

**A QUALITATIVE INVESTIGATION INTO THE
EXPERIENCES, PERCEPTIONS, BELIEFS AND
SELF-CARE MANAGEMENT OF PEOPLE WITH
TYPE 2 DIABETES**

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Glossary and Definitions

Blood glucose levels – The amount of glucose measured in the blood.

Blood glucose meters – Electronic machines that are used to test current blood glucose levels in conjunction with test strips.

Diabetes specialist nurses (DSNs) – Qualified nurses with specialist training in diabetes and are often the main point of contact for anyone with diabetes, and can be key to the patients care plan.

Diabetes UK – A self-help charity in the United Kingdom. They are also a professional organisation for diabetes care.

Diet – Refers to the types of food that an individual eats and is considered an important part of the management of diabetes. It is recommended that individuals eat a healthy balanced diet that is low in saturated fat, salt and sugar, and high in fibre.

Dietician – A healthcare professional qualified to offer specialist advice on healthy eating and the impact that different food types may have on an individual regarding their diabetes control.

Erectile dysfunction – Can also be known as impotence, it is the inability to get and/or keep an erection for sexual intercourse, and can affect men who have diabetes. This can be due to a poor blood supply to the penis and/or nerve damage caused by diabetes complications.

Fasting blood glucose – Blood glucose test which is taken prior to eating, usually in the morning, this can be used to diagnose diabetes.

General practitioner – A medical doctor also known as a GP, they provide preventative care and can diagnose and treat acute and chronic conditions.

Glucose – A simple type of sugar that comes from the digestion of starchy food such as bread, rice, potatoes, sugar and sweet foods. The liver also produces glucose.

Healthcare Professional – Refers to an individual who is professionally qualified to deliver preventative care, education, advice and rehabilitation. This may take the form of: Nurses, Podiatrists, Dieticians, Physiotherapists and Occupational Therapists.

Hyperglycaemia – Relates to high blood glucose levels in the blood.

Hypoglycaemia – Relates to low blood glucose levels in the blood and is also known as a 'hypo'.

HbA1c – A blood test which shows how much glucose has bound to the red blood cells over the previous two or three months and can be a good indicator of overall glucose control.

Insulin – A hormone produced naturally in humans and animals in the pancreas. Insulin helps glucose in the blood to enter the body's cells where it is used as fuel by the body.

National Health Service (NHS) – Originated in 1948 following the National Health Service Act of 1946. Its overriding core principles were to provide free healthcare at the point of delivery for all individual's needs, based on clinical needs and not on their ability to pay. The organisation provides the majority of healthcare across the United Kingdom including primary and secondary care services, dentistry and ophthalmic services.

National Institute for Health and Care Excellence (NICE) – A non-departmental public body that is set up within the National Health Service. Founded in 1999 and originally called, National Institute for Clinical Excellence it later joined with the Health Development agency in 2005 and was then known as, National Institute for Health and Clinical Excellence. Following the Health and Social Care act of 2012 the department was renamed in 2013. The department was set up in order to develop appropriate and consistent advice on healthcare technologies, and to commission evidence-based guidelines.

National Service Framework and Strategies (NSFs) – The diabetes National Service Framework was first introduced in 2001 by the Department of

Health in order to set national clear quality guidelines and requirements for care. The report was designed in order to improve the health outcomes for people with diabetes, based on the best available evidence of the treatments and services which work most effectively for patients. Whilst also raising the quality of services and reducing unacceptable variations between them.

Nephropathy – Known more commonly as kidney disease, this is when the kidneys start to fail. It is more prevalent in people with diabetes or individuals with high blood pressure.

Neuropathy – Damage to the nerves, which carry messages to and from the spinal cord. It can be caused by many years of high blood glucose levels (hyperglycaemia). The symptoms may include pins and needles, numbness or pain in the feet or hands.

Non-Compliant – This is a term given where the respondent does not comply or refuses to comply with the law, rules, regulations or instructions.

Nurse Practitioner - A nurse who has completed a higher level of clinical education in order to allow them advanced practitioner status.

Ophthalmologist – Doctors with specialist training in the diagnosis and treatment of diseases affecting the eye.

Optometrist – Healthcare professionals who are experts trained to perform eye examinations and test for eye problems. A person with diabetes should have an eye test at least once a year.

Pancreas – An organ in the abdominal cavity that produces digestive enzymes, released into the intestines, in order to help with food digestion. Glucagon and Insulin are two of the hormones that are made in the pancreas and help to regulate the blood sugar levels.

Podiatrists / Chiropodists – Healthcare professionals with expert knowledge of the lower limb and foot disorders. A person with diabetes should have their feet checked at least once a year and an individual care plan should be put into place.

Retinopathy – This can be a complication of diabetes that can ultimately lead to blindness and results from damage to the blood vessels at the back of the eye due to many years of high blood glucose (hyperglycaemia).

Retinal screening – Refers to regular eye examinations where the pupils are dilated to detect any early changes at the back of the eye, which could be signs of retinopathy. A person with diabetes should have their eyes checked at least once a year.

Significance – Can be a measure of the confidence that can be placed in a result. It can also be seen as the importance denoted by an individual in relation to a medical condition.

Test strips – Devices used in conjunction with a blood glucose meter in order to test blood glucose levels. Test strips may be available on prescription or alternatively can be purchased.

Type 1 Diabetes – Formerly known as insulin dependent diabetes or IDDM, develops if the body is unable to produce any insulin. This type of diabetes usually appears before the age of thirty. It is treated with insulin injections, a healthy diet and regular physical activity.

Type 2 Diabetes – Formerly known as non-insulin dependent diabetes or NIDDM, develops when the body does not produce enough insulin, or when the insulin that is produced does not work effectively (known as insulin resistance). This type of diabetes more commonly appears in people over the age of forty. It can be treated in a variety of ways: diet and physical activity; diet, physical activity and tablets; diet, physical activity and insulin injections; or by diet, physical activity, insulin injections and tablets.

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Abstract -

Diabetes is a complex, chronic, insidious metabolic disorder. The marked prevalence in individuals with diabetes due to obesity, sedentary lifestyles and a poor diet, is proving a considerable challenge for healthcare systems across the world. In order to reduce diabetes related complications, it is imperative that individuals are able to effectively self-manage their condition. For this to be achieved it is crucial that the appropriate healthcare professionals provide on-going support and education. To date, this aspect has not been explored and we do not know what people with diabetes need in relation to support and education. Therefore, the aim of this study was to understand the experiences, perceptions and beliefs of what is important to a person with diabetes, in order to effectively self-care manage.

A qualitative enquiry was undertaken, using a grounded theory approach to underpin sampling, data collection and analysis. Seventeen participants with type 2 diabetes were interviewed using a conversational style approach. Formal ethical approval was obtained from the NHS National Research Ethics Service and the University of Salford Research and Ethics Committee. All participants gave consent prior to data collection.

Five principal concepts emerged from the data:

- i) Education, what education?
- ii) Why can't they just tell you what diabetes is?
- iii) They just tell you what to do, they never ask about me
- iv) I just wanted a leaflet I could read and understand, they make you feel stupid
- v) I just carry on as normal

The key theory to emerge illustrated that at the point of diagnosis limited significance was placed on the self-care management of type 2 diabetes. This study has revealed for the first time, that due to the apparent lack of significance the participants placed on type 2 diabetes, people do not sufficiently engage in appropriate self-care management. The participants did not necessarily view type 2 diabetes as a chronic condition due to experiencing little or no signs or symptoms, pre or post diagnosis. Despite the lack of full acceptance, participants passively recognised that '*something needed to be done.*' Participants expressed a desire to be treated as a person with diabetes rather than the clinician's focus on treating the disease in a generic manner.

The theory suggests that there is a crucial and urgent need for timely, person focused, tailored information to be communicated effectively. Person centered care delivered in this way would maximise the effectiveness of self-care management in order to reduce the risk of serious consequences of diabetes.

Further research opportunities could investigate the dialogue that takes place between healthcare professionals and individuals with type 2 diabetes. By establishing the individual's comprehension of the information or education provided, this may afford a greater insight into patient understanding towards self-care management.

1. Framing the Thesis

1.1 Introduction

This chapter is set to provide the reader with a brief insight into the chosen subject I will be covering in my thesis. It begins with an overview of the research background and explores the particular significance of the study. I opted to undertake this study after many years working as a podiatrist in a chronic rehabilitation department, where I listened to patients expressing their feelings and fears about their diabetes. My story began back in 1985 when my father, had just been diagnosed with type 2 diabetes following an inpatient hospital stay, for a relatively straightforward procedure. I was nineteen years old and this was the first time I had ever heard of diabetes. Within two years he had died due to complications associated with the disease.

After his initial diagnosis I remember clearly asking my father what diabetes was. He told me that he did not know, although the doctor had informed him that he could no longer have salt in his diet and would no longer be able to eat sweets. I found this a perfectly acceptable answer at the time and never gave it any further consideration. Life carried on as normal and diabetes was never mentioned thereafter.

I could never put into words the grief, sorrow and huge sense of loss that I felt whilst attending his funeral, but it was at that point I remember starting to question why he had died so young of a disease that he appeared to know little about.

1.2 Personal Experiences from Clinical Practice

Following on from the earlier experiences with my father I went on to develop a keen interest in providing foot care education and awareness of diabetes for people, which then led me to complete a degree in Podiatry. Being a clinician I hoped that I would be able to help make a positive contribution to the effective management of the foot and lower limb, thereby making a difference to the lives of people with diabetes.

Unfortunately, during my time working for a range of National Health Service organisations I became aware that there appeared to be a distinct lack of diabetes education programmes in both the community and hospital settings. On consultation with patients I found that they had very limited knowledge of their condition, with the majority knowing nothing at all about diabetes. Much to my frustration, I was also constantly required to work across numerous clinics over a wide geographical area and I felt this did not provide adequate continuity of service, education, or care for the patient. This was due to increasing demands of the service, which was exacerbated by short-term staff sickness, holidays and lack of funding within the department for additional podiatrists.

As a healthcare professional I could not imagine what it would be like to be diagnosed with such a chronic disease, yet in my career I was required to provide education on a daily basis to individuals.

Feeling despondent and disillusioned with the constant restraints I experienced within the National Health Service, I decided to move to Australia to work as part of a multi-disciplinary team. Once again I started to question the reasoning behind the same generic diabetes information provided to every individual, regardless of gender, age or levels of literacy. Tang *et al.* (2007) found that education approaches have to take into consideration patients' health literacy levels and self-care skills in order to develop efficient patient education, hence improving patients' diabetes control and self-management. As in the United Kingdom I was also surprised by the lack of awareness and knowledge that patients had in relation to their chronic condition. In contrast to the United Kingdom, however, I found that there were rarely time restrictions for appointments, allowing the patients the freedom to open up and ask me questions about diabetes. They would discuss their fears regarding amputation, diet, early death and the problems that they had with poor management of the condition. It was again at this point that I questioned the podiatrist's role and where patients received their diabetes education from and who should provide this education.

With such newly found freedom of being able to converse with patients about diabetes, I was inspired to help them in any way I could. I was also saddened at the number of times I read in the patient notes 'non-compliant patient' and I questioned whether they were really non-compliant or was it that they did not necessarily understand the information in order to comply. As a podiatrist I was taught to treat the cause and not the symptoms and I therefore feel that education has become merely an add-on element rather than being a crucial tool of effective management. I believe that if podiatrists continue treating the symptoms and not the cause then they are not sufficiently tackling the disease management appropriately. With increasing numbers of professional questions being evident in my everyday practice, I felt that I could no longer practice effectively without finding the answers to the questions about diabetes education. In order for me to move forward and make a positive impact on the future lives of my patients I took the decision to conduct this particular research.

1.3 Identifying the Problem

Diabetes Mellitus is fast becoming a disease of increasing concern with its prevalence being described as a global epidemic. It was reported in 2013 by the International Diabetes Federation that the current number of people diagnosed with diabetes was 371 million with this estimated to rise to 500 million by the year 2030. The World Health Organisation stated in 2014 that the number of people diagnosed with diabetes worldwide stood at 347 million. Diabetes UK (2014) however, stated the world-wide prevalence for diabetes in 2013 was estimated at 382 million with a potential to rise to 592 million by the year 2035.

Furthermore, there are currently 3.2 million people in the United Kingdom diagnosed with diabetes mellitus and this represents a 128 per cent rise since 1996, where the figure was initially 1.4 million (Diabetes UK 2013).

The two main types of diabetes are type 1, formally known as Insulin dependent diabetes mellitus (IDDM) and type 2, formerly known as non-insulin

dependent diabetes mellitus (NIDDM). It is estimated that 90 – 95 per cent of people diagnosed have type 2 diabetes. For the purpose of this study I will be focussing on type 2 diabetes as it is currently; '*One of the most important diseases confronting the United Kingdom's healthcare system*' (Forbes et al. 2010 p.6).

Diabetes UK (2013) stated that type 2 diabetes is becoming increasingly common in young people and children, whilst figures show that one in twenty people over the age of 65 and around one in five people over the age of 85 currently have this disease.

If diabetes is not managed effectively it can lead to a number of serious complications including cardiovascular disease, stroke, retinopathy, neuropathy and nephropathy. The cost to the National Health Service will be catastrophic and according to the Department of Health in 2010 almost 10 per cent of the NHS budget was spent on diabetes treatment, which equates to in excess of £13.75 billion per annum or £1.6 million per hour. This cost does not take into consideration the life changes, suffering and socioeconomic impact that takes place for both the individual and their families when a person is diagnosed with a chronic disease such as diabetes.

In the United Kingdom there are up to 100 people a week that have a limb amputated as a result of diabetes. This is mainly due to the complications that arise from damage to the nerves and blood vessels. As many as 50 per cent of patients newly diagnosed with type 2 diabetes already have one or more complications (Hippisley-Cox *et al.* 2009).

If healthcare professionals do not have the knowledge of what an individual requires in relation to education then they are not satisfactorily meeting the needs of that person, a generic approach prevails without being tailored to the individual. The knowledge of healthcare professionals is less likely to be gained from the personal experiences of having a chronic disease, and is more likely to have been gained from professional practice and training. I therefore believe as healthcare professionals, we may be disempowering the

patient by assuming that we have all the knowledge. If healthcare professionals are not educating people with type 2 diabetes then opportunities for the self-care component of management are missed. The Department of Health stated in 2008 that patient centred care would be at the forefront of the latest National Health Service agenda so with this in mind and as a healthcare professional I feel the patient should always take priority. This can be achieved by initially enabling them a voice for their opinions, feelings and perceptions regarding the education that is provided to them.

My observations and the above findings led me to ask a number of pertinent questions. For example, I questioned what do people diagnosed with type 2 diabetes know about this disease and where do they receive this information in regards to self-care? If further education is being received, is it sufficient to support self-care management effectively and who has the responsibility to deliver the education, also how do people with type 2 diabetes relate to the educators?

In order to explore all these aspects related to diabetes education for people with diabetes, I have chosen a qualitative approach as opposed to a quantitative approach in order that individual's perceptions, experiences and beliefs may be discovered. It is not my intention to quantify the impact of patient education on an individual with diabetes. I am taking a step back to the fundamental question as to how they feel and what they know about diabetes and hence what they require. In addition, this approach ultimately enabled individual participants' to reveal their feelings and beliefs. Specifically, I have adopted a grounded theory methodological approach. Despite having had experience of diabetes education and patient's complications, I wanted to ensure that I was not influenced by previous research or literature in any way and was keen to develop my own hypotheses.

Grounded theory is a qualitative enquiry method that looks systematically at qualitative data aimed at the generation of theory that accounts for a pattern of behaviour that is relevant and problematic for those involved (Glaser and Holton 2005). Humans construct theories in order to explain, predict and

master phenomena. Prior to data collection I did not conduct a literature review in relation to patient's perception of education or healthcare as I felt this would be detrimental to my findings and I did not want to be influenced by previous research findings before undertaking data analysis. I was guided by the Strauss and Corbin (1990) approach and my rationale for this is explained in chapter four. With regards to completing a literature review prior to such a study Strauss and Corbin state the following:-

'You will come to the research situation with some background in the technical literature, and it is important to acknowledge and use that... However, there is no need to review all of the literature beforehand (as is frequently done by researchers trained in other approaches) because if we are effective in our analysis, then new categories will emerge that neither we, nor anyone else, had thought of previously. We do not want to be steeped in the literature as to be constrained and even stifled by it!' (Strauss and Corbin 1990, p.50).

1.4 The Research Purpose

Many people embark upon research conducting a comprehensive literature review in order to pose a particular question or achieve a specific aim. My research however, did not commence with a specific aim or objective but originated from my clinical experience and passion to aid people with their diabetes education. I did therefore have a particular focus and purpose for undertaking the research, and felt it was important as a clinician to hear first-hand the experiences of living with a chronic condition. The research focus evolved as soon as some of the concepts started to emerge. Using my intuition as one has to in the grounded theory process; I was further guided to the next stage of the research phase. At this time I did not have a final research question as I was still not aware of precisely what I was looking for. I was merely gathering information and through data analysis allowing emerging concepts to appear by remaining open minded and going with the flow. I allowed the data to guide me and the concepts to emerge into a final theory.

Patient engagement with diabetes educators is paramount when trying to achieve an empathetic approach to patient care. By understanding what is important to the individual it may enable healthcare professionals or educators to gain an in-depth understanding of how individual patients react, when being diagnosed with a chronic disease, and the effect it has on their future self-care management.

Therefore, the overall purpose of this research was to gain an insight into the experiences, perceptions and beliefs of people with type 2 diabetes and their understanding of self-care management. In order for healthcare professionals to understand what is important to the person, we have to recognise what they identify to be benefits, potential benefits and barriers to self-care management.

1.5 Thesis Overview

Chapter one is aimed at providing a historical view of my position both personally and professionally. Whilst providing a brief overview of current diabetes statistics it also highlights the various complications which may occur as a result of the disease. It further provided the rationale for undertaking this piece of work and the research methodology chosen.

Chapter two offers an introduction to type 2 diabetes, the extent of the disease and the effects it has on individuals and society as a whole, followed by chapter three which will focus on education, empowerment and self-care management in order to provide an increased understanding of the importance and the crucial relationship of all three elements.

Chapter four will explain the methodology approach I undertook for this research and the history of grounded theory, followed by chapter five which covers the method used, incorporating ethical approval, interview technique through to transcribing and analysis of the data collected.

Chapter six provides a brief overview of the participants who took part in this study.

Subsequently, chapter seven will demonstrate the results and findings in the study and ultimately theory. You will hear the participants' voices that have been directly taken from the transcripts, and the concepts that have emerged from the data analysis.

Chapter eight allows for discussion of the concepts and the substantive theory that was discovered, also incorporating any limitations of the study and methods of reflective practice.

Chapter nine provides the conclusions and future recommendations for clinical practice and research.

2. Background to Type 2 Diabetes

2.1 Introduction

In order to understand the background of this research study, this chapter will aim to afford the reader with an insight into type 2 diabetes mellitus and the complications associated with the condition. The chapter will highlight the prevalence of the disease and the various impacts that may affect individuals and the wider society.

2.2 Diabetes – The Current Situation

Diabetes, also known as diabetes mellitus is an insidious, complex and chronic condition that is now found to affect almost every population worldwide (World Health Organisation 2013). The metabolic syndrome is characterised by high blood glucose levels caused by the body's inability to produce or use insulin effectively (Kumar *et al.* 2003). Insulin is a hormone that is made by the pancreas and allows the glucose from food that is consumed, to pass from the blood stream into cells that produce energy. If individuals are not capable of producing enough insulin or are not able to use it effectively, this may lead to raised glucose levels in the bloodstream, known as hyperglycaemia. The long-term effects of individuals having high glucose levels can be associated with damage to the body and eventual failure of organs and tissues (International Diabetes Federation 2013).

The disease can cause a variety of life threatening health complications and in many cases may reduce individual's life expectancy. Research suggests that a range of complications such as cerebrovascular and coronary heart disease, nephropathy, retinopathy and gangrenous feet may be evident due to a lack of suitable and appropriate treatment (Isarankura-Na-Ayudhya *et al.* 2010). The wide range of complications associated with diabetes will be highlighted and discussed further within the next section. Recent epidemiological evidence suggests that without the introduction of effective prevention programmes the prevalence of diabetes will only increase on a global scale (Alberti *et al.* 2007 and Shaw *et al.* 2010)

There are currently three main types of diabetes as defined by the International Diabetes Federation (2013):-

- i) Type 1 diabetes – where the pancreas does not produce insulin
- ii) Type 2 diabetes – where the pancreas does not produce enough insulin or the insulin cannot be processed
- iii) Gestational diabetes – where insulin produced during pregnancy is less effective

Type 2 diabetes is the most common condition with approximately 90 per cent of those diagnosed being affected worldwide (World Health Organisation 2013). For the purposes of this study the research focus remains on type 2 diabetes, and individuals diagnosed with type 2 diabetes only, were invited to participate.

2.3 Diabetes Signs and Symptoms

The symptoms in both type 1 and type 2 diabetes mellitus may vary. The main symptoms of diabetes which can be common to both types however, are:-

- Feeling extremely thirsty, also known as polydipsia
- Urinating frequently, particularly at night, this can be known as polyuria
- Experiencing fatigue

Initial symptoms in type 2 diabetes may be mild; therefore many people may have the disease for a number of years before being officially diagnosed. Early diagnosis and treatment however, may reduce individual's risks of developing further complications in later life.

Some individuals may also experience additional milder symptoms such as:-

- Regular incidences of thrush (yeast infection) itching around the genital area
- The lens of the eye becoming very dry which could lead to blurred vision
- Stomach cramping or regular constipation
- Skin infections

Individuals may evidence either specific or a range of symptoms, whereas others may show no signs or symptoms, either before or after diagnosis (Diabetes UK 2013).

2.4 Prevalence in the United Kingdom

In the United Kingdom 1.4 million people were recorded to have diabetes mellitus in 1996 with this figure rising to 3.2 million people by 2013, representing a 128 per cent increase (Diabetes UK 2014).

In 2008, it was estimated that 400 people per day were being diagnosed with the condition in the United Kingdom, and this translated as being approximately 3 people every 10 minutes. Of this figure, 360 people per day (representing 90 per cent) were diagnosed with type 2 diabetes. Table 1 illustrates the prevalence of overall Diabetes Mellitus and type 2 diabetes across the United Kingdom in 2013.

Table 1: Prevalence of diabetes in the United Kingdom

Country	Overall DM Prevalence	Overall % Prevalence	Type 2 DM Prevalence	Type 2 DM % Prevalence
England	2,703,044	6.0%	2,432,740	5.4%
Scotland	252,599	5.6%	227,339	5.0%
Wales	173,299	6.7%	155,969	6.0%
Northern Ireland	79,072	5.3%	71,165	4.8%
Total	3,208,014	6.0%	2,887,213	5.4%

* - Type 2 diabetes estimated at 90 per cent of overall UK diabetes prevalence
Source: Quality and Outcomes Framework, Diabetes UK (2013)

In 2013 of the 3.2 million people diagnosed with diabetes mellitus approximately 2.9 million (5.4 per cent of the population) were related to type 2 diabetes and this figure is expected to rise to 5.0 million by 2025. Diabetes UK also stated in 2014 that 1 in 17 adults in the United Kingdom have diabetes mellitus, whether diagnosed or not.

2.5 The Effects on Society

The World Health Organisation (2013) predicts that deaths from diabetes mellitus will increase by more than 50 per cent over the next 10 years. A large percentage of the deaths, estimated between 50 – 80 per cent are anticipated to be caused by cardiovascular disease associated with the disease. It is evident that due to the widespread projections of diabetes increases, the disease is going to have an effect on society as a whole across the world. The Department of Health identified in 2010 that a range of factors, may contribute towards individuals increasing their risk of developing type 2 diabetes, including obesity, family history of diabetes or living a sedentary lifestyle. Other studies conducted also focus on the link between diabetes, obesity and socio-economic status, indicating that the increased frequency of obesity accounts for the growing prevalence of diabetes in more deprived areas (Evans *et al.* 2000). With diabetes becoming an increased issue there are far reaching consequences affecting societies worldwide. Individuals with the disease may have their life expectancy shortened by as much as fifteen years, with seventy five per cent of those dying from various macro vascular complications (Gillies *et al.* 2007).

2.6 The Effect on the United Kingdom Health Service

The cost of diabetes management in the United Kingdom has increased considerably during recent years and research indicates that in 2010 almost ten per cent of the NHS budget was spent on diabetes and its complications, equating to approximately £13.75 billion per annum (Diabetes UK 2013). The figure can also be represented by the category of spend as detailed in Table 2:-

Table 2: Costing for diabetes management in the United Kingdom

Area of Expenditure	Cost (£)	% of Total Cost
Diabetes Drugs	1.06 billion	7.8
Non-Diabetes Drugs	2.09 billion	15.2
Inpatient Costs	9.05 billion	65.8
Outpatient Costs	1.33 billion	9.7
Other Costs (Including social services)	0.23 billion	1.7
Total Costs	13.75 billion	100.0

Source: Kanavos, van den Aardweg and Schurer: Diabetes expenditure, burden of disease and management in 5 EU countries, LSE (Jan 2012)

2.7 The Impact of Type 2 Diabetes on the Individual

This section will identify the various ways in which diabetes may affect individuals, whether psychologically, physiologically or socially.

2.7.1 Psychological Effects

Medication, diet and exercise are more commonly used in the traditional management of diabetes although the psychological aspects associated with the disease are considered overwhelming (Penckofer *et al.* 2007). Individuals with diabetes have been widely reported as suffering from a range of psychological effects such as depression, anxiety, eating disorders or sexual dysfunction. Studies carried out by Anderson *et al.* (2001) and Fisher *et al.* (2008) found that the presence of diabetes considerably increases the odds of comorbid disorders such as depression by as much as 50 per cent in patients with diabetes. There is still a lack of knowledge as to the most appropriate treatment for those patients with diabetes suffering from depression, although it is widely recognised that depression can have an adverse effect on their quality of lifestyle. This may be evidenced by factors such as poor disease management, poor metabolic control, higher complication rates, absence from

work, increased use of healthcare facilities, and a greater mortality (Egede and Ellis 2010 and Van der Feltz-Cornelis *et al.* 2010). Ho *et al.* (2010) commented that individuals have psychological and emotional distress such as anxiety and frustration due to change in eating habits, unstable blood sugar levels and fear about potential future complications. Fisher *et al.* (2008) states that healthcare screening for patients displaying depressive health disorders should be carried out at each patient contact and not on an irregular basis. A significant increase in healthcare costs, morbidity and mortality are associated with those patients who suffer from both diabetes and depression. It was reported by Egede and Ellis (2010) that depression is a condition that affects approximately 340 million people worldwide at any given time.

Another important consideration for individuals is coming to terms with the original diabetes diagnosis and the adjustments required in order to be able to cope with such a chronic illness. The inability to develop a suitable coping strategy may present psychological distress and further complications for individuals (Bedfordshire Diabetes 2014). The International Diabetes Federation introduced global guidelines for the management of psychological factors associated with diabetes in 2006. Their findings identified people coping with diabetes are more likely to be affected by mental health problems and this in turn may have an effect on appropriate self-management of the disease. The organisation also stated that due to such poor psychological functioning, health outcomes may be adversely affected and healthcare costs may significantly increase. The regular monitoring of psychological well-being has also been suggested as being an integral part of routine diabetes care (International Diabetes Federation 2006).

2.7.2 Physiological Effects

Individuals with diabetes may also be affected by a variety of different physiological symptoms. Men and women alike may experience sexual dysfunction, with differing symptoms requiring various treatments. Sexual dysfunction may occur where narrowing of the arteries reduces the blood-flow necessary for arousal or diabetic neuropathy causes damage to specific

nerves. Male patients may experience erectile dysfunction formerly known as impotence, which may affect over half of all men with diabetes and complications are known to increase with age (Diabetes UK 2013).

There are often no symptoms in the early stages of diabetic retinopathy for many patients, although the later stages of the disease may cause severe complications such as blurred vision or even blindness. Blurred vision occurs when the macula part of the retina swells from leaking fluid and is referred to as macular oedema. As new blood vessels grow on the retina surface they can then bleed onto the eye causing total blindness (National Institute of Health 2012).

Patients who suffer from diabetic neuropathy may experience a range of symptoms that are associated with nerve damage including: numbness, tingling or pain in the legs, toes, feet, arms, hands or fingers, wasting of the feet or hand muscles, indigestion, nausea or vomiting, urination problems, diarrhoea, constipation, and dizziness (National Institute of Diabetes and Digestive and Kidney Disease 2013).

Peripheral neuropathy is associated with nerve damage to the arms and legs and can be common in patients with diabetes. The condition may cause numbness or insensitivity to pain or temperature or extreme sensitivity to touch. Individuals with diabetes may also experience sharp pains or cramps and a loss of balance or coordination. Further complications caused by the condition may include muscle weakness or a loss of reflexes. This may also result in blisters or sores appearing on numb areas of the foot and deformities occurring where individuals are forced to change the way they walk. With individuals losing nerve sensation, foot injuries may not always be treated promptly and infections may spread to the bones, ultimately leading to amputation (National Diabetes Information Clearinghouse 2012). The National Institute of Diabetes and Digestive and Kidney Disease stated in 2013 that; over half all amputations due to minor problems can be avoidable if they are treated in a timely manner.

Marshall and Flyvbjerg (2006) emphasised the wide ranging effects of complications to the individual and wider society. In order to reduce the complications they advocated the importance of rapid intervention by annual screening, enabling early identification of risks. This early detection and prevention is crucial in the initial stages of management of type 2 diabetes and may minimise the further impact of complications.

