitations of this research are discussed in terms of the measures used and different potentials for bias that occurred. The results are framed within the theoretical framework from the qualitative research and the implications of this research are explored. Finally, future recommendations and final conclusions are presented.

7.2 Results

7.2.1 Summary of main results

7.2.1.1 Qualitative

It was evident from the two focus groups conducted with people with diabetes and their family members, that there was a lack of understanding of the information regarding diabetes. This affected how people perceived diabetes in terms of its cause, seriousness, lifestyle recommendations, control of the illness and ultimately its impact on daily life. It is the illness *perceptions* that proved important, for example, some participants demonstrated a good level of knowledge about the causes of their illness but did not feel confident about their level of knowledge. This exploratory phase of the research confirmed the importance of understanding peoples' perceptions of diabetes and how it impacts on control. There were no obvious differences in this qualitative stage between those in poor control and those in good control of their diabetes. Finally, the benefit of including family members in research on type 2 diabetes was confirmed and the research demonstrated that including family members in type 2 diabetes research gives an insight into their understanding and concerns.

7.2.1.2 Quantitative

Of the 345 eligible patients who attended the clinic, only 163 (47%) were invited to participate. There were several reasons for this. Firstly, the duration of each meeting with a patient (approximately 40 minutes) meant that at most three to four patients could be seen within the duration of one clinic. Even when there were two researchers collecting data, the average number of patients seen was 3.2 per clinic. Other factors played a role such as the size of the clinic and the number of doctors present, which affected how long patients were in the clinic. Finally, the recruitment of potential participants was dependent upon the nurses, who had many other duties to perform during the clinic. This meant that at times there were eligible patients who may not have been recruited because the nurses were busy with other tasks. All eligible patients were marked on the master clinic attendance list and the nurses were briefed that every eligible patient should have an equal opportunity of participating in the research. This point was reiterated by the researcher (PW) on several occasions and beyond this, it was difficult to control the actual selection of the patients. Nevertheless, there was the potential for a selection bias, with nurses recruiting patients they felt would be more suitable for the research. However, given the range in ages, education and comprehension levels, mobility and health of the patients who participated, nurse selection bias in the recruitment of participants was unlikely. However, it is not possible to measure if a bias did exist with nurses inviting patients they felt would be more approachable and agreeable to the research.

Ninety four percent of people with diabetes (N=153) who were invited to take part in this study volunteered their time and participated. This high level of participation could be interpreted as people having an interest in their illness or as feeling obliged to accept the invitation from the nurses in the diabetes clinic.

When asked to identify a family member to take part in a related postal questionnaire, only 66% of those with diabetes suggested someone. This shows that as important as it is to include family members in research, it is not always an option for everyone because (a) they may not have a family member living near by and (b) they may not want to include their family in their diabetes care. Either way, the choice should always remain with the patient. Of those family members that were invited, 73% returned their questionnaires, demonstrating an acceptable return rate for a postal questionnaire. What proved statistically significant was that a much higher percentage of family members of those in

good control rather than those in poor control participated. This could be seen as a reflection of perceived social support and that those in good control of their diabetes have higher perceived or actual support. The evidence for the impact of social support on illness is still limited but there is evidence for the positive effects on emotions and behaviour changes of the direct, indirect and stress buffering effects of social support (Schwarzer, Knoll & Rieckman, 2004). Of the family members who participated there was also a significantly higher percentage of women, and patients' wives made up the largest group of family members (47.9%). Although there is an accepted link between poor control of diabetes and deprivation (Meadows, 1995), none of the demographic measures (socio-economic status, GMS patient and education level) showed any difference between the two groups, which was unexpected. A consistent finding with the literature was that those in poor control of their diabetes had had diabetes for a longer duration and were more likely to be taking insulin (Blaum, Velez, Hiss & Halter, 1997). It may be that this study lacked the statistical power to detect these changes and that a larger sample would have be necessary if a relationship between control and demographic factors were to be found. There was no significant relationship between glycaemic control of diabetes and number of complications or other illnesses. Whilst unexpected, this result may be more of a reflection of the unreliable recording of patients' co-morbidities than a lack of a relationship. Where possible, data on patients' illnesses was extracted from the charts and the database, but reservations about the reliability of this data can be raised. The lack of consistency and clarity in the recording of data by the researchers was due to the lack of detail being recorded, illegible writing and discrepancies in the co-morbidities recorded by different health professionals.

(i) Diabetes Knowledge

The average score on the diabetes knowledge questionnaire for people with diabetes was 67% and for family members was 64%, which show an acceptable level of knowledge. There were no differences in relation to control for people with diabetes or family members. This is in contrast to the impression given by participants during the interview-administered questionnaire and the opinions voiced by participants in the qualitative phase of the research. What it does highlight is the importance of *perceived* knowledge or as described in the qualitative phase the understanding of the information. This may be best understood in relation to the concept of self-efficacy (Bandura, 1977), which refers to the belief that a person has the abilities or skills necessary to complete a given task.

While participants do not feel they have adequate knowledge about their illness or their family member's illness, they demonstrate an acceptable level when asked directly. Answers to specific questions provided important insights. For example, two fifths of those with diabetes still agree that a diabetes diet consists mainly of special foods despite the newer guidelines that exist regarding healthy diabetes diets. This is similar to the qualitative findings from Smith et al. (2003), who found despite dieticians' discouragement of the use of 'diabetic' labelled foods, many of their patients were unaware of the current guidelines and viewed such foods positively. The participants in the current study all had the opportunity to receive education from the diabetes nurses and to visit the dietician as a routine part of their attendance at the diabetes clinic.

Both those with diabetes and their family members had very low scores on the signs of hyperglycaemia and hypoglycaemia. This is important because not only are those with diabetes unsure of their own symptoms and what they mean, but those closest to them are unable to recognise when they need help. It appears that although the education and information provided is understood, it is not empowering those who receive it to feel confident enough to act upon it. One possible explanation is that there is *low* self-efficacy in relation to diabetes self-management – people do not feel that they have the skills and abilities to change their behaviours and achieve good glycaemic control.

One of the difficulties with knowledge of diabetes is finding an appropriate measure. The questionnaire used in this study originated in Mexico and was developed in both Spanish and English for people with type 2 diabetes (Garcia et al., 2001). It has not been as extensively used in diabetes research as other measures, but on examination of the available measures, it proved to be the most straightforward, up-to-date and accessible for participants. It has also been included in studies with family members of those with diabetes and has demonstrated reliability and validity. However, given the difference in culture and health systems, a questionnaire assessing diabetes knowledge from an Irish diabetes education perspective, (e.g. taking Irish diets, characteristics of the Irish health care system into account) has yet to be developed.

(ii) Satisfaction with Diabetes Treatment

It is difficult to comment on the level of satisfaction with diabetes treatment, given the highly skewed results. This reflects characteristics that prevail in assessing patient

satisfaction (Cohen, Forbes & Garraway, 1996) and has been reported in other diabetes studies (Petterson et al., 1998). Possible suggestions have been made to counteract this (Pouwer et al., 1999) such as changing the scale to an asymmetric seven point scale, with only two of the points describing dissatisfaction and the remaining five describing varying degrees of satisfaction. This approach however, may lead to even lower levels of dissatisfaction being reported and their suggestions have not been considered to date (Bradley, 1999). One possibility is that this measure, although diabetes-specific may be too general in relation to satisfaction. It has been found that when patients are asked about their overall satisfaction that they tend to reply more positively than when asked about more specific details (Williams & Calnan, 1991).

Comments made by participants during the data collection are not consistent with the results of this questionnaire. Although there was a lot of praise for the diabetes outpatient clinic and the hospital in general, many spoke of their dissatisfaction with waiting times, the different doctors that are seen on each visit and the lack of opportunity to see the consultant. However, participants reported that they did not want to appear critical of the diabetes clinic and many appeared to separate their opinions and their questionnaire responses. It could be concluded from the results that patients are highly satisfied and many mentioned positive aspects of their treatment. However, comments consistently made by participants during the data collection were not in accordance with their responses on the questionnaire. In particular, they spoke of their dissatisfaction with waiting times, the lack of consistency in medical personnel (in particular doctors) and their lack of contact with the consultant. The qualitative phase of this research did not specifically address patient or treatment satisfaction. Nevertheless, participants were in general, positive about the care they received and although critical of certain aspects such as information provided and dietary advice, they showed a reluctance to mention anything negative about the service they received.

Differences in measuring patient satisfaction with quantitative and qualitative methods were found in Smith et al.'s (2003) study on the introduction of a shared care service. They found that despite the use of an accepted and validated satisfaction questionnaire, there was a discrepancy between the satisfaction scores and the qualitative research. It was the qualitative research however, that provided greater insights into the patients' views and expectations. There is a concern in the literature on assessing satisfaction in

general that the concept of patient satisfaction may lack validity, as it does not allow the patient to express their perceptions of their care in their own words (Roberts et al., 2001). Choosing methods of assessing patient satisfaction and interpreting the results needs to acknowledge the complexity of the construct and the social context in which it takes place.

The diabetes treatment satisfaction measure used in this research also assessed the frequency of hyperglycaemia and hypoglycaemia events. Those in poor control experienced statistically significantly more hyperglycaemia episodes than those in good control. This finding reflects the higher blood glucose levels experienced by this group in general.

(iii) Illness Perceptions

The benefit of taking an illness perceptions approach was evident from how the qualitative and quantitative research provided insights into how people think about diabetes. Both those with diabetes and their family members had the same top five causal beliefs of diabetes: hereditary, diet, ageing, stress and own behaviour. For those with diabetes the only difference in terms of control was that those in poor control reported hereditary as a cause significantly more often. From the patients' charts it was not possible to know their family medical history in relation to diabetes, so these casual beliefs may indeed be accurate. Family members of those in good control reported chance/bad luck as a cause more often than those in poor control. These results could also reflect the possibility of a Type 1 error occurring, as 18 comparisons of causal attributions were made (for every 20 comparisons, one significant result can be expected by chance alone (Coolican, 2004)). One way of clarifying these results and reducing the possibility of a Type 1 error would be the replication of the study, or alternatively reducing the significance level to .01. However, neither of these steps were taken, the study could has not been replicated and reducing the significance level may only serve to increase the possibility of a Type II error. These causal attributions are important as they have been shown to affect emotional responses, coping behaviours and ultimately, health outcomes (Cameron & Moss-Morris, 2004). Not every illness and situation is the same but in general, causal beliefs that are stable and uncontrollable (trait, environmental pollution) are associated with poorer health outcomes (Roesch & Weiner, 2001). It may be that because those in poor control believe that they have diabetes for hereditary

reasons, they feel that they had no control over the cause and feel less inclined to act in a preventative way. The fact that family members of those in good control see the cause as something out of the person's control may mean that they are less likely to blame the patient for the onset of the illness and its subsequent complications.

Those in poor control of their diabetes had a stronger illness identity. This is not unusual given that illness identity is measured by the number of illness-related symptoms experienced. Those in poor control in this sample experienced more episodes of hyperglycaemia but did not have more recorded complications of their illness.

How people view illness can be divided into whether they see it lasting a short or long time, and whether it's perceived as stable and consistent or cyclical in nature. In this study, perceiving timeline as acute/chronic was the only dimension for family members where there was a significant difference between poor and good control groups. Family members of those in poor control saw diabetes as a more chronic illness. There was no difference for those with diabetes. Examining the cyclical aspect of timeline perceptions demonstrated that those in poor control perceive diabetes as significantly more cyclical than those in good control. Those in poor control are characterised as having more hyperglycaemic episodes and more likely to be on insulin. Their diabetes is not a static illness, but one that fluctuates according to their level of glycaemic control. Those in good control experience less symptoms of poor glycaemic control and view their illness as more stable and consistent. Overall, family members view diabetes as a more cyclical illness than those with diabetes. This could be explained in terms of family members experience of diabetes. It is unlikely that they are aware every moment of how the person is experiencing their diabetes and it may only come to their attention through external indicators such as illnesses, hospital appointments or changes in medication. Family members in the focus groups discussed their perceived severity of diabetes in this manner, focussing on tangible indicators. This reliance on external cues may explain family members' cyclical perception of diabetes.

Related to this, family members also perceived diabetes as a more serious illness than those with diabetes. They reported more consequences of the illness, which echoes the sentiments expressed in the focus groups. For those with diabetes, those in poor control perceived diabetes to be significantly more serious and have more consequences than

those in good control. This awareness of the severity of the illness does not seem to be a acting as a motivating factor to changing behaviours. In health promotion, it is recognised that while fear can act as a motivator, it can lead people to avoid situations that trigger the feelings of fear (Hammersly, 2000).

One explanation for the observation that those in poor control are not changing their behaviours is because they are significantly more emotionally distressed about their illness than those in good control. Family members as a group reported more emotional distress about diabetes than those with the illness, supporting the findings from the focus groups. It appears that those who are worse off in their control of diabetes and those who can act as a support are the most emotionally distressed about the illness. The significant differences found on the emotional representations dimension of this questionnaire adds support to the addition of this dimension in the most recent version of the Illness Perceptions Questionnaire (Moss-Morris et al., 2002) and to Leventhal et al.'s Self-regulatory Model (1984).

The adequate control of diabetes is central to successfully managing the illness. How people perceive personal and treatment control is often considered essential in understanding the management of diabetes (Bradley, 1994; Macrodimitris & Endler, 2001). This research however, found no differences in either personal or treatment control for those in good or poor control of their diabetes. For treatment control, this is most likely explained through the results of a reliability analysis on this measure that revealed a low level of reliability (Cronbach's alpha = 0.43). The wording of the items on this dimension needs to be examined as it was noted during data collection that many participants had difficulty with them (e.g. "the negative effects of my treatment can be prevented (avoided) by my treatment"), and with items that were negatively worded (e.g. "there is nothing which can help my condition"). When comparing people with diabetes and their family members on this measure it was found that family members perceived diabetes as significantly less personally controllable and significantly more controllable by treatment. Given the problems with reliability on this dimension, these results need to be interpreted with caution. Nevertheless, it is interesting to note that family members view the control of diabetes very differently to those with the illness. The differences between patient and family members in approaches to controlling diabetes highlight the

potential difficulties that could exist in promoting family support and inclusion in diabetes care.

Overall, when comparing the results with previous studies, these results are in line with the findings that show that those with a stronger illness identity, also see the illness as having a more consequences. However, a stronger illness identity was not correlated with a more chronic timeline (r = .08) or less personal or treatment control (r = .06, r = .08 respectively) as in earlier studies (Moss-Morris et al., 1996; Petrie et al., 1996; Weinman et al., 1996).

(iv) Daily Activities

The daily activities that people with diabetes engage in to manage their illness were examined in relation to diet, exercise, blood glucose testing and medication. Significant differences were found only in relation to the diet subscales. Those in poor control were less likely to adequately follow their diet in general and had a lower fibre, higher fat and higher sugar content to their diets than those in good control. Exercise was the least well adhered to component of the diabetes regimen, with over a quarter of people with diabetes reporting that they had engaged in no exercise at all in the previous week. Glucose testing was well adhered to, with almost two-thirds of participants reporting that they had followed their recommended guidelines 'every day' or 'most days' in the previous week. The very high adherence levels to medication that were found in this research (95.8% of participants who took insulin, reported taking all of their injections in the previous week and 90.8% of participants on medication reported taking 'all of them' in the previous week) are similar to previous studies that also found strong ceiling effects on this subscale (Glasgow et al., 1992; Glasgow et al., 1998). The possibility that these high adherence levels may reflect socially desirable answers should be noted. The participants were in a clinical setting being asked directly about their adherence to medication, knowing that the next health care professional they would be talking to was their doctor. The strong ceiling effects for the medication subscale has been addressed in a newer version of the scale, which alongside simplifying the scoring, has included other aspects of the diabetes care such as smoking behaviours and foot care (Toobert, Hampson & Glasgow, 2001). Differences in adherence to diet were not evident from the exploratory phase of this research but this measure has clearly highlighted the differences in diet between those in good and poor control.

(v) Social Support

The results on this measure show an extremely high level of satisfaction with social support. Despite the accepted reliability and validity scores of this measure, it is difficult to ascertain whether the scores are a reflection of people's excellent social support or of socially desirable answers. For social support, there were no differences between good and poor control either for those with diabetes or their family members. The lack of a relationship between diabetes control and social support was unexpected. The literature on social support now confirms the empirical link between social support and health (Uchino, Cacioppo & Kiecolt-Glaser, 1996). Despite this confirmation, little is known as to which aspects of social support contribute to the relationship and there is a lack of agreement even on the definition of social support (Roberts et al., 2001). The lack of a link between diabetes control and social support in this research may be attributable to the measure used or may be a reflection of the lack of consensus regarding the definition, the elements and the assessment of social support.

As previously mentioned, those in good control of their diabetes were more likely to have nominated a family member to participate. When social support was examined separately for those who had nominated a family member and those who had not, significantly higher satisfaction levels with support were found for those who had nominated a family member. Patients who perceived they had a family member available and interested in taking part in research about their diabetes, were more likely to be satisfied with the support they had. Perhaps by simply asking a patient if they have a family member interested in their diabetes could be an important indicator of how satisfied they are with the support they have, although this has yet to be tested in the literature. However, the difference in satisfaction between those who did and did not nominate a family member, although significant, is only a two point difference on a 42 point scale and the substantive significance of this finding should be taken into account.

Comparing results on this measure for those with diabetes and their family members showed that family members were significantly less satisfied with the support they have. This ties in with comments from family members in the focus groups who expressed a need for more support (e.g. emotional, informational) from health care professionals. What cannot be deduced from this research is why family members are less satisfied. What needs to be clarified is whether it is diabetes-specific social support that family

members are lacking, whether they feel burdened by the disease or indeed if they feel that they are at risk themselves of developing the illness and would like information for example in relation to screening.

(vi) Psychological Well-being

There were no differences in general well-being between good and poor control of diabetes either for patients or their family members. It was expected that those in good control of their diabetes would have better psychological well-being (Bradley, 2003). The lack of such a finding in the current study is unclear, it may be that more distressed patients did not participate in the research, that there was a lack of power to detect the difference or that newer shorter version (despite its reported reliability and validity) was not responsive enough to detect well-being differences in extreme groups research. Overall, on inspection, those with diabetes had lower general well-being scores when compared with other studies (Adriannse et al., 2004; Pouwer et al., 1999). This study group as a whole had similar General Well-being scores as patients with complications from Pouwer et al.'s (1999) research. However, this was a hospital based study and may be more likely to include patients who are not as well as those from a community based sample. Family members and patients' scores were compared and although there was no difference in general well-being, family members reported significantly lower levels of positive well-being than those with diabetes. From this result it becomes clearer that there were no differences between people with diabetes and their family members on the subscales of depression and anxiety levels (negative well-being), and energy levels but they do differ in how positive they are feeling about their lives. The qualitative results suggested that family members perceive diabetes to be more serious and to have a greater impact on daily life than those with the illness. This heightened anxiety regarding diabetes may lead to a less positive outlook and lower positive well-being. However, psychological well-being is calculated by the sum of the subscales and as there was a lack of differences in overall general well-being on this scale, the possibility remains that the difference between those with diabetes and family members on the positive well-being subscale could be due to a Type 1 error.

(vii) Coping

The coping measure used in this research differentiated between four types of coping: distraction, palliative, instrumental and emotional preoccupation. The scores for those

with diabetes on this measure all fell within normal ranges. When differentiating between those in good and poor control, the only difference was that those in poor control used distraction coping significantly more than those in good control of their diabetes. Rather than focussing on the goal of successful diabetes management, those in poor control avoid preoccupation with their health problem. They divert their thoughts and behaviours to other unrelated and more pleasant activities. This fits in with the findings regarding the perceived severity of diabetes for those in poor control. When feelings of fear are high (e.g. 'my diabetes has major consequences on my life'), people avoid situations that bring about the feelings of fear.

7.2.1.3 Applying a Model to Diabetes Control

Results from the logistic regression demonstrated that the variables chosen for this study explained differences between those in good and poor control of their diabetes. The variables that were statistically significantly associated with good diabetes control were: being married, having a higher satisfaction with treatment, having more stable perceptions of the illness's timeline, having fewer diabetes-related emotions, believing immunity to be a cause of diabetes, adhering more to diet, and using less distraction and palliative coping and more instrumental coping strategies.

There was a surprising result in relation to knowledge, with lower levels of knowledge increasing the chances of being in good diabetes control. The relationship between knowledge and control of diabetes is not straightforward. From the qualitative results, a key theme was people's understanding of diabetes, which is more than simple facts they have learned. It includes how the person relates information to themselves and make subsequent diabetes management decisions. The results from the diabetes knowledge questionnaire showed similar levels of diabetes knowledge for those in good and poor control. What is clear therefore is that good diabetes control is about more than education and acquiring knowledge. The move to involving the patient in decisions regarding their care has lead to the development of self-management programmes. More recent self-management programmes have moved beyond the provision of information to address practical and psychosocial issues, and teach skills which can be used in daily life (Newman et al., 2001). Assessing knowledge on its own does not provide the insight into how the information is transferred into behaviours. Further exploration into diabetes knowledge and its impact on behaviours, and in turn glycaemic control needs to be

conducted using suitable assessment tools. An explanation previously mentioned is that people may have high diabetes knowledge but low diabetes self-efficacy. Bandura (1991) noted that the higher the self-efficacy, the better the outcomes. In relation to diabetes management, those with low self-efficacy do not feel that they have the skills and abilities to put the information they have learned into practice. Studies have confirmed that higher self-efficacy can positively influence health behaviours and outcomes in diabetes (Glasgow et al., 1992; Havermans & Eiser, 1991). A comprehensive self-management programme provides both the knowledge and skills to manage diabetes and so improve knowledge, self-efficacy and physical outcomes.

The finding that being married was associated with good diabetes control links in with previous research on the health protective nature of marriage (Burman & Margolin, 1992; Waldron, Hughes & Brooks, 1996). The reasons for this relationship relate to marriage being associated with higher incomes, more material resources and a higher perceived quality of social support (Wyke & Ford, 1992). Although there were no significant associations found between social support and diabetes control in the current research, being married in itself, may be indirectly acting as a form of social support which can influence diabetes control.