2.7.3 Social Impact

It was recognised by De Graw *et al.* (1999) that the quality of life for patients with a chronic disease is extremely important when evaluating care outcomes. This is measured by the impact of the disease and the individual's ability to function on a daily basis. Research indicates that the 'quality of life' is markedly reduced for people with diabetes compared to healthy individuals due to the many complications associated with the disease (De Graw *et al.* 1999). Bachmann *et al.* (2003) suggest that the control of diabetes and its associated complications are influenced by a range of factors including the healthcare available, attitudes, behaviour and biology, although these are rarely studied at the same time in community settings.

Cooper *et al.* (2003) identifies that individuals need to be able to introduce varied competences in order to gain an increased control over their condition. This may be achieved by education which promotes healthy living, whilst also preserving an individual's ability to make their own lifestyle decisions.

2.8 Conclusion

Diabetes mellitus is a complex chronic metabolic disorder characterised by high blood glucose. The marked increase in individuals with diabetes due to obesity, sedentary lifestyles and a poor diet, particularly in developing countries, is proving a considerable challenge for healthcare systems across the world. Future growth projections indicate that diabetes mellitus will continue to have far reaching consequences for society, the individual and healthcare providers. Given that a significant proportion of diabetes

management can be self-care, the effective support of patients by healthcare professionals is paramount.

Chapter three will therefore focus on the areas of patient education, empowerment and self-care management. The chapter will also highlight the government guidelines and policies that are currently in place.

3. Education, Empowerment and Self-Care Management

3.1 Introduction

This chapter investigates the importance of effective patient education in order for individuals to feel suitably empowered to enable an appropriate self-care management approach for their condition. The following literature review was undertaken during and after the data analysis process, in accordance with the grounded theory methodology. The literature selected for the review, as detailed in Table 6 was chosen in accordance with the concepts and themes that were emerging from the data.

Diabetes education, patient empowerment and effective self-care are widely considered to be integral elements of diabetes management and are vital in maintaining successful clinical outcomes (Graber *et al.* 1977 and Wilson and Gyi 2010).

3.2 Patient Education

Assal *et al.* (1997) quoted Konrad Lorenz, who demonstrated the challenge facing the medical profession in providing healthcare education to patients;

*'Said but not heard,
Heard but not understood,
Understood but not accepted,
Accepted but not put into practice,
Put into practice but for how long?'*
(Assal *et al.* 1997, p.64)

Although initial diabetes education was suggested as early as 1922 by Joslin it was not widely accepted until the 1970's. An individual's ability and willingness to comply with medical and lifestyle advice depends upon their understanding and management of the disease (Assal *et al.* 1997).

Wikblad (1991, p.843) recommended the following from research that took place over in the early 1990's:-

- i) *Patients need confirmation that they can handle their diabetes*

- ii) *A need exists to increase support for patients in their social context in addition to medical care provided*
- iii) *Patients require more in depth discussions concerning how to live and cope with diabetes. Continuity is also required in order to develop discussions and ensure they remain meaningful for the patient*
- iv) *Education and information for the patient should be based on individual assessments and taking into considerations such as specific skills, abilities and knowledge*

Research undertaken by Eigenmann *et al.* (2009) established four patient-centred outcomes as a result of successful diabetes education, which included: knowledge and understanding, self-management, self-determination and psychological adjustment. Despite a range of tools being available they concluded that few methods were rigorous or suitable due to issues surrounding their purpose, feasibility or burden.

Wilson and Gyi (2010) explain that diabetes education provides supportive environments for patients and ultimately improves their quality of life through the transfer of knowledge, skills and tools. By gaining such knowledge, patients are able to become aware of potential problems regarding their condition and are more likely to become involved in decision making (Anderson and Funnell 2009). Health education should be treated as a continuous experience based learning process with its main focus to enable patients by fostering compliance and co-operation. Education provided should also be targeted at changes in behaviour and also in knowledge, skills, understanding and attitudes in order to improve health outcomes (Cooper *et al.* 2003).

In a systematic review of the clinical effectiveness of diabetes education Forbes *et al.* (2010) found that there is a need for a clear education programme from the outset, and that resources need to be given to the educators to ensure that programmes are delivered correctly. Cooper *et al.* (2003) argue that whilst patients can be educated toward a greater autonomy, not all healthcare professionals were ready and willing to work in partnership with them. A recommendation from the National Institute of Clinical Excellence

was that every person with diabetes should be offered structured education (Department of Health 2010). Whilst I am aware that education courses are available not all National Health Service Trusts currently offer such courses and places can often be limited.

Health education and information may be provided in a range of formats and settings such as:-

- i) 1 to 1 education provided by a healthcare professional
- ii) Group education
- iii) Structured course or programme
- iv) Internet
- v) Information sheet, leaflet or booklet
- vi) A combination of the above

Anderson and Funnell (2009) identified specific overriding principles of diabetes self-management education. Table 3 explains the principles:

Table 3: Guiding principles of diabetes self-management education

Ref.	Principle
1	Diabetes education is effective for improving clinical outcomes and quality of life, at least in the short-term.
2	Diabetes self-management education has evolved from primarily didactic presentations to more theoretically based empowerment models.
3	There is no one 'best' education program or approach; however, programs incorporating behavioural and psychosocial strategies demonstrate improved outcomes. Additional studies show cultural and age appropriate programs improve outcomes and group education is effective.
4	On-going support is critical to sustain progress made by participants during the diabetes self-management education program.
5	Behavioural goal-setting is an effective strategy to support self-management behaviours.

Source: Anderson and Funnell (2009)

The importance of diabetes education followed up by on-going information and support is highlighted by Funnell *et al.* (2007) where evidence has shown that patient improvements tend to diminish after six months and only with

continued support are patients able to achieve sustainable improvements and successful behavioural changes.

Research indicates that there are extensive assumptions suggesting that the transfer of knowledge will ultimately improve health outcomes. Knight *et al.* (2006) highlights there is little evidence to support this view and many individuals are not receiving adequate education. Quinn *et al.* (2011) explain that patients who are provided with information, instructions and guidance during healthcare appointments have a better understanding of their treatment options and plans, accept any health issues and modify their compliance behaviours accordingly. Wilson and Gyi (2010) illustrate the educational change from a medical model, concerning decisions taken by the healthcare professional and the amount of information provided, to a joint decision making process incorporating the patients understanding, experiences and responsibility for their self-care management.

Anderson and Funnell (2008) also stress the importance of the educator across all healthcare settings and the need for them to have the interpersonal skills, values and personal characteristics needed to develop relationships with patients to gain trust, respect and acceptance. They continue to explain the most thoughtfully constructed patient education programs '*will only be as effective as its least effective educator*'. Mensing and Norris (2003) continue to express the importance of healthcare professionals and patients both adjusting to new approaches, environments and technology in order for educators to improve the delivery of education and for patients to learn about their condition.

3.2.1 Current Education Programmes

'Patient education is not one of the treatments, it is the treatment.'

Elliot P. Joslin (1916)

At the time of the research taking place, three formal structured education programmes across the United Kingdom were in existence for individuals diagnosed with either type 1 or type 2 diabetes. This is not to say however

that the programmes were readily available to each individual as my research will later reveal that only three of the seventeen participants interviewed were offered an education programme. Of the three individuals, two attended education programmes and one declined due to personal circumstances and was not provided an opportunity to participate at a later and more convenient time. The three structured educational programmes are: -

- X-PERT – Provides diabetes education to healthcare professionals and lay educators and delivers group education programs to those individuals with the disease. The courses are aimed to increase patient's knowledge and understanding of their condition and to assist them in making appropriate and effective lifestyle choices concerning the management of their blood glucose levels. Group education courses are based on patient empowerment and activation and are carried out for 2.5 hour session per week over a six week period, with individuals receiving a comprehensive booklet as an aid and inclusion in annual follow up sessions. Courses are delivered free to individuals through National Health Service referrals and operate across the United Kingdom at a range of centres.
- DESMOND (Diabetes Education and Self-Management for Ongoing and Newly Diagnosed Programme) – DESMOND is a collective description for a range of self-management education modules, toolkits and care pathways aimed for individuals with type 2 diabetes or those who are at risk of developing the disease. The programme was initially developed in 2003 as a collaborative between service users, workers, Diabetes UK and the Department of Health and now operates four principal education modules across the UK. The project also provides education for lay educators to be able to deliver specific modules. The structured education programmes claim to be evidence based and in full compliance with The National Institute for Clinical Excellence (standard three) concerning self-management. The courses are run over six hours either one full day or two half days. They are facilitated by two healthcare professionals and are aimed at group education between six to ten patients or their family members or carers. Programmes are intended to be commissioned by

health services in order that courses may be provided free to all individuals.

- DAFNE (Dose Adjustment for Normal Eating and Exercise) – DAFNE is a group education programme targeted for adults with type 1 diabetes, that commenced in the UK in 1998. The programme aims to empower individuals by providing an understanding of their condition, enabling the management of insulin delivery in a flexible manner. The courses operate over a five day period, are aimed at six to eight individuals and provide advice on aspects of living with the disease, such as lifestyle, exercise and hyperglycaemia.

One participant in the study attended the DESMOND course and one participant attended the DAFNE course. Both participants commented that given the opportunity they would like to attend their course again or any other courses that were made available to them. Of the remaining fifteen participants in the study only two stated that they would decline any education course as they believed that they would know more than the person providing the education. This was apparently based on their past experiences with the practice nurse and their general practitioner.

3.2.2 Barriers to Education

The barriers that exist between patients and clinicians must be limited wherever possible. This can be achieved by educating patients and providing them with effective tools in order for them to realise the crucial role they play in making decisions and the potential consequences they may cause (Barry and Edgman-Levitan 2012). Communication between patients and healthcare professionals may be affected by a range of factors that are reliant upon the patient. These barriers need to be addressed by the healthcare professionals in order to ensure that patients understand the information provided to enable effective self-care (Assal *et al.* 1997). Mensing and Norris (2003) stress that the teaching of knowledge alone is insufficient and the educator must develop an effective relationship with the patient to enable them to take responsibility and support change when required. Patient education has been considered

authoritarian and didactic (e.g. 'do as I say') and one-off educational programmes are not considered effective to be able to sustain the necessary behavioural change required for prolonged diabetes self-management. According to Anderson *et al.* (1991) assisting patients to undertake prolonged changes to their lifestyle and becoming comfortable with patients negative emotions is one of the most difficult issues facing diabetes educators. A range of factors including inadequate education, insufficient diabetes information, poor justification of diet and lifestyle advice, appointment time pressures and complex medical terminology have all been considered obstacles to comprehensive understanding of the disease and its many complications (Ho *et al.* 2010).

3.3 Empowerment

Ouschan *et al.* (2006, p.1071) identify patient empowerment as a three dimensional process incorporating:-

- i) Patient sphere – patient control over their disease management
- ii) Patient / healthcare professional sphere – patient involvement during the consultation
- iii) Healthcare professional sphere – patient education and support provided to the patient

It is evident that effective consultations with patients that target the empowerment of individuals and enable goal setting and specific treatment plans to be developed, have been associated with positive health outcomes (Ouschan *et al.* 2006).

Empowerment can only begin when healthcare professionals acknowledge that patients are in control of their daily diabetes care (Anderson and Funnell 2009). The empowerment principle requires educators to change from feeling responsible for patients to feeling responsible to patients, which requires the provision of information, expertise and relevant support to enable individuals to choose the most appropriate self-care management strategies (Anderson and Funnell 2005). The transition to the empowerment model introduces a range of advantages for patients and healthcare providers. The healthcare

educators feel empowered to no longer resolve the individual's self-care needs, have a better understanding of the non-compliant patient and feel more comfortable with not having to instruct the patient in aspects that they themselves may find difficult to adhere to (Funnell *et al.* 1991). Table 4 demonstrates the differing traditional and empowerment models.

Table 4: Comparison of traditional and empowering educational models

Traditional Medical Model		Empowering Person Centred Model	
1	Diabetes is a physical illness	1	Diabetes is a biopsychosocial illness
2	Relationship of provider and patient is authoritarian based on provider expertise	2	Relationship of provider and patient is democratic based on shared expertise
3	Problems and learning needs are usually identified by professional	3	Problems and learning needs are usually identified by patient
4	Professional is viewed as problem solver and caregiver (i.e. professional responsible for diagnosis, treatment, and outcome)	4	Patient is viewed as problem solver and caregiver (i.e. professional acts as a resource and both share responsibility for treatment and outcome)
5	Goal is compliance with recommendations. Behavioural strategies are used to increase compliance with recommended treatment. A lack of compliance is viewed as a failure of patient and provider	5	Goal is to enable patients to make informed choices. Behavioural strategies are used to help patients change behaviours of their choosing. A lack of goal achievement is viewed as feedback and used to modify goals and strategies
6	Behaviour changes are externally motivated	6	Behaviour changes are internally motivated
7	Patient is powerless, professional is powerful	7	Patient and professional are powerful

Source: Funnell *et al.* (1991, p.39)

Anderson and Funnell (2005) stated that by adopting a collaborative approach it is evident that self-management can also empower the healthcare professional as well as the patient.

3.4 Self-Care Management

The biggest challenge facing any person diagnosed with diabetes mellitus is how best to make appropriate decisions in order to self-care effectively (Diabetes UK 2013). Type 2 diabetes is traditionally managed by diet, exercise, medication, insulin or a combination of all four. Whilst treatment should be aimed at alleviating symptoms and minimising the risk of long-term complications, Clarke (2008) found that measuring long-term impact is important, as self-care interventions are often only implemented short-term.

In order to successfully achieve self-care management and reduce diabetes complications it is important to gain an understanding of the patient's outlook and perceptions of the disease and their health beliefs and attitudes regarding their illness (Thomas *et al.* 2014).

The introduction of effective diabetes education and self-management initiatives creates a supportive environment for patients but more importantly facilitates improvements in their quality of life through the provision of knowledge, skills and tools. This enables patients to become more aware of potential problems and assist in their decision making (Wilson and Gyi 2010). The process of diabetes self-management education was described by Mensing *et al.* (2000, p.685) as '*an interactive, collaborative, on-going process*' involving the diabetes educator and patient. They continue to describe self-management as a process involving the following stages:-

- i) Assessing the individual's specific education needs
- ii) Identifying the individual's specific diabetes self-management goals
- iii) Education and behavioural intervention directed toward helping the individual achieve identified self-management goals
- iv) Evaluating the individual's attainment of the self-management goals

Heisler (2007) also recognises that individuals must successfully execute a number of disciplines in order to self-manage their condition. The aspects may include following diet and exercise regimes, taking prescribed medications, self-monitoring blood glucose levels and coping physically and emotionally with all aspects of the chronic disease. Obtaining knowledge of their type 2 diabetes may assist patients although research has indicated that knowledge alone is not satisfactory for patients, to control their condition effectively (Coates and Boore 1996).

Increased concentration on a tailored centred approach, incorporating patient's beliefs about their illness, may lead to improved patient understanding regarding their disease and increase the likelihood of effective self-care management (Thomas *et al.* 2014).

Diabetes self-management education is considered to be the cornerstone of care in order to achieve successful health outcomes and Clarke (2008) illustrates that there is an ever increasing body of literature to support this view. Patients are more likely to experience improved health outcomes if they are aware of their conditions and are actively involved in their care decisions (Levinson *et al.* 2005).

Shrivastava *et al.* (2013) reported that 95 per cent of diabetes treatment is carried out by patients or their associated family and the provision of self-management recommendations varies considerably across healthcare providers, with many individuals reported to have received no assistance. An increased communication and sharing of decision making has shown to improve patient satisfaction, adherence to treatment regime and improved health outcomes (Heisler *et al.* 2002). The following table highlights the essential self-care behaviours in individuals with diabetes which is aimed to achieve good health outcomes (Shrivastava *et al.* 2013, p.1).

Table 5: Essential self-management behaviours

Essential Self-Management Behaviours	
1	Healthy Eating
2	Being Physically Active
3	Monitoring Blood Sugars
4	Compliant with Medications
5	Good Problem Solving Skills
6	Health Coping Skills
7	Risk-Reduction Behaviours

Source: Shrivastava *et al.* (2013, p.1)

With an increasingly fragmented healthcare system, patient centred care requires the need for healthcare professionals to refocus their emphasis from the disease itself to the specific needs of the individual and their family (Barry and Edgman-Levitan 2012).

3.4.1 Barriers to Self-Care Management

Patients are known to experience multiple barriers to effectively self-manage and they may include a lack of sufficient knowledge of the condition, lack of self-confidence or necessary skills to manage their condition, lack of financial resources, limited support from family or friends and specific comorbidities (Heisler 2007). Mulvaney (2009) investigated specific barriers that cause a low adherence to self-care management and the need for on-going motivation amongst patients. The research identified that supported relationships with family members and successful problem solving behavioural strategies would potentially benefit health outcomes. The recognition of barriers to adherence or initial recognition and awareness of problems were also mentioned as key steps to developing self-management skills.

Aspects of communication with healthcare providers, education levels, support from significant others, patients ability to problem solve and learn, physical

factors (i.e. comorbidities and motivation) spiritual and cultural beliefs, psychological and physical factors (i.e. ability to self-test, income levels, mental and emotional well-being) have also been detailed as potential barriers to effective self-management (Wilkinson *et al.* 2013). Barriers may also exist in relation to the healthcare provider themselves such as limited access to facilities, lack of appropriate patient time or the quality of care and support provided to various individuals (Wilkinson *et al.* 2013). In addition Heisler *et al.* (2002) indicates that physicians may feel that time is also limited for patient consultations which therefore impacts on individual's ability to self-care.

Patients may also experience barriers due to their levels of health literacy, communication issues with healthcare professionals, mental health disorders such as depression or Alzheimer's disease, where adherence to self-management plans and goals may be adversely affected. The setting of specific goals in terms of diabetes self-management has been examined by DeWalt *et al.* (2009) where improvements in patient's self-efficacy, behavioural changes and improved health outcomes may be evidenced.

Traditional care models have tended to focus on the provision of information or literature rather than on the creation of goals or the motivation of patients in order to solve problems or achieve behavioural changes. The importance of initially setting small '*baby step*' behavioural changes and patients receiving a well-designed and easy to read guide along with on-going coaching and support, could assist them in achieving improved coping mechanisms (De Walt *et al.* 2009). Heisler *et al.* (2002) highlights a range of studies where patient appointments for less than eighteen minutes have resulted in patients being unsatisfied with the information provided and fifty per cent of individuals leaving without knowing how to effectively self-manage their condition.

3.5 Denial of Diagnosis

Denial according to Goldbeck (1997, p.575) is commonly applied to patients who:-

- i) Do not accept their diagnosis or appear oblivious to it
- ii) Minimise the implications of their illness

- iii) Delay seeking medical advice
- iv) Refuse or comply poorly with treatment
- v) Appear unperturbed and detached in the face of their illness

At the beginning of my data analysis and at the initial coding stages, one of the concepts that I could see emerging was that some of the participants in the study were in denial of their diagnosis. After eighteen months of reading, analysing and listening to the participants' words several times, I realised that denial was not the correct terminology to use. When speaking with both of my supervisors on numerous occasions I found I was still unable to fully disregard the word denial as one of the initial concepts. Eventually after much deliberation and many sleepless nights I realised that both supervisors were right to question my thought process regarding participant denial. Garay-Sevilla *et al.* (1999) commented that denial can involve individuals reducing the seriousness of the disease. People may attribute symptoms to another source, avoiding conflict with stress factors, the emotion they induce or introducing coping methods to limit undue anxiety.

Upon reflection of my original finding of the concept of denial I subsequently realised I had been assuming the position of a healthcare professional and not that of a researcher in training. Goldbeck (1997) also highlights that although patients may not necessarily point denial to themselves, clinicians and researchers are more likely to label patient denial due to their previous experiences and views. Several of the participants in this study commented during the interviews that they were either wrongly diagnosed or that their diabetes had gone away and they had no symptoms of the disease. This led me to continue questioning, were they actually in denial? However, as the participants agreed to take part in this study, this aspect alone established that they were not in denial of their chronic condition but had placed limited significance on the disease.

3.6 National Institute for Clinical Excellence

The National Institute for Clinical Excellence (NICE) develop and publish clinical care guidelines and recommendations for the education and

management of type 2 diabetes. The organisation promotes a patient centred care approach where efficient communication between healthcare professionals and patients are deemed to be essential. They advise that structured education should be provided to all individuals and all of their carer's at and around the time of diagnoses, with annual re-enforcement and review. The organisation consider structured education a key element of diabetes care and recommend that individualised and ongoing nutritional advice is provided by appropriate healthcare professionals. Further recommendations are centred on the management of hypoglycaemia and self-monitoring with support from an appropriately trained and experienced healthcare professional (NICE Guidelines 2014, Appendix I). The guidelines highlight a number of key priorities that were considered significant to successful implementation.

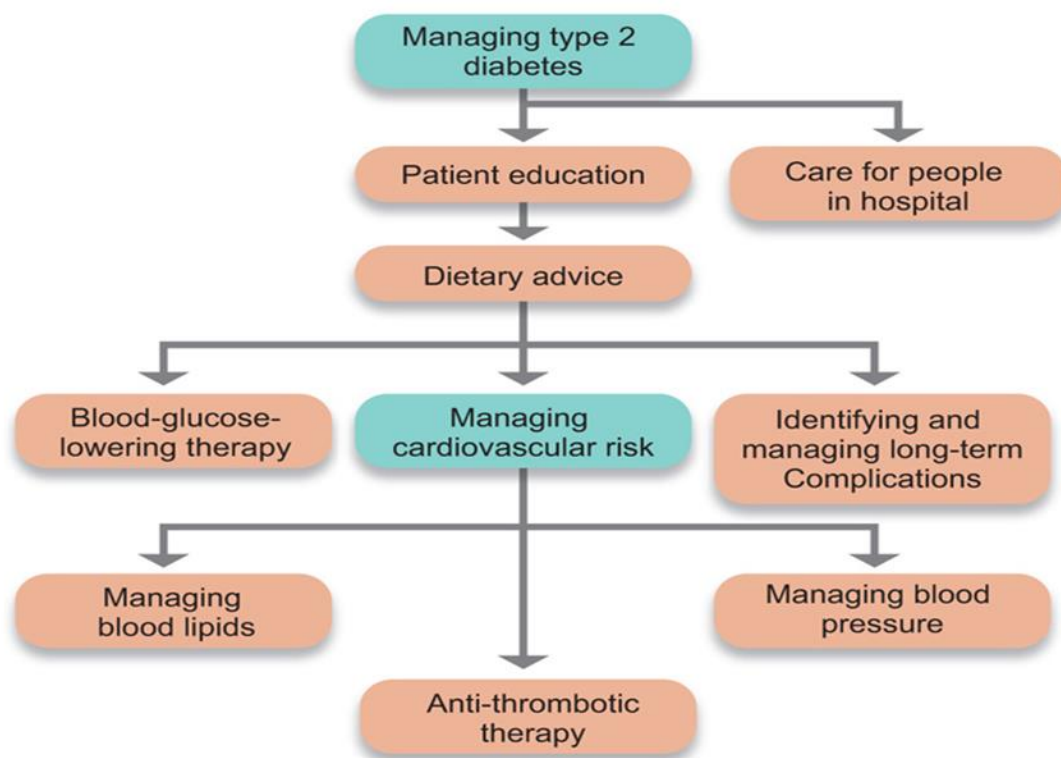
NICE recommend that individuals with diabetes should receive health checks every year to monitor and manage their condition, in addition to reducing the risk of complication of the disease. The organisation acknowledge however less than 10 per cent of individuals are being offered the full set of tests recommended in some areas of England. Data is captured by a voluntary incentive scheme for general practitioner practices across the United Kingdom and is entitled the Quality and Outcomes Framework. The scheme is aimed to reward general practitioner practices for how well they care for their patients and enable them to focus resources where they are most required (NICE 2014).

The Department of Health (2005, p.3) produced a document which identified that:

'Patient centred care is one of the central pillars of the Diabetes National Service Framework. People living with diabetes have a crucial role in managing their condition on a day-to-day basis, so supporting self-care should be central to any local diabetes service. Patient education is a vital part of this support package.'

In order to improve the quality of life for a person with diabetes, the Department of Health (2005) recommended that for individuals to self-care effectively, structured education would have to be considered an essential part of any high quality diabetes service.

In 2011, a patient pathway was created by the National Institute for Health and Clinical Excellence in order to prescribe a uniformed approach to type 2 diabetes service delivery. The patient pathway algorithm (Figure 1) is intended to be used for patient information and the planning of consistent services.



Adapted from NICE Algorithm for managing type 2 diabetes⁶. Date accessed: May 2011

Figure 1: Algorithm for managing type 2 diabetes

Healthcare professionals should ensure that all diabetes healthcare team members are acquainted with the specific education programmes available and that they are fully integrated with care pathways (Hairon 2008).

3.7 Reflections in my Practice

Reflecting on the time I spent as a full time practitioner working in both the United Kingdom and Australia I discovered that there was a predominant focus upon the treatment of diabetes with very little emphasis concerning empowerment of the person who has the disease. Working within the National Health Service I was extremely time pressurised, received little guidance and was required to hand out a generic diabetes leaflet containing basic information to each patient. The leaflet had been photocopied numerous times and some sections were almost unreadable. As a healthcare professional I have to say I was embarrassed that this was the level of education that I had to offer each individual. I often questioned having worked in three different National Health Service Trusts why this generic leaflet appeared to be the standard approach to podiatry diabetes education. I thought, as the specialist in the lower limb I should be encouraging and promoting self-care management. With podiatry resources appearing to be limited I felt that education should be the predominant focus of the patient appointment.

Heisler *et al.* (2002) indicates that various studies have reported that patient requests for information have been unsuccessful due to the short appointment times with practitioners. They further commented in some cases it was noted that less than one minute was spent on patients being given education in a twenty minute appointment.

Reflecting on the generic leaflet that I had previously given, I realised that I had to change my approach and focus on the individual and not the disease. Brackenridge (1999) highlighted that the art of diabetes education required healthcare professionals to adopt distinct skills, which are separate from knowledge of the disease's treatment. The first opportunity arose in Australia where I no longer had time constraints and I was now able to put the person with diabetes first. I asked all of my patients what I could do for them, in order to enhance or improve their understanding of diabetes. I was then careful to listen to the answer and incorporate this into future appointments. Barry and Edgman-Levitan (2012) state the importance of shared decision making and

responding to patients needs through being able to understand the healthcare experience through the individual's perceptions. From then onwards I enjoyed my approach to diabetes and eventually became an integral part of the chronic disease management team. This is something I may never have achieved had I not reflected on my previous practice.

3.8 Literature appraisal

The following table highlights the principle literature selected, in relation to the concepts that emerged through the data analysis process. The key search areas focussed on type 2 diabetes and: Patient education, self-care management, patient empowerment, chronic disease management, Denial in diagnosis, patient empowerment, and doctor patient relationship.

Table 6: Literature appraisal

Author Year	Inclusion criteria, Type 2 diabetes	Method used	Findings	Conclusion
Assal et al 1997	Patient education	Qualitative assessment of a group education programme	Educating a person with diabetes is a complex process	Health-care professionals are aware they require more knowledge and skills to assist the patient
Wikblad 1991	Patient education	Interviewed 55 people with diabetes	Information was overwhelming and only provided on one occasion	Education should be an ongoing process
Forbes et al 2010	Patient education	Scoping review	Patient education, Self-care support and Care organisation and delivery	Diabetes care pathways need to be clearly defined and accessible to all patients
Wilson and Gyi 2010	Health education	Appraising an existing medical model	Diabetes care is complex as it involves both self-care and key processes from the provider	Sociocultural variations exist in the management of diabetes, and should be considered

Anderson and Funnell 1991 to 2009	Patient empowerment	Numerous studies and papers evaluated	Diabetes self-management education programs have become more patient-centred	Self-management education is essential for effective diabetes self-care.
Ouschan et al 2006	Patient empowerment	Comprehensive mail survey of adults with a chronic disease	Patients are more trusting and committed when physicians adopt an empowering communication style	Empowering patients presents a means to improve the patient physician relationship
Heisler 2007	Barriers to self-care management	A survey involving 2,000 people receiving diabetes care	Little is known about the impact of differing interaction styles between the doctor and the patient	Appropriate time should be allocated to enable doctors to provide clear information to a person with diabetes
Shrivastava et al 2013	Self-care management	Looking at 7 behavior's that correlate with quality of life	By patients participating in their own care it can have a positive impact on disease management	The role of clinician in promoting self-care is vital and must be emphasised
DeWalt et al 2009	Self-care management	Quasi experimental study	Goal setting interventions and self-management guides for patients	To facilitate patients to achieve healthy behavioral goals
Thomas et al 2014	Self-care management	Questionnaire surveys to assess illness representations	Patients beliefs may be influenced by perceptions of the quality of care they receive	Greater patient centeredness may lead to a better informed patient
Lutfey and Wishner 1999	Self-care management	Evaluation of existing research	Change the word non-compliance and compliance to adherence	If practitioners understand patient behaviour they can increase explanations aiding adherence

Goldbeck 1997	Denial in physical illness	Literature review	Denial is a complex concept which adopts different meanings in different contexts	Denial should be explicitly defined
Hibbard and Gilbert 2014	Patient activation	Looking at UK and USA based evidence	Patient activation can be used to deliver improved health outcomes and quality of care	People engage more actively in management of their own health

3.9 Conclusion

The Quality and Outcomes Framework (2010) highlights that variations exist in the standard and quality of care people receive, whilst the National Diabetes Support Team (2007) report that not every healthcare professional has the relevant skills to provide such care, so that inequalities and variations in the delivery of diabetes care occurs nationally. According to the Department of Health (2010) the delivery and organisation of diabetes care across the United Kingdom is fragmented and requires review.