From the logistic regression model, it was found that higher satisfaction levels with diabetes treatment were associated with good diabetes control. Since Korsch, Gozzi and Francis's (1968) early work on paediatric consultations, which found that mothers who were more satisfied with the doctor-patient interaction were three times more likely to adhere to recommendations than dissatisfied mothers, there has been a large body of work confirming this finding (e.g. DiMatteo et al., 1993; Ley, 1997). In 1997, Ley put forward a theory that adherence to recommendations and regimes is influenced by patients' understanding of information, their memory of it and their level of satisfaction with the consultation. Despite the concern regarding the assessment of patient satisfaction, it is an important variable to consider in relation to adherence.

Good control of diabetes was also found to be associated with less cyclical perceptions of the illness. It is difficult to ascertain as to whether this is cause or effect as those in good control of their diabetes would experience less periods of hypoglycaemia or

hyperglycaemia and therefore would have a more stable experience of their illness than those in poorer control.

The finding from the logistic regression model that good control is associated with fewer negative emotions regarding diabetes is in line with the research that has confirmed the higher prevalence of depression in diabetes (Anderson et al., 2001; Nichols & Brown, 2003; Peyrot & Rubin, 1997). The results of having depression have been linked to higher levels of hyperglycaemia and diabetes complications (DeGroot et al., 2001; Lustman et al., 2000). Patients' negative emotions related to their diabetes and the higher depression rates for those with diabetes need to be carefully considered.

There was only one causal attribution which was found to be associated with better diabetes control - immunity. A belief that diabetes is somehow caused by ones immune system may be protective as it removes the blame for the onset of diabetes from one's own actions (i.e. diet, lack of exercise) or genetic history to something that may be perceived as largely uncontrollable.

It is not surprising that good control is significantly associated with a better adherence to diet. What this research has shown is that it is diet alone that differs in relation to control. Exercise, blood glucose monitoring and medication adherence did not show any differences between those in good and poor control. Dietary behaviours are however amenable to change and Clark et al. (2004), have demonstrated this through their effective brief tailored intervention for reducing fat intake and increasing exercise behaviours in those with diabetes.

Coping provided several important predictors of diabetes control in the logistic regression model. Lower levels of both distraction and palliative coping and higher levels of instrumental coping were associated with good control. From this evidence, people in good control of their diabetes engage in more task-oriented, problem-focused strategies to cope with their illness and use less avoidance and 'feel good self-help' type behaviours than those in poor control. The use of problem-focused coping in the management of diabetes is particularly appropriate given the amount of control the person with diabetes can exert over their daily management of the illness (Maes, 1996) in relation to other illnesses e.g. cancer. The literature has highlighted the benefits of such a problem-focused

approach to controllable situations (Endler et al., 1994; Myers et al., 2004) and how it is related to more favourable health outcomes (Macrodimitris et al., 2001; Rose et al., 2002).

With the exception of knowledge, the results from the logistic regression model, based on the theory from the first stage of the research, confirm the previous literature relating health to satisfaction, illness perceptions, adherence and coping.

7.2.2 Hypotheses

The original three main hypotheses were divided into the various psychosocial dimensions they related to. Given the number of these dimensions, the original hypotheses and the results of the research are presented in tabular format (see Tables 7.1-7.3)

Table 7.1 Results of Hypothesis I

Hypothesis I – that there is a difference between those in good control and poor control of their diabetes on the following psychosocial dimensions:	Findings
Knowledge of Diabetes	No difference
Diabetes Treatment Satisfaction	No difference in satisfaction Poor control experience more hyperglycaemia events
Illness Representations	No difference in timeline acute/chronic, personal control, treatment control or illness coherence Differences in causal attribution (poor control view hereditary as cause) Differences in illness identity, timeline, consequences and emotional representations (good control weaker illness identity, less cyclical timeline, fewer consequences and emotional representations)
Daily Self-care Activities	Difference in diet amount and type
Social Support	No difference
Psychological Well-being	No difference
Coping	Difference in distraction coping

Table 7.2 Results of Hypothesis II

Hypothesis II – that there is a difference between the family members of those in good control and poor control of their diabetes on the following psychosocial dimensions:	Findings
Diabetes Knowledge	No Difference
Illness Representations	No Difference on identity, timeline cyclical, consequences, personal control, treatment control, illness coherence or emotional representations Difference on causal attribution 'chance/bad luck' (good control higher) Difference on timeline acute/chronic (good control higher – more chronic timeline)
Social Support	No Difference
Psychological Well-being	No Difference

Table 7.3 Results of Hypothesis III

Hypothesis III – that there is a positive relationship between family members and those with diabetes on the following psychosocial dimensions:	Findings
Diabetes Knowledge	No Difference
Illness Representations	No Difference in identity, timeline acute/chronic or illness coherence. Difference in timeline cyclical, consequences, treatment control and emotional representations (family members higher) and in personal control (diabetes higher)
Social Support	No Difference in number of people for support. Difference in satisfaction with support (family members less satisfied)
Psychological Well-being	Difference on the Positive Well-being subscale (family members lower)

7.2.3 Linking qualitative and quantitative results

A particular strength of this research is the similarities in findings between the qualitative and quantitative approaches. This was particularly true for the family members who participated, as there was a lack of previous research on their views and cognitions. From the focus groups it was difficult to ascertain the levels of knowledge for those in good and poor control. A quantitative measure of diabetes knowledge was included to examine potential differences. As with the focus groups, no differences between those in good control and poor control of their diabetes were found. What both approaches have done is to not only raise the issue of the usefulness of assessing diabetes knowledge but has

recognised that having good diabetes knowledge does not mean having a thorough understanding and control of the illness. Educational approaches need to acknowledge this and indeed the move to a patient empowerment and self-management approach has been part of this.

Family members in the qualitative study spoke of the lack of support and information they felt they had and many perceived the focus group itself as a source of support. This was also found in the quantitative assessment of social support, where family members reported lower levels of satisfaction with the support they had. Analysis of the family members in the focus groups portrayed them as having a heightened perception of the severity of diabetes and were overall more anxious and stressed about diabetes than those with the illness (e.g. 'he does control his well but I'm always thinking about it'). This was reflected in family members' higher scores on consequences of diabetes, their lower scores on positive well-being and reporting more emotional representations about diabetes. Despite their level of anxiety, including family members in research does not have a negative effect on their psychological well-being (Pierce et al., 2000).

The quantitative results helped to clarify the questions that the qualitative phase had raised and it has provided more questions that have still to be answered (e.g. role of knowledge? Appropriateness of social support? How family members could/should be included in future research? Possible interventions for those in poor control? Importance of emotional representations?) The quantitative research yielded a large amount of data but it was harder to get the overall sense of the impact of diabetes on daily life, which was evident from the focus groups. This research has benefited from the use of different types of triangulation (Begley, 1996): triangulation of methods (qualitative and quantitative) and triangulation of participants (people with diabetes and family members). It has led to a completeness and confirmation of results that would not have been possible otherwise (Tobin & Begley, 2004). With the growing recognition within the field of health psychology of the limits of taking a purely positivist approach to understanding health, there has been a rise in the use of qualitative methods (Chamberlain, 2004). However, health psychology has been slow to adapt many of these methods e.g. Gray, Fergus and Fitch (2005) discuss the absence of the narrative approach despite its potential in understanding illness from the patient's perspective. The use of triangulation can combine

the newer qualitative methods to the more traditional quantitative approaches in health psychology to achieve a more complete answer to research questions.

7.2.4 Contribution of family members to the research

Previously in the literature on type 2 diabetes, family members were most noted for their absence from the research (Fisher et al., 1998; Gonder-Frederick et al., 2002; Warren & Hixenbaugh, 1998). The qualitative and quantitative phases of this current research has shown that family members of those with type 2 diabetes are interested and want to be included in the care of diabetes. This was evident from their acknowledgement of this in the focus groups and from their response rate (73%) to the postal questionnaire. What this research has also shown is that family members have similar levels of knowledge of diabetes to those with the illness and perceive that they actually have more knowledge than their family members. However, they also have their own concerns regarding diabetes – they view it as more serious and they perceive it as a more cyclical illness than those with the illness, they see diabetes as an illness that is controlled more by treatment than by the individual, they are more distressed about the illness and they are less satisfied with the support they have. These are important factors to document and to investigate further. These current findings are in line with studies that have found higher levels of anxiety amongst spouses of those with diabetes (Gonder-Frederick, Cox, Kovatchev, Julian & Clarke, 1997; Stahl, Berger, Schaechinger & Cox, 1998).

7.3 Theoretical Framework

There is a lack of general theories in the area of chronic illness (Wright & Kirby, 1999) and more specifically within type 2 diabetes (Glasgow et. al, 2001). As this field continues to grow, integrating the research findings in a meaningful way to inform practice becomes significantly more challenging. This research developed a theory, grounded in the participants views and used it as its guiding theoretical framework. It provides a model of adjustment to diabetes and proved to be a considerable strength in bringing the many dimensions of this study together. By including features of the illness itself, the personal, social and background factors and the cognitive approach to the coping process, it encompassed all of the elements that had emerged from the qualitative phase and how they potentially impact on glycaemic control in type 2 diabetes. This

theory was also used in the analysis of the results. It provided the framework for adding the different predictors to the logistic regression model in a meaningful way.

The emphasis that was placed upon the cognitive appraisal of illness in the earlier stages of the research was beneficial in determining the differences between those in good and poor control. With the lack of family studies on illness representations, it is worth noting that this research took a different approach to that of other similar studies (Figuerias & Weinman, 2003; Heijmans et al., 1999). These studies included only the patient's spouse and did not extend to other family members. Patient and spouse scores on the Illness Representations Questionnaire were compared and the degree of similarity/dissimilarity computed. However, the emphasis in this study was not the level of agreement between patient and family member but rather on building a more complete understanding of psychosocial factors in diabetes and how they impact on glycaemic control.

The return to measuring dimensions more closely associated with Leventhal's (1984) original model of illness representations, i.e. emotional representations, means that an important element of the model is no longer ignored. Central to his original theory was the parallel processing of cognitive *and* emotional representations of illness. Prior to its recent inclusion in illness representations research (Moss-Morris et al., 2002), illness representations were synonymous with cognitive representations. The consequences of taking such an exclusively cognitive approach to illness perceptions and its suitability for all patients has recently been questioned (Weinman, 2005). This has led to a study which evaluated whether emotions play a role in the success of an illness perceptions-based education programme (Cameron, Petrie, Ellis, Buick & Weinman, 2005). The results of this study showed that the intervention was of most benefit to those with low negative affectivity. The interventions emphasis on cognitive factors was inhibiting for those with higher negative affectivity. Future research in the area of illness perceptions needs to be aware of the overemphasis that has existed on cognitive factors and consider the emotional aspects of self-regulation.