Due to the pressures facing health economies it is extremely unlikely that the healthcare system or individual professionals will be able to support this growing epidemic on a continual basis. Individuals will increasingly therefore be required to undertake self-care management, which is now recognised as a key and integral element of diabetes management.

The overall purpose of the research is therefore to gain an insight into the experiences, perceptions and beliefs of people with type 2 diabetes and their understanding of self-care management. In order for healthcare professionals to understand what is important to the person, we have to recognise what they identify to be benefits, important issues, and potential barriers to self-care management.

The following chapter will examine the specific methodological background and approach chosen to undertake this research.

4. Research Methodology

The term research methodology refers to a way of thinking about and '*studying social phenomena*' (Corbin and Strauss 2008). Perhaps taking a less specifically social science view, Crotty (2003, p.3) defines methodology more broadly as '*the strategy, plan of action, process or design lying behind the choice and use of particular methods and linking the choice and use of methods to the desired outcomes.*'

4.1 Introduction

The aim of this chapter is to describe and justify the methodological approach I chose to undertake this study. This research was designed with the intention to understand what was important to an individual diagnosed with type 2 diabetes in order to enable them to successfully self-manage their condition. The initial research question came from my many years' experience as a practitioner. Having attended numerous conferences throughout the world and lectured to nursing students I remained frustrated by the lack of patient involvement in relation to the self-care management of type 2 diabetes. As referred to in chapter one, diabetes is a disease I have had an interest in for almost thirty years. I feel it is important that if I am to continue being a healthcare professional and aid other practitioners in the future, appropriate education or information should be provided in order to make a difference to a person's life. This is why I therefore considered it was fundamental to gain insight directly from individuals with type 2 diabetes in order to understand what is important to them when diagnosed with this chronic disease.

Specifically, the methodology chosen needed to enable an increased understanding of the views, beliefs, and experiences that individuals hold in relation to their chronic condition. Whilst I am aware that I approached the study with prior knowledge and experience of type 2 diabetes, I did not have an appreciation of what each participant would bring to the study. Cutcliffe (2000) advocates that a researcher puts aside any prior '*preconceptions, values and beliefs*', whilst undertaking qualitative research. However, Lincoln and Guba (1985) are of the belief that by acknowledging prior and tacit

knowledge this aids the generation and emergence of a theory. This notion is supported by McGhee *et al.* (2007) who have the view that having prior knowledge of a subject would not necessarily be a hindrance, but may in fact be a benefit to a grounded theory study.

4.2 Selection of an Appropriate Methodology

My research question was to gain an in depth understand of the experiences, perceptions and beliefs that people held regarding type 2 diabetes and their self-care management of this chronic condition. Using this as a focus I came to the realisation that a positivistic approach using quantitative methods would not fit in with my research question. Marshall *et al.* (1996) suggest the choice of methodology should not be selected by the researcher's preference but should reflect the research question. It was proposed by Kennedy and Lingard (2006, p.101) that a grounded theory approach allows the researcher to investigate '*social interactions or experiences*' and that a theory can be developed or a process explained. The authors also advise that data collection may be obtained by using a range of methods in order to gain experience and perspectives that are pertinent to the research aim. They further comment that '*When applied properly and thoughtfully, grounded theory can address research questions of significance to the domain of medical education*' (Kennedy and Lingard 2006, p.101).

When deciding upon a research approach I realised that a qualitative enquiry would be a more appropriate fit for my research question as this would enable me to gain a more in-depth understanding of the phenomena under enquiry. The process of grounded theory allows the researcher to be able to reach the experiences of individuals and to establish how meanings are created, by discovering, rather than testing variables (Corbin and Strauss 2008). The approach I therefore adhered to was a grounded theory methodology and this was undertaken by using interviews as an appropriate method of data collection. Jeon (2004) reinforces that this methodology is fundamentally grounded in and obtained from data, where simultaneous and ongoing data collection and analysis is carried out. This is in order that a theory is

generated from the source data and adequately explains and interprets the area of enquiry.

The following table (Silverman 2010) provides an overview of the way in which both quantitative and qualitative methods may be approached. Having reviewed both methodologies I soon realised that in order to gain a deep and meaningful understanding from the participant's perspective, a qualitative approach would be appropriate and the most effective method would be for me to conduct a series of interviews.

Table 7: Comparison of quantitative and qualitative methods

Method	Quantitative Research	Qualitative Research
Observation	Preliminary work e.g. prior to framing questionnaire	Fundamental to understanding another culture
Textual Analysis	Content analysis i.e. counting in terms of researchers categories	Understanding participants categories
Interviews	Survey research - mainly fixed-choice questions to random samples	Open-ended questions to small samples
Transcripts	Used infrequently to check the accuracy of interview records	Used to understand how participants organise their talk and body movements

Source: Silverman (2010)

4.2.1 My Paradigm

When evaluating a suitable qualitative methodology I felt it was important to consider not only the research question but also an approach that was in alignment with my world view. Evans (2013) stresses the importance of the researcher's paradigm and the associated impact of varying methodological approaches. This method is further supported by Jeon (2004) who prescribes that a researcher's paradigm should incorporate ontological, epistemological and methodological considerations.

Strauss and Corbin (1998, p.7) clarified their views on the characteristics of a grounded theorist as follows: -

- i) *The ability to step back and critically analyse situations*
- ii) *The ability to recognise the tendency towards bias*
- iii) *The ability to think abstractly*
- iv) *The ability to be flexible and open to helpful criticism*
- v) *Sensitivity to the words and actions of respondents*
- vi) *A sense of absorption and devotion to the work process*

Whilst investigating grounded theory as a methodological approach to my research question and considering the attributes that Strauss and Corbin (1998) deemed a grounded theorist researcher should have, I realised that this methodology may be best suited to enable me to answer my research question. For the purpose of this study I chose to use a grounded theory approach.

I was about to embark on undertaking a grounded theory study and was enthusiastic about being afforded the amazing opportunity of speaking with an individual on a one to one basis on a subject I am passionate about. I was excited that this research would enable me to spend unrestricted time with people for the first time in my career. I was aware however, that as exciting as this may seem I was also apprehensive by the challenges that lay ahead. Corbin and Strauss (2008) agree that for an inexperienced researcher to be embarking on '*doing qualitative analysis*' this may become a daunting experience.

4.3 Selection of an Appropriate Grounded Theory Methodology

When selecting an appropriate grounded theory methodology I deliberated over a range of approaches. The various methods that I selected for further consideration were: Glaser and Strauss (1967), Glaser (1992), Strauss and Corbin (1998), and Corbin and Strauss (2008).

Grounded theory is a methodology that was first described by Barney Glaser and Anselm Strauss in their book, *The Discovery of Grounded Theory*, in

1967. Both authors were sociologists, with Glaser's background being in quantitative research whilst Strauss's experience was more aligned to qualitative methods. Glaser and Strauss's (1967) original aims were to standardise the process of collecting, coding and analysing qualitative data in order to generate a theory. Their approach resulted in the development of two of the principal concepts for grounded theory, which are constant comparison and theoretical sampling (Cooney 2010).

Following their original joint publication and not having adequately explained their epistemological and ontological interpretations the authors then moved on individually to develop more divergent views. This difference in approach to grounded theory became more apparent when Strauss (1987) and later Strauss and Corbin (1990) were said to have redesigned the original methodology (Heath and Cowley 2004). The methodological approach incorporated by Strauss and Corbin was developed from their own research experiences. They advocated that the process of undertaking analysis states that reality may not be known but involves making interpretations and crucially incorporates the voice of the informant (Hallberg 2006). The intentions of Strauss and Corbin (1998) were to introduce a categorised coding methodology which verified the findings during the entirety of the research process. Heath and Cowley (2004) explain that this further development of analytical procedures and clearer guidance to the methodological approach has provided assistance to novice researchers.

Glaser felt that the Straussian approach should no longer be classed as grounded theory. Glaser criticises the Strauss and Corbin approach whilst claiming that the data can be 'forced' and theories are not allowed to 'emerge'. However, Kelly (2004) suggests that Glaser's criticism of the Straussian approach may over exaggerate the risks of this particular methodology.

Glaser (1992) disagrees with the method of grounded theory prescribed by Strauss and Corbin and describes it as rigid, descriptive and stresses that it is no more than conceptual description with the data being forced. However, Corbin and Strauss (1998) continually modified their approach to grounded

theory and stated that it was never their intention to advocate rigidity and explained that the processes that were described were merely guidelines for the researcher and not set in stone. Strauss and Corbin (1998) and Corbin and Strauss (2008) emphasise that the researcher should allow flexibility in relation to their abilities, trust the research process and not be too concerned about rigid adherence to the guidelines. The overall emphasis of the Strauss and Corbin grounded theory methodology is to allow a theory to develop in order to aid understanding and guide action and practice (Cooney 2010). I considered therefore, that a methodological approach offering a degree of flexibility whilst advocating a set of guidelines, to assist the process, would be the most suitable and appropriate.

After careful deliberation I decided upon the version of grounded theory developed by Strauss and Corbin. Following a period of reflection I felt as a trainee researcher this approach would offer a more prescribed and structured methodology to follow and would enable me to adopt a more involved position in relation to the data collection and analysis. Fendt and Sachs (2008) highlight the importance of selecting a methodology that is the most appropriate for the researcher.

The theoretical orientation of grounded theory studies is symbolic interactionism, which emphasises that human conduct is developed through human interactions, through on-going process of negotiation and re-negotiation. Indeed, symbolic interactionism focuses on how people define events and realities and how they behave based on their beliefs (Evans 2001). Researchers use grounded theory to explore the social processes that are present within human interactions and to develop explanations of key social processes that are grounded in empirical data (Hutchinson 2001).

4.4 Symbolic Interactionism

Symbolic interactionism involves understanding an individual's view point in relation to their lived experience, behaviour and perceived meaning of their unique situation (Jeon 2004).

Glaser and Strauss (1967) stated that there was a historical relationship between grounded theory and the interpretive tradition of symbolic interactionism. Symbolic interactionism offers a perspective on life, society and the world according to the pragmatist philosopher and social psychologist George Herbert Mead (Crotty 2003). Early in the 20th century symbolic interactionism became known as the '*Chicago tradition*' due to the presence and influence of both George Herbert Mead and Herbert Blumer at the University of Chicago (Blumer 1969).

Herbert Blumer was a former student of George Herbert Mead who, whilst working on Mead's principles invented the term symbolic interactionism in 1937.

Blumer broke symbolic interactionism down into three premises:-

- i) *Human beings act toward things on the basis of the meanings that these things have for them*
 - ii) *The meaning of such things is derived from, or arises out of, the social interaction that one has with one's fellows*
 - iii) *These meanings are handled in, and modified through, an interpretative process used by the person in dealing with the things he encounters.*
- (Blumer 1962, p.79).

In order for me to appreciate what was important to a person with diabetes I had to understand the meaning that participants placed when diagnosed with this chronic condition. Blumer (1962) emphasised that by ignoring an individual's meaning would effectively falsify the behaviour under study.

4.5 Grounded Theory Methodology

One of the founders of grounded theory, Anselm Strauss, studied symbolic interactionism whilst working under Herbert Blumer at the University of Chicago.

Barney Glaser worked alongside Anselm Strauss and together they wrote the book, *Awareness of Dying*, in 1965, which lead both authors to look closely at the methodological approach to questioning dying patients. From this study

the methodology that we now know as grounded theory was created. In 1967 the book *The Discovery of Grounded Theory* was published and this was the beginning of a whole new methodological approach for the social sciences (Morse *et al.* 2009).

In recent years, there has been an increase in the number of papers published using grounded theory involving investigations of the healthcare system. Qualitative research, including grounded theory, was the focus of research in the social sciences for many years and was developed in response to the overwhelming belief held by positivists that qualitative research approaches were unscientific and anecdotal (Britten 2005). The grounded theory approach, it could be argued, is only one of numerous accepted qualitative research approaches, which has contributed to minimising the debates about the effectiveness of qualitative research within nursing and related disciplines.

Grounded theory was originally developed by Glaser and Strauss (1967, p.1) as a means to make possible the '*systematic discovery of theory from the data of social research*', which was described in their book entitled, *The Discovery of Grounded Theory* (Glaser and Strauss 1967). In earlier times, only phenomena which were controlled through experiments were commonly regarded as acceptable by positivist thinkers. They believed that qualitative research approaches only explore or describe the phenomena under investigation, in naturalistic settings such as hospitals or outpatients departments, without taking into account any hypothesis or null hypothesis at the beginning of the study. As a result of such a philosophy, the grounded theory methodology was developed to attempt to generate a theory.

It is becoming increasingly accepted within healthcare settings that the grounded theory approach provides a systematic way to generate theoretical constructs and or concepts that illuminate human behaviour in the social world (Harris 2003). Debates concerning the current status of grounded theory have been varied. May (1996) for example, has raised questions about diffusion and dilution of the grounded theory. Furthermore, issues have been raised concerning the quality of research labelled as grounded theory (May 1996 and

Benoliel 1996). Wilson and Hutchinson (1996) concluded that the corruption of grounded theory in recent years has placed its trustworthiness at risk, and the findings generated could earn a reputation as insignificant or obvious. Morse *et al.* (2009, p.17) however, argues that grounded theory has continued to emerge and develop since its genesis and concludes that; '*science changes, develops and improves over time.*'

Morse *et al.* (2009) states there has been a distinct genealogy of grounded theory over time, and that the methodology is an important way of allowing the researcher to consider the data. As grounded theory is on a constant continuum and all researchers will adopt a different approach, each study is therefore individual and cannot be replicated. Corbin, in Morse *et al.* (2009, p.52) agrees with this theory and also comments that '*readers of research construct their own interpretations of findings.*' Whilst also making clear that all studies are different with each individual bringing their own existing life experiences, the same patterns within the data may still be discovered.

4.6 Features of Grounded Theory

The following section provides a summary of the principle features and components of grounded theory and the relationship with my particular methods of enquiry. Grounded theory is a qualitative inductive inquiry method that both produces and examines qualitative data, aiming at the generation of theory that accounts for a pattern of behaviour that is relevant and problematic for those involved (Glaser and Holton 2005). Humans construct theories in order to explain, predict and master phenomena and unlike quantitative inquiry approaches, grounded theory does not normally begin with an existing theory, but rather generates a specific substantive or formal theory for the phenomena of interest (Tavakol *et al.* 2006). Glaser and Strauss (1967) differentiated a substantive theory from a formal theory with the former being grounded in data on a specific substantive or empirical area of investigation, such as patient care or professional education. It can be a facilitator for formal grounded theory, which involves developing a higher abstract level of theory

from a collection of substantive theory studies regarding the phenomenon of interest.

Kearney (1998) used an analogy to differentiate substantive theories and formal theories. In this analogy, substantive theories are assumed to be like custom-tailored clothing and formal grounded theories are assumed to be as ready-to-wear clothing. Therefore, formal theories (ready-to-wear) can fit a wider variety of users, and they are not personalised like substantive theories (custom-tailored). Rather, they provide a conceptualisation that applies to a broader population experiencing a common phenomenon. Formal grounded theories are ideally generated by formally studying a substantive grounded theory. Such theories are essential to develop a scientifically based practice for all disciplines, including health education. Therefore, if health education and health related research is to develop scientifically, educationalists should debate about generating substantive grounded theories (Kearney 1998).

One of the main features of grounded theory is to investigate causal relationships and to develop an appropriate theory from the data collected. It should be noted however, that although speculation and theorisation of causes may be possible, the confirmation of cause can only be determined by undertaking experiments. The qualitative researcher in grounded theory is therefore drawn towards the evolving, fluid and dynamic nature resonated by this approach. Corbin and Strauss (2008) emphasise that, by connecting with the research participants at a human level the grounded theorist has a natural curiosity, which affords them the opportunity to study subjects that other researchers may not have access to. Particular attention is drawn to an interpretation of individual's feelings, experiences and behaviours and how these may interact.

4.6.1 Initial Research Question

In grounded theory studies inquirers undertake their research with a question, and not objectives or hypotheses (Creswell 2003). The research question in a grounded theory study is different to a hypothesis or null hypothesis generated at the beginning of an experimental design quantitative study. Furthermore,

the question must be flexible and open-ended to allow the theory to develop. It should be sufficiently broad to enable a systematic inquiry to be conducted of all the aspects of a phenomenon in depth (Creswell 2003).

Since the methodology of grounded theory is an emergent design (a design that unfolds in the course of a grounded theory study as the inquirer makes on-going design decisions reflecting what has already been learned) researchers improve the research question as they generate and analyse the study data. It should be noted that the data generated in grounded theory might change the focus of the study. Therefore, the original question only lends focus to the study. It is therefore argued that a really precise research question is not possible to pose before beginning any grounded theory study (Hutchinson 2001). Consequently, it was reasonable to assume that the original research question for this study was likely to change as the study developed. Morse *et al.* (2009) states the initial research question in a grounded theory study may change over time as due to the nature of this methodology the original research question will fall in line with the findings.

4.6.2 Sampling

Unlike the quantitative inquirer, the grounded theorist does not decide on the size of the sample population before the study begins. Participants are not recruited on a representative basis, but rather because of their expert knowledge of the phenomenon under inquiry (Green and Thorogood 2005). In fact, the researcher selectively samples informants who are closely experiencing the social process under investigation. The sample size is not fixed as in statistical sampling used in the quantitative approach; rather, it ideally relies on what is known as theoretical sampling (Corbin and Strauss 2008). Glaser (1978, p.12) had initially indicated that the process should involve the researcher simultaneously collecting, coding and analysing data, whilst making decisions regarding the subsequent data to be collected and where this should be obtained, to develop the emerging theory. Glaser continues by explaining that this may lead the researcher in different directions that seem appropriate and work. Breckenridge and Jones (2009)

indicate that remaining open to a range of different possibilities and adopting an open and patient approach may yield more useful and relevant theory emergence. Theoretical sampling is therefore an integral part of the constant comparative method of data collection and analysis. The main purpose is to collect data from a variety of sources, including, individuals, places, and events, in order to generate opportunities for identifying emerging concepts or themes (Strauss and Corbin 1990).

Strauss (1987, p.57) emphasised that '*much calculation and imagination on the part of the analysts*' was required to identify relevant information, which is constantly sought in order to refine ideas as they emerge (Draucker *et al.* 2007). The central question in theoretical sampling is; what groups or subgroups, does one turn to next in data collection? That is, the selected participants should be determined by the emerging data, and data analysis will offer further participants for further interview.

Becker (1993) has revealed some common pitfalls in published grounded theory research. She criticised that researchers often fail to adhere to the underlying principles of the grounded theory study. There is often a tendency to ignore the fact that theoretical sampling endeavour to discover categories and their properties and to present interrelationships that take place in the substantive theory.

4.6.3 Data Collection and Analysis

Data collection usually follows the normal procedures for field research. The grounded theorist will immerse him or herself in the setting being studied and gather data by such means as participant observation, unstructured interviews, or other written documents or a combination of methods (Strauss and Corbin 1998, and Green and Thorogood 2005). In some disciplines, however, as is the case in this study, the research includes a range of sources including interview data, field notes, observations and previous experiences for creating the theory (Backman and Kyngas 1999). The process of data generation requires the researcher to collect, code, and analyse data

concurrently. This process allowed me to evolve richer data where needed. Indeed, simultaneous collection and analysis of data and emerging theoretical structure help to orient further data collection (Strauss and Corbin 1998). The choice of data treatment and collection methods are directed mainly by inquirer choice with the researcher usually using digitally-record interviews, transcribing verbatim, and then analysing them using specific procedures (Corbin and Strauss 2008).

4.6.4 Coding and Memo Writing

Coding is a fundamental analytical process, which involves the deriving and developing of concepts from data. Strauss and Corbin (1998) define three distinct coding definitions in grounded theory: -

Open Coding is a process tasked with discovery of categories and their properties, which groups or classifies them into themes or categories, while, at the same time, looking for trends in the data. Elliott and Jordan (2010) explain that 'open coding' should be a straightforward process, with the researcher assuming a 'naïve position', free from any preconceived ideas or predetermined concepts. Draucker *et al.* (2007, p.1138) identifies open coding as the '*initial close line-by-line or word-by-word examination of the data for the purpose of developing provisional concepts.*' The process does involve comparing events, actions and interactions with others to identify similarities or differences and by applying 'labels' that can be categorised into relevant groups to form categories and subcategories (Corbin and Strauss 1990).

Axial Coding is the technique of re-assembling data that has been fractured during open coding. As additional data is collected, the researcher moves back and forth amongst the data collection, all the time open coding and axial coding continually refining the categories and their interconnections. This allows categories to develop and link to their subcategories to form more precise and complete explanations of phenomena. Corbin and Strauss (1990, p.13) further explain that '*categories are related to their subcategories with relationships being tested against the data*' and further development of categories is undertaken.

Selective Coding is the practice of integrating and refining the core categories whilst, systematically relating it to other categories in order to develop a theory. Corbin and Strauss (1990) identify the activity occurs towards the end of the study although it is essential in unifying all categories around a 'core' category. At the same time, this involves the validation of these relationships, and then filling in any categories that may require refinement or further development.

Corbin and Strauss (1990) highlighted the importance of memo writing in formulating and revising a theory and providing a solid base for reporting the research. This important aspect of grounded theory takes place during the commencement of coding stages and on an on-going basis until the end of the research process. Memos may vary in type and can be in the form of written records of analysis, or represented as diagrams. The aim of memos is to give direction to the analyst and they are usually written in a conceptual style rather than in a descriptive manner. McGhee *et al.* (2007) indicates that memo writing can aid researcher awareness in realising their potential effects on the data and can assist in ensuring any preconceived ideas held by the researcher are not forced into the process. Jeon (2004) also quotes Glaser who states that strong theories will not emerge until a researcher starts and continues memo writing. The author adds the importance of taking time to think and complete memos in order to contribute to the process of theory generation.

4.6.5 Theoretical Sensitivity and Saturation

Theoretical sensitivity relates to the condition a researcher must adopt in order to remain aware of developing concepts that may arise from the emerging data. According to Glaser (1978) the iterative and interactive process involves the researcher paying particular attention to detail and surroundings. The method involves the researcher constantly going backwards and forwards and often referring to the original data, whilst ensuring that decisions are not made prematurely. Theoretical saturation has been described by Morse (1995) as '*data adequacy*'. This is a point that is reached when no new information

emerges from the data. Data collection then continues until saturation is reached, where exploring further data does not add to the insight already gained. At this point, the analytical framework is deemed to be saturated, and further analysis is no longer necessary (Breckenridge and Jones 2009). Glaser and Strauss (1967) had earlier stated that saturation only occurs when data collection produces no new leads and categories are deemed to be adequately dense. It should be noted that the participants in this research were not recruited prior to the inquiry commencing but only as they were needed for their theoretical relevance for developing further emerging categories. Although I do believe the concepts and emerging theory were formed through adequate data I maintained an appreciation and understanding that contrary cases or new findings may always appear, even after considerable extensive research processes. The theory is therefore deemed 'true' based on the evidence collated in this study although cannot be claimed to be comprehensively or completely true, due to the nature of the phenomena and process adopted.

4.6.6 Constant Comparison

Evans (2013, p.40) indicates that the process of constant comparison consists of three elements:-

- i) *Incident to incident for the emergence of concepts*
- ii) *Concepts to more incidents for further theoretical elaboration, saturation and densification of concepts*
- iii) *Concepts to concepts for their emergent theoretical integration and through theoretical coding*

Elliott and Jordan (2010) highlight the importance of conducting constant comparison early during the research process and ensuring integrity is achieved by the researcher constantly '*working back and forth*' between the data and new codes that are identified. This is aimed to obtain a sense of the emerging theory from the participant's input. The authors also stress the crucial task of re-examining data to assess links between concepts and

incidents and for the researcher to remain open to respond to new emerging ideas and revise concepts accordingly (Elliot and Jordan 2010).

4.6.7 Rigour

A common requirement of grounded theory research involves being able to demonstrate that rigour has been applied to the methodological process. Jeon (2004) explains that Glaser and Strauss considered rigour assurances were dependent upon '*credibility, plausibility and trustworthiness*' and the generation of the theory from the data, opposed to the actual research process.

Chiovitti and Piran (2003, p.430) indicate that although the definitions and standards of rigour, in relation to qualitative research, have been proposed and debated consistently by scholars, the principal elements concern credibility, auditability and fittingness. The author suggests a range of methods may be adopted under each category in order to enhance overall credibility whilst undertaking grounded theory research. A selection of Chiovitti and Piran's proposed methods detailed below reflects varying aspects of my approach in ensuring rigour was ultimately maintained.

Credibility – '*Using participants actual words in the theory*' – I felt it was extremely important to ensure that the participant's words were directly quoted also through a process of transcription I was able to transfer the participant's words and phrases to the data collection and coding processes.

Auditability – '*Specifying how and why participants in the study were selected*' – All of the participants who requested information about the study expressed a desire to take part. They were initially selected because of their experience of the phenomenon under enquiry.

Fittingness – '*Describing how the literature relates to each category which emerged in the theory*'. A formal literature review did not take place prior to any data collection. I have acknowledged that I brought existing knowledge of the subject matter prior to data collection and analysis. Once the core concepts began to emerge, only then did a full literature review take place.

This literature review continued until a substantive theory emerged from the data collected. Chapter 7 highlights the interrelation of the literature and specific theories that subsequently emerged.

4.6.8 Reflexivity

The process of reflexivity is described by Robson (2002) as an awareness of the ways in which the researcher as an individual with a particular social identity and background has an impact on the research processes.

McGhee *et al.* (2007) stresses the importance of the researcher being able to adopt a self-questioning and open-minded approach whilst developing a sense of self-awareness, therefore allowing any previous prejudices to be removed by the contrasting data. The authors also believe that reflexivity is crucial in order to eliminate the possibility of prior knowledge potentially distorting a researcher's observation of the data. I remained mindful throughout the research process that I had prior knowledge of type 2 diabetes. In order to remain true to the grounded theory iterative analytical process however, I constantly questioned myself and deliberated with my supervisors regarding the concepts that were emerging from the data. I also reflected on my role as a researcher in training and my role as a practitioner still in practice, which caused tension on certain occasions.

4.7 Conclusion

Grounded theory is a qualitative enquiry using an iterative process. This chapter was aimed to provide a background to the methodology and the reason as to why it was chosen for this particular study. The following chapter will explain the methods used to gain access to the participants and the way in which grounded theory was undertaken as a methodology.

5. Method Undertaken for the Research Process

5.1 Introduction

This chapter will feature the research approach adopted, and the methods and procedures employed for both the collection and analysis of the data.

5.2 Ethical Approval

Prior to any research activities taking place and in order to ensure that all ethical issues were addressed, I was required to obtain formal ethical approval, from both the University of Salford Research and Ethics Committee and the NHS National Research Ethics Service, allowing Patient Identification Centres (PICS) to be accessed at NHS Stockport Primary Care Trust. Approval from the Academic Audit and Governance Committee was also awarded. The Research Ethics Panel reference was REP11/105, and is detailed in Appendix II. Further ethical approval was also granted by Health Research Authority NRES Committee North West – Greater Manchester North, REC Reference number: 12/NW/0182, R&D Reference number: 2012/045, which is located in Appendix III.

Ethics is an important consideration in the way in which participants may be involved or affected by research (Saunders *et al.* 2009). Furthermore, as a member of the Health and Care Professions Council (HCPC) I was required to comply with their standards of conduct performance and ethics in order to achieve the best outcome for both the participants and myself in relation to the research. The organisation maintains a series of standards and guidelines that all clinicians should be familiar with and adhere to in order to perform their roles effectively.

5.2.1 Ethical Principles

Beauchamp and Childress (2001) identified four key principals in relation to medical ethics whether in a clinical setting or otherwise. During the research process I remained mindful, whilst following the principles, in order to ensure that the participants were treated in a respectful and considerate manner at all

times. With the participants interests as my main consideration I therefore adhered to the following principles:-

- a) **Respect for autonomy** – Relates to an individual's ability to make informed choices at any time during the research process.

Prior to any research taking place all of the participants were contacted via telephone and were informed of the purpose of the research and the processes involved. Information sheets were distributed to all individuals who had expressed an interest in participating in this study. Prior to the interview date and time being set, individuals were given every opportunity to ask any questions or request any further information or clarification before signing the consent form. In order to ensure that participants were given freedom of choice they were assured that they could leave the study at any time and that this would not affect any aspect of their future healthcare.

- b) **Beneficence** – Provides assurance that the individual's welfare and best interests are considered at all times.

In order to ensure that the participants felt as comfortable as possible, interviews were arranged at a time and place of their choice. It was important that participants could feel at ease in a familiar environment, whilst ensuring any perceived power imbalance between me and the participant was reduced. On a personal level I adhered to the lone working policy and I informed my husband of my movements on the day of each interview. I rang him prior to entering the individual's home and I called him when I left. The participants address was held in an envelope at my home which I destroyed on my return.

- c) **Non-maleficence** – Refers to the principle of avoiding harm or minimising the effects of harm to an individual. Lawrence (2007) states that the principle of non-maleficence may be summed up as '*primum non nocere*', which translates as '*first do no harm*'.

I was extremely mindful of managing and mitigating any risks that could unnecessarily distress the participants during the interview process. In alignment with grounded theory I only asked the participants to expand on any

subject matters that they stressed were important or that had been mentioned previously.

d) **Justice** – Treating all individuals in a fair and equitable manner.

All of the participants were provided with an equal opportunity in which to discuss or express their opinions and thoughts. I felt it important that I had no bias towards race, gender or age and I treated each individual in a fair and honest way and with respect.

As well as adhering to the four key principles I also considered it important to take account of the following areas of ethical concern:-

Table 8: Areas of ethical concern and actions taken

Ref	Area of Ethical Concern	Actions Taken
1	Participant Deception	Participants were fully informed of their rights when taking part and were free to withdraw at any time. The purposes of the research were fully explained and individuals had an opportunity to ask questions at any stage of the process.
2	Access to Confidential Information	All the information given by the participants was kept in a secure location.
3	Financial Inducements	All individuals participated of their own free will and received no payments or benefits.
4	Possible Psychological Stress	All research activities were undertaken at the individual's choice of location and were informed that they could bring a person of their choosing with them in order to make them feel comfortable.
5	Any other Special Circumstances	All individuals were informed that the information provided by them would be treated anonymously and confidentially; All of the participants however, waived their right to anonymity.

5.2.2 Anonymity and Confidentiality

The subject of anonymity has been described as the methods of ensuring individuals are not identified during the conduct of research activities (Walford 2005). Anonymity is a way in which confidentiality may be achieved by safeguarding the information collected relating to an individual and this will not be disclosed without their permission (Wiles *et al.* 2008).

It was my original intention to re-name all of the participants in the study in order to maintain each individual's anonymity. Upon presenting the consent form however, and explaining each participant's rights to anonymity, they all expressed that they wanted to use their own name and did not see the purpose in changing it. One participant, Derek, commented he wanted to use his first and second name and stated;

"What is the point of allowing us a voice if no one knows who we are?"...Derek

Wiles *et al.* (2008) found that there is an increasing trend, particularly in children and young people, for the need to be identified and not anonymised in research. The age range of the participants in this study was 27 to 92 years and I found that none of them wished to be anonymised. The individuals involved in this research were keen for their voices to be heard and their stories to be told and this certainly correlates with the findings of Wiles *et al.* (2008) who describes that there appears to be a changing culture regarding research subjects wishing to waive their right to anonymity.

Each interview was audio recorded and the files were downloaded onto a password protected computer to which only I had access to.

5.3 Commencing the Research

I initially approached local general practitioner surgeries in order to recruit participants for this study. I explained the research focus related to the study initially via the telephone to the practice manager at each surgery. This was followed up by a letter confirming the study (Appendix IV), a copy of the

participant information sheet (Appendix V), and a poster to be placed on their premises notice board (Appendix VI), subsequent to their approval.

Most of the general practices were satisfied to proceed as per the original study guidelines. One of the practice managers referred all of the information to the '*diabetic practice nurse*'. On speaking to the nurse I was informed that '*only non-compliant patients would be referred for the study*' and that she would '*choose who to send to take part.*' I explained that it was not my intention to recruit potential participants in this way and that I sought to hear from all volunteers diagnosed with type 2 diabetes and not just the patients the practice deemed non-compliant by the '*diabetic nurse*'. I was informed that this was the only way they would allow '*their patients*' to take part in the study. Unfortunately, this resulted in my poster not being displayed at this particular practice. Fortunately however, several of the participants in this study attended this practice.

The rationale for using local surgeries was due to the nature of the research methodology grounded theory. Whilst conducting this particular study it was important that the epistemological integrity of grounded theory was dependent upon the participants having freedom of choice at all times. This would include choosing the place and time for their interview. As the researcher I could do nothing to interfere with this without un-grounding the study or theory. I wanted to ensure the participants felt safe in an environment that they were accustomed to and at no point did I wish to make them feel uncomfortable in an unfamiliar setting.

Being an experienced practitioner for many years and maintaining an awareness of the dangers of lone working, I did not necessarily want to travel to any area that I was not familiar with or possibly late at night, in order to carry out my research. Due to the lack of engagement with my local surgery I however, took the decision to recruit participants via other surgeries, outside of the local area. Fortunately, only five participants requested evening interviews due to work or family commitments, with the other participants happy to be interviewed during the day.

5.4 Participant Recruitment and Sampling Process

The potential participants were recruited through a poster advertisement in eight general practitioners practices. The posters were placed in an area that could be accessible to all individuals who attended the surgeries. My contact details, mobile and home telephone numbers, and both my private and university email addresses were displayed on the poster to allow volunteers the opportunity to contact me in order to gain further information in order to decide whether to participate in the study. As a podiatrist who has practiced in both the public and private sector I was familiar with providing both my mobile and home telephone numbers in order for individuals to contact me.

The sampling process ensured that only those individuals who had been diagnosed with type 2 diabetes and were aged 25 or over were able to participate. The individuals who participated in this study were also required to provide informed consent. Upon being contacted by each individual I verbally confirmed they were eligible to meet the criteria and therefore be included in the study.

No potential participants were excluded from the study and this approach was confirmed as acceptable by the ethics department at The University of Salford and the NHS National Research Ethics Service.

The majority of participants initially contacted me via telephone and it was at this point a full explanation of the research was explained to them. This was then followed up with a participant information sheet being mailed out prior to the initial interview being arranged. This allowed each person ample opportunity to ask any further questions regarding the research, prior to signing a consent form. One participant, Alan, requested all of the information to be emailed to him in order that he could take it on holiday and decide whether he wanted to take part in the study. All of the other participants either received their information sheet in the post or I delivered it personally to their home.

Prior to each interview I made a note of the participants address and telephone number with the date and time of the arranged interview, and this was then kept in my study at home in a sealed envelope. I informed my husband of the time of my interviews and called him when I was outside of the participant's house. I also called him within ten minutes of leaving the property. Once safely home I destroyed the address and telephone number by putting it through my shredding machine.

The participants were afforded every opportunity to ask as many questions as was necessary in order that they felt completely comfortable prior to the initial interview taking place. Each individual was informed that once they had agreed to participate they were free to withdraw from the study at any time without it affecting their future care in any way. Once the participants felt comfortable and wished to proceed with the study they were asked to sign a consent form (Appendix VII) and complete a demographics questionnaire (Appendix VIII). I also explained that the initial interview could take between 60 to 90 minutes and that any follow up meeting may take slightly longer. The follow up meeting was intended to ensure that the transcriptions were an accurate record and fully reflected the participant's comments.

One person was recruited to the research via a friend of mine who was aware of my research proposal. His name was Majid and he approached me at a garden party and asked if he could take part in my research. He explained to me that he thought he had something '*of value*' to add to my study and wanted to offer his opinions on what it was like to be diagnosed with diabetes.

Ten men and seven women applied to take part in the research. The youngest participant was Rebecca, aged 27 and the oldest was Winnie, aged 92. The participants spanned across a wide range of professions and differing educational backgrounds. The participants' duration of diabetes since diagnosis ranged from less than one year to over forty years. On my initial meeting the demographics questionnaire asked the participants to rate their health from poor through to excellent. Only one participant rated their health as excellent, five rated their health as very good, three as good, four as fair,

with the remaining four participants rating their health as poor. A summary of the participants can be found in Table 9: -

Table 9: Patient demographic information

Name	Age	Duration of diabetes (years)	Treatment method	How would you rate your health?	Would you like education regarding diabetes?
Wilf	62	8	Tablet	Good	Yes
Stuart	54	6	Tablet	Very Good	Yes
Winnie	92	4	None	Very Good	Yes
Derek	51	8	Tablet	Fair	Yes
Ruth	72	Over 10	Tablet/Insulin	Fair	Yes
Gail	60	2	Tablet	Very Good	Yes
Angela	68	6	Tablet	Fair	Yes
Bob	49	4	Tablet	Poor	Yes
Jon	42	4	Insulin	Good	Yes
Martin	69	Over 20	Insulin	Good	No
Alan	58	Over 10	Insulin	Excellent	Yes
Peter	77	Over 40	Tablet/Insulin	Fair	Yes
Don	78	Over 10	Tablet	Poor	Yes
Pauline	75	Over 40	Tablet	Poor	Yes
Majid	55	2	Tablet	Very Good	Yes
Rebecca	27	Less than 1	Tablet	Poor	Yes
Chris	69	10	Tablet	Good	No

5.5 Data Collection

For the purpose of this research I did not interview the participants using structured or semi structured questions. I discussed what the participants deemed important to them, merely adding a few prompts when needed. I did however arrange an appointment date and time and audio recorded the interviews, which would normally be in line with semi structured interviews. My interviews appeared to take on an informal style approach. One of the reasons for this may have been we were not in a clinical or formal setting. In line with grounded theory all of the participants were asked the same opening question to commence the interview. In grounded theory the opening question is also known as the 'Grand Tour Question' (Glaser 1998). The grand tour question I asked all of the participants was, "*Could you tell me a little bit about yourself in order that anyone reading the transcript would get a clear picture of who you are?*"

I interviewed seventeen participants with the recorded conversations totalling over eighteen hours in duration. The interviews were then transcribed verbatim representing over 75,500 words, which I then analysed in accordance with the grounded theory research process. I also wrote many memos after the initial interviews and often completed memos to myself during the transcribing process. This would vary from an A4 page to numerous post-it notes that I attached to each completed transcript. I adopted this method in order to remember key points that participants had mentioned which may not have been recorded. On my first visit I spent between sixty minutes to several hours with each person but the audio recorder may only have been switched on for around one hour of this time. I became aware that even though I had asked all of the participants what important point they wanted to be taken away from our meeting before I turned the recorder off, certain people provided more information to me once the recorder was switched off. This was one of my biggest challenges, but I am considered to be a good listener and came to anticipate this may happen and I therefore became less anxious about turning the recorder off.

Despite using interviews as the method of data collection I aimed to ensure that the participants felt at ease. One of the participants, Angela, mentioned that she was '*very nervous*' and didn't think that she would know the correct answers. I explained to Angela that there were no right or wrong answers, and in fact there may be no answers at all. I clarified that I would only discuss the information that the participants gave to me freely about what they felt was important to them. Angela seemed much happier after this explanation and appeared keen to continue with the research process.

I felt that the interviews naturally adopted an open conversational approach and it was not my intention to ask a question about a subject that the participant had not previously made reference to. To remain in line with the grounded theory methodology I was aware after each interview concepts were emerging from the raw data. I wanted the participants to feel at ease and that they could stop the interview at any time. The participants were informed that there was no pre-set format and that I would endeavour to not ask a question that may make them feel uncomfortable in any way.

Eighteen participants initially verbally consented via the telephone to take part in the study and seventeen were interviewed using a grounded theory approach. The one person who was not interviewed wanted to receive dietary and medical advice as had informed me that she had recently been diagnosed with type 2 diabetes and did not know who to speak to regarding her weight, also that her practice nurse would not refer her to a dietician. I advised this lady to speak to her general practitioner about her concerns regarding her weight in order to obtain a referral to a dietician.

All of the participants were interviewed at a time and place of their choosing. Fourteen of the participants chose to be interviewed at their home. Wilf and Gail requested to be interviewed at their place of work. Whilst one participant, Derek, a pub landlord, chose to be interviewed at my home due to the fact that his living accommodation was above his pub and was, "*too noisy and we would be constantly interrupted.*"

All the interview dates and times were at the choice of the participants and I had no influence over their decision. All of the individuals were made aware that the interviews were to be digitally recorded and transcribed verbatim. Before each interview took place I explained that a follow up meeting would take place and all of the participants agreed. At the end of the interview, I once again explained that I would contact them regarding the follow up meeting once all the data had been collected and the interview was transcribed verbatim.

The first participant that I interviewed was Wilf; this was at his place of work. This interview led me into a false sense of security in the research process. It was organised and ran smoothly. We initially sat at a table whilst I explained the study. The consent and demographics forms were then completed and I turned the digital recorder on. The interview was very informal and I felt it went extremely well. I had made the decision not to make any notes during the conversation as I wanted it to appear more like an informal chat rather than a formal interview. I was also keen to sit and listen and I personally felt that if I made notes I may lose my focus on the conversation. The interview ended and the recorder was switched off and we said our goodbyes. This was my first interview and I felt very enthusiastic. I assumed at this point that the entire process would be fun but little did I know that not everything in research runs this smoothly.

Following the interview I remember having a big smile on my face, as I was excited at the thought of getting home in order to start the transcribing. I had already arranged the next interview which was to take place at Stuart's home in the evening in one weeks' time. I was keen for this to take place sooner and spent that evening and the following day transcribing Wilf's interview. I paused several times during the transcribing process just to read and review what I had written. This was due to the fact that I had become aware that I was not necessarily reading the words, but I was remembering the exact way Wilf had pronounced phrases, or when he laughed, became angry, or looked sad. I was aware of my actions yet I still followed the same process when I transcribed the following sixteen interviews. This process enabled me to not

only see the words that I was reading but also hear the emotion in the participants voices as they spoke. It was not until much later during my constant analysing of the data that I realised this phenomenon was one of the overall concepts of the research and I still hear the participants speaking as I prepared the writing up of this study.

Whilst initially analysing the first six transcripts, I struggled to read the words as I could not escape from the emotions that I heard from the participant's voices during the interviews. I discussed my thoughts with my supervisors and I explained that I was experiencing difficulties putting the participant's emotions to one side and focussing on the written words. I was starting to fear that I had become too close to the participants and it was only following much deliberation I accepted that this would prove to be an important and necessary element of the research process I was undertaking.

I came to the realisation that not only the facts actively expressed by the participants were important, but also the emotional context of how things were conveyed would also be a crucial factor that needed to be taken into consideration whilst analysing the data.

Having finally read the completed transcript of Wilf's interview, I suddenly realised the enormity of the project I was about to undertake. Even though I was still looking forward in anticipation for my next interview with Stuart, I was a little more daunted by all the information that I was about to receive from any further participants in my study.

When I arrived at Stuart's house, through large electronic gates with video cameras surrounding the property, all I could think of was, 'please do not have a big dog.' This was something I would have asked prior to attending a person's house as a podiatrist, but as a researcher for some reason I never thought to ask. That proved to be the least of my problems in conducting this interview. From the moment Stuart opened the door he started talking, not only about his diabetes, but his dad's diabetes and his wife's cancer. My recorder was in my bag, switched off, and I remember thinking that I had the demographics questionnaire and consent form to complete. This was in total

contrast to the experience I had encountered in my first interview with Wilf, where I had felt in complete control.

When I eventually sat down, I desperately tried to remember the vast amount of information that Stuart had already given to me, as we were walking rapidly through his home. As Stuart completed the relevant forms and once the consent form was signed, I switched on the recorder and composed myself in order to carry on with the conversation. The interview continued at Stuart's pace, whilst referring back to the information that Stuart had so graciously given to me on my arrival. The interview proceeded well and the recorder was switched off at the end. When I left the dining room and headed towards the door, Stuart took it upon himself to continue to divulge further information. He sounded frustrated, sad, defeated, annoyed and said he just wanted someone to talk to. I quickly thought what should I do? Do I reach for the recorder and break this bond we seem to have created in regards to his feelings about his diabetes diagnosis or do I run to my car afterwards and make copious amounts of notes? I decided to do the latter and sat in my car for thirty minutes recapping on Stuarts comments. When I eventually reached home I realised that Stuart had given me so much information, in fact, far more when we both stood at his doorstep than anywhere else. Funnell and Anderson (2004) refer to this as the '*hand on the knob syndrome*', whereby individuals provide information or ask questions when a meeting or appointment is about to conclude. In order to avoid this situation, they advocate encouraging the participant to speak about what they regard as important at the beginning of a meeting. I sought the participants to speak about what was important to them and not what I felt was important for this research. I did become familiar during the course of the research with, what I termed as, my 'doorknob moments.'

In my capacity as a healthcare professional I was aware that on previous occasions I had asked questions often in a very short space of time due to work constraints. This was to allow me the answers I required in order to make either further recommendations, an informed diagnosis, or to complete medical notes. Although having worked in private practice for many years I can afford myself the time and freedom to ask a question then sit back

(metaphorically) and enjoy listening to the answer. At the same time I was able to gather information at a pace and time that suited the individual and this was the approach I applied with this research. I was conscious that I wanted to ask one initial question at the beginning of the interview and then listen to the reply given. This would further enable me to ask open-ended questions dependant on the reply that the participant deemed important to them in relation to having type 2 diabetes. It is the aim in grounded theory that the researcher probes for detail and clarity during the interview process.

I became aware during some of the interviews that I had asked a few closed questions but this was to enable me to bring the participant back on track. This style of questioning, however, was only used when they had wandered off the subject for too long. I was mindful never to prevent a participant from speaking and I became aware that all of the information provided to me was deemed important to them.

I always felt comfortable with the interview process and was made to feel welcomed by all of the participants. I enjoyed the dialogue from participants and did not necessarily want the interviews to end, although I knew there had to be a natural conclusion to the interview stage. Cryer (2006) referred to the excitement that a new researcher found when using interviews as a research process. I have to admit that I found the experience of undertaking the interviews, both exciting and equally as daunting.

One of the difficulties I found as a practitioner was interviewing in the role of a researcher. From time to time I sensed there were three people involved in this project, Mandy the researcher in training, Mandy the podiatrist and Mandy the person. I had to remind myself before, during and after each interview that my role at that moment in time was as a researcher and not a healthcare professional. It proved very easy to sit and listen to the participants talking about their lives and what they prioritised, such as carrying on as normal, but I had to remain focussed on my research objectives

I was often amazed by the participants' generosity and kindness. Prior to our first meeting I did not know this person, but now here I am sat in their house

being offered a cup of tea, whilst being made to feel incredibly privileged by the trust they put in me, I was after all a total stranger, and they trusted me enough to tell me their inner most thoughts on a subject very personal to them, their health. Some participants felt it important to give me a tour of their home and show me their family photo albums. This did not inconvenience me in anyway, and I felt it was indeed part of the overall research process. I was after all there to find out what was important to them as an individual.

Prior to arriving at the participants' homes to carry out the interviews I had initially spoken to each of the participants on the telephone, confirming my name and the topic under discussion. During the interview process I was never once asked at any point to verify who I was or show any identification. I did however take several forms of picture identification with me to the interview just in case it was required. Majid was the only person with prior knowledge of me, but I am not certain if he was aware of my profession as a podiatrist.

Prior to undertaking the research I had made the decision that in the event of any of the participants asking my profession during the interview that I would be totally honest and state that I was a podiatrist. None of the participants asked such a question and when I introduced myself at the start of the study I simply explained that I was carrying out a piece of research on behalf of Salford University. I was particularly keen to ensure that I did not influence the participant's responses in any way and this may have taken place if they knew my background from the outset.

I wore casual clothes for all the interviews, and although I am not sure if this put the participants more at ease, it may have been one of the reasons why they did not ask about my profession as I was not wearing a uniform of any description. I do feel that this may have also assisted in individuals feeling more comfortable in divulging information to me.

Only one participant, Rebecca, asked me if I had diabetes. When I explained that I did not, she told me rather sadly, "*You are really lucky.*"

5.5.1 Transcribing

The participants were informed that I would be the only person transcribing the audio recordings with the information that I had obtained from them. Each person was made aware that at any time either one of my supervisors may request to listen to the recordings or read the transcripts. The participants did not object and several of them commented that they did not care who read the transcripts. I made the decision to undertake the transcribing process myself. I considered as a new researcher I needed to become immersed in the data and the most appropriate way for me to achieve this was to solely undertake this work. Each interview was fully transcribed within 24 hours of taking place. Thus allowing for emerging concepts to be explored and memos to be written whilst still fresh in my mind. It also assisted further concept maps to be designed and enabled developing concepts to be taken into consideration.

Each transcript took between eight and twelve hours to transcribe. In some cases I had to listen to the same sentence several times over to accurately record the correct wording. One participant, Ruth, spoke with a strong Welsh accent and although I thought I understood every word she said at the face to face meeting, I struggled with hearing some of the words on the recording. I was also aware whilst listening to the transcripts that several of the female participants would lower their voice almost to a whisper several times during our meeting. I was not aware of this taking place during the interview, so this came as a surprise and also frustrated me during the transcribing phase. Listening to the interviews, as I have numerous times, I was aware of the emotion that the participants placed on certain topics they wished to discuss. I remembered when participants were sad or happy or smiled or cried and this may have been lost if I would have allowed another person to transcribe on my behalf. I remained upbeat during the actual interviews and always left with this inner happiness that I had gathered so much information. When I undertook the transcribing, however, I became very emotional, sometimes laughing out loud but often crying.

5.6 Data Analysis

The data analysis was undertaken using a grounded theory approach.

A unique aspect of grounded theory study is that the data collection, coding and analysis run concurrently from the beginning of the research. Furthermore, the stated aim of grounded theory is the discovery of a core variable category. Strauss and Corbin (1998) suggest that the identification of the core category, which is an essential element of a theory, illuminates the main theme of the participants in the setting, and explicates what is going on in the data. Once sufficient data had been collected and transcribed verbatim, I continued to listen to the recordings and re-read transcripts and memos until I felt I was closely familiar with them in their entirety. From the first transcript I started a mapping process and set up tables in order to simplify the coding and allowing the data to identify the key concepts that emerged throughout. This allowed me to investigate and analyse the collected data in order to form concepts using a coding scheme. Although using a grounded theory approach I was still very much aware that I wanted the individuals in this study to remain just that, individual. It was never my intention to fit the participant's voices into a group of nodes or codes; this was never the purpose of this research.

5.7 The Coding Process

After the first interview was transcribed I reviewed the memos I had prepared both after the interview and during the transcribing phase. I then started to use the open coding system to code the individual words or phrases that Wilf had stated. Strauss and Corbin (1990, p.59) describe this as '*the process of breaking down, examining, comparing, conceptualising and categorising data*'. Once the second interview with Stuart had taken place I realised that I had so much material that I had to make sense of the information that the participants were providing me with and I also needed to feel comfortable with the coding procedure. An example of one of the first concept maps I produced is presented in Appendix IX. Whilst reflecting on the open coding process and the formation of concepts I originally created an overall mapping process which is detailed as Figure 2. This mapping system I devised proved to be an

iterative process which I continued throughout the earlier interviews where I then deemed it more appropriate to construct concept maps in order to fully incorporate the participant's voices. The mapping system allowed me to remain focused on the information that I had received from the participants but also to remain true to grounded theory and to observe the theories that were emerging. In the individual boxes of the mapping process I would write words or phrases that the participants had mentioned to me. I would also write down questions that I may have been asking myself during this entire process. I used an open coding method where I observed all of the participant's words.

The concept maps illustrate the words and comments that the participants at the beginning of the study expressed when discussing their diagnosis of type 2 diabetes.

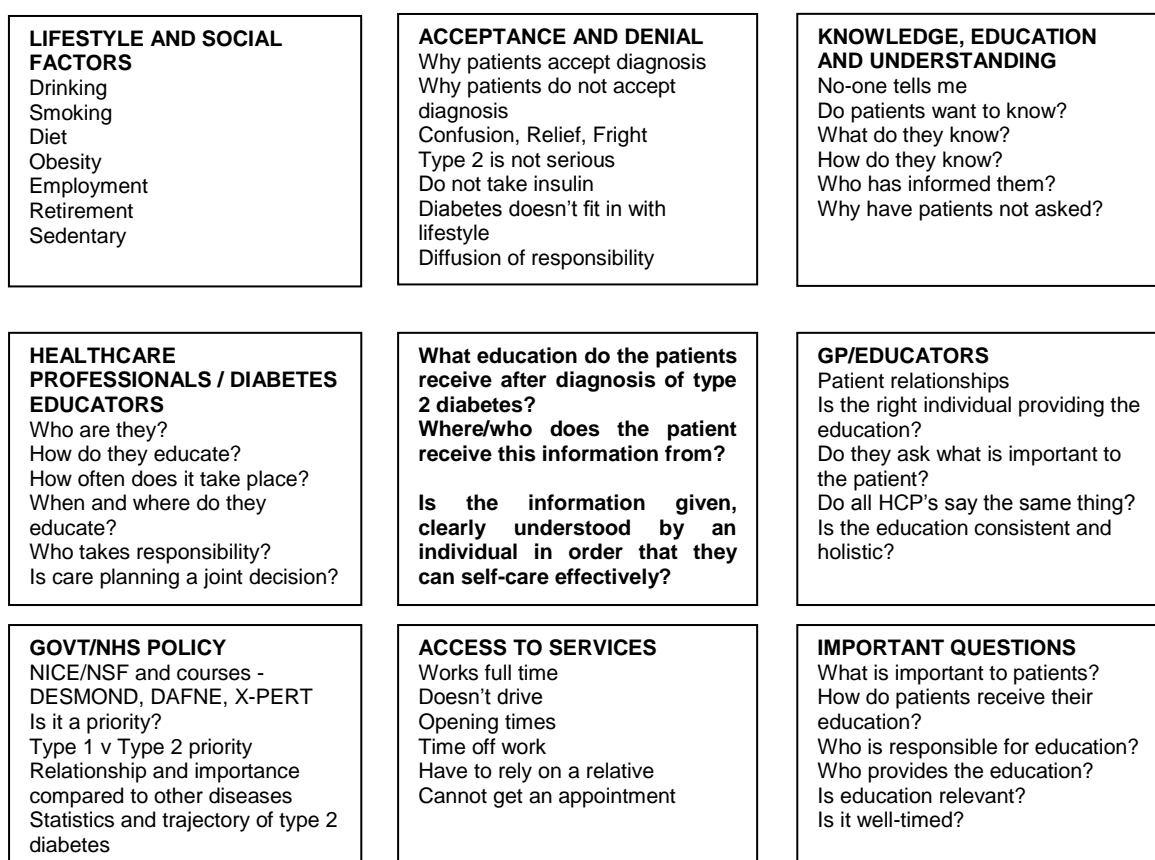


Figure 2: Continual Coding Process

During the interview and analysis process I remained aware that I was obligated to look at all of the words and phrases that the participants had given to me and to not merely focus on the points where they were emotional about a particular theme. It was at times like this that I spoke to my supervisors and expressed my anxiety about the emergence and the forcing of the data. I wondered if I was just focussing on certain concepts or if they were truly emerging from the data. As each new interview took place I was cognisant of concepts that were already emerging from the data previously gathered. I had to focus on each interview in its own entirety firstly as a new piece of information and secondly to appreciate any new concepts being created. This allowed me to establish and validate the relationships between the codes and enabled me to select the appropriate concepts and the causal relationships that are used in the selective coding process. I continuously compared each new transcript and all of the memos that were written with all of the previous information that I had been given. I constantly updated and remained focussed on potential emerging concepts that emerged from the data. The concept map (Figure 3) provides details of the key concepts that were emerging during the constant comparison process after four interviews.

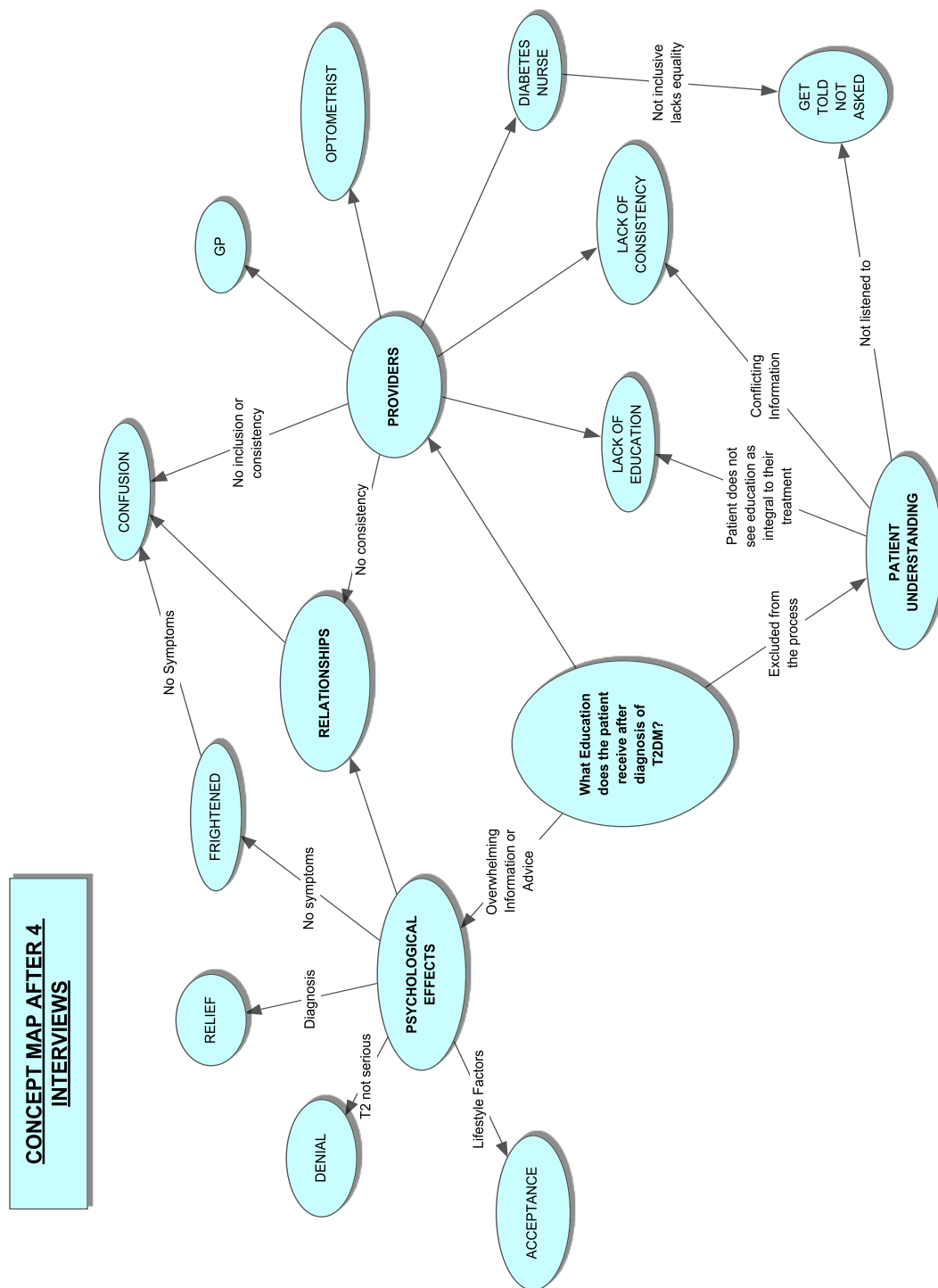


Figure 3: Concept map after four interviews

The key concepts that were emerging from the data after the first four interviews were:-

- i) The relationship with healthcare professionals
- ii) What the participants hear
- iii) What the participants understand
- iv) Thoughts and feelings about type 2 diabetes

I continued the concept map process throughout the research incorporating all of the interviews in the coding process. Figure 4 highlights the recurring concepts throughout the entire interviews. I remained mindful during each interview when any of the concepts were mentioned and I always encouraged the participant to expand on subject matters that were raised where possible.