7.4 Addressing the Limitations of Research

Several potential limitations of the qualitative stage of the research need to be acknowledged. As previously mentioned (section 2.11), there were only four focus groups

held in total, two with those with diabetes and two with family members. However, the aim of this exploratory phase of the research was not to provide definitive answers but to generate and confirm ideas for the larger second phase of the research. One of the facilitators had met with some of the participants previously in her role as a research nurse. Because of this familiarity, this facilitator conducted the family members focus group but it is unknown how much of her previous role impacted on their perception of the purpose of the current research. To ensure that the qualitative research was conducted in a rigorous manner, the issues of credibility, transferability, consistency and neutrality were considered throughout (see section 2.9.3.2).

Despite every effort in the design of the second quantitative phase of the research, several limitations emerged in the quantitative stage. These have been divided into those related to the measures used, the potential for bias that existed and dichotomisation.

7.4.1 Measures

The responses on both the social support satisfaction measure and the treatment satisfaction measure were both highly skewed towards high satisfaction. Both of these measures have validated psychometric properties yet reflect a wider problem in assessing levels of satisfaction. The very high reported adherence to medication and insulin injection on the Summary of Daily Self-care Activity Scale could be addressed in future research by the use of the revised version of the scale (Toobert et al., 2000).

As previously mentioned, (in 7.2.1.2), the recording of patients co-morbidities and complications was not done in a systematic and reliable way. Although the information that was available was analysed, it does not form a major component of this particular research. Nevertheless, it has highlighted the importance of thorough fieldwork and pilot studies for future research.

The two different sub-groups of participants: those with diabetes and family members, did not complete the measures in the same environment. Whilst those with diabetes had the benefit of a private room in an outpatients clinic and the presence of the researcher to answer any questions, family members completed their measures in their own home. This meant that there was no way of checking the extent to which family members understood the questions or how much assistance they received from others. Another aspect for all of

the participants, was that the measures were all self-report measures. This calls into question the problems in relation to accuracy and reliability of the respondents' answers. To counteract this, only measures that had been previously used with people with and without diabetes, and with accepted reliability and validity were used. A potential solution to ensure that every participant completed their measures under the same conditions, would be to send a letter out to patients with diabetes reminding them of their appointment and asking them to invite a family member to attend with them. This was considered but not possible in this research, as the patient charts for each diabetes clinic were only available on the morning of the clinic and the computer database was in its early stages of development. This meant that it was only possible to compile a list of eligible patients on the morning of their appointment.

7.4.2 Potential for bias

As previously discussed at the start of this chapter, the potential for a nurse bias in the selection of participants, although unlikely, was nevertheless a possibility. However, by working closely with the clinic nurses and briefing them that every eligible patient should have an equal opportunity of participating in the research, this possibility was minimised.

With changing and varying guidelines for what is considered 'good' and 'poor' control of diabetes, it could be argued that a HbA₁c of 8%, rather than 8.5% be used for the poor control group. This research took an extreme groups approach and taking the higher recommended cut off point is a reflection of this. By taking the lower cut off point of 8%, the groups would have not been as extreme in their division. Using this extreme groups approach, it was not possible to take a random sample of all those with type two diabetes with all levels of HbA₁c to eliminate any possibility of a regression to the mean effect. However, the purpose of this research was to establish what the differences are between a group of people in good control of their diabetes and a group in poor control. This was a cross-sectional study using a clinically reliable test (HbA₁c) to differentiate between the two groups. The samples were then randomly selected from within these groups and were measured at one point in time. There was no manipulation of conditions and therefore no pre-post testing which is often where a regression to the mean effect occurs.

7.4.3 Dichotomisation

This thesis took an extreme groups approach and transferred data to categorical variables for use in the logistic regression. The choice of extreme groups was deemed the most appropriate to answer the research question and within diabetes there are clinically recognised cutpoints for the dichotomisation. For the multivariate analysis, dichotomisation was justified because of the number of variables and again was performed in a meaningful manner. Nevertheless, it is important to recognise the potential disadvantages of treating the data in this manner such as the potential loss of data, loss of power and increased likelihood of a type 1 error (Austin & Brunner, 2004). What this thesis allowed for was a trade-off in terms of continuous predictors' greater statistical power and dichotomous predictors' greater ease of interpretation and relevance to clinical outcomes (Iacobucci, 2001).

7.5 Implications of Research

Firstly, this research has shown the benefit of using triangulation of methods in research. Qualitative research in health psychology is still a nascent field (Chamberlain, 2000) and the use of triangulation should be considered as an appropriate research design for achieving a truth close to reality and a more complete knowledge of the psychology of health and illness.

Secondly, the importance of including family members in research on adults with chronic illness must be acknowledged. It has been recognised that family members are often neglected in type 2 diabetes research (Fisher et al., 1998; Gonder-Frederick et al., 2002). To date, there has been a lack of reviews in this area and it is not possible to make concrete assumptions regarding the neglect of family members (White, Smith & Hevey, 2005)¹. Family members can influence illness management, social support and illness representations and they can play an important role in interventions to improve the management of type 2 diabetes (White, Smith & O'Dowd, in press).

It is important to be aware that whilst endeavouring to include family members in research, many adults may choose not to have their family included in their diabetes

¹ Title submitted to the Cochrane Metabolic & Endocrine Disorder Group to conduct a systematic review to assess the effectiveness of family based interventions for patients with type 2 diabetes

treatment or they simply may not have family members who are alive and living in close proximity. In this research, only 66 % of participants chose to include a family member. Adults with chronic illness must reserve the right to be treated confidentially and to receive their care in *their* chosen manner. A further consideration of this familial approach, is its potential to influence the patient's 'sick role' behaviour. It is unknown whether placing such importance on the adult with a chronic illness within the family could encourage dependence rather than self-management and in effect endorse secondary gain. Itkowitz, Kerns and Otis (2003) have published some preliminary research on this from the field of coronary heart disease. They found that the more positive attention patients received from significant others to the expression of their symptoms of coronary heart disease, the higher the patients' perceptions of the severity of their symptoms and the more illness-related disability they reported. Further research is needed to see if these results are particular to heart disease, as they have reinforced the importance of the social context of patient's understanding and management of their illness.

7.5.1 Future recommendations

7.5.1.1 Interventions

Marks (1996) commented that "psychological support is widely recommended but rarely available" (p. 60). Almost a decade later, this is still the case. With the body of research on psychology and diabetes, there is a need not only for that research to have an underlying and unifying theoretical approach, but for the research to improve the care and daily lives for those living with diabetes. Nichols (2005) has discussed this as the failure of psychology to improve the care for the 'average patient'. He states that for all of the advances within health psychology over the past two decades, routine care for the average patient does not include psychological care. Within diabetes as with most chronic illnesses, psychological care for patients may simply mean a heightened awareness of their psychological needs, or where needed interventions to improve education, emotional care or support and psychological therapy for those who require it (Nichols, 2003). Type 2 diabetes, with its impending epidemic and current prominence, alongside obesity in health priorities, may provide the opportunity for psychology to make its contribution to the care of those with chronic illness.

This research has shown that there are psychosocial differences in determining glycaemic control. Improving the care for those in poor control should take cognisance of these differences. An important way of beginning this process is through the establishment of theory driven rigorous interventions. Whilst the last two decades have seen the development of many interventions to improve patients' management of their diabetes in order to avoid or delay the onset of diabetes-related complications (Steed et al., 2003), these interventions, as with many chronic illness interventions, have focussed solely on the person with the illness and have failed to place them in their wider family, community and social context. With the majority of diabetes management occurring outside of a clinical setting, interventions need to be developed which include family members.

Self-management interventions have shown improvements in psychological well-being (Griva et al., 2000), glycaemic control (Norris, Engelgau, & Narayan, 2002) and lifestyle behaviours (Clark et al., 2004). However, several systematic reviews of psychological interventions in diabetes (Hampson et al., 2001; Ismail et al., 2004; Steed et al., 2003), have highlighted variance in the findings and methodological inconsistencies. This field of research can only advance through addressing these methodological problems (Snoek & Skinner, 2002). These include the facts that few interventions are based on a clearly specified theoretical background and that a combination of process indicators and outcome measures are rarely reported, more specifically, given the importance of cardiovascular risk reduction (UKPDS, 1998), risk factors such as blood pressure are not routinely included. Also, many studies lack sufficient power and are inadequately controlled, and most intervention studies lack any information on the components of the intervention, making it difficult to for other researchers to replicate. The tendency of interventions to be small, single trials has affected their repeatability and ultimately their adoption into mainstream clinical diabetes care (Gonder-Frederick et al. 2002). Finally, the cost effectiveness of interventions is rarely considered making it difficult to prioritise service development initiatives.

The results of this research are in line with the psychosocial literature on understanding the management of chronic illness, which consistently reports the importance of understanding the illness from the patient's perspective (Leventhal et al., 2001). A true understanding of how people think about their illness can only be reached by placing their thoughts about their illness within their social context. This was recognised early on in the

development of models on illness representations; "every component of the illness control system from the representation of disease through the development and execution of coping to appraisal is heavily influenced by interaction with the family and by its impact on the family unit" (Leventhal et al., 1986). As Weinman et al., (2003) noted, this influence is more pronounced now, given that most chronic illnesses are managed at home, yet family context has been neglected in the research on illness representations. With the growing realisation that managing adult chronic illness does not happen in isolation, it is imperative that interventions include other family members and to place it in the community setting where most of diabetes management takes place. ²

7.5.1.2 Broader social context

Expanding our understanding of diabetes to the family is in itself limiting. It is important that future research takes account of the broader social and cultural context of the individual. The demographics of the Irish population are changing – there has been a 30% increase in reported levels of obesity over the past four years (National Nutrition Surveillance Centre, 2003). Research on diabetes will also need to take account of how aging and cohort factors influence a person's perception of their health. MacFarlane and Kelleher (2002), in their qualitative study of older Irish adults demonstrated how the illness beliefs of older adults had been shaped by the changes and advances in health care they had experienced throughout their life. The participants in their study had a more biomedical approach to illness and a high regard for medical practitioners and their knowledge. Understanding the medical advances that have been made since this group had been born and the changes in the health care system, provided an understanding of illness beliefs from a broader social context.

Another issue that has been addressed in other multi-cultural societies is the meaning of a diagnosis of diabetes for different ethnic groups (Maillet et al., 1996; Sissons Joshi, 1995; Sunday & Eyles, 2001; Thompson & Gifford, 2000 and Zgibor & Simmons, 2002). As Ireland becomes a more multi-cultural country, an understanding of cultural differences in health and illness is essential if all members of our society are to receive optimal care.

² A project grant from the Health Research Board of Ireland has recently been awarded to PW to conduct a three year randomised controlled trial of a brief family intervention to improve outcomes in type 2 diabetes

7.6 Conclusion

Using an extreme groups approach and triangulation in research is an effective means of understanding the many factors that contribute to good and poor control of diabetes. This research has shown that people in poor control think differently about their illness, they use different coping strategies, are less adherent to their diet and they report more diabetes-related emotions than those in good control.

Family members, where relevant should be included in type 2 diabetes care. Compared to patients, they have higher levels of concerns and distress about the illness and lower levels of satisfaction with the support they have. Health care professionals should be aware of the potential role of family members in diabetes care and the social context of peoples' lives and health.

Enough evidence now exists to demonstrate the central role that psychosocial factors play in diabetes management (Delamater et al., 2001; Glasgow et al., 1999; Gonder-Frederick et al., 2002; Hampson, 1997). People in poor control of their diabetes would benefit from routine psychological care addressing social support, illness cognitions, coping strategies and emotional distress. Only a small number of people with diabetes need specialised psychological therapy. As DeVries, Snoek and Heine (2004) note "a biopsychosocial model, with close cooperation between diabetologists, educators and behavioural scientists has been repeatedly advocated" (p. 1266). It is now time for a true biopsychosocial approach to diabetes care to be *implemented* rather than advocated (Glasgow et al., 1999), only then can the psychosocial determinants of glycaemic control be addressed.

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Appendix A - Member Checking Form with Preliminary Analysis

Date
Dear
I'm sure you have forgotten all about this research on diabetes, it seems so long since we met in the Artane Community Centre at the end of January. I hope this letter finds you well.
What I have (eventually) done is written up a short summary of what I feel are the main points from the discussion. All that I'd like you to do is to read it and let me know if it is an accurate description of what was said on the night (I'm sure you've forgotten by now but have a read and hopefully it'll jog your memory).
I've been using the information from all of the group discussions to nelp design a large study looking at how people think about their diabetes and how that influences their control of it. I'm also hoping to present the results from the groups in a poster format at a European Health Psychology Conference in October.
So I'll ask you to return the <u>blue</u> form to me in the envelope provided and if you have any queries, please do not hesitate to contact me. Thank you once again for all your time and contributions, it wouldn't have been possible without you.
Γhanks,
Patricia White Health Psychologist.

SUMMARY OF DISCUSSION POINTS (F2)

Diagnosis

Most of you were surprised at how the diagnosis had come about from a simple test, when you were in for something completely different.

Daily Life

On a day to day basis most said how you feel well. Aren't bothered by diabetes and just get on with life but it is always there at the back of your mind 'I feel I'm not a diabetic'

'it's always there'

One of you mentioned how you 'treat it with contempt' which seemed to sum up how many of you felt.

Food and diet appears to be an issue, the quote 'you stick to it and you don't stick to it' applied to everyone.

Information

It was very obvious that there are still many questions about your diabetes that need to be answered. More information needs to be given and in a way that you don't 'need to be a doctor to understand it'.

Causes

When asked what causes diabetes, the main reasons given were; too much sugar or sweet things, the blood, being overweight and it's hereditary.

Seriousness

It seemed to be half in half when asked whether diabetes was serious or not. It was mentioned though that you'd have certain fears eg. about going on insulin, having an amputation and that it would affect the eyes.

Family

As many have families who are grown and living elsewhere, family members don't appear to play a big role in your diabetes. However, it was mentioned that husband/wife are a help e.g. 'my husband is good with the tablets'. There does seem to be a lack of information for family members but whether this is intentional or not is unclear.

'they don't know enough'

'they don't want to know'

Care

A few problems in relation to care were mentioned e.g; never seeing the consultant 'it's always his understudy', a doubling up on tests and visits with a new system and the rules and regulations of the diet. Overall, however, everyone seems happy with the care they receive and there were many positive comments in relation to doctors, nurses etc.

Recommendations

There were only a few recommendations made. These included more education for everybody e.g. in schools and that screening for family members should be available.

PARTICIPANTS COMMENTS

Is this an accurate summary of the discussion that was held?
Is there anything inaccurately reported?
Is there anything else that should be included that was said on the night?
Any other comments?

Thank you

Appendix B – Letter of Invitation to Focus Group Participants

January 11th 2002

«Title» «FirstName» «LastName» «Address1» «Address2» «address3»

Dear «FirstName»

We would like to invite you and a family member to talk us about your diabetes and the care you receive. I visited you last year in your home to discuss your diabetes and take some bloods. We are now hoping to learn more about your views and opinions as this will help us to provide better care for you. It will be an informal meeting which will be co-ordinated by myself and another researcher.

I am inviting six to seven other people to have a group discussion. £10.00 will be given towards your travel expenses should you decide to attend. We plan to hold this discussion the last week of January.

I will be in contact with you over the next week to see if you can attend or not. Please feel free to call me at 4730893 if you have any questions.

I look forward to meeting you

Kind regards

Martina O Leary Diabetes research nurse

Appendix C - Consent Form for Focus Groups

PARTICIPANT CONSENT FORM FOR RESEARCH

DIABETES	
CONSENT OF V	DLUNTEER:
Ι	of
Have read and und	erstood the information leaflet.
I give my consent	erstood the information leaflet. to take part in a focus group to discuss my beliefs and attitude
I give my consent	
I give my consent around diabetes.	to take part in a focus group to discuss my beliefs and attitude
I give my consent around diabetes. Date:	to take part in a focus group to discuss my beliefs and attitude
I give my consent around diabetes. Date:	to take part in a focus group to discuss my beliefs and attitude
I give my consent around diabetes. Date: Signature of Volu	to take part in a focus group to discuss my beliefs and attitude

Appendix D - Notes for Observers of Focus Group

NOTES FOR 'INDEPENDENT OBSERVER'

- Welcome participants as they arrive and engage in small-talk, don't bring up issues that may be brought up later.
- Take notes of the main responses and key phrases/well-said quotes (with names)
- Indicate body language and facial expressions (leans in, hangs head, bangs fist on table) or laughter/silence to indicate mood of conversation.
- Keep an eye on the tape-recorder for battery and tapes running out
- Deal with unexpected intrusions e.g. latecomers, background noise, someone's chair breaking...
- Provide a brief summary of what was said
- Engage in debrief session with moderator and fill out Focus Group Report form

Appendix E - Notes for Facilitators of Focus Group

INTRODUCTION

Welcome and Thank you

Good Evening and you're all very welcome. Thank you for making it here tonight and leaving the comfort of your homes on a dreary winters night.

Introduce Self and 'Observer'

My name is Patricia White, I'm a health psychologist and I'm currently working in the area of diabetes. This is Ros who will just be observing us and taking notes, kind of like the guy who's in the corner when they're doing the lotto and just nods, she's here to make sure I do my job!!

Explanation

As I said I'm interested in the area of diabetes and being a psychologist I like try to understand how people think and feel about things so now that I am working in the area of diabetes, I'm doing research but I want to make sure that it will have a real impact on the care or daily lives of people with diabetes. So, I thought I'd start by going straight to the experts - who are you guys. I'm going to ask you several questions about what it's like to live with diabetes and as there are **no right or wrong answers**, you may have different things to say - which is great. Don't worry about saying something that is different to someone else, it's your experience that's important. As you can see, the session will be taped, this is so that poor XXX doesn't have all the responsibility and to make sure we don't miss anything. There'll be no names included in anything that'll be written from this session and I can assure you that everything you say is **private and** confidential, the only person who will be listening to these tapes will be me.

All I'm going to do is ask the questions and listen. I'm interested in what you have to say and so that **everyone is included**, if you're talking a lot, I may ask you to give other people a chance.

If I could ask you first to sign this **consent form** to show that you are all here of your own free will.

Ok, lets begin with the first question.....

INTRODUCTION

Welcome and Thank you Introduce Self and 'Observer' Explanation

- experts emphasise they are experts, what they say is important
- no right or wrong answers, don't worry about not agreeing with other people
- the session will be taped so that nothing important is missed
- private and confidential names will be changed, tapes destroyed
- everyone is included so eg if talking a lot may ask you to give others a chance

Consent Form

 ask everyone to put their name, address (we'll need this for further correspondence) and signature on consent form

Ok, lets begin with the first question.....

Ending the Focus Group

- Sum up what has been said
- Ask if this summary is accurate
- Any questions? Have we missed anything?
- Discuss what happens next. Interviews transcribed and summarised. These summaries posted out and asked for your opinion or if have anything else to add.
- Thank for coming
- Distribute travel expenses
- Debrief meeting with observer and fill out Focus Group Report

Appendix F - Standardised Interview Guide for Focus Groups

INTERVIEW GUIDE FOR FOCUS GROUPS

Person with diabetes

Opening Question

E.g. name and what would normally be doing now?

Introductory Question

• Think back to when you first heard that you had diabetes, what were the first things that came into your mind?

Transition Questions

- How long did it take to sink in?
- Did you feel you got enough information about diabetes?
- Is diabetes a serious illness?

Key Questions

- What do you feel are the main causes of diabetes? (ACTIVITY)
- How does your diabetes affect your day-to-day life?
- What role do family members play in managing diabetes?
- How much control do you have over diabetes?
- What about the long-term consequences of having diabetes?

Final Questions

- What do you think would help the management of diabetes?
- What would you like to see in the future for the families of people with diabetes?
- Well, that's all my questions, is there anything else that anyone would like to add?

INTERVIEW GUIDE FOR FOCUS GROUPS

Family Members

Opening Question

E.g. name and what would normally be doing now?

Introductory Question

• Think back to when you first heard that your father/mother, husband/wife had diabetes, what were the first things that came into your mind?

Transition Questions

- How long did it take to sink in?
- Did you feel you got enough information about diabetes?
- Is diabetes a serious illness?

Key Questions

- What do you feel are the main causes of diabetes?
 (ACTIVITY)
- How does diabetes affect your day-to-day life?
- What role do family members play in managing diabetes?
- How much control does a person have over diabetes?
- What about the long-term consequences of having diabetes?

Final Questions

- What do you think would help the management of diabetes?
- What would you like to see in the future for the families of people with diabetes?
- Well, that's all my questions, is there anything else that anyone would like to add?

Appendix G - Report Forms for Focus Group

FOCUS GROUP REPORT
Date:
Place:
Participants:
Moderator:
Observer:
Duration:
Participant involvement:
Setting:
Group Dynamics:
Comments and Feedback:
Comments and Feedback.
Signed:

Appendix H - Decision Trail for Codes, Categories and Themes

PRELIMINARY ISSUES FROM FOCUS GROUPS - pre-coding

Person with Diabetes

- Need more 'real' information that can be understood
 - ³/₄ (from FG1) don't ask questions anymore
- Don't really understand the mechanics of diabetes, no one person had a clear understanding of what diabetes is, what causes diabetes, why they're on the treatment they're on and what the possible complications are.
 - Eg. is it in the blood? Is it from all the sweets I ate?
- Lot of contradictions in what people say possibly stemming from this lack of information
 - Eg. conflicting information re: diet, what is ok and not ok?
 - E.g. Beliefs about causes:
 - If it's weight then how come I know 3 really skinny people who have it
 - If it's age, then how come my brother-in-law's cousin's baby has it?
 - If it's hereditary, well no-one in my family, except my brother has it
- Other factors important with this group; age and other illnesses
- Is a sense that just live with it and get by on a day to day basis

Family Members

- Information/ education and awareness feel they need
- Person with diabetes has enough information
- ♦ Causes;
 - lifestyle (eating too much sugar/ overweight)
 - age
 - hereditary (but everyone only had one relative with diabetes!!)
- Day-to-day basis one group felt it had no effect, the other said constantly thinking of it
- Seriousness of diabetes had varied responses
- Need; more information in layman terms, support ('nights like this'), counselling from the beginning
- Note: at least two family members came across as angry and frustrated with diabetes.