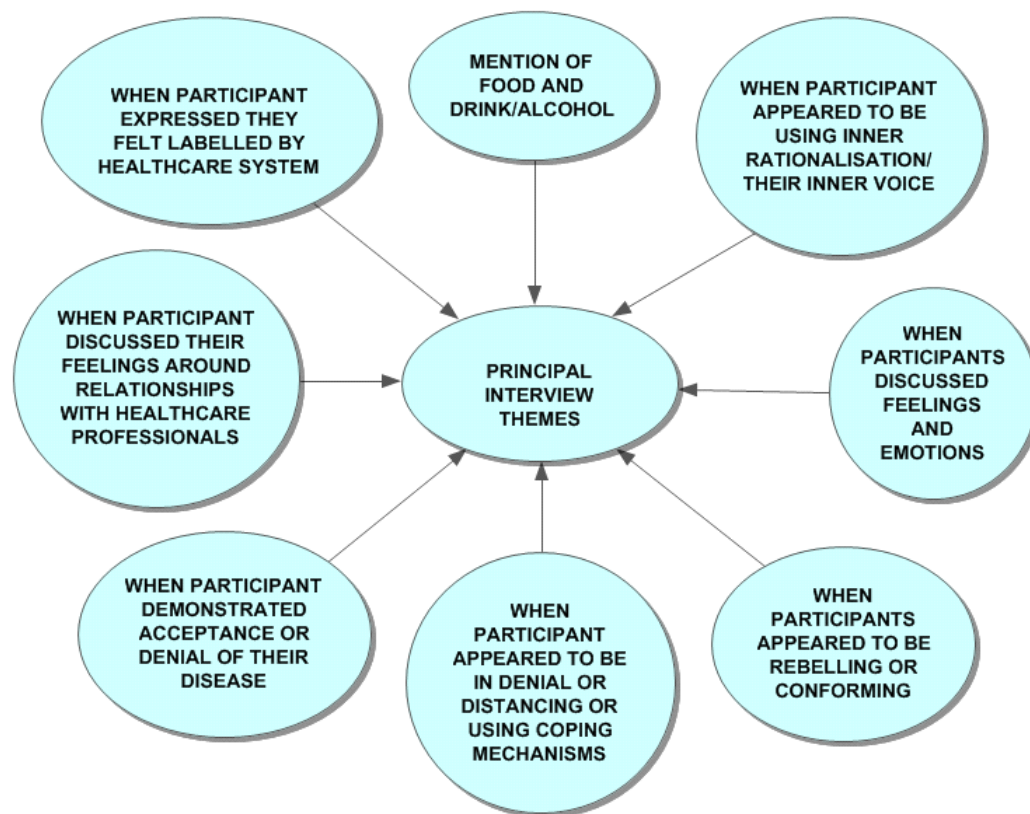


Figure 4: Key emerging concepts

In order to explain the findings more clearly the concept maps were further refined and are detailed and explained in chapter seven.

5.8 Conclusion

This chapter has explained the processes that were put in place prior to research commencing. Obtaining ethical approval, the recruitment of the participants and the initial interviews that took place. The chapter further explained how the methodology was undertaken in order to collect and analyse the data. The grounded theory method of constant comparison, formation of categories and subcategories and development of key concepts emerging from the data were undertaken.

The following chapter will give an overview of the participants who gave their time and without whom this research would not have been able to take place. For this reason I felt I had to give them their identity.

Chapter seven will then highlight the findings from the data analysis.

6. Introducing the Participants

6.1 Introduction

It was initially my intention to provide the reader with a complete background of each participant detailing their journey from initial diagnosis to this point. This was discussed at length with both supervisors as to whether this would be best placed in the body of the thesis or as an appendix. I had initially felt uncomfortable with the suggestion that the participants section would be more appropriate as should be an appendix, however, as a novice researcher I respect the experience that both my supervisors bring and came to realise that a full description of the participants in the main body of the thesis could potentially detract the reader from the research aim itself.

I have however provided a concise summary of each participant in this chapter as I am aware that this piece of research would not have taken place if they had not given up their time so generously. I did, after all agree to offer them a voice, so I feel it is important that they should be given an identity, and provides background and further context for the thesis findings

Prior to the interviews taking place the participants were provided with a questionnaire allowing them an opportunity to provide specific information, it included how they rated their health the duration of their diagnosis of type 2 diabetes and how their condition was being controlled.

6.2 The Participants in this Study

The following descriptions represent the seventeen participants who volunteered to take part in this study. For a more detailed understanding of the individuals stories please refer to Appendix X.

Wilf is a 62 year-old married man who is educated to college level and works as a handyman. He was diagnosed eight years ago and his diabetes is tablet controlled. He describes his health as 'good' and would like education regarding diabetes on a one to one basis and in an easy to understand format. Wilf further explained that he would like the education to be positive.

Stuart is a 54 year-old married man who is educated to college level and is a company director. He was diagnosed six years ago and his diabetes is tablet controlled. He describes his health as 'very good' and would like education regarding diabetes at a time to suit him, after working hours.

Winnie is a 92 year old widow who is educated to secondary school level and is a retired receptionist. She was diagnosed four years ago and since diagnosis has been told that no intervention or treatment is required. She describes her health as 'very good' and her daughter, who provides her care, would like to have some information regarding diabetes. Winnie commented that she was too old for education now.

Derek is a 51 year old married man who is educated to secondary school level and is a pub landlord. He was diagnosed eight years ago and his diabetes is tablet controlled. He describes his health as 'fair' and would like some education regarding diabetes but would not go to his local surgery for the education.

Ruth is a 72 year old married woman who is educated to secondary school level and is a retired NHS receptionist. She was diagnosed with diabetes over ten years ago and her diabetes was tablet controlled, during my second meeting, Ruth informed me that insulin is now part of her daily regime. She describes her health as 'fair' and would welcome some education regarding diabetes and her husband also expressed that he would like to attend.

Gail is a 60 year old married woman who is educated to college level and is a deep cleaner. She was diagnosed two years ago and her diabetes is tablet controlled. Gail describes her health as 'very good' and would like some education regarding diabetes, although she stated, it would need to be in plain English for her to be able to understand it.

Angela is a 68 year old widow who is educated to secondary school level and is a retired office worker. She was diagnosed six years ago and her diabetes is tablet controlled. Angela describes her health as 'fair' and would like some

education regarding diabetes and would prefer someone to visit her as it is difficult for her to attend her local surgery.

Bob is a 49 year old married man who is educated to secondary school level and is a care-worker. He was diagnosed four years ago and his diabetes is tablet controlled. Bob describes his health as 'poor' and would like some education regarding diabetes in the form of an education course.

Jon is a 42 year old married man who is educated to college level and is a prison guard. He was diagnosed four years ago and his diabetes is insulin controlled. He describes his health as 'good' and would welcome further education regarding diabetes. Jon would wish to attend another course, explaining that he enjoyed interacting with other people as this made him feel he was no longer alone.

Martin is a 69 year old widowed man who is educated to college level and is a retired HGV driver. He was diagnosed over ten years ago and his diabetes is insulin controlled. He describes his health as 'good' and would not wish to receive any education regarding diabetes. Martin expressed that he knows more about his body than any healthcare professional and explained that he listens to what his body is telling him regarding his medication.

Alan is a 58 year old married man who is educated to university level and is a retired researcher. He was diagnosed over ten years ago and his diabetes is insulin controlled. He describes his health as 'excellent' and would like some education regarding diabetes. Alan is happy to attend a course, but feels after ten years he has nothing new to learn.

Peter is a 77 year old married man who is educated to college level and is a retired surveyor. He was diagnosed over forty years ago and his diabetes is tablet and insulin controlled. He describes his health as 'fair' and would like some education regarding diabetes. Peter would like a DVD with subtitles as he does not hear very well, and further explained this would enable him to learn at a his own pace.

Don is a 78 year old married man who is educated to college level and is a retired minister. He was diagnosed over ten years ago and his diabetes is tablet controlled. He describes his health as 'poor' and would be happy to attend a further education course. He would like the educator to see him as a person and not merely treat the disease.

Pauline is a 75 year old married woman who is educated to secondary school level and is a retired telephonist. Pauline was diagnosed over forty years ago and her diabetes was tablet and insulin controlled. However, Pauline has not taken her insulin for over twenty years. She describes her health as 'poor' and would like some education regarding diabetes. Pauline is happy for Don to attend a course and then explain the information to her.

Majid is a 55 year old married man who is educated to university level and is a company director. He was diagnosed two years ago and his diabetes is tablet controlled. He describes his health as 'very good' and would like some education regarding diabetes. He would not attend a course however, as he feels that the information and the people who would attend would be negative, but would welcome a one to one session.

Rebecca is a 27 year old single parent who is educated to college level and is unemployed. She was diagnosed less than one year ago and her diabetes is tablet controlled. She describes her health as 'poor' and would like some education regarding diabetes. Rebecca would prefer someone to visit her home on a regular basis, in order that she could ask questions, until she fully understood diabetes.

Chris is a 69 year old widow who is educated to university level and is a retired head teacher. She was diagnosed ten years ago and her diabetes is tablet controlled. She describes her health as good and does not want to receive any education regarding diabetes. Chris explained that she would know more than the educator, but did comment that she would like a leaflet that she could refer to at her leisure.

6.3 Conclusion

This chapter was aimed to provide the reader with a brief summary of each of the participants.

The next chapter will illustrate the findings in relation to the participant's interviews and detailed analysis of the transcripts. The findings will incorporate the voices of the participants, my interpretation using an iterative analysis process, of the information conveyed by the participants, and the associated literature underpinning their experiences, beliefs, and perceptions in relation to their chronic illness.

7. The Findings

7.1 Introduction

The focus of this research was to understand what is deemed important to an individual upon diagnosis of a chronic disease, and how this may affect their quality of life and decision-making in relation to self-care management in the future. Through using the Strauss and Corbin (1998) and Corbin and Strauss (2008) methodological approach, the following five concepts emerged from the data as a result of the constant comparative and iterative analytical process;

- 1) **Insufficient education provided to participants** (in vivo code, *'Education what education?'*).
- 2) **Lack of information and support to self-manage the condition** (in vivo code, *'Why can't they just tell you what diabetes is?'*).
- 3) **Relationships with their healthcare professionals** (in vivo code, *'They just tell you what to do, they never ask about me'*).
- 4) **The participant's experiences, perceptions and beliefs** (in vivo code, *'I just wanted something I could read and understand. They make you feel stupid'*).
- 5) **The participant's feelings with regards to their lifestyle and type 2 diabetes** (in vivo code, *'I just carry on as normal'*).

An in vivo code can be a word, a phrase or a concept that is found in the data. It can be a feeling or a belief or an experience provided by an individual, and the words are not modified in any way. This may then develop into a concept and is designed to inform the reader as to what is occurring in the data (Strauss and Corbin 1998).

The following sections provide further insight to the specific findings, incorporating the participant's quotes and commentaries, supported by academic literature in relation to the emerging concepts. The work will also include the substantive theory found as a result of the methodological research process undertaken.

7.2 Participants' Education and Information

'Education is the most powerful weapon which you can use to change the world.'

Nelson Mandela (1994)

The management of diabetes mellitus requires the crucial element of effective patient education in order for it to be successful (Anderson and Funnel 2009). Graber *et al.* (1977) however, stated that an assessment of its value and effectiveness was limited. Assal *et al.* (1997) further explain that patients who do not receive appropriate education will potentially require more frequent hospital visits and increased episodes of hospitalisation. Their literature also illustrates that those patients with a poor metabolic control may lose confidence due to experiencing progressive negativity from healthcare professionals.

Seventeen participants took part in this study, with only three being offered any form of structured education. Two of the participants attended an education group and the other participant declined due to '*not being in the right frame of mind, at the time*', and having '*many other illnesses to think about.*' Five participants stated when questioned that they would decline an education course for the following reasons: - one person because he would not be able to hear the teacher, two people stated they would know more than the teacher, one person declined because he did not want to hear negativity or be around negative people, and one person expressed she would feel uncomfortable in group situations. Four of the five participants stated however, they would be happy to have a one to one session with a diabetes specialist in order to discuss their condition. The remaining twelve participants, including the two individuals who had previously attended a course indicated that they would be willing to attend an education course, should it be offered. It was also apparent during the interviews relatives of the individuals, namely, Stuart and Peter's wives, Ruth's husband and Winnie's daughter, also commented

that they would like to attend any diabetes courses that were offered, in order to provide support.

Figure 5 represents a concept map that was constructed during the interview process and analyses the data in relation to the education or information participant's received and their perceptions and beliefs towards diabetes education.

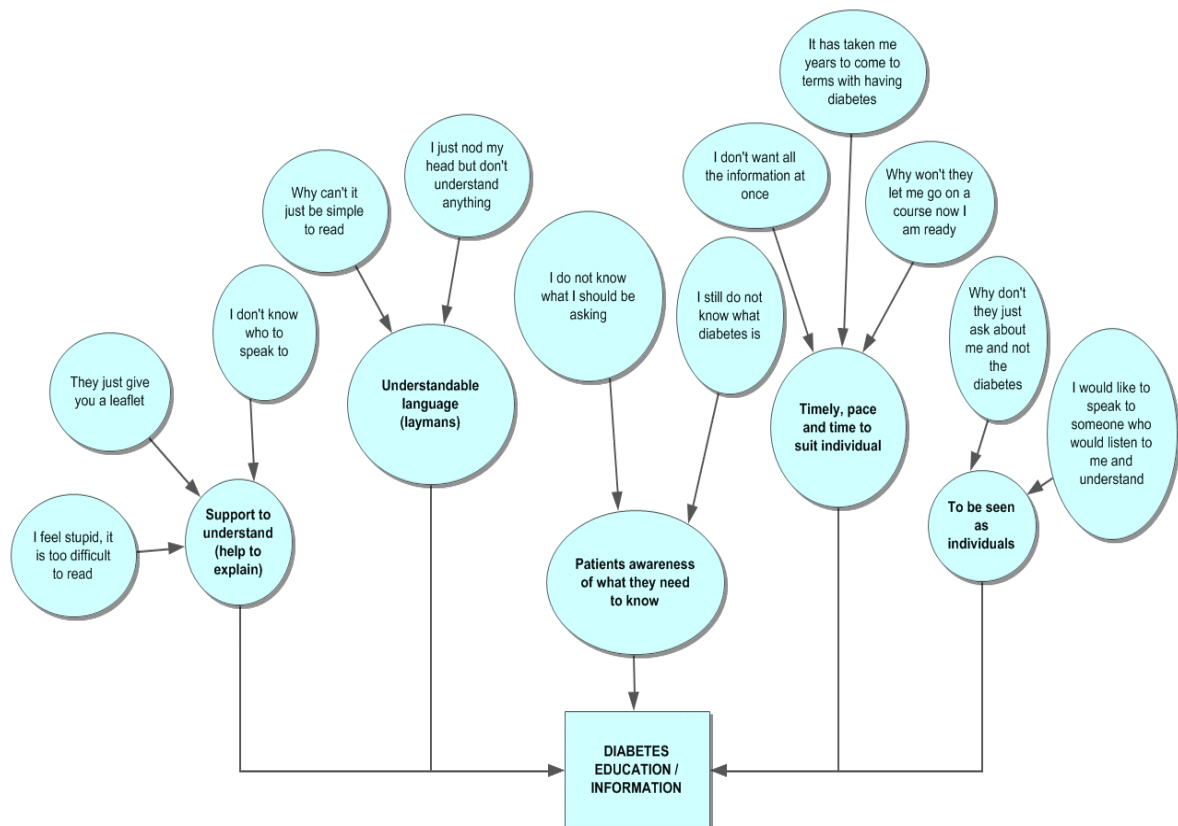


Figure 5: Diabetes education / information

The concepts that emerged from the data were:-

1. Lack of support regarding information given
2. Language used
3. Patients awareness of what they need to know
4. Information at a timely pace
5. To be seen as an individual, not a disease

During the interview process, I became aware that the participants did not appear to question any healthcare professional that they came into contact with. On discussion with the participants they generally informed me that they

did not feel it was their place to ask or question the general practitioner or the nurse. They further mentioned that they did not necessarily know the appropriate questions to ask regarding diabetes.

Prior to the interviews taking place, all of the participants were provided with a participant consent form. A section of the form asks participants to provide consent in order that anonymised quotations could be incorporated and utilised in the writing up of the study in order to anonymise the comments. Each of the participants was asked how they would wish to be referred to within the main study text. Each participant stated that they preferred to use their own name and therefore not be anonymised. I consequently advised the participants to strike through the word anonymised and provide their initials in the box provided in order to gain their consent for this to take place. I have subsequently retained all the consent forms, thus enabling the participants to maintain their own identity in this study.

All of the individuals were asked what education or information they were provided with post diagnosis in relation to their chronic condition.

Winnie was diagnosed with type 2 diabetes four years ago and said she had not been given any education or information since being diagnosed. During an inpatient hospital stay and she questioned;

“Education, what education?”...Winnie

When I asked Winnie who she had been referred to in the healthcare team, she laughed and commented;

“Care team, what care team? I never knew anything like that existed, maybe it is because I would be too old to understand”...Winnie

Chris explained;

“I don’t recall having very much information at all in regards to my diabetes, I got nothing from the doctor”...

Chris

Chris commented concerning her knowledge of the disease and mentioned that this was something she felt strongly about as she was the head of a school for many years;

"I only think that we can make up our mind with the knowledge that they give us and if they do not allow us to get the knowledge in the way that suits us, then we are not making the right decisions are we. There has to be information before people can make an informed decision"...Chris

Several participants explained to me that they had no idea what diabetes was;

"I have never been told what diabetes is. I don't expect the doctors to come and visit me but I only go every blue moon and they never have time for you, how can I look after this diabetes if I don't even know what it is?"...Angela

"I have never once had diabetes explained to me, I still don't know what it is, but at my age I am past caring now"...Martin

"How can I look after my diabetes if I don't know what I should be doing"...Gail

"I still have no idea what diabetes is, I just know I have to take my insulin, although I don't take it a lot of the time, I just take my tablets instead"...Peter

"No one ever told me what diabetes was, they gave me insulin and I didn't even need it, perhaps they don't know what it is"...Pauline

The timing of education was a common theme that ran throughout the interviews and participants were not in agreement as to when and how this information should be given. This particular aspect was an element of the research that surprised me the most. As a practitioner I had always considered that I had provided comprehensive and valuable information to all of my patients at each and every appointment. This made me reflect if indeed my patients had understood the guidance and the information that I had provided for them;

"I would have preferred to have been told I had diabetes and then given information in stages, because it was just too much at the time and I had other things in my life that were more important to me at the time. If you are given too much information you cannot digest it all in one go" ...Bob

"You cannot just tell somebody what to do, they have to get the message themselves and that is the way the diabetes education should be" ...Don

"You need to understand diabetes for yourself, you will not take anything in until you have accepted that you have diabetes" ...Majid

"I am not able to discuss my diabetes with the doctor or the nurse, I don't know what I should be asking because I don't know what I am supposed to know. How do you know what you should know if they don't tell you anything" ...Gail

"It would not have done me any good to go on an education course when I was first diagnosed, because at the time I was not in a good place and doctors should take that into consideration when they tell you that you are ill. They don't understand that you can't just do what

they want, when they want you to do it, life is not that easy”...Bob

During his interview Majid stated that he only dealt with his diabetes once he had come to terms with it psychologically, but was ‘*frustrated*’ that it took him twelve weeks for this to become evident. He was ‘*annoyed*’ that there was no information or help during this adjustment or ‘*believing period*’ as he called it and maintained that;

“This is the time when it is vital to give information to patients so that they are not diagnosed and then left in disbelief”...Majid

Majid admitted that when he was first diagnosed he searched on the internet in order to try and find some answers, and articulated that this act merely led to him being more ‘*confused*’, as he still did not associate himself as having diabetes and the information ‘*frightened him.*’ Majid then went on to further explain;

“What I would have liked is that the doctor’s practice would have had some kind of programme or something that they insist that you go on for say six weeks, for three hours a week, that is enough to digest. I would also suggest that it is a one to one and not a group as everyone is an individual”...Majid

However, Majid stated he would no longer be willing to attend any group style of education course as;

“I simply do not need it, I have come to terms with the fact I have diabetes, for me it has always been about accepting it, I don’t want to sit in a room full of negative people”...Majid

Lalau *et al.* (2006, p.73) recommend that ‘*every individual should have access to a type of education that enables maximum development of their potential*

and capabilities.' They also explain that healthcare professionals may become so absorbed in healthcare objectives and forget that a crucial element of their role is to action and transfer '*dialogue*' to the patient.

One of the key factors in this research was that some of the participants were only given an information leaflet or booklet and told to go away and read it. This led me to reflect on my previous practice, as a practitioner in my first podiatrist role. I had always handed out photocopied leaflets and wrote in the patient notes, diabetes education provided, proudly recording the date and signed the notes. Questioning this I now realise, I had met the needs of the healthcare service I was employed with; however, did this meet the individuals' needs.

Gail mentioned that she was provided with a leaflet and explained, whilst crying, that she could not understand the information. This made Gail feel very frustrated and she explained that she genuinely wanted information concerning her condition as she had epilepsy most of her adult life and wanted to know if her diabetes could affect it. Gail also commented that she required explanations in a way that she could understand.

"I did start reading all the paperwork that the nurse was printing off and it was boring me. I just want a leaflet I can read and understand. I just want it written in plain English, just how I speak. The leaflets make me feel stupid because they are too difficult to read" ...Gail

Gail was emotional and cried throughout her interview, reiterating she was '*not stupid*', but although this that is how she was '*made to feel*', as she had no one to talk to regarding her condition.

Angela stated;

"I would just like something simple to read, something that I would understand that would not go over my head. I would feel alright if they just gave me little updates every now and then. I would feel ok with that" ...Angela

Angela has a son in law who has type 1 diabetes and she has tried previously to read the literature that he receives by post from Diabetes UK;

"My son in law gets a special magazine through the post and I have tried to read it, I don't understand a lot of it and you feel daft asking him, because he has proper diabetes, you know the one where you have to take insulin"...Angela

Winnie commented;

"I don't think I would understand a leaflet, I am a bit old to be reading now"...Winnie

Her daughter Barbara expressed;

"I would really like to try and read it, but I don't know if I would understand it. The nurse who comes to the house wouldn't have time to explain it, she is always so busy. It is not her fault, she just takes mums blood and never talks about diabetes"...Barbara, (Winnie's daughter)

Bob commented;

"The stuff that they give you to read is difficult to take in and when you have a question, who do you ask?"...Bob

Wilf admitted;

"I had no education, nothing, not even a leaflet from my doctor, I looked at a work colleagues once but it was too difficult. I tried to read it but it just talked about blood sugars being too high and I don't understand it, it was too medical for me (laughing)"...Wilf

Martin was diagnosed with type 2 diabetes over twenty years ago, and noted;

"At the time I just wanted a leaflet I could read and understand, I picked up a diet sheet but you would not be able to stick to that. There is no explanation"...Martin

Rebecca explained that she would need to speak to someone and go through the information;

"I don't want a load of leaflets that are not explained to me. I don't understand the information that they give to me, they should treat us as individuals and not treat us all the same. My mum has diabetes as well and she is not very good at reading so she is embarrassed to tell the nurse, but that nurse, she doesn't care she just ticks her boxes"...Rebecca,

Gail, Bob and Ruth all explained that they were given an information leaflet after diagnosis but felt embarrassed as they were unable to understand the terminology;

"I am not a stupid person but the leaflet made me feel stupid"...Gail

"The leaflet was too complicated anyway and was far too medical, I mean why can't they let you just speak to someone who can explain it to you in a way that makes sense"...Bob

"They just give you a one page print out; it was about checking your feet. I didn't understand the rest of it. If it was important, they would tell you at your check-up, wouldn't they?"...Ruth

Schillinger *et al.* (2002, p.475) described health literacy as an assessment of an individual's '*ability to be able to read, comprehend and act on medical instructions.*' They also highlighted that poor health literacy may contribute to poor health outcomes and are common in elderly people and those patients

suffering with chronic conditions. Healthcare professionals must consider patients self-management skills and health literacy levels in order to improve health outcomes and potentially reduce complications (Tang *et al.* 2007). The development of effective communication strategies has also been suggested in order to gain an increased understanding of patient's needs and competencies.

Don explained that he felt that '*they*' had no time for him as a person at the clinic and that they just treated every person with diabetes the same way;

"They have never once asked me a question at the clinic, I was diagnosed 13 years ago and I couldn't read then, I never learnt to read till I was 74. I suppose the nurse just assumed I could read at my age, but she never asked me if I had read the leaflet, if she would have asked about me at the time I would have said, I can't read"...Don

Don went on to explain that his wife Pauline had previously read for him;

"What if I had no Pauline? I am sure not everyone can read or has a partner that can read for them. They should find out more about us. Why do they treat us all the same? If the nurse had given me a video, I could have watched that instead"...Don

On diagnosis Majid initially received a diet leaflet and was informed by his doctor that this was merely a guide. Majid was glad to be told this as he commented;

"To be frank the diet leaflet excluded just about everything except for oatcakes and all the boring stuff. I threw it straight in the bin"...Majid

In terms of further education, Majid explained that he relies on the internet for information regarding diabetes and understands that his doctor does not have the time to explain in detail his condition to him.

Initial assessment of a patient's knowledge was suggested as a starting point by Graber *et al.* (1977) although it was also recognised that knowledge alone was not enough and its application would be required in order to improve daily management. As part of the interview process I asked all of the participants to tell me what they knew about diabetes. I also asked how they would prefer to receive education or information regarding their condition. The reply from Peter led me once again to reflect on the information that I had provided as a practitioner, and if it indeed suited the patients specific requirements. Peter commented;

"I never knew I was supposed to know anything about diabetes or that I have to look after it myself. You are the first person who has mentioned it to me. If I do need to know something, I would like a video, where I could stop and start it. I don't hear very well you see so sometimes I have to listen to things a few times. So is this diabetes important then if you are asking questions about it?"...Peter

Most of the participants agreed that they would readily attend an education course and that they felt it would be beneficial to their understanding of the disease. I found by speaking to the participants that they did not necessarily appear to be aware of the complications that may arise from type 2 diabetes. They also appeared to assume that type 2 diabetes was not as serious as type 1 diabetes and that only people with type 1 would eventually develop symptoms and complications.

Lochrie *et al.* (2009) explored the issues faced by healthcare professionals in avoiding the presentation of detailed and alarming information to newly diagnosed patients who did not necessarily suffer from diabetes complications. Both Winnie and Chris relayed separate stories to me about

close friends who had experienced complications which led to lower limb amputations and premature deaths. Winnie and Chris also however, informed me that both friends had ‘*serious diabetes type 1*’ whereby both were taking insulin. With the increasing variety and formats of information now being available to patients, Lochrie *et al.* (2009) raised the importance of patients receiving quality information from a ‘*diabetes expert*’ in order to aid understanding and interpretation.

Some of the participants were aware of the need to speak to someone in relation to their condition, however when I asked if they had actually spoken to anyone, the following comments were recorded;

“Do you know I have never seen a proper diabetes nurse, you know a specialist, who can explain things to you”...Gail

“Where are you supposed to get information from? The doctors say nowt and the nurses won’t see me and the receptionist don’t make me an appointment. Surely there must be somewhere I can go to find out what diabetes is”...Derek

“They never tell me anything, I am very overweight, at the start I wanted to see a dietician, I did go to weight watchers but it is too difficult”...Angela

Other participants also expressed having some knowledge of self-care management;

“I think I am supposed to get my eyes checked and see a foot person, chiropodist or someone but I haven’t been told to go so I don’t”...Stuart

“They do tell me why it is important to have your feet checked, but I know that anyway”...Alan

“I know my feet are important that is why I pay to have them looked at”...Chris

“I know what I should be eating and what I shouldn’t as this is important for your sugar levels, whether I am doing it right, I do not know”...Ruth

Gillibrand (2010) observed that research undertaken by Gorter *et al.* (2010) revealed that eighty per cent of individuals studied, preferred education during their check-up appointment and that tailored education should be provided by healthcare professionals to those newly diagnosed with type 2 diabetes. Mensing and Norris (2003) also identify that group education can be a cost effective alternative to individual education provision.

Only two participants had attended a group education course, but commented that they would most definitely go to another one if it was available;

“I went on a DAFNE course eighteen months after I was diagnosed, it was the right time, and I wouldn’t have understood it when I was first diagnosed. It was great because there were people of all ages and I no longer felt alone. I could talk to other people who knew what I was going through. I would love to go on another education course”...Jon

“When I attended the DESMOND course they started off and they explained a little bit about diabetes, but all they were concerned about was weight, and losing weight. It made us all laugh, the nurse was over 21 stone, how could she talk to us about losing weight, I said to her physician heal thyself”...Don

The following participants who were not offered any structured and education, commented;

"I would love to go on a course, I would absolutely, definitely. I crave information about anything, everything and anything. To me there is no trivial information. They have never offered me anything at that surgery, who do I ask?"...Derek

"They never told me to come back when it had sunk in they never asked me if I had any questions, they just told me I had diabetes and that was it. I would go on a course, I could ask questions there"...Gail

"They have told me nothing at the surgery, just nothing. If there is a course I will go on it, but I would prefer to speak to someone one to one until I can understand it"...Rebecca

"I never got given anything, but I have had diabetes for a long time, they probably didn't have courses in those days"...Martin

Rebecca, was 'extremely annoyed' at the 'inadequacy' of the healthcare system. Having recently been diagnosed with type 2 diabetes, she expressed that she would love to speak to someone in order to understand how to control her sugar levels;

"I want to see a diabetes educator, not a nurse. I want to go through everything. I just want someone that I can go to because maybe I would have forgot what they told me three weeks ago so I could go over it. I just want someone who would take the time to sit down and explain it to me so that I can understand it"...Rebecca

Rebecca explained that due to her bi-polar condition she did not feel confident going into a group education session, but stressed;

“I would love someone like you to just come around, like you did today, not in a uniform and telling me what to do but just someone who would listen to me and then explain things clearly or at least until I was able to understand, I would be able to explain it to my mum then”...Rebecca

Diabetes education may be considered a complex and varied task due to the aspects of the disease that need to be controlled; the behavioural changes that are required; and the strategies required to enable individual patients to achieve their medical objectives. Assal *et al.* (1997) highlight that patient's may experience denial regarding the silent long-term complications and that healthcare professionals may become bored with treating a chronic complex disease, where patients appear de-motivated. Medical staff may have ideas and aims of curing individual's disease but this will prove a fruitless endeavour with diabetes being a chronic incurable disease (Assal *et al.* 1997). Wilkinson *et al.* (2013) illustrate that individuals undergo different learning experiences although patients with chronic diseases do appear to improve their self-management techniques by learning from others.

Gail expressed that she receives all the information she requires regarding her type 2 diabetes from her colleague who has type 1 diabetes. Bob also commented that his work colleague, who has type 1 diabetes, informs him of what he needs to know. Derek however, has a friend that had previously been diagnosed with gestational diabetes who has advised him that his type 2 diabetes will no longer present if he follows her course of action and loses weight.

It was reported by New (2010) that patient education must involve individuals as part of the learning process in order to motivate and promote competence, meet their personal learning needs, reinforce positive behaviours and to develop awareness of the consequences of their actions.

Tessier and Lassmann-Vague (2007) have recognised that there are a multitude of barriers in existence that limit the successful transfer and application of knowledge.

Bob explained that he did not understand what he was being told in regards to diabetes for the first two years;

"I have had other more pressing issues in my life to deal with" ...Bob

Bob did however inform me that after a period of around two years he had started to think about his diabetes. At this point he enquired with his practice nurse as to whether any education was available and was informed that it was no longer offered. Bob then proceeded to make his own enquiries via the internet for any up to date information on type 2 diabetes. He discovered an on-line diet that led him to reduce his calorific intake to 500 calories a day in the hope that his diabetes would 'go away'. I discovered this practice on my return visit to him and Bob explained that he had read an article entitled '*Getting free of type 2 diabetes*' and that if he followed the 500 calorie a day diet, his diabetes would no longer be present. He also advised that he had not mentioned or discussed this with any other healthcare professionals or his general practitioner.

This section has highlighted that the need for information or education is vital for a person with a chronic condition and that the time and place for this must be flexible and ongoing. Most of the participants stated that they were not entirely sure what diabetes was and others did not appear to demonstrate knowledge or awareness of its implications. Many viewed the disease in terms of restrictions on their lifestyle, such as reducing the sugar content in their tea, for example. The participants stressed that they wanted information to be provided in a way that was easily understandable and not written in medical terminology. It was also a recurring theme that they wanted to be spoken to in dialogue that they could comprehend and it appeared important that each person felt that they were being listened to instead of "*being told off, or told what to do.*" I therefore feel it is imperative that the healthcare professional

providing the education has the appropriate skills and knowledge in order to establish individual needs or requirements in terms of the information and format in which they wish to receive it. Willaing (2013) as part of the DAWN2 study found that healthcare professionals are aware that there is a necessity for key developments regarding diabetes education. There are very few healthcare professionals however, who are skilled in this field to provide the relevant education and support required (Willaing 2013).

This section indicates that the participants do not necessarily possess the relevant knowledge, information or education in order to self-care effectively.

‘The patient who knows the most lives longest’

Elliot P. Joslin (1916)

7.3 Participants’ Empowerment and Self-Care Management

‘Diabetes belongs to the patient. Knowing what is best for a patient’s diabetes is not the same as knowing what is best for that person.’

Funnell and Anderson (2004)

Self-management education is complex and emotionally challenging but should enable patients to feel empowered to know and understand their condition (Funnell and Anderson 2002). They are, after all being tasked with the management of their daily diabetes care and may be required to change their behaviours, set personal goals in relation to diet and exercise, cope emotionally and physically, solve specific problems and ultimately make decisions about their health and lifestyle. Norris *et al.* (2002) advocate that for self-management to be effective, behavioural interventions should be feasible, long-term, cost-effective and practical in a variety of settings, and patients must be willing to participate and psychological outcomes and quality of life should also be taken into consideration. Thomas *et al.* (2014) illustrate that a range of studies associate self-management with a reduction of hospital tendencies, emergency room and outpatient appointments and health suffering for individuals.

Figure 6 identifies the factors that the participants deemed to be important to them in relation to their self-care management. It became apparent at this stage that most of the participants in the study did not seem to be aware of what they were supposed to manage, as they appeared to have a limited understanding of type 2 diabetes and the complications that may arise from their conditions.

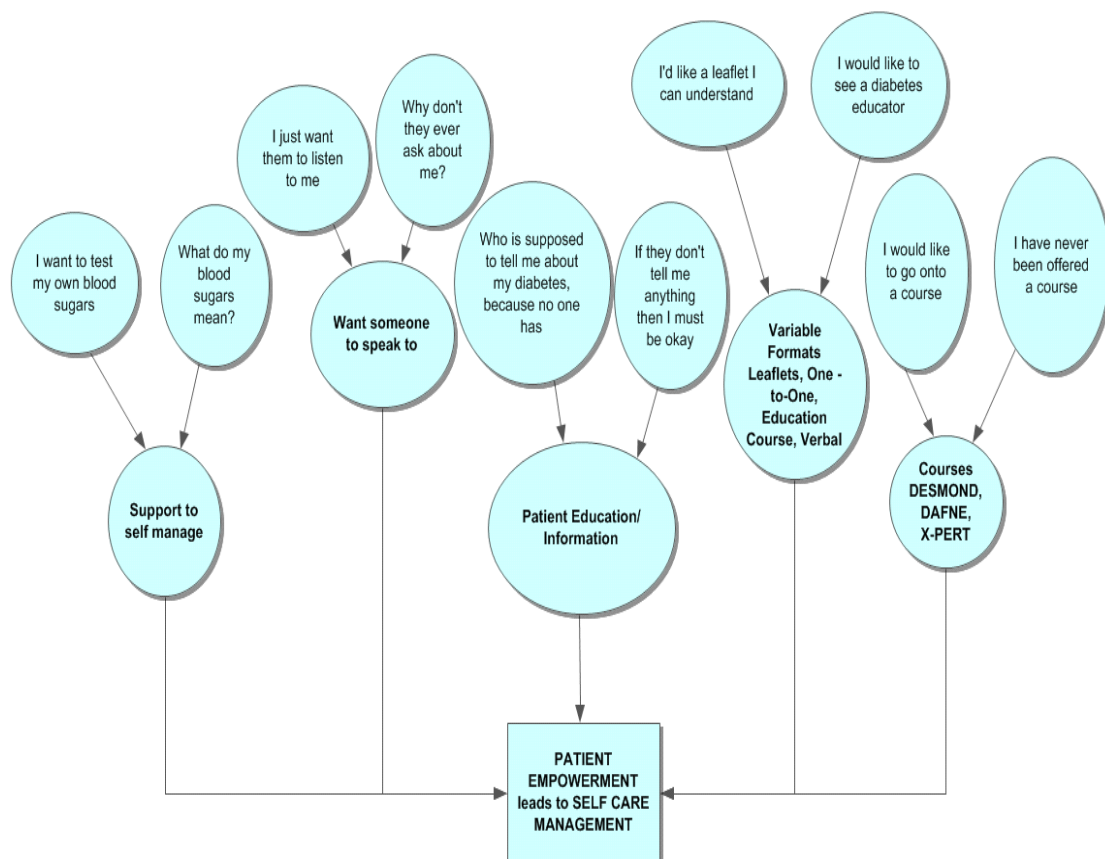


Figure 6: Patient empowerment and self-care management

The concepts emerging from the data in relation to patient empowerment and self-care management were:-

1. Support to self-manage
2. Require two way conversation
3. Patient education/information
4. Different formats of education
5. Courses available

There has been a considerable amount of academic literature produced in relation to the subject of self-management for patients with type 2 diabetes. Diabetes self-management education is often considered to be a critical element of care that ultimately improves patient outcomes and may be classified as *'the on-going process of facilitating the knowledge, skill and ability necessary for diabetes self-care'* (Funnell *et al.* 2009, pS87).

Several of the participants commented that they did not know what they were supposed to know about their diabetes in relation to self-care;

"When I was diagnosed with my wife, they told us nothing. We never knew what to ask, we just thought the doctor would tell you" ...Martin

"I haven't really been told what to do and I am a very big girl as you can see, but the doctor or nurses haven't mentioned my weight or my diabetes" ...Ruth

"If the doctor wanted me to know more about diabetes he would have told me" ...Pauline

"What am I supposed to know about diabetes, I have regular check-ups for my epilepsy but I have never had a check-up for my diabetes" ...Gail

Baumann and Dang (2012, p.33) illustrate a wider definition of self-care as; *'The ability of individuals', families and communities to promote health, prevent disease and maintain health and to cope with illness and disability with or without the support of a healthcare provider.'*

By encouraging patients to actively self-manage their condition it is envisaged that mortality and disability rates may be improved, healthcare costs would be reduced and individuals may increase the quality of their life (Jerant *et al.* 2005).

I found that the majority of participants sought to test their own blood sugars and that certain individuals had requested self-testing kits but had been

refused by the practice nurse due to financial restrictions. Although the participants in this study did not mention the specific terms, 'self-care' or 'self-management' they did however make reference to activities such as testing their own blood sugar or controlling their own diet.

I asked the participants during the interview process if they knew what their blood sugar levels currently were;

"They have never told me what my blood sugars are. My friend tested me with her machine and it was 15.5, and she were saying that was high. I had been diagnosed a couple of years then and I have never had them tested since, is 15.5 high, I have no idea?"...Derek

"I think I am supposed to have one of those blood testing kits, but that nurse will not let me get one, I asked her once and she said, men never use it properly, it is a waste of money, so I have no idea what my sugar levels are"...Don

"I don't know what my sugars are and even if we were allowed to test our own sugars, I wouldn't know what normal means anyway"...Peter

"I wanted to know what my blood sugars were, so I bought my own machine as the clinic would not let me have one. I am not sure if I am using it properly as no one has ever shown me and the strips are really expensive"...Angela

Stuart has been given a testing kit from his local practice in order to check his own blood sugar levels but told me;

"It is still in the box, I have never felt the need to check my sugar levels because I have never felt wishy washy

like my dad used to. When I have to take insulin I will test my sugars but only if I have to"...Stuart

Majid has been given a self-testing machine from his local doctor's practice and commented;

"I have not had the need to use it because I am very self-aware. I know when my blood sugars are getting low"...Majid

Majid further explained;

"From time to time I feel that you do need a little bit of sugar to prop me up because I feel so tired or so irritable, I have a biscuit or a banana or anything with just a tiny bit of sugar in and I come back to life again"...Majid

Heisler *et al.* (2005) indicated that those patients who were aware of their HbA1c levels had an increased awareness and understanding of glycaemic control. It was evident however that this alone was not satisfactory for self-management with behavioural strategies also deemed necessary to motivate and assist individuals.

Alan and Majid were the only participants who were aware of their blood sugar levels during the first interviews. At the second meeting Ruth knew her blood sugar levels as she had recently become insulin dependent. Prior to this she had been informed that there was no need for her to test her own blood sugar levels.

Ingadottir and Halldorsdottir (2008) identified that patient adherence involves co-operation by two parties; the healthcare professional who prescribes and the patient who adheres. Their research includes reference to a World Health Organisation report in 2003 that described poor adherence as a '*worldwide problem of striking magnitude*' and that only fifty per cent of patients in developed countries followed treatment plans.

Traditional assumptions regarding the responsibility for diabetes management are being challenged and terms such as ‘adherence’ and ‘compliance’ are being replaced by self-care and self-management. Table 10 represents a summary of Ingadottir and Halldorsdottir’s (2008) findings.

Table 10: The essential structure of mastering diabetes

Knowledge, Understanding and Experience	Fighting Fear in the Search of Safety	Dealing with Desires	Freedom or Constraint? – The Question of Autonomy
Learning about diabetes, insulin, and their effects on the body	Fear of hyperglycaemia	Desire to do right	Independence and being responsible for oneself; the meaning of diabetes
Listening to the body – the guiding light	Fear of diabetes complications	Desire to be normal	Knowing oneself
Learning self-monitoring of blood glucose and insulin injection	Fear of the truth	Temptations	Self-determination and controlling oneself; the meaning of adherence
Learning to be organised and proactive in the social context			The value of person-centred support

Source: (Ingadottir and Halldorsdottir 2008)

Some participants in the study felt that diabetes had been allowed to control everything in their life and it had proved to be a ‘*constant battle*’. Despite knowledge, understanding, adherence, and experience proving fundamental to self-management, they are not sufficient on their own.

Typical self-management involves patients paying close attention to their diet, levels of physical activity, blood glucose monitoring and diabetes medication

(Gregg *et al.* 2007). The idea of patients with diabetes being able to manage their own condition has been discussed for many years and Elliot Joslin's early writings (1916) talked of the three elements of insulin control, diet and exercise in order to achieve 'victory' over diabetes and effectively self-manage.

Albright *et al.* (2001) expressed that self-care trends have recently developed from 'education only' to 'education plus behavioural' models whereby specific aspects of patient characteristics, the patient relationship with their doctor, psychological stress and their social context may be taken into consideration. Their research highlighted the importance of family support and knowledge of diabetes in order for patients to be able to self-manage. The shift from a traditional model of care where the patient played a more passive role, to a position whereby the patient plays an active role as a '*partner*' in their disease management has taken place. The traditional model was based on a didactic approach involving the transfer of instructions and knowledge, whereas the focus now concentrates on changing patient's behaviours in order that they may successfully manage their daily conditions and improve their quality of life (Trappenburg *et al.* 2013).

The need to introduce and continually improve diabetes self-management education standards was highlighted by Mensing *et al.* (2000) where the appropriateness, relevancy and scientific basis of education standards were to be formally reviewed on a regular basis.

Participants indicated that they wanted the information that they were provided with to remain positive;

"I just want someone to tell me what diabetes is and how I can control it, if this type of diabetes has to be controlled. I just want it to be positive, what they say" ...Gail

"I fear the person giving the education would just be negative, I would like to ask someone questions as I

would like a few answers, but I just feel as if they will tell me off, so I put the shutters up”...Chris

“Why can we not just speak to a normal person, someone who is not judging us, you feel like you have done something wrong by getting diabetes”...Rebecca

Funnell *et al.* (2007) explained that self-management model should not focus on ‘*success or failure*’, but should consist of a continual learning experience where patients become aware of the barriers and support they require, as well as recognising the behavioural changes that may be necessary.

In terms of the social issues surrounding non-adherence, patients are more inclined to relate to their individual experiences whereas medical professionals use medical knowledge, facts and figures. Patients may also resist due to the stigma of diabetes, experience difficulties in accessing or navigating the medical system or have conflicting ideas about the illness and its treatment. They may experience embarrassment or a lack of social support, encounter work or family constraints or find it difficult to time manage aspects of the regimen (Lutfey and Wishner 1999).

Rosenbek Minet *et al.* (2011) studied that patients’ acknowledge the support of healthcare professionals, although they do not consider they learn about the disease through knowledge but more through their involvement in managing their diabetes during everyday life.

Both Martin and Chris stated that they knew more about their diabetes than the healthcare professionals and for that reason they would not attend an education course;

“I know more about my body than the dietician, she might know about diets, but I know about me and she doesn’t and I know that they don’t ask about you so what is the point of seeing her”...Martin

“I think that I could teach the course better than the person teaching it. I am sure they are all just generic I don’t think that the course will be designed for the individual just for the disease”...Chris

Chris went on to mention that she had taught in a “very rough, inner Manchester secondary school” for most of her career and explained;

“Doctors and nurses may have medical knowledge of what diabetes is but they do not have the skills to educate the patient, in a way that helps them to understand diabetes”...Chris

Chris felt that she was being “a disruptive patient by asking questions” and further commented;

“I know they have no time to answer the questions, but who are we supposed to ask. I never gave up on any of my students, but I feel that the doctor and that nurse have given up on me. I never treated any two students alike as we are all different with different backgrounds and education needs”...Chris

Rosenbek Minet *et al.* (2011) stated that Maunsbach (1999) identified if patients had a consistent and supportive network behind them, they would experience a more sustained and long-term adherence to self-management, particularly in relation to diet and exercise.

The difficulties faced by patients with diabetes should be acknowledged and understood by healthcare professionals and individuals should be supported in their daily management of their diet, exercise, medication and blood glucose monitoring activities (Rosenbek Minet *et al.* 2011). Mulvaney (2009) recognised that patients faced their greatest challenges as soon as they left the clinic, a point where rules and information transferred into various psychosocial factors forming a web of skills, abilities, influences, feelings and motivations. Patients have to deal with many competing priorities in their life

and adherence may be complicated by issues such as embarrassment, low self-esteem or their ability to communicate or plan effectively (Mulvaney 2009).

Maclean (1991) found the importance of diet in effective self-management but discovered that the majority of diabetes patients do not rigorously follow dietary compliance. This is due to a range of factors including; the condition not being considered serious by patients, the lack of information and education received by patients; interference with lifestyle; poor knowledge and management skills; and reduced knowledge and management skills. Patients studied had to consider retaining a balance in their life where they were able to feel satisfied although they did not unduly jeopardise their health.

Wilf did state however, that he was willing to attend an education course and that he would adjust his lifestyle once his diabetes got '*serious*' or '*something serious*' happened to him. Wilf said that he would go on a course to get out of work and see what they had to say, but stated that he would not learn anything because he would not change until he knew he had;

"The proper diabetes, you know the one that makes you ill"...Wilf

Hunt and Arar (2001) propose that healthcare providers may be misinterpreting patient's non-compliance as a lack of information or intention and their efforts to educate and ensure patients are more cooperative may be misdirected. They suggest that the issue of 'non-compliance' may be too over simplistic for such a complex disease and they may be better placed to identify and address the different views and perspectives of the provider and patient.

Stott *et al.* (1996) identified that patients who were required to introduce radical lifestyle changes varied in time in relation to their readiness to change. The pursuit of clinical appropriate treatments for individuals varies along with patient's levels of compliance and the clinician's ability to communicate.

Questions were also raised regarding the amount and timing of training in order to receive the most effective changes and medical outcomes.

Hindmarsh (2009) suggests that a gap exists between the acquisition of knowledge and its conversion into safe and appropriate care. He also proposes that the healthcare system does not fully understand or appreciate that diabetes management is complex and requires a considerable amount of patient involvement. The model is ineffective and outdated as it relies on the classical medical model and a radical rethink is required in the way that education and training is provided for patients, their families and healthcare professionals alike. Medical and non-medical aspects need to be considered and '*multi-component interventions*' are required rather than maintaining a specific medical focus (Hindmarsh 2009).

Patient empowerment has been described as a process involving collaborative partnership, where decision making is shared and the freedom to make choices and take responsibility for one's own actions is paramount (Ho *et al.* 2010). The idea of empowering patients to make informed decisions about their own health decisions is not a new concept.

Alan, Peter, Martin and Jon take insulin as part of their diabetes treatment. They informed me that they adjust their insulin intake on a weekly basis in order to suit their specific lifestyles. They also advised me that they do not inform their general practitioners of this behaviour, as they feel they know their body better than the healthcare professionals. Jon further commented that he will always push the boundaries by reducing or withholding his insulin, and admitted, this was in the hope that one day he would no longer need to take his insulin and he would be '*normal again*';

"I want to go back to just taking my tablets, I don't like taking insulin so I am going to keep trying until one day I no longer have to take the insulin"....Jon

The patient empowerment concept however, is not aimed at improving compliance, but instead concentrates on developing self-care knowledge, skills and self-awareness in order that the patient takes charge of their own

diabetes care (Anderson *et al.* 1991). The empowerment model views patients and healthcare professionals as '*equal and active partners*' of the treatment process and whereas the clinicians know what is clinically best for the patients, they do not necessarily know what is best for the patient's life (Anderson and Funnell 2009). By adopting a process of empowerment, with patient and healthcare professional interaction, the development of tailored treatment plans, achievement of goals and improvement of health outcomes may be possible (Ouschan *et al.* 2006).

Despite the many initiatives that encourage and promote patient empowerment it should be noted that such practices need to be designed with an awareness of the patient's social and cultural context. Specific areas such as the provision of emotional support, understanding of patient's traditional diet problems, individual attitudes to self-management and potential barriers to knowledge acquisition need to be taken into consideration (Stone *et al.* 2005).

The process of empowering patients should be viewed as a mutual positive approach that provides an emphasis on the whole person, involves the setting of shared and negotiated health goals, emphasises personal strengths and encourages the patient to actively identify solutions to problems (Funnell *et al.* 1991). Anderson and Funnell (2009) designed the fundamental principles of empowerment, Table 11, and explained that in order for a patient to self-manage a chronic disease effectively, they are required to be in control at all times whilst being supported in making effective decisions by their healthcare professional.

Table 11: The fundamental principles of empowerment

Ref	Empowerment Principle
1	Patients provide 98 per cent of their own diabetes care.
2	The greatest impact on patient's health and well-being is the result of their self-management decisions and actions during the routine conduct of their daily life.
3	Diabetes is so woven into the fabric of the patients life that many, if not most, of the routines of daily living affect and are affected by diabetes and its self-management.
4	Because patients are in control of their self-management decisions, they are responsible for those decisions and the resulting consequences.
5	Patients cannot surrender the control or responsibility they have for their diabetes self-management no matter how much they wish to do so. Even if patients turn their self-management completely over to a healthcare professional, they can change their mind about that decision at any time. Thus, they remain in control at all times.
6	Healthcare professionals cannot control and therefore cannot be responsible for the self-care decisions of their patients.
7	Healthcare professionals are responsible for doing all they can to ensure their patients are making informed self-management decisions, i.e. informed by an adequate understanding of diabetes self-management and an awareness of the aspects of their personal lives that influence their self-management decisions.

Source: Patient empowerment: myths and misconceptions (Anderson, R.M. and Funnell, M.M 2009, p.278)

Anderson and Funnell (2005) also explored the misconceptions and potential barriers that surround patient empowerment where it may be difficult for instance, to change healthcare professional's behaviours from the traditional

care model as the approach may be seen as an attempt for them to 'give-up' control of patient care.

Participants further commented;

"I asked that nurse a few times for a tester and she just keeps saying that is not for you that. Now I do not know what she meant by that; they are fucking ignorant bastards they tell you nothing at that doctors"...Derek

"The doctor never has time to explain anything to you he just gives you more tablets"...Angela

"I went to the doctors and he told me I had got diabetes, just like that no warning. He told me nothing about it and just put me on some tablets, the first tablets he gave me I felt like my fingers and toes were going to explode"...Stuart

"Why can't they just let us manage it ourselves it is our diabetes, all I want is some guidance, I can do the rest"...Ruth

The change to a new paradigm for healthcare professionals may also be difficult as they have been trained to deliver education and support in a specific manner and are not familiar with such a collaborative approach with the patient. Healthcare professionals may retain the belief that it is ultimately their duty for patient care and that they have been entrusted with such responsibility (Anderson and Funnell 2005).

Despite specific concerns being raised, Funnell and Anderson (2004, p.127) state that, *'patients that are actively collaborating in the decision making process are better able to achieve the outcomes they identify as important to them.'*

They also reinforce that traditional care models are not effective for diabetes treatment due to the fact that such a large proportion of managing one's

lifestyle choices is to be determined by the individual. The healthcare professionals are required to give up feeling responsible for their patients and become responsible to them by providing the knowledge, skills and tools in order for them to self-manage effectively (Funnell and Anderson, 2004). Participants feel resentful when they are not involved in the care process and often see being '*told what to do*' as a negative, which in effect just stops them from listening.

Healthcare providers must be mindful that despite that fact they may only see a patient for a few minutes every few weeks or months, the patient must make self-care decisions numerous times every day (Hunt *et al.* 1998).

There was a feeling from the participants that the healthcare professionals did not have time for them as individuals and instead focused on treating the disease. It was also evident that the participants wanted someone to talk to and for someone to listen to them. This section has emphasised the need to understand an individual's requirements, whilst supporting them to self-care effectively. If self-care is the solution with regards to the management of chronic diseases, healthcare professionals with the relevant knowledge have to find the appropriate method in which to provide each individual the tools in order to carry this out successfully.

7.4 Relationship with Healthcare Professionals

'The purpose of getting power is to be able to give it away.'

Aneurin Bevan (1950)

'Whilst education can empower patients to take on greater responsibility for the management of their disease, they cannot achieve long term success without the co-operation of healthcare professionals who can support and facilitate achievement of patient's goals' (Cooper *et al.* 2003, p.205).

In this study the seventeen participants have been diagnosed with type 2 diabetes for a collective duration of one hundred and ninety five years. If we take into consideration that only three of the participants in this study were

offered any formal group education we may question; who, takes on the responsibility to educate an individual with type 2 diabetes in order that they may self-manage effectively?

The participants appeared to display a common characteristic in that they did not feel that they were addressed as individuals by either their general practitioner or the practice nurse. They also noted that appointment times were limited and often rushed, and their diabetes condition was not being discussed on routine appointments.

I designed three concepts maps containing the words or phrases that the participants deemed the most important by listening carefully to individuals' contributions and mapping them into recurring concepts.

The concept maps are detailed within the following sections and will indicate the relationship that the participants have in their own words with their general practitioner, the practice/diabetes nurse, the podiatrist, dietician and optician. It is by no means exhaustive and I have endeavoured to explicate the participant's voices in the greatest way possible by allowing direct quotations throughout this piece of work.

7.5 Participants' Relationship with their General Practitioner

'Progress is impossible without change, and those who cannot change their minds cannot change anything'

George Bernard Shaw (1899)

There is a call for general practitioners to learn new essential skills such as the promotion of behavioural change and risk reduction, as well as building relationships with patients and consideration of patient attitudes and beliefs towards their disease. Wens *et al.* (2005) describe adherence as an '*elusive yet flexible goal*' and believed that the patient / doctor relationship should involve the patient playing a primary role, with the doctor being able to support the individual.

Frosch (2015, p.1) described his experiences of being diagnosed with diabetes and the difficulties faced with managing the chronic condition '24/7,

365 days a year to prevent complications.' Although a fellow and associate professor, he explains as a patient he feels communication with his healthcare team is lacking and he does not feel at the centre of patient care.

The concept map (Figure 7) illustrates the relationship the participants have with their general practitioner, post diagnosis of type 2 diabetes.