NVivo revision 1.3.146 Project: Diabetes Focus Groups CODE LISTING

Number of Codes: 72 1 Adherence 2 Adherence 2 3 Age 4 Age 2 5 **AGREE** 6 AGREE 2 7 Alcohol 8 Alcohol 2 9 Anger 10 Anger 2 Blood tests 11 Blood tests 2 12 13 C 14 C 2 15 Cause 16 Comments about person w D 17 Conseq 18 Control 19 Control 2 20 coping 21 coping 2 22 Counselling 23 Counselling 2 24 Count 25 Count 2 26 D 27 Day2day 28 diagnosis Effects on Fam 29 30 Emotion 31 Experience 32 **FAmily** Family Needs 33 34 Food 35 Н Hereditary 36 37 Identity 38 Information

Inject

J

JN

Insulin-cause

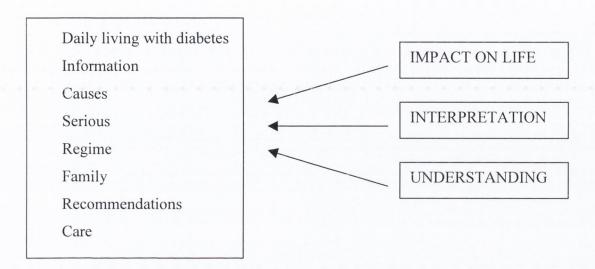
39

40 41

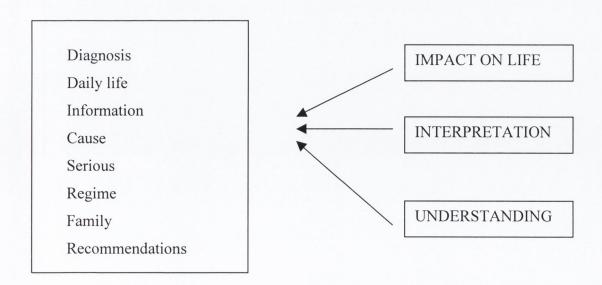
42

- 43 L
- 44 Lifestyle
- 45 Live
- 46 M
- 47 MAR
- 48 Medication
- 49 Moody
- 50 N
- 51 Other Illness
- 52 Overweight-cause
- 53 P
- 54 Pancreas
- 55 Problem
- 56 PROCESS
- 57 R
- 58 Recom
- 59 Research
- 60 S
- 61 Seek Clar
- 62 Serious
- 63 Service
- 64 Society
- 65 Summary
- 66 Support
- 67 T
- 68 Testing
- 69 Thirst
- 70 Understanding
- 71 Weight
- 72 Worry

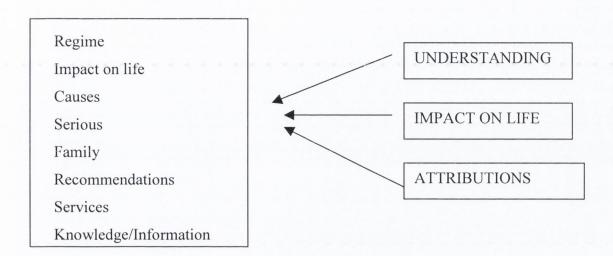
CATEGORIES & THEMES - FOCUS GROUP DIABETES 1



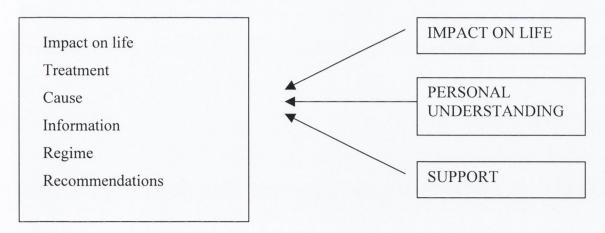
CATEGORIES & THEMES - FOCUS GROUP DIABETES 2



CATEGORIES & THEMES - FOCUS GROUP FAMILY MEMBERS 1



CATEGORIES & THEMES - FOCUS GROUP FAMILY MEMBERS 2



Appendix I - Form for Medical and Demographic Details Taken in Clinic



Research	Ma	
Research	IVO.	

PARTICIPANT INFORMATION FORM - D

Research Use Onl

Name:	
Chart No.:	
Address:	
DoB:	
Gender: Male Female	
Marital Status:	
Single Married Widowed Separated Divorced	
Occupation:	
Educational Attainment: No formal Primary Junior/Inter Leaving/Tech Non-degree Degree P.G.Degree Medical Card Holder: Yes No	

Diabetes Psychosocial Research, Patricia White, TCD.



Research	Ma	
Kesearch	INO.	

Research Use Only

Duration of Diabetes:
Type of Treatment: Diet only Diet and medication Insulin
HbA _{1c} : Date taken:
Diabetes Complications:
(a) Retinopathy
(b) Neuropathy
(c) Hypertension
(d) Nephropathy
(e) Others

Diabetes Psychosocial Research, Patricia White, TCD.

Appendix J - Diabetes Knowledge Questionnaire

Diabetes Knowledge Questionnaire (DK-24)

(Please tick appropriate answer)

Item	Question	Yes	THE PARTY OF	I don't know
1	Eating too much sugar and other sweet foods is a cause of diabetes			KIIOW
2	The usual cause of diabetes is lack of effective insulin in the body			
3	Diabetes is caused by failure of the kidneys to keep sugar out of the urine			
4	Kidneys produce insulin			
5	In untreated diabetes, the amount of sugar in the blood usually increases			
6	If I have diabetes, my children have a higher chance of having diabetes			
7	Diabetes can be cured			
8	A fasting blood sugar level of 9 is too high			
9	The best way to check your diabetes is by urine testing			
10	Regular exercise will increase the need for insulin and other diabetic medication			
11	There are two main types of diabetes; type 1 (insulin-dependent) and type 2 (non-insulin dependent)			
12	An insulin reaction is caused by too much food			
13	Medication is more important than diet and exercise to control diabetes			
14	Diabetes often causes poor circulation			
15	Cuts and abrasions on people with diabetes often heal more slowly			
16	People with diabetes should take extra care when cutting their toenails			
17	A person with diabetes should cleanse a cut with extra care			
18	The way a person with diabetes prepares their food is as important as the foods they eat			
19	Diabetes can damage your kidneys			
20	Diabetes can cause loss of feeling in your hands, fingers and feet			
21	Shaking and sweating are signs of high blood sugar			
22	Frequent urination and thirst are signs of low blood sugar			
23	Tight elastic socks or tights are not bad for people with diabetes			
24	A diabetes diet consists mainly of special foods			

Garcia et al (2001) adapted from the Starr County Diabetes Education Study

Appendix K - Diabetes Treatment Satisfaction Questionnaire

The Diabetes Treatment Satisfaction Questionnaire (change): DTSQc

For the past few weeks/months you have been taking part in a diabetes treatment study. At the start of the study you may have had a change of treatment. Today we would like to know how your experience of your current treatment (including medication and diet) has changed from your experience of treatment before the study began. Please answer each question by circling a number on each of the scales to indicate the extent to which you have experienced changes. If you have experienced no change, please circle '0'.

1.	How	satisfied are you with you	r curren	nt treatn	nent?					
		much more satisfied now	3	2	1	0	-1	-2	-3	much less satisfied
2.	How	often have you felt that yo	ur bloo	d sugar	s have	been u	ınaccep	tably h	igh recentl	y?
		much more of the time now	3	2	1	0	-1	-2	-3	much less of the time
3.	How	often have you felt that yo	ur bloo	d sugar	s have	been u	ınaccep	otably lo	ow recently	?
		much more of the time now	3	2	1	0	-1	-2	-3	much less of the time
4.	How	convenient have you beer	n finding	g your t	reatme	nt to be	recent	ly?		
		much more convenient now	3	2	1	0	-1	-2	-3	much less convenient
5.	How	flexible have you been fin	ding yo	ur treat	ment to	be rec	ently?			
		much more flexible now	3	2	1	0	-1	-2	-3	much less flexible now
6.	How	satisfied are you with you	r under	standin	g of you	ur diabe	etes?			
		much more satisfied now	3	2	1	0	-1	-2	-3	much less satisfied
7.	How diabe	likely would you be to rece etes?	ommen	d your p	oresent	treatm	ent to s	omeon	e else with	your kind of
		much more likely to recommend the treatment now	3	2	1	0	-1	-2	-3	much less likely to recommend the treatment
8.	How	satisfied would you be to	continu	e with y	our pre	esent fo	rm of tr	eatmer	nt?	
		much more satisfied now	3	2	1	0	-1	-2	-3	much less satisfied
		Please make sure that y	ou hav	e circle	ed one	numbe	er on ea	ach of	the scales	

Appendix L - Illness Perceptions Questionnaire - Revised

YOUR VIEWS ABOUT YOUR FAMILY MEMBERS DIABETES

Listed below are a number of symptoms that your family member may or may not have experienced since their diabetes. Please indicate by circling *Yes* or *No*, whether they have experienced these symptoms since their diabetes, and whether you believe that these symptoms are related to their diabetes.

		experienced this nee their diabetes	This sympto their dia	om is related betes
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 own personal views of how you now see your family members current diabetes.

Please indicate how much you agree or disagree with the following statements about their diabetes by ticking the appropriate box

	VIEWS ABOUT YOUR FAMILY MEMBERS DIABETES	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOF DISAGREE	AGREE	STRONGLY AGREE
	Their diabetes will last a short time					
1	Their diabetes is likely to be permanent rather than temporary					
97	Their diabetes will last a long time					
1	Their diabetes will pass quickly					
15	I expect they will have this diabetes for the rest of their					
B	Their diabetes is a serious condition					
	Their diabetes has major consequences on their life					
7	Their diabetes has major consequences on my life					
8	Their diabetes does not have much effect on their life					
18	Their diabetes does not have much effect on my life					-77
39	Their diabetes strongly affects the way others see them					
210	Their diabetes has serious financial consequences					
20	Their diabetes causes difficulties for those who are clos them					
212	There is a lot which they can do to control their sympto					
P12 (b)	There is a lot which I can do to control their symptoms					
P13	What they do can determine whether their diabetes gets better or worse					
M3	What I do can determine whether their diabetes gets bet or worse					
P14	The course of their diabetes depends on them					
14	The course of their diabetes depends on me					
115	Nothing they do will affect their diabetes					
15	Nothing I do will affect their diabetes					
16	They have the power to influence their diabetes					
16	I have the power to influence their diabetes					
17	Their actions will have no affect on the outcome of the their diabetes					
P17	My actions will have no affect on the outcome of the th diabetes					