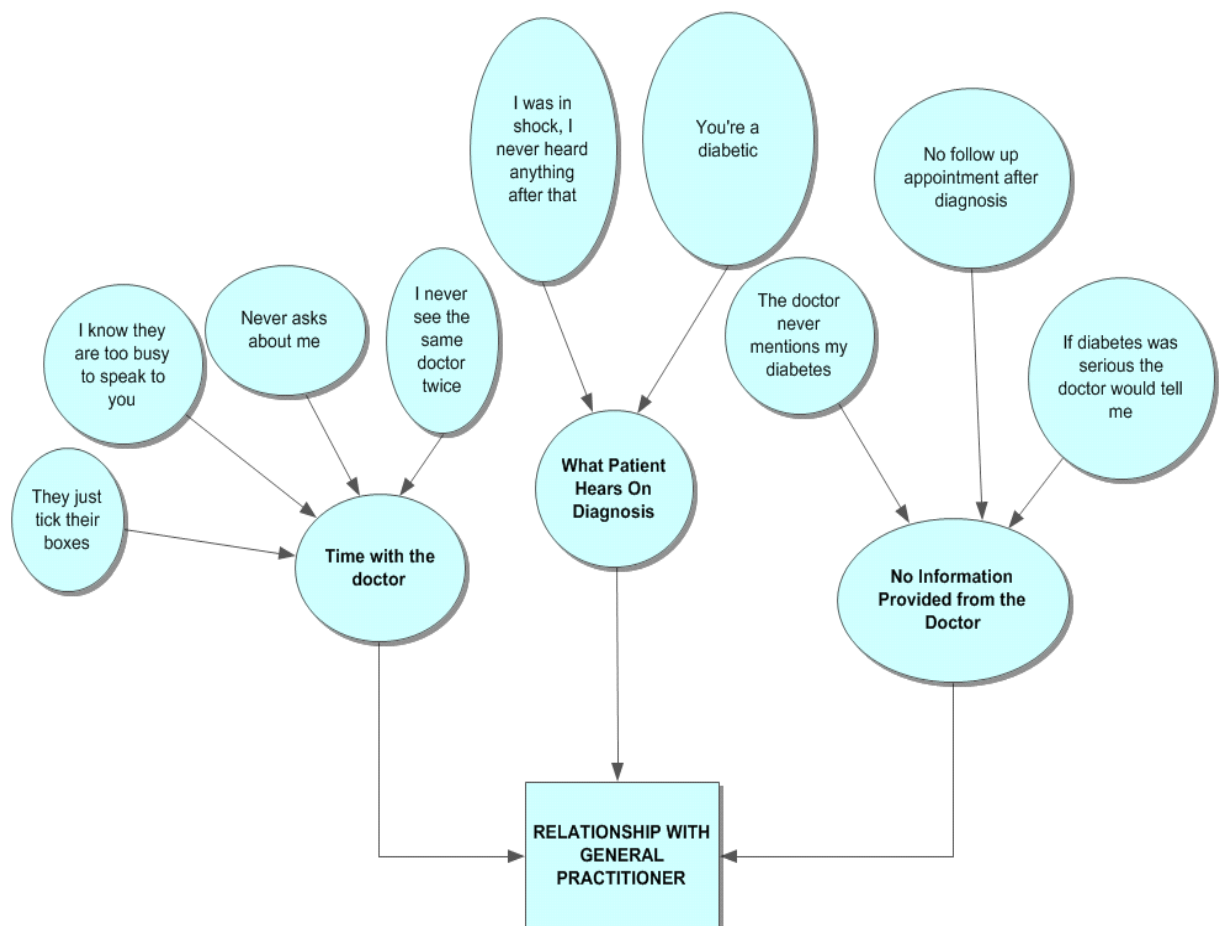


Figure 7: Relationship with general practitioner

The main concepts emerging from the data were:-

1. Time spent with the doctor
2. What an individual hears on diagnosis
3. No information provided by the doctor post diagnosis

Blakeman *et al.* (2006) viewed the self-management of chronic diseases from the general practitioners perspectives, determining that helping patients to understand their underlying condition, risks and management, was critical to

care. Other important aspects noted were the reinforcement of advice given, the provision of on-going support and the need to encourage patients. Their research indicated that general practitioners had mixed views on the level of responsibility patients should have in managing their condition. The professionals expressed concern over allowing too much responsibility without being able to provide sufficient support or guidance and although they recognised the potential benefits of self-management, they stated that it was not always straightforward and required confidence and time to develop. General practitioners suggested they need to feel in control to meet their professional responsibility and also expressed concern over patient overconfidence which may limit them asking for assistance (Blakeman *et al.* 2006)

I enquired of all the participants in this study to tell me which questions their general practitioner or practice nurse had asked them in relation to their diabetes care or treatment;

The participants commented that they were not asked any questions about their diabetes self-care management at their doctor, nurse or podiatry appointments.

“They have never once asked how I am, I know I am an inconvenience to them at that clinic”...Derek

“They are not interested in what we feel just about giving us tablets and getting us out as quickly as possible, that is why I never go up there”...Stuart

“What is the point, she has never once asked a single question about how I feel, that nurse, she just wants me in and out as fast as she can”...Gail

Kalra and Holt (2013) highlight in the DAWN 2 study that only twenty four per cent of the 8,000 participants with diabetes stated that they had been asked how they were coping with diabetes and how this was affecting them on a personal level. However, the same research found that fifty two per cent of the

4,800 healthcare professionals involved, claimed that they ask their patients on a regular basis how diabetes was affecting them on a personal level. It was further found that only one third of the participants commented that they believed the care they received was patient centred; whilst over half the healthcare professionals stated that they believed they were patient centred in the care they provided.

Wilson *et al.* (2012) expressed that patients found the reviews that took place on a regular basis at clinics were merely viewed as a test or ‘*tick-box*’ exercise. This is in agreement with several of the participants in the study who felt that their appointments with the general practitioner were merely for the doctor’s benefit and to ‘*allow them to tick the boxes.*’ Chris and Alan stated that their visits with the doctor and nurse were conducted in this way and were very vocal when discussing that their blood sugar levels and cholesterol levels were more for the doctor to achieve their targets, rather than assisting them in managing their condition;

“They have their statistics and their boxes to tick, I am not stupid. I know how the system works, why would they be interested in me, they just treat the diabetes and get their funding”...Chris

I asked Chris to expand:

“I am big enough, to know what I am doing, but the doctor likes to tick his boxes, I can’t believe that healthcare comes down to ticking boxes”...Chris

Alan commented;

“They are paid to look at the disease not the person, it is like we are in the way, that is the way it has always been and I can’t see any change in the future. As long as our numbers fit in with the clinical guidelines the doctors couldn’t care less how we feel or what we do”...Alan

Participants also commented that after the initial diagnosis by the general practitioner, their diabetes was never mentioned at any future appointments;

"The doctor never mentions my diabetes so I still think he has misdiagnosed me as he never mentions it when I see him"...Wilf

"He has never spoke about my diabetes with me"...Angela

"It is never mentioned when I go to the clinic, they mention my epilepsy but never my diabetes"...Ruth

Winnie said that she was shocked when diagnosed with diabetes and explained;

"I never felt it coming on, you know, as you do with a cold"...Winnie

"When the doctor told me my mum had diabetes, it was as if he was blaming me for it because I look after her"...Barbara, (Winnie's daughter)

Derek expressed that the relationship with his doctor was not good and stated;

"That doctor was so reluctant to tell me that I got my prescriptions for free, he were fuming when I mentioned it to him. I had been paying for all my medication for two years. I had to pay for four different lots of tablets. His face was like thunder that doctor, you can't trust them"...Derek

During the interviews, I became aware of the different emotions that some of the participants expressed when discussing the healthcare professionals they came into contact with.

Patients expressed their feelings and the effect of being diagnosed with diabetes;

"When I first got diagnosed with diabetes I thought....shit...what is it. I had enough on my plate with my husband's cancer. I was in shock"...Gail

"I was in hospital with pneumonia, and the doctor came up to my daughter and said to her, did you know that your mums got diabetes? My daughter said no, well she has the doctor said, just like that as if it was her fault"...Winnie

"I went for a check-up after having breast cancer and the doctor just did a test and gave me diabetes. He told me nothing, I always thought he would refer me to someone who would tell me what diabetes was and what I had to do"...Angela

"I have never seen the same doctor twice, so the diabetes has never been mentioned"...Winnie

"The doctor took some tests and at the end of it he said, 'Yes you have got diabetes', and I said, 'how'? And he said that is what we would like to know. I was in shock; I never listened to anything after he said that. Yes I was shocked when I was diagnosed, and I thought the doctor would explain it when it had sunk in but he never mentioned it again"...Pauline

"When the doctor told me I had diabetes he just said, right you are a diabetic, just like that, no warning nothing. Just called me a diabetic and gave me a prescription and that was over eight years ago"...Derek

Martin explained that he had arrived at his doctors for a routine check-up;

“He just pricked my finger and said, err, how long have you been a diabetic? I said, I didn’t know I was, and he said, well you are”...Martin

Martin went on to explain that he had never been given any information from his doctor post diagnosis, the doctor told him;

“I never see you, that is why you don’t know you are a diabetic”...Martin

Bob was going through a very traumatic period in his life which he described in detail to me during the interview and felt that his diagnosis was an inconvenience to the doctor, remarking;

“It was just one more lot of tablets he had to give me, as if I wasn’t on enough. Why couldn’t he just have asked how I was, it might have been better for me to explain how I was feeling, rather than him talk at me and me not take anything in, I never listened to a word he said it just wasn’t important in my life at that time”...Bob

Bob explained in relation to his initial diagnosis;

“I had so much going wrong in my life at the time, if it would have been a year later I would have accepted it and understood more, but they never wanted to help me then it was too late, I missed my chance”...Bob

Lutfey and Wishner (1999) explain that in order to convey complex and individual treatment to patients, considerable communication skills are required. They suggest that healthcare professionals should have a greater understanding of patient behaviour and ask patients which areas they face are the most challenging and what changes they would like to introduce in order to improve their self-management of diabetes.

Wens *et al.* (2005) explains that issues involving compliance and adherence are varied and complex and patients require an approach centred round them,

with health promotion, communication and a partnership relationship with their general practitioner. During their study, general practitioners felt that barriers to adherence involved the patient's social circumstances, their lack of knowledge in relation to the disease and the underestimation of symptoms and complications. General practitioners were generally aware of the need to assess individual's abilities to comprehend information and instruction and were mindful to not overload patients with information or provide health information that doesn't interest the individual. Agarwal *et al.* (2002, p.14) explains that general practitioners are aware of the obstacles involved in providing effective care to people with diabetes. In the postal study undertaken by Agarwal involving 1,370 general practitioners, it was found that the main barriers to providing good quality healthcare were: -

1. Lack of time with the patient
2. Under funding
3. Keeping up to date with current diabetes knowledge
4. Lack of space to provide the service
5. Inadequate services including podiatry, dietetics and ophthalmology
6. Access to secondary care

During our interview, Martin displayed the insulin he kept in the fridge and explained how organised he had become. He cried when stating;

"He ruined my life that doctor, he told me nothing about diabetes. If he would have told me I had to lose weight and get healthy otherwise I would have to go on insulin, I would have done it. I lost my licence because of him you see, I had to give my HGV licence back once I was on the insulin. That doctor never told me anything about blood sugars, never once did he mention that to me"...Martin

Martin explained that he had spent his entire working life as a long distance lorry driver and was 'devastated' when he lost his licence due to his uncontrolled diabetes;

“I have not had a good education so I might not be as clever as someone else but you would take notice if the doctor explained that it was serious. I think that was my problem, no one ever told me anything about it. I felt like I had done a bad thing when I got diabetes and the doctors didn’t help or the nurse. I would have done more if I had known. I would because I did not want to lose my licence. I never knew that could happen, nothing was explained. They just don’t have time and I understand that but why could they not send me to someone who had the time to talk and help me”...Martin

Don and Martin appeared incredibly sad and disappointed when they explained that if they had known, ‘*being overweight*’ would lead to having diabetes, and they would both have lost weight a long time ago;

“I would have lost weight twenty years ago if I knew I was going to get diabetes, why don’t the doctors tell you these things?”...Don

Wikblad (1991) commented that patients who experienced poor metabolic control felt that very little communication took place with general practitioners and problems were not explained and the advice given was often unrealistic. They expressed that such negativity and lack of support made them feel punished and controlled. Patients were asked what they expected from diabetes care and the responses included continuity with the same healthcare professional, accessibility to education and diabetes care, the provision of support, consideration, interest and medical knowledge shown by the practitioner, and responsibility to be trusted to self-manage.

Further comments received by the participants explained;

“They don’t seem to have time to want to reason with us until we have time to understand what we should be doing”...Don

"I don't know how we are supposed to know about diabetes, we have not got a medical background. I wouldn't expect a doctor to do my job" ...Wilf

"We have to carry on with our lives, if they want us to do more about this diabetes well they should tell us in a way that we understand. I can't just stay at home all day and take tablets; I have a business to run. Imagine if we all took it seriously, nothing would get done" ...Stuart

Lutfey and Wishner (1999, p.635) define 'compliance' as '*the extent to which a person's behaviour in terms of taking medications, following diets, or executing lifestyle changes, coincides with medical or health advice.*' They also advise that the word compliance implies that the patient is required to obey medically defined goals. It suggests that '*a submissive patient obeys an authoritative practitioner*', and by not doing so they are being '*difficult*' or '*bad*'. The word '*adherence*' is preferred by the authors as it considers the complex nature of diabetes care and assumes that patients possess intelligence and are independent to be able to take an active role in the management of their illness. Lutfey and Wishner (1999) further commented that general practitioners felt that increased time spent with patients was required in order to ultimately improve self-management of diabetes and to aid more complex issues. It was felt doctors needed to have the confidence to '*share control*' with the patients and although the importance of '*empowering*' patients was recognised this was not generally discussed or prioritised between colleagues and would continue to prove difficult for general practitioners to manage (Lutfey and Wishner 1999).

A study of 4,785 healthcare professionals, who were responsible for the application of self-care management for people with diabetes, was carried out as part of the Diabetes Attitudes, Wishes and Needs second study (DAWN2). It was found that training, education and information for people with diabetes was limited. It was apparent that although advances have been made in relation to the treatment of diabetes, most of the participants in this study

agreed that the system was not equipped well enough to provide people with the sufficient education or information that they require in order to self-care successfully. More than fifty per cent of the healthcare professionals involved in the study were willing to attend an education course in order to provide them with the correct information to be able to assist people with diabetes in a way that improves their self-care management (Holt *et al.* 2013).

In my personal opinion I felt that the participant's considered the general practitioner as the individual who should be in overall control of their diabetes. The participants commented that if their diabetes was deemed important, then it was the doctor's responsibility to inform them. Doctors may have to be increasingly aware that when they are diagnosing an individual who has no symptoms of a disease, it may take patients a lot longer to come to terms with the diagnosis, if at all. At the point of diagnosis or at the person's earliest convenience, type 2 diabetes needs to be appropriately explained to an individual in a language and format they are able to easily comprehend. In this study only Jon felt that he had diabetes properly explained to him in a way that he could fully understand.

This section has highlighted that the participants believed that their general practitioners did not provide sufficient or adequate information regarding the disease following their initial diagnosis. Participants also felt that if type 2 diabetes was as serious as type 1 then the doctor would have discussed and explained this to them. This research has also shown that the participants are aware that their general practitioner is time pressurised and they feel there is often never sufficient time to ask questions.

7.6 Participants' Relationship with the Practice Nurse/Diabetes Nurse

'I think one's feelings waste themselves in words; they ought to be distilled into actions which bring results.'

Florence Nightingale (1913)

The participants referred to their nurses by several different titles; the practice nurse, the diabetes nurse or merely the nurse at the clinic. One of the main concepts that arose when participants spoke about their nurse was that they

appeared to take on a didactic role when speaking to them regarding their diabetes self-care management. This approach was commented on by Chris as '*speaking down to us*' and was '*not appreciated*'. Participants often missed appointments with the nurse and stated that this was in order to avoid a '*telling off*.' The concept map (Figure 8) highlights the relationship that the participants have with their practice nurse.

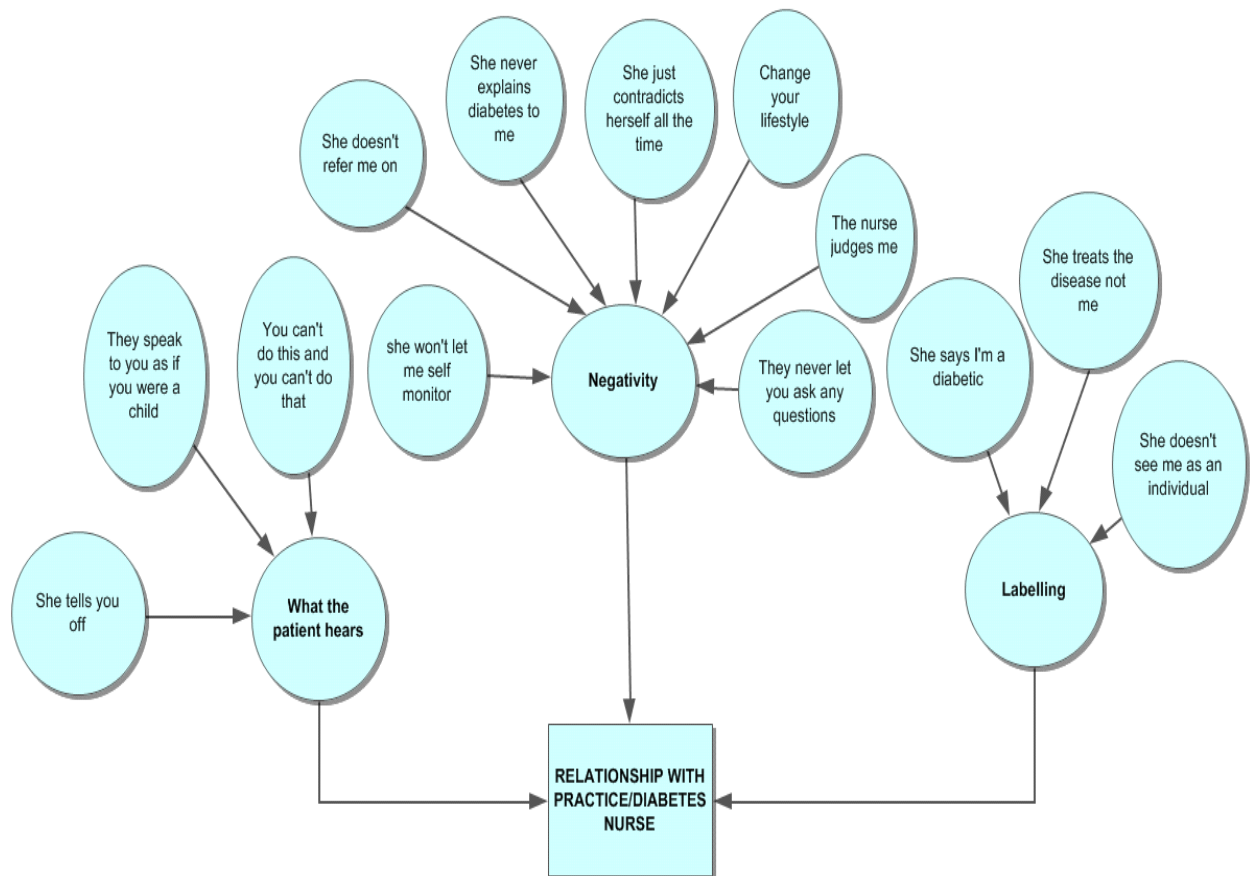


Figure 8: Relationship with practice nurse / diabetes nurse

The three main concepts emerging from the data analysis;

1. What the individual hears
2. Negativity
3. Labelled as a diabetic

The participants felt that being told what to do by way of threats or warnings had little impact on adherence levels and their awareness or knowledge of the disease. Chris and Don commented that such behaviour made them "*feel like a child*" and sometimes had the opposite effect on their adherence to

treatment. Many of the participants felt that the disease was being treated and they were not necessarily viewed as an individual by the practice nurse.

Only one participant, Jon, had a care plan written up between him and his practice nurse. Unfortunately when she left the practice several years later to return to Spain, Jon received no further contact from the practice and explained that he didn't even know if they have a nurse anymore. Jon spoke enthusiastically about his relationship with the original nurse;

*"She was brilliant the nurse, absolutely brilliant. I kept going back to see her all the time till I understood it. If I asked her a question she would get her books out, she even got the dietician in as well it was like a three way conversation and she would go over it all the time. She never once said, don't do this and don't do that. I could even text her and she would be at the end of the phone"...*Jon

Bob laughed and commented;

*"One nurse asks me what I am eating, then she weighs me and then she shouts at me, in a nice way, she is the one that is alright, she is not a dragon"...*Bob

Funnell and Anderson (2002) emphasise that effective self-management does not involve telling patients what to do, but involves a collaborative approach that empowers the patient, allowing them to develop their own solutions and personal motivations. The work of Peyrot and Rubin (2008) also illustrates that self-management proves more effective when it is not delivered in a didactic manner, but when it is more intensive, executed over longer periods and incorporates individual behaviour.

Derek stated that he does not have a good relationship with his doctor, his practice nurse or the receptionist who he called '*pig ignorant.*' He was

annoyed when he explained that he had to miss a routine appointment with the nurse over eighteen months ago and since then the receptionists speak to him like a *'piece of dirt.'* He does not trust his doctor or the nurse and states;

*"That nurse constantly fobs me off, when I ask for help"...*Derek

Stuart explained that due to work commitments he rarely sees his practice nurse, but also feels confused by her comments;

*"She tells me I am fat and then she tells me to eat or I will get hypos, which one is it? She has never once asked me if I am alright so I just let her go on and on. She tells me I should be doing this and I should be doing the other, I just walk out of there and do what I want"...*Stuart

Rebecca became very upset when she explained that due to her medication for bi-polar, she had gained a *'tremendous amount of weight'*, causing her to have back problems and therefore leading a sedentary lifestyle. Her main grievance was that she was never told to lose weight or that she was at risk of diabetes. This has made her extremely *'resentful'* of her practice nurse and the healthcare system. She explained that she was embarrassed about her size and raised her voice when remarking;

*"I'll always be a cog in the healthcare system. That practice nurse told me, no matter how much weight you lose now, you will always be a diabetic. They talk to me as if I am stupid or a child, they often just tell me off, well that is how it sounds to me"...*Rebecca

Rebecca expressed further frustration from when she was initially diagnosed;

"Well at my first check-up appointment, that nurse told me my blood sugars were 21 and asked me what I had been doing, as if it was my fault. I told her that I had

been drinking pints of water during the night. She said I was to go away and come back in two months and if my sugars were still the same I would have to just go on insulin. I was so angry when I left, why didn't she give me some help or send me to someone who knows about diabetes? I asked her if I could test my own sugars every day and she said, NO, just come back in two months. She knows nothing that nurse, I was in and out in five minutes and she had kept me waiting forty minutes. Maybe they spend longer with the patients they like"...Rebecca

Funnell *et al.* (2007) describe the 'self-determination' theory where individuals are more likely to feel motivated to develop knowledge and skills if they consider behaviours to be meaningful to them. They also considered 'autonomy support' which associated the level of support patients received from their healthcare professionals in respect of their diabetes related priorities, needs, feelings and behaviours.

Don, Gail and Derek discussed the relationships they have with their practice nurse;

"To be truthful, I don't trust the nurse because she never listens to you, there are too many people telling you what to do, and you know what happens, you just switch off. Oh! We are back at school are we? That is what they do not realise, that people do not listen because they are fed up of being told what to do by the nurse"...Don

"I just don't want them to keep telling me what to do and not asking about me, they only talk about my epilepsy not my diabetes"...Gail

"She is cunning that nurse, she likes to keep control, she won't refer me on and she won't give me any answers, it

is ok for her to tell me what to do, well that is what she does"...Derek

"The nurse just takes your blood, when we ask her why she just says, the clinic will let you know if there is a problem"...Pauline and Don

When I asked them both to expand on this, Pauline and Don explained;

"Well the nurse comes to take my blood at the house. I am housebound and have a few things wrong with me. I have asked her several times what the blood tests are for and she never has any answers, she should have the answers she is a nurse"...Pauline

"I go to the clinic, well the doctors, and I have a different nurse to Pauline. I always ask what my latest results were and she says if it was important the doctor would let me know. I have stopped asking now, I have no idea what she is testing my blood for"...Don

Almost all of the participants referred to the practice or diabetes nurse as someone who was continuously saying, 'You can't have that' or 'That has to stop.' This had resulted in the participants not engaging with the practice nurse;

"The nurses at that practice just don't listen to you, they take one look at you and judge you and just make up their own mind, I avoid going up there"...Don

"She told me I can't have biscuits, or sugar in my tea. She said, well you've got to do this and you can't have that, I said I might as well join a monastery"...Wilf

"I was really overweight and that nurse at the practice would not refer me to a dietician. It is my body and I was trying to do something about it and she said, it is not for

you. It is no skin off her nose to send me to see someone else is it"...Derek

Pill *et al.* (1999) revealed that encouraging patients to make their own decisions and set their own targets proved difficult for healthcare professionals to 'let go'. Nurses had issues with allowing greater autonomy to patients that did not manage their levels of diabetic control effectively.

Participants further commented;

"The nurse never asks you what you want to know and they never ask us what is important to us"...Pauline

"The nurse would not give me a machine to test my blood sugars, I asked her for one, and so I went out and bought my own"...Angela

"Why can't she just ask me how I am feeling?"...Gail

"That nurse won't refer me on to a dietician and she won't give me a tester, how am I supposed to manage my own diabetes?"...Derek

Gonzalez (2008) expressed the importance of patients being able to set their own goals and for small successes to be celebrated rather than condemning patients when goals were not achieved. The practice of regularly reviewing goals and positively encouraging patients to succeed was also deemed to be essential.

Hunt *et al.* (1998) explain that practitioners express frustration at patient non-compliance and may present scenarios of how devastating complications may be if patients do not adhere to advice or lifestyle changes. There may also be threats or negotiation methods that take place in order to control patient's behaviour, although patients, when questioned, expressed that they wanted to control their diabetes, despite living stressful lives. It was evident that control is a central factor for both patients and practitioners although they may view the methods to achieve this in different ways by using various methods.

Alan stated that he had a good relationship with the nurses at the hospital but was despondent when he stated;

"I kept a journal of all my blood sugar readings and a food diary for months. When I got to the hospital the two nurses were not even interested in it and wouldn't even look at it"...Alan

I asked Alan if I could see his journal and he was only too happy to show me this and also go through the contents with me. I did not make any judgement on this merely explaining it was very well prepared and put together. Alan appeared to be pleased with my comment and certainly appeared proud of his achievements.

It was further recognised by Alazri *et al.* (2007) that in order for healthcare professionals to function effectively, there is a need for good working relationships and communication within teams, especially involving the patient.

Some of the participants revealed how negative the nurse could be towards them and this made them feel as if they were merely an inconvenience;

"She sent the wrong message to me that nurse when I asked her for that tester, and she said NO. I thought well I can't be half as bad as the people that are using them otherwise if I were that bad I would need one"...Derek

"That practice nurse has told me I can't eat biscuits in the afternoon, how does she know what my blood sugars are, or how I feel in the afternoon, no one stops her eating biscuits. They are so negative those nurses"...Chris

"When I go and see that diabetes nurse lady she is always concerned about me having hypos, that is all she ever goes on about but she never explains it to me. She

mentions my eating and drinking and then tells me I will get hypos, what is a hypo?"...Stuart

"They just tell you what to do, they never ask about me, that is if you can get an appointment at the doctors"...Derek

"I was taking my tablets all wrong for five years and the nurse told me off. They don't explain these things to you; you see this is where I find it a bit thingy, they don't explain these things to you"...Wilf

I asked Wilf if he had ever attempted speaking to the practice nurse about his concerns and he explained;

"The nurse says you can't drink alcohol, you can't eat butter, you can't have sugar in your tea and she says I can't have cake or biscuits. She never tells me what I can have, which according to her, would be nothing"...Wilf

"Until I see something probably happen to me, I'm sorry but I am not following what that nurse says. I may as well be dead; she won't let you have anything. I just nod my head and then ignore her when I leave, she never checks up"...Wilf

Both Gail and Rebecca expressed that they had been seeing their practice nurse for several years prior to being diagnosed with diabetes. They were frustrated that they discussed being overweight and were not aware this would lead to diabetes;

"They never told me how to lose weight, they just said lose weight. They never sent me to see anyone. They don't give you any help they just tell you what to do"...Gail

“Why did they not tell me to lose weight, they told me 2 years earlier I had pre diabetes but they never sent me to a dietician, they knew I would get diabetes, I didn’t”...Rebecca

Wikblad (1991) explored communication difficulties between the healthcare professional and patient. Patients with poor metabolic control felt that they were not always considered a person and the demands from practitioners were not always achievable.

Don also mentioned his weight, but felt strongly that the two nurses he had come into contact were in his opinion, ‘huge’. Don referred to this constantly throughout the interview;

“What is the point of going to see the nurse, she is huge, and how can she talk to me about my weight. Why would I take advice from her”...Don

Gail explained that she was annoyed at her practice nurse and felt judged by her;

“The nurses judge you, you see, they look down on you because they think that they are the clever ones. Well that nurse, she is really fat and unhealthy looking so she might get ill one day and then she won’t be so nasty when she knows what it feels like”...Gail

I asked Gail if she was able to speak to the practice nurse regarding her concerns with her diabetes and epilepsy;

“The practice nurse does not know enough about diabetes to educate us, just because her mother’s got diabetes doesn’t mean she knows all about it. I don’t think that they have any training in it they just tell one person one thing and one person another. She just contradicts herself all the time. She does it to get us out

of the clinic quicker. They know we won't ask questions because we don't understand what diabetes is and what's the point, my nurse just makes up the answers anyway"...Gail

Derek explained that he feels angry that his nurse never gives him any straight answers;

"She has a real condescending manner that nurse, when I asked her a probing question she said, well it doesn't help when you are not doing such a thing, or you are still eating chocolate. All right, I get the message, but she still won't give you a straight answer. It should not be a bargaining thing, this is my life and it is really frustrating"...Derek

Hunt and Arar (2001) comment that medical practitioners have traditionally viewed non-compliance as a lack of motivation or knowledge by patients and efforts to educate or motivate individuals may be considered '*scare tactics*'. Practitioners frequently cited that their principal concern with disease management was enabling patients to cooperate following guidance and advice. Some participants commented about specific episodes that they had with their practice nurse;

"The nurse told me I will get hypos like my dad used to and he was always collapsing in the street. He lost one of his legs to diabetes but I never told the nurse"...Stuart

"I try and walk every day and I take a banana with me in case I need a lift. That nurse said I should also go swimming, but she has no idea how much I struggle just walking"...Peter

"I never go and see the nurse anymore. I just get my prescription sent to the chemist and sort my own diabetes out. The nurse knows nothing about diabetes

and she knows nothing about me, she has never asked me a single question about me, so I will not go back to her”...Martin

Angela expressed her frustration in attempting to obtain getting an appointment with the practice nurse;

“Every time I try and get an appointment with the diabetic nurse she is always off, what are you supposed to do? I can see another one but what is the point, they never pass any information on”...Angela

The participants also expressed concern over seeing different healthcare professionals for various visits, who did not have sufficient time to familiarise themselves with their background. A study by Wikblad (1991) found that patients stated that they do not always feel trusted to self-manage their conditions and they do not receive appropriate support in order to carry this out.