IP18	Their diabetes will improve with time					
IP19	There is very little that can be done to improve their diabetes					
IP20	Their treatment will be effective in curing their diabetes					
	VIEWS ABOUT YOUR FAMILY MEMBERS DIABETES	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOF DISAGREE	AGREE	STRONGLY AGREE
IP21	The negative effects of their diabetes can be prevented (avoided) by their treatment					
IP22	Their treatment can control their diabetes					
IP23	There is nothing which can help their condition					
IP24 (a)	The symptoms of their condition are puzzling to them					
IP24 (b)	The symptoms of their condition are puzzling to me					
IP25 (a)	Their diabetes is a mystery to them					
IP25 (b)	Their diabetes is a mystery to me					
IP26 (a)	They don't understand their diabetes					
IP26 (b)	I don't understand their diabetes					
IP27 (a)	Their diabetes doesn't make any sense to them					
IP27 (b)	Their diabetes doesn't make any sense to me					
IP28 (a)	They have a clear picture or understanding of their diab					
IP28 (b)	I have a clear picture or understanding of their diabetes					
IP29	The symptoms of their diabetes change a great deal from day to day					
IP30	Their symptoms come and go in cycles					
P31	Their diabetes is very unpredictable					
IP32	They go through cycles in which their diabetes gets bett and worse					
P33 (a)	They get depressed when they think about their diabete					
IP33 (b)	I get depressed when I think about their diabetes					
IP34 (a)	When they think about their diabetes they get upset					
P34 (b)	When I think about their diabetes I get upset					
IP35 (a)	Their diabetes makes them feel angry					
P35 (b)	Their diabetes makes me feel angry					
IP36 (a)	Their diabetes does not worry them					
IP36 (b)	Their diabetes does not worry me					

IP37 (a)	Having this diabetes makes them feel nervous		
IP37 (b)	Their having this diabetes makes me feel nervous		
IP38 (a)	Their diabetes makes them feel afraid		
IP38 (b)	Their diabetes makes me feel afraid		

CAUSES OF THEIR DIABETES

We are interested in what <u>you</u> consider may have been the cause of your family members 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 family members diabetes rather than what others including doctors and family may have suggested to you. Below is a list of possible causes for their diabetes. Please indicate how much you agree or disagree were the causes for you by ticking the appropriate box.

+ 42	POSSIBLE CAUSES	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOF DISAGREE	AGREE	STRONG AGREE
Cl	Stress or worry					
C2	Hereditary – it runs in their family					
C3	A germ or virus			Service August 19		
C4	Diet or eating habits					
C5	Chance or bad luck					
C6	Poor medical care in their past					
C7	Pollution in the environment					
C8	Their own behaviour					
C9	Their mental attitude e.g. thinking about life negatively					
C10	Family problems or worries					
C11	Overwork					
C12	Their emotional state e.g., feeling down, lonely, anxious, empty					
C13	Ageing			10000		
C14	Alcohol					
C15	Smoking					
C16	Accident or injury					
C17	Their personality					
C18	Altered immunity					

In the table below, please list in rank-order the three most important factors that you now believe caused <u>YOUR FAMILY MEMBERS</u> diabetes. 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.					
_						

Appendix M – Summary of Diabetes Self-Care Activites

Diabetes Self-Care Activities

The questions below ask you about your diabetes self-care activities *during the past 7 days*. If you were sick during the past 7 days, please think back to the last 7 days that you were not sick. Please answer the questions as honestly and accurately as you can.

T	w			г
		М.	-	

The first few questions ask about your eating habits over the last 7 days. If you have not been given a <u>specific</u> diet by your doctor or dietician, answer Question 1 according to the general guidelines you have received.

1. How often did you follow your recommended diet over the last 7 days?

1. Always2. Usually 3. Sometimes4. Rarely5. Never							
2. What percentage of the time did you successfully limit your calories as							
recommended in healthy eating for diabetes control?							
0% (none)25% (1/4)50% (1/2)75% (3/4)100% (all)							
3. During the past week, what percentage of your meals included high fibre							
foods, such as fresh fruits, fresh vegetables, whole grain breads, dried beans							
and peas, bran?							
0% (none)25% (1/4)50% (1/2)75% (3/4)100% (all)							
4. During the past week, what percentage of your meals included high fat							
foods such as butter, ice-cream, oil, nuts and seeds, mayonnaise, avocado,							
deep-fried food, salad dressing, bacon, other meat with fat or skin?							
0% (none)25% (1/4)50% (1/2)75% (3/4)100% (all)							
5. During the past week, what percentage of your meals included sweets and							
desserts such as pie, cake, jelly, soft drinks (regular, not diet), biscuits?							
0% (none)25% (1/4)50% (1/2)75% (3/4)100% (all)							

EXERCISE							
6. On how many	of the las	t 7 days d	id you par	rticipate in	at leas	t 20 minu	utes of
physical exercise	?						
0 1	2	3	4	5	6	7	
7. What percenta	age of the	time did y	ou exerci	se the am	ount su	ggested	by
your doctor? (E.g	g. if your o	loctor reco	mmende	d 30 minu	ites of a	ctivity?)	
0% (none)	25% (1	/4)5	50% (1/2)	75% ((3/4)1	100% (all)	
8. On how many	of the las	st 7 days o	did you pa	rticipate i	n a spec	cific exer	cise
session other tha	an what yo	ou do arou	ind the ho	use or as	part of	your wor	k?
0 1	2	3	4	5	6	7	
GLUCOSE TEST	ΓING						
9. On how many	of the las	t 7 days (t	hat you w	ere not si	ck) did	you test y	your
glucose (blood s	ugar) leve	el?					
1. Every day	2. M	lost days	3. Som	ne days	4. No	one of the	days
10. Over the last	7 days (1	that you w	ere not si	ck) what p	percenta	age of the	Э
glucose (blood s	ugar or ur	ine) tests	recomme	nded by y	our doc	tor did yo	ou
actually perform?	?						
0% (none)	25% (1	/4)5	0% (1/2)	75% (3/4) _	100% (a	all)
DIABETES MED	DICATION	N					
11. How many of			d insulin i	niections	did vou	take in th	ne last
7 days that you v				.,00	a.a.you		
1. All of the			3. Sc	me of them	4. N	None of the	em
8 I do not t	ake insulin						
12. How many	of your re	commend	ed numbe	er of pills t	to contro	ol diabete	es did
you take that y	ou were s	upposed t	0?				
1. Al	l of them	2. Mos	st of them	3. So	me of the	em4	. None
of them		8 I do	not take p	oills to con	trol my d	liabetes	

Appendix N - Social Support Questionnaire - 6

Social Support Questionnaire (SSQ6)

The following questions ask about people in your environment who provide you with help or support. Each question has two parts. For the first part, list all of the people you know, excluding yourself, whom you can count on for help or support in the manner described. Give each person's initials and their relationship to you (see example). Do not list more than one person next to each of the numbers beneath the question. Do not list more than nine people per question.

For the second part using the scale below, circle how satisfied you are with the overall support you have.

6	5	4	3	2	1
Very	Fairly	A little	A little	Fairly	Very
satisfied	satisfied	satisfied	dissatisfied	dissatisfied	dissatisfied

If you have no support for a question, tick the words 'No one' but still rate your level of satisfaction. The example below has been completed to help you. All your responses will be kept confidential.

Example

Who do you know whom you can trust with information that could get you into trouble?

(a) No one						
1)			4)			7)
2)			5)			8)
3)			6)			9)
(b) How satisfied?	6	5	4	3	2	1

1. Whom can you re	eally count	on to dis	stract	you from	m your worrie	s when y	you
feel under stress?							
(a) No one							
1)			4)				7)
2)			5)				8)
3)			6)				9)
(b) How satisfied?	6	5		4	3	2	1
2. Whom can you re	eally count	on to he	lp yo	u feel m	ore relaxed w	hen you	are
under pressure or te	ense?						
(a) No one							
1)			4)				7)
2)			5)				8)
3)			6)				9)
(b) How satisfied?	6	5		4	3	2	1
3. Who accepts you	totally, inc	luding b	oth y	our wors	st and best po	oints?	
(a) No one							
1)			4)				7)
2)			5)				8)
3)			6)				9)
(b) How satisfied?	6	5		4	3	2	1
4. Whom can you re	ally count	on to ca	re ab	out you,	regardless o	f what is	
happening to you?							
(a) No one							
1)			4)				7)
2)			5)				8)
3)			6)				9)
(b) How satisfied?	6	5		1	2	2	1

5. Whom can you really count on to help you feel better when you are feeling							
generally down-in-the-dumps?							
(a) No one							
1)			4)			7)	
2)			5)			8)	
3)			6)			9)	
(b) How satisfied?	6	5	4	3	2	1	
6. Whom can you co	ount on t	o console yo	ou when you	are very up	set?		
(a) No one							
1)			4)			7)	
2)			5)			8)	
3)			6)			9)	
(b) How satisfied?	6	5	4	3	2	1	
7. Whom can you co	ount on t	o help you v	vith your dia	betes?			
(a) No one							
1)			4)			7)	
2)			5)			8)	
3)			6)			9)	
(b) How satisfied?	6	5	4	3	2	1	

Well-Being Questionnaire (W-BQ12)

Please circle one number on each scale, from 3 (all the time) to 0 (not at all), to indicate how often you feel each statement has applied to you in the past few weeks.

		all the time		not at all
1.	I have crying spells or feel like it	3	2	1
2.	I feel downhearted and blue	3	2	1
3.	I feel afraid for no reason at all	3	2	1
4.	I get upset easily or feel panicky	3	2	1
5.	I feel energetic, active or vigorous	3	2	1
6.	I feel dull or sluggish	3	2	1
7.	I feel tired, worn out, used up or exhausted	3	2	1
8.	I have been waking up feeling fresh and rested	3	2	1
9.	I have been happy, satisfied, or pleased with my personal life	3	2	1
10.	I have lived the kind of life I wanted to	3	2	1
11.	I have felt eager to tackle my daily tasks or make new decisions	3	2	1
12.	I have felt I could easily handle or cope with any serious problem or major change in my life	3	2	1

Please make sure that you have considered each of the 12 statements and have circled one number in response to each statement.

Appendix P - Coping with Health and Injury Problems

CHIP by N	orman S. Endler, Ph.D.	., F.R.S.C. & Já	ımes D.	A. Parke	r, Ph.D.
Name or ID:	_ Gender: M F A	ge: Tod	ay's Da		/ dd yyyy
Occupation:N	Iarital Status:	Educa	tion:		
The following are ways of reacting to HEALTH P typically difficult, stressful, or upsetting situations. a number from 1 to 5 for each of the following it encountered your health problem. Please be sure to Please state your most recent	We are interested in your mo ems. Indicate how much yo	st recent illness,	sickness,	or injury. P	lease circle
health problem:		Not at All	Mod	lerately	Very Much
1. Think about the good times I've had		1	2	3 4	5
2. Stay in bed		1	2	3 4	5
3. Find out more information about the ill	ness	1.1	2	3 4	5
4. Wonder why it happened to me		1	2	3 4	5
5. Be with other people		T	2	3 4	5
6. Lie down when I feel tired		1	2	3 4	5
7. Seek medical treatment as soon as poss	ible	1	2	3 4	5
8. Become angry because it happened to r	ne	1	2	3 4	5
9. Daydream about pleasant things			2	3 4	5
10. Get plenty of sleep		1	2	3 4	5
11. Concentrate on the goal of getting bette	c Water to the same		2	3 4	5
12. Get frustrated		1	2	3 4	5
13. Enjoy the attention of friends and famil	y	1	2	3 4	5
14. Try to use as little energy as possible		1	2	3 4	5
15. Learn more about how my body works		1	2	3 4	5
16. Feel anxious about the things I can't do		1	2	3 4	5
17. Make plans for the future		1	2	3 4	5
18. Make sure I am warmly dressed or cover	ered	1	2	3 4	5
19. Do what my doctor tells me		经基础 1	2	3 4	5
20. Fantasize about all the things I could do	if I was better	1	2	3 4	5
21. Listen to music		. 1	2	3 4	5
22. Make my surroundings as quiet as poss	ible	1	2	3 4	5
23. Try my best to follow my doctor's advi	国的国际国际公司中国共和国公司 经国际联合工作的现在分词 计正式设计 计设计	1	2	3 4	5
24. Wish that the problem had never happe	ned	1	2	3 4	5
25. Invite people to visit me			2	3 4	5
26. Be as quiet and still as I can		1	2	3 4	5
27. Be prompt about taking medications		1	2	3 4	5
28. Feel anxious about being weak and vuli		1	2	3 4	5
29. Surround myself with nice things (e.g.,	flowers)	1	2	3 4	5
30. Make sure I am comfortable	A NOT THE	1	2	3 4	5
31. Learn more about the most effective tre	atments available	1 - 1	2	3 4	5
32. Worry that my health might get worse		1	2	3 4	5

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Appendix Q. Modified Items for Family Members' Version of the Illness Representations Questionnaire – Revised

Consequences

Patient

- Their diabetes has major consequences on their life
- Their diabetes does not have much effect on their life

Family Member

- Their diabetes has major consequences on my life
- Their diabetes does not have much effect on my life

Patient

- There is a lot which they can do to control their symptoms
- What they do can determine whether their diabetes gets better or worse
- The course of their diabetes depends on them
- Nothing they do will effect their diabetes
- They have the power to influence their diabetes
- Their actions will have no effect on the outcome of their diabetes

Personal Control

Family Member

- There is a lot which I can do to control their symptoms
- What I do can determine whether their diabetes gets better or worse
- The course of their diabetes depends on me
- Nothing I do will effect their diabetes
- I have the power to influence their diabetes
- My actions will have no effect on the outcome of their diabetes

Patient

- The symptoms of their condition are puzzling to them
- Their diabetes is a mystery to them
- They don't understand their diabetes
- Their diabetes doesn't make any sense to them
- They have a clear picture or understanding of their diabetes

Illness Coherence

Family Member

- The symptoms of their condition are puzzling to me
- Their diabetes is a mystery to me
- I don't understand their diabetes
- Their diabetes doesn't make any sense to me
- I have a clear picture or understanding of their diabetes

Patient

- They get depressed when they think about their diabetes
- When they think about their diabetes, they get upset
- Their diabetes makes them feel angry
- Their diabetes does not worry them
- Having this diabetes makes them feel nervous
- Their diabetes makes them feel afraid

Emotional Representations

Family Member

- I get depressed when they think about their diabetes
- When I think about their diabetes, I get upset
- Their diabetes makes me feel angry
- Their diabetes does not worry me
- Their having this diabetes makes me feel nervous
- Their diabetes makes me feel afraid

Appendix R - Family Illness Perceptions Questionnaire - Revised

YOUR VIEWS ABOUT YOUR FAMILY MEMBERS DIABETES

Listed below are a number of symptoms that your family member may or may not have experienced since their diabetes. Please indicate by circling Yes or No, whether they have experienced these symptoms since their diabetes, and whether you believe that these symptoms are related to their diabetes.

	They have experienced this symptom since their diabetes		This sympt	om is related abetes
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 own personal views of how you now see your family members current diabetes.

Please indicate how much you agree or disagree with the following statements about their diabetes by ticking the appropriate box

	VIEWS ABOUT YOUR FAMILY MEMBERS DIABETES	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOF DISAGREE	AGREE	STRONGLY AGREE
	Their diabetes will last a short time					
	Their diabetes is likely to be permanent rather than temporary					
	Their diabetes will last a long time			1	p	
1	Their diabetes will pass quickly					
5	I expect they will have this diabetes for the rest of their					
,	Their diabetes is a serious condition					
7	Their diabetes has major consequences on their life					
	Their diabetes has major consequences on my life					
3	Their diabetes does not have much effect on their life					
3	Their diabetes does not have much effect on my life					
,	Their diabetes strongly affects the way others see them					
10	Their diabetes has serious financial consequences					
1	Their diabetes causes difficulties for those who are clos them					
2	There is a lot which they can do to control their sympto					
)	There is a lot which I can do to control their symptoms					
13	What they do can determine whether their diabetes gets better or worse					
13	What I do can determine whether their diabetes gets bet or worse					
4	The course of their diabetes depends on them					
14	The course of their diabetes depends on me					
15	Nothing they do will affect their diabetes					
15	Nothing I do will affect their diabetes					
6	They have the power to influence their diabetes					
6	I have the power to influence their diabetes					
7	Their actions will have no affect on the outcome of the their diabetes					
7	My actions will have no affect on the outcome of the th diabetes					

3	Their diabetes will improve with time					
	There is very little that can be done to improve their diabetes					
	Their treatment will be effective in curing their diabetes					
	VIEWS ABOUT YOUR FAMILY MEMBERS DIABETES	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOF DISAGREE	AGREE	STRONGLY AGREE
1	The negative effects of their diabetes can be prevented (avoided) by their treatment					
2	Their treatment can control their diabetes					
3	There is nothing which can help their condition					
4	The symptoms of their condition are puzzling to them					
4	The symptoms of their condition are puzzling to me					
5	Their diabetes is a mystery to them					
5	Their diabetes is a mystery to me					
6	They don't understand their diabetes					
6	I don't understand their diabetes					
7	Their diabetes doesn't make any sense to them					
7	Their diabetes doesn't make any sense to me					
8	They have a clear picture or understanding of their diab					
8	I have a clear picture or understanding of their diabetes					
9	The symptoms of their diabetes change a great deal from day to day					
0	Their symptoms come and go in cycles					
1	Their diabetes is very unpredictable					
2	They go through cycles in which their diabetes gets bett and worse					
3	They get depressed when they think about their diabete					
3	I get depressed when I think about their diabetes					
4	When they think about their diabetes they get upset					
4	When I think about their diabetes I get upset					
5	Their diabetes makes them feel angry					
5	Their diabetes makes me feel angry					
6	Their diabetes does not worry them					
6	Their diabetes does not worry me					

37	Having this diabetes makes them feel nervous		
37	Their having this diabetes makes me feel nervous		
8	Their diabetes makes them feel afraid		
8	Their diabetes makes me feel afraid		

CAUSES OF THEIR DIABETES

We are interested in what <u>you</u> consider may have been the cause of your family members 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 family members diabetes rather than what others including doctors and family may have suggested to you. Below is a list of possible causes for their diabetes. Please indicate how much you agree or disagree were the causes for you by ticking the appropriate box.

	POSSIBLE CAUSES	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOI DISAGREE	AGREE	STRONGL AGREE
C1	Stress or worry					
C2	Hereditary – it runs in their family					
C3	A germ or virus					
C4	Diet or eating habits					
C5	Chance or bad luck					
C6	Poor medical care in their past					
C7	Pollution in the environment					
C8	Their own behaviour					
C9	Their mental attitude e.g. thinking about life negatively					
C10	Family problems or worries					
C11	Overwork					
C12	Their emotional state e.g., feeling down, lonely, anxious, empty					
C13	Ageing					
C14	Alcohol					
C15	Smoking					
C16	Accident or injury					
C17	Their personality					
C18	Altered immunity					

In the table below, please list in rank-order the three most important factors that you now believe caused <u>YOUR FAMILY MEMBERS</u> diabetes. You may use any of the items from the box above, or you may have additional ideas of your own.

PARTICIPANT INFORMATION

Title of Study: The Role of Illness Perceptions in the Control of Type II Diabetes.

Introduction: The purpose of this one-off study is to find out how people think about their diabetes and how that influences their control of it. We are also interested in the role that family members play in living with diabetes. You will be asked to fill in a number of questionnaires with our researcher. This should take no more than 40 minutes. You will then be asked to name a family member who would also like to take place in the study and a number of questionnaires will be sent to them.

Benefits: This study will allow us to have a greater insight into how those with diabetes and their families understand, control and cope with illness.

Confidentiality: Your identity will remain confidential. Your name will not be published and will not be disclosed to anyone outside the hospital.

Voluntary Participation: You have volunteered to participate in this study. You may quit at any time.

Further information: You can get more information or answers to your questions about the study, your participation in the study, and your rights, from the researcher, Patricia White who can be telephoned at 6081510 or contacted through the diabetes daycentre on 4143223.

Thank you for your time and participation

CONSENT FORM

The Role of Illness Perceptions in the Control of Type Il Diabetes

This study and this consent form have been explained to me. The investigator has answered all my questions to my satisfaction. I believe I understand what will happen if I agree to be part of this study.

I have read, or had read to me, this consent form. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction. I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights. I have received a copy of this agreement.

PARTICIPANT'S NAME:	
PARTICIPANT'S SIGNATURE:	
Date:	
Date on which the participant was first furnished with this form:	

Statement of investigator's responsibility: I have explained the nature, purpose, procedures, benefits, risks of, or alternatives to, this research study. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.

Investigators' signature: Date:





Appendix U – Postal Forms Sent to Family Members with Measures

To Whom It May Concern,

Thank you for taking the time to take part in this study. Your family member

who is attending the diabetes clinic at Tallaght hospital kindly put your name

forward.

This is a one-off study that looks at how people with diabetes and their family

members think and feel about their diabetes. By taking part it will give us a

greater insight into how people understand and cope with diabetes in the

family.

Your participation is of course entirely voluntary and your identity will remain

confidential, so please do not put your name anywhere on any of the forms.

When you have completed the questionnaires, please return them in the

stamped addressed envelope provided.

By responding you will be providing valuable information that may help to

improve the care for those with diabetes and their families. If you have any

questions about the study, you can get more information from myself, the

researcher, Patricia White, at 01-6081510 or through the diabetes day centre at

Tallaght hospital (01-4143223)

Thanking you,

Yours sincerely,

Patricia White

Research Fellow.

If you consent to taking part in this study, please sign your name here:
PERSONAL INFORMATION
Firstly we would like to ask you some questions about yourself.
Everything you write is confidential to this study and your answers will remain
anonymous.

Educational Attainment: (please tick highest level achieved)

Date of Birth:

Occupation:

No formal___ Primary___ Junior/Inter__ Leaving__ Tech___ 3rd Level (Non-degree)*__ Degree ___ Post Graduate Degree___

*Certificate/Diploma

CONSENT

We will now ask you to fill in the following questionnaires about how you feel and think about diabetes.

Thank you for taking the time to fill in these questionnaires. By retuin the stamped addressed envelope provided you will have made an contribution to psychosocial research on people with diabetes in Irel	important
If you have any comments that you would like to make in relation to in the family please feel free to do so in the space below:	diabetes
	Thombour

Thank you