Most of the participants were willing to see a diabetes educator, and they remarked that in their opinion the practice nurse did not have the relevant knowledge or skills to deal with them as an individual and treated diabetes in a generic way.

This section has highlighted the urgent need for the nurse, practice nurse or diabetes nurse to establish a way in which to effectively communicate information to individuals. Participants felt that the appointment with the nurse was the time for a ‘*telling off*’. This research has brought to light that the participants feel that the nurse ‘*tells*’ them what to do rather than making suggestions or working collaboratively. The participants were aware that there was never an explanation from the nurse as to why they could not have a certain food type for instance. It also emerged that the participants felt that they were not provided with the relevant information from the nurse in order to self-manage confidently. This may be a potential factor as to why the majority

of the participants commented that type 2 diabetes is not deemed as serious or as important as type 1 diabetes.

7.7 Participants' Relationship with the Podiatrist, Dietician and Optician

'Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.'

World Health Organisation (1948)

Participants discussed the appointments with members of the healthcare team, including the podiatrist, dietician and optometrist. Some of the participants were not referred to any healthcare professionals and were not aware that they should have been. Other participants were aware that they should visit a podiatrist or an optician but had not necessarily been referred directly. There were a wide range of comments concerning this area and the concept map (Figure 9) illustrates the participants' experiences.

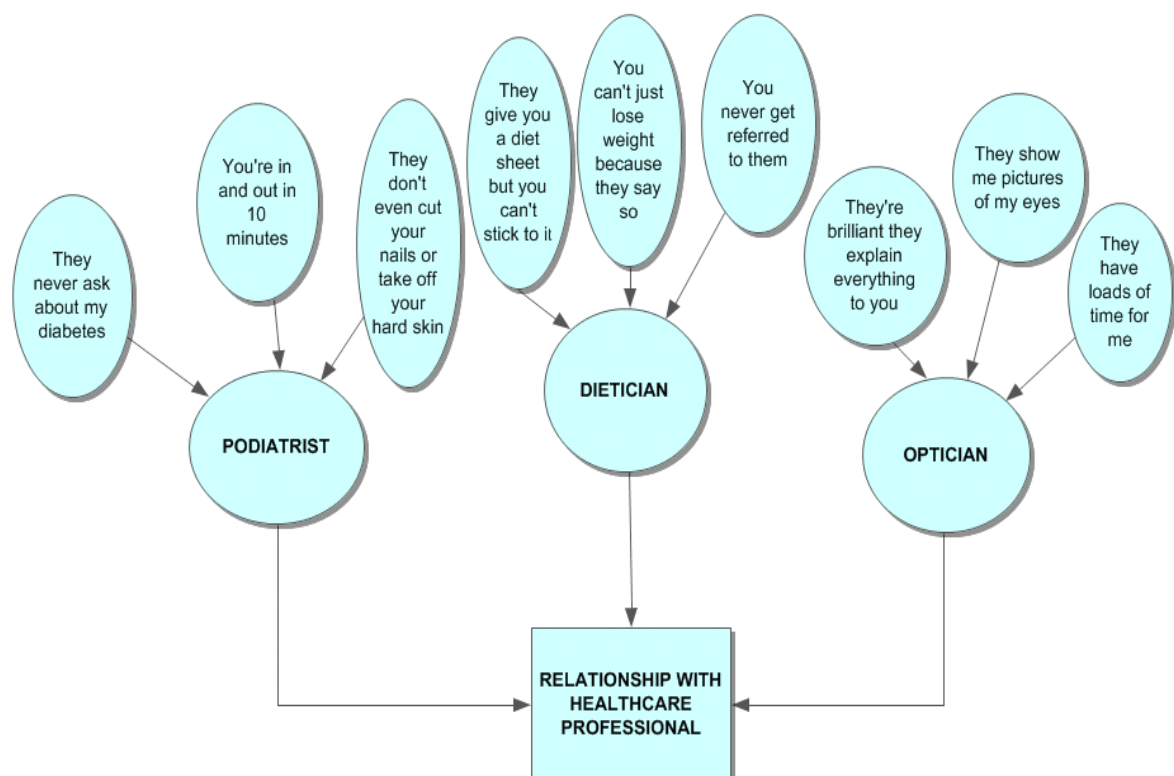


Figure 9: Relationship with healthcare professionals

The concepts that emerged from the data analysis were;

Relationship with the podiatrist;

1. Diabetes is not discussed
2. Appointments are rushed
3. No podiatry skills administered

Relationship with dietician;

1. Unable to adhere to diet sheet
2. Told to lose weight
3. No referral

Relationship with optometrist;

1. Excellent at explaining the service and procedure
2. Take charge of the appointment process
3. Have lots of time with an individual

The participants appeared to be enjoying speaking about their experiences with the optometrist. Chris produced a letter that she had recently received from her local optometrist with her appointment date and time. Chris explained that she does not have to worry about her appointment being overdue as the optometrists arrange everything for her and she finds the service excellent and attends her appointment annually. Many of the participants made reference to how much time the optician spent with them and how good the experience was. This led them to question as to why the nurse and the podiatrist were not deemed to be providing the same service or satisfaction levels.

Participant's good experiences included;

"The optician is spot on and they send the report through to you, they explain everything to you at the appointment, they take plenty of time to speak with you. The appointments are as regular as clockwork"...Alan

“The opticians are brilliant, and my ordinary opticians that I go to are brilliant”...Gail

Chris spoke about the positive experience provided by the optometrist and was surprised that other healthcare professionals did not offer the same level of service;

“The opticians are the only ones who get it right, why can’t the others learn from them. The podiatrists in the park don’t see me from one year to the other. Why can’t they have a database like the opticians, and I can’t remember the last time I saw that nurse, they never send for a check-up at the doctors”...Chris

Wilf mentioned that the only person who has ever shown an interest in his diabetes is his optician;

“The opticians always let you see pictures of your eyes and this is really good and they explain things in a way that you understand, not all that medical stuff, they never rush you, not like at the doctors”...Wilf

Don explained that the optician was the only person who asked him if he understood the information provided;

“I know I am old but the optician speaks to me in a normal way, you know until I understand, they always ask if I have any questions”...Don

Hunt and Arar (2001) highlight that healthcare professionals make important contributions by including social and cultural considerations as part of disease management. They also point out that self-care behaviour involves educating and motivating individuals to choose the right course of actions. They recognise that patients adapt and modify their understandings and measures of long term care when introducing them within the constraint of their daily lives.

Some of the participants when asked about which healthcare providers they had been referred to made the following comments about their experiences;

"I like the podiatrist, she told me what cream to buy" ...Peter

"I have been told I might have to see a podiatrist, but I will wait until something goes wrong first. My feet are ok at the moment" ...Majid

"There's no point going up to that park to see the podiatrist, you are in and out in ten minutes, they never cut your nails and they never ask about my cold feet, they must feel they are cold, what are they there for" ...Ruth

"The last time I went to the podiatrists at the park, I was in and out in a few minutes. They told me I had to make my yearly appointment with them and that it was not up to them to contact me. I know they have a thirty minute appointment for diabetes checks so why was I out in less than ten minutes?" ...Chris

"I know how important my feet are, so I pay private. I can't afford it, but you can never get an appointment at that park, and they do nothing to your feet anyway. I can't remember the last time I had a diabetes check-up" ...Angela

"They were useless those two girls, they just told me my nail was digging in and I knew it wasn't. I put my socks on and I have never gone back. That was years ago and I still have that pain in my foot" ...Derek

I was concerned listening to Derek speaking about his only experience with the podiatry service. During the interview Derek commented about still having

a pain in his foot after many years. I had to remain focussed on being a researcher at this point and not a podiatrist, although I was tempted to deal with his complaint and assist where I could. I was conscious however, that I needed to retain my principal research role. As a podiatrist whilst conducting a researcher's role, was something that I struggled with at several points during the interview process. This was especially difficult with Derek as he was in my home and I had access to podiatry equipment that I could have used to relieve his foot pain. Reflecting on this, I believe that most healthcare professionals in this situation would have felt the same way as I did and would also have wanted to assist Derek in order to relieve his pain.

When asking Alan about which healthcare providers he had been referred to, Alan commented;

"The doctors and the medical profession should be looking after my diabetes; it should not be up to me"...Alan

When I asked Alan to expand on this comment he mentioned that the doctor should be making his appointments and that it should not be up to him to chase up his diabetes reviews. He did however, mention that he was "*quite happy*" with the care that he receives from the community and enjoys his visits to the optician and the podiatrist. Despite this however, he commented that he has to continually chase up his appointments with the podiatry service, which frustrates him;

"My view is, it is their responsibility to make our appointments, we have enough to do, and it is not our responsibility. You always have to chase up the podiatry review it is never easy, trying to get an appointment"...Alan

Jon informed me that at his last appointment with the podiatrist she told him that he had forty per cent nerve damage to his feet but not to worry and that the nerve ending damage would come back over a period of time once his

blood sugar levels were stable. He informed me he has had trouble with his feet on several occasions and also explained;

“I never wear anything on my feet at home or in the garden, I have stood on stair rods before now and I haven’t even felt it. The only thing I have noticed is the blood on the floor”...Jon

I asked Jon if there may be another podiatrist he could go and speak to and he informed me that there were employees at his local clinic. I advised him to enquire about neuropathy at the next available appointment, writing the word down for him. I reflected on this for many days afterwards and questioned if I should have undertaken this during the research process. I came to the same conclusion that if I found myself in this situation again I would still provide the advice. I have knowledge of neuropathy and the devastating damage that it can cause, and common sense told me therefore I was a person with knowledge first and a researcher second in this instance. There was much more information that I wanted to share with Jon regarding foot healthcare, but I became aware that I did not want to turn this into an education session and detract from the research objectives.

Several individuals who participated in the study mentioned receiving a diet leaflet. Only one of the participants however, mentioned having an appointment with the dietician. A minority of the participants had previously asked the practice nurse for a referral to a dietician, but were subsequently informed that it was not necessary;

“I asked that nurse a few times if I could speak to a dietician, and she just told me to stop eating chocolate”...Derek

“I know I need to lose weight, but the nurse has never mentioned me seeing someone about it”...Chris

"I am very thin and when the nurse comes to take my blood I asked her what I should be eating and she just says, carry on as you are"...Pauline

"I knew Don had diabetes years before he was diagnosed, he put on so much weight and fat people get diabetes. The nurse or the doctor never once mentioned him seeing a dietician"...Pauline

Don informed me that he had not been referred to a dietician at the clinic but he spoke to a dietician on his DESMOND course;

"She just told us all to lose weight, it was a joke really. We were on a diabetes course and they were feeding us tea and biscuits all day long. Then this dietician who was stick thin, just told us to lose weight, just like that, lose weight. If only it was that easy"...Don

Martin explained that when he and his wife were first diagnosed they went to a dietician;

"The dietician gave us certain things to eat and just told us to both lose weight. She just gave me a diet sheet and never asked me if I could follow it. Well you just couldn't it was impossible, so in the end I joined weight watchers and lost four stone"...Martin

Peter and I were discussing healthcare professionals and his wife entered the room. I informed her that we were recording this session prior to her making any comments. She thanked me and explained that she knew nothing about his condition and that it 'frustrates' her as she made all his meals and was not sure what he should be having. She explained that he had a sweet tooth and would often eat a full box of chocolates in one day;

"There should be more talk around the diet I want to know what he can and cannot eat. He is grossly overweight but will not do anything about it and just

blames the insulin for making him fat. He has never seen a dietician and neither have I. They just do not involve the family. I know your health is personal but surely doctors must know that we do the cooking”...Peters’ wife

Peter’s wife wanted to speak to a dietician in order that she could understand what she should be cooking for Peter and commented;

“He eats cauliflower cheese as he likes cheese and I do not think he should eat a full box of chocolates in one sitting I would like some advice”...Peters’ wife

Peter laughed when he told me;

“I suppose you have to die of something so I might as well die of diabetes (laughing)”...Peter

Kovacs Burns (2013, p.22) found that ‘*diabetes is a known burden for people living with diabetes, but is a hidden burden for their families.*’ Funnell *et al.* (2009) further indicate, the patient and their family have an enormous amount to learn in order to be able to manage their diabetes effectively.

Whilst discussing the participant’s experiences of healthcare providers I found that they had forgotten I was there to speak to them about their experiences of having diabetes, and they would suddenly start asking me questions about their condition. They would ask “*What should my blood sugar be? Where do I get information on my diet?*” I felt this might have been partly because I could have been the first person to speak to them about their diabetes in an informal setting and was taking the time to listen to their answers. Some of the participants did inform me that apart from the optician I was the only person who had ever asked about them and how they felt about their disease. I was also mindful not to use medical terminology or jargon at any time during the interviews and this is an approach I have always consciously followed whilst working as a healthcare professional.

Wikblad (1991) indicates during his research patients did not possess adequate knowledge of diabetes and rarely achieved medical objectives when education programmes focused on theoretical knowledge. Communication was also deemed important and it was found to be more effective with those patients who used similar vocabulary and were of the same social class. Patients sometimes felt their interaction with their healthcare professional created feelings of mistrust, humiliation, despair or aggression.

The importance of providing diabetes knowledge and education to the patient and their closest family members was raised by Wikblad (1991) with the need for follow up sessions to sustain knowledge development. This was also evident in this study as members of the participant's family that I came into contact with, expressed a desire to attend a diabetes education course in order that they could support their family member.

Matthews *et al.* (2009) established that the patient-provider relationship was considered the most important element to affect levels of patient adherence. Study participants expressed that they had expected a '*more caring approach*' when they had initially been diagnosed with the disease. Patients also felt that the communication style of the healthcare professional was important and this had a direct impact on their adherence levels.

This section has revealed that the participants who had attended an optometrist appointment generally enjoyed their experience. The visual aids, such as being shown pictures of their eyes allowed the participants to feel that they were being treated as a person and not a disease. It was also evident that the optometrist appeared to have sufficient time to speak with the participants and this was reflected when the participants discussed their specific appointments. The participants also felt as though they were an integral part of the process with the optometrist spending time with them and explaining the changes to their eyes. The optometrist appeared to be the only healthcare professional that the participants enjoyed visiting. The opticians organised the participant's annual appointments and this made the

participants satisfied that it was no longer their responsibility, enabling them to carry on with their life as normal.

In conducting this research, it would offer the impression that there were very few, if any, recent referrals to the dietician, even though the majority of participants in this research referred to themselves as obese or very overweight. Speaking with the participants they did not seem to be aware of who should be responsible for referring them to a dietician, although a few did mention that they would like to speak to somebody in relation to their weight.

Participants who had not been referred to a podiatrist noted that they would see a podiatrist only when a problem arose. I felt that the podiatry services in this study did not necessarily provide the appropriate care required for the individuals concerned. Participants explained that the appointment system was difficult to navigate whilst the podiatry service appeared to be fragmented. Little or no coordinated foot-care advice or diabetes education was offered to the participants who had attended podiatry appointments.

This section has illuminated that there is a need for clear referral guidelines to be adhered to in respect of diabetes education and information. In order for a person to develop competency in the self-care management of their diabetes they require information that is tailored to their needs.

7.8 Participants' Experiences, Perceptions, Beliefs and Normalisation

'If you wish to keep as well as possible, the less you think about your health the better.'

Oliver Wendell Holmes (1891)

Mulvaney (2009) points out that healthcare providers may focus on the patient's need to change their lifestyles in order to self-manage and frustrations may be evident if their instructions are not met with appropriate *'frequency or quality.'* The view of adherence however may be considerably different when viewed from the patient's perspective and they may modify or adapt recommendations to suit their own lifestyles (Mulvaney 2009). Doctors for instance, may focus on those strategies that effectively reduce blood

glucose levels, whereas the patient may deem the barriers that cause particular stress and anxiety require immediate attention. It has been suggested that healthcare providers adopt an approach that motivates and sustains problem solving for patients by providing both expert knowledge as well as supporting patients in addressing their specific lifestyle issues (Mulvaney 2009).

This section will focus on the participant's feelings regarding their diabetes and the concept map (Figure 10) was structured around the comments or statements that the participants discussed during their interview.

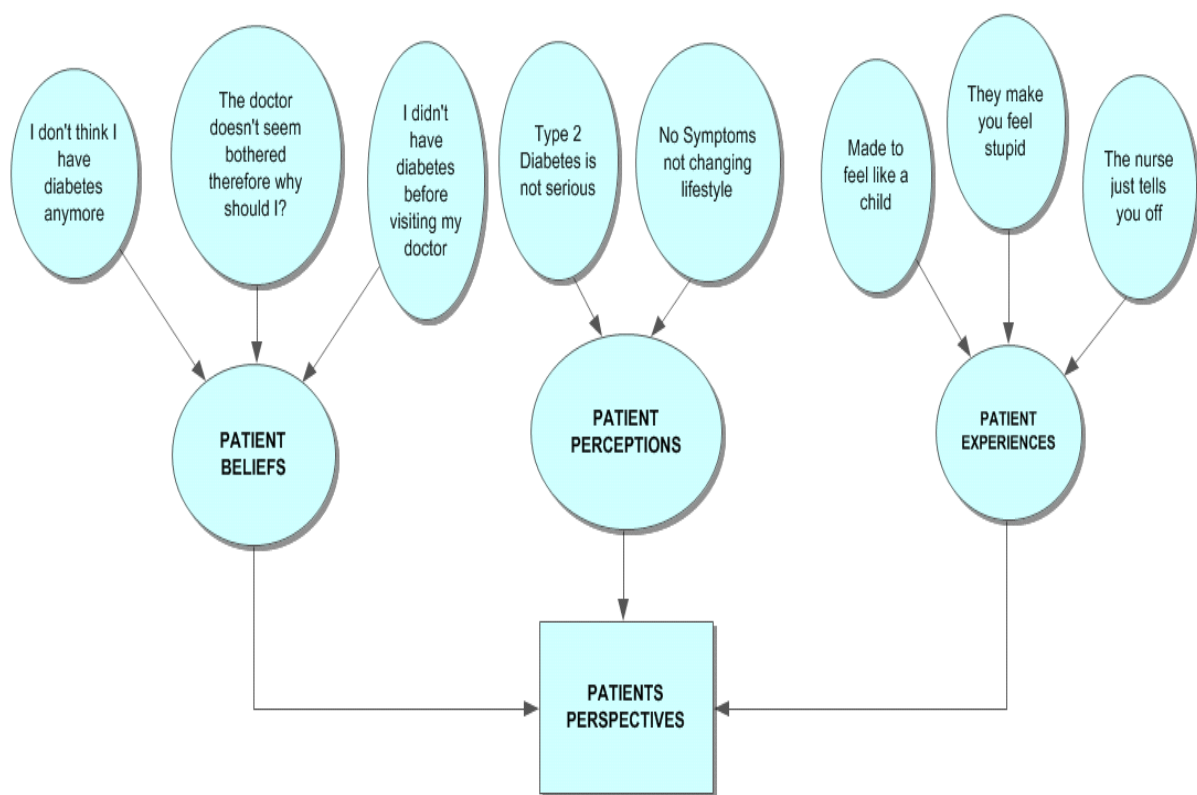


Figure 10: Patient perspectives

The main concepts that emerged from the data in relation to the participant's beliefs, perceptions and experiences were:-

1. Type 2 diabetes is not serious
2. My diabetes has gone away
3. Doctor doesn't mention my diabetes
4. Didn't have diabetes before seeing the doctor

5. No symptoms not changing lifestyle
6. Feel like a child
7. Made to feel stupid
8. Do not want to be told off

Most of the male participants in the study explained that they did not tell their wives about the medication they were taking. Majid explained that his diabetes;

“Just lives in a box in the cupboard”...Majid

Majid explained he does not discuss his diabetes with anyone not even his wife who he explained is a nurse. When first diagnosed he demanded a second opinion asking his doctor;

“Why me? Are you sure you have not mixed me up with someone else?”...Majid

Majid further commented that the first twelve weeks after his diagnosis were the worst as he was in total denial. He explained that he could not accept his diagnosis and this is the point where he would like to have had someone to talk to and explain it to him.

Rebecca explained that she was ‘*very annoyed*’ at being diagnosed with diabetes and blamed the ‘*lack of support from the system.*’ She explained that she now has a disease that she will carry for the rest of her life, due to the fact that she was unable to lose weight, therefore stopping her having the bariatric surgery she was promised.

Martin explained he was made to “*feel stupid*” and as a long distance lorry driver never had time to make a doctor’s appointment stating;

“My health deteriorated quickly due to diabetes. How was I supposed to know what I should know”...Martin

He appeared sad when he spoke to me and remarked;

“If I had known then what I know now I would have lived my life very differently”...Martin

Martin then proceeded to show me pictures of him when he was a young man on his wedding day. He became very upset and petted his dog for a short while, explaining that his dog had been his constant companion since his wife died. We both sat in silence for a while and then Martin told me a funny story about having all his teeth out in his twenties. It was at times like this I wanted to say, let's not discuss diabetes and illness anymore, let's just talk about all the happy times you have had in your life. We carried on looking at the photo album for a while and then I brought the conversation back to the research and resumed the interview.

Upon diagnosis, patients are faced with the dilemma of following recommendations to change their lifestyles and ensuring they meet their own needs, by taking part in '*normal life*' and being able to '*fit in*' (Rosenbek Minet *et al.* 2011). This balancing act involves patient's making adjustments to their behaviour to be able to fit into different social situations, whilst adhering to medical and lifestyle recommendations (Rosenbek Minet *et al.* 2011). As further evidenced by Hunt *et al.* (1998) patients often express a desire to '*maintain a sense of normality*' and take part in their regular social roles. Often the most difficult area concerns food intake as this can play a key role in social interaction and retains a powerful '*emotional and symbolic force*' (Hunt *et al.* 1998).

All of the participants in the study discussed their food intake with me. This was a subject that I never initially raised with them, although all of them thought it important enough to discuss with me. Wilf informed me whilst laughing;

“I have just eaten a large cake full of peanut butter and it is only 10 o'clock in the morning. It's like I say I do not get over worried, I think that being anxious about something could be worse than not worrying about it so I try not to worry about it”...Wilf

Wilf explained that he enjoyed going on holiday with his family several times a year. He explained he worked hard in two jobs and this was what he lived for;

"I abuse food and alcohol when I go on holiday (laughing) I'll be honest with you. When it is all inclusive you get as much as you can. You know I take it very light heartedly this diabetes thing"...Wilf

Participants who had not adjusted their lifestyle in light of being diagnosed with diabetes remarked;

"I love cauliflower cheese, the doctor hasn't told me I can't have it so I eat it all the time, I'm having it tonight actually"...Peter

"Diabetes does not play any part in my life; I just carry on as normal. I still eat rounds of toast and butter every day and still eat all my normal food. I have cake when I want"...Gail

"I still eat a large bar of Cadburys chocolate every night, I know I shouldn't do it but I do it plain and simple"...Derek

"I have not changed my eating and drinking habits one bit. I get up and have breakfast with my wife and then I go to work and have a huge fry up with the lads. We have done this for years now, even before I was diagnosed and nothing has happened to me, so I think it has gone away"...Stuart

"I still eat what I want, I don't want my blood sugars to drop and I have a sweet tooth anyway"...Peter

"I'll be honest I enjoy a drink and I have a drink most nights and I don't intend to stop that no matter what anybody says to me. It is my only outlet"...Wilf

"I have never changed my life drastically, well all I really did was stop drinking sugary drinks"...Derek

A study by Beverley *et al.* (2014) found that older people with type 2 diabetes may weigh up the cost of having a quality of life against the advancement of the disease. They further discovered that the demand to follow a multifaceted regime may not fit in with their preferences.

Participants discussed their beliefs regarding diabetes;

"I was diagnosed with type 2 diabetes but I don't think that I have it anymore because I don't have any symptoms"...Stuart

"It might harm me eventually but it has never harmed me yet and I've been carrying this diabetes now as the doctor told me I've got it for about seven years. I still don't believe he got it right, that doctor. I don't even feel ill. I have not deteriorated at all like you do with the other one. I just carry on as normal"...Wilf

"I just thought if I took the tablets it would go away. I think my diabetes is just temporary, and I am sure that my body will one day go back to normal. I will just carry on eating as normal then"...Bob

"I don't feel any different and I don't take tablets or have injections, I wonder if it has just gone away. I imagine if the doctor thought my diabetes was serious he would have come out to see us"...Winnie

"The doctor told me I had diabetes because of my weight, but it is not from what I eat. It is not as if I shove sugar down my throat because I don't. They said my diabetes can go away and there again it could not. Can it go away?"...Gail

“Everyone will catch it eventually won’t they, I mean it seems to be going around at the moment”...Stuart

“They do get it wrong doctors, so I am sure lots of people haven’t got diabetes but have been told that they have”...Pauline

“I don’t know why it is not explained to you. Why do I have to have sugar some times and not others? I thought diabetes was because you ate too much sugar, but I don’t have sugar in my tea. I eat lots of fruit and I have cheese and biscuits after a meal so I don’t understand why I still have diabetes”...Ruth

There were several participants in the study who felt that they were unable to discuss having diabetes with their family or friends and just wanted to appear ‘normal’. This was mainly due to not displaying any signs or symptoms so individuals often ignored the fact that they had an illness. Angela explained that she no longer discussed her diabetes with one of her daughters as she felt that she was being chastised as she does not have, “*serious diabetes*” and does not take insulin.

I became aware during the interviews that participants appeared to have a lack of understanding of their medication regarding type 2 diabetes and its associated complications. Stuart wanted his medication explained;

“How can you and I take the same amount of tablets for diabetes and expect them to work the same? I mean I am three times your size but the doctor will give us the same prescription, how can that work, no one explains that”...Stuart

Don informed me that Pauline stopped taking her insulin years ago and now feels that it is fine for him to stop taking his tablets when he feels like it;

“If I don’t feel like eating I don’t take my tablets, Pauline hasn’t taken her insulin for years and nothing has happened to her”...Don

Jon explained to me that he stopped taking his insulin before going on holiday as he knew that this would enable him to lose weight quickly. He also explained that his body did not feel any different when not taking his insulin, so he was pushing it further and further every time;

“I push the limits with my insulin, I am trying to see how long I can go without it and then one day I will no longer need it”...Jon

Jon’s belief was that once his blood sugars stabilised his body would return to normal. Jon explained that he was no longer able to maintain an erection. He explained that this was affecting his relationship as he just recently had a commitment ceremony. Jon commented;

“I know this is just a temporary problem and that once I no longer have to take insulin my diabetes will be under control and everything will function as normal again”...Jon

It was so easy to speak with Jon as he remained jovial and upbeat throughout our conversation. John left the room after this comment to attend to his cats. It gave me time to pause and think, and come to the realisation that Jon wanted to feel in control. I felt that he should know how insulin works and if he is not aware then that is of a concern. He is however, making that valued judgement between the risks and the perceived gains. I asked Jon if he had spoken with his doctor about reducing or stopping his insulin and he informed me that this conversation between him and his general practitioner had never taken place.

Derek, Wilf and Stuart, often made statements and asked questions then looked at me as if they were seeking clarification or an answer. I had to think quickly as due to my educator experience, I wanted to discuss diabetes and help them to understand the invisible symptoms. I did however, remain

professional, impartial and managed to maintain my role as a researcher, as difficult as this was;

“The nurse says I am borderline type 1 and that my pancreas is going to stop producing insulin, is that right can that just happen?”...Derek

“I would like another opinion because it is like I say; I have never felt any different than when I was diagnosed eight years ago, should I start to feel different, if I have this diabetes?”...Wilf

“I don’t take insulin, I don’t feel any different, I still believe that it has gone away”...Stuart

Murphy and Kinmonth (1995) stated that general practitioners might see diagnosis as a ‘*solution to a puzzle*’, whereas this is merely the start of the journey for a patient. Patients can often be expected to make radical lifestyle changes, which may prove complex and difficult to maintain and their study found that patients might focus on the symptoms by ignoring the diseases complications or doubting the initial diagnosis. They also found that patients with type 2 diabetes differed in their views on the seriousness of the disease. In their study individuals felt the disease was serious but didn’t actually concern them specifically and others knew how serious the disease could be but felt they could control it. Doctors were also questioned as to why they felt patients would or would not adhere to medical advice. They cited individual’s motivation, intelligence levels, degree of social support, ability to understand their condition, financial constraints and social circumstances (Murphy and Kinmonth 1995).

Stuart and Wilf, expressed that they would carry on with the same lifestyle they had prior to diagnosis;

“Once something serious happened or when I have to take insulin, then I know I will have the proper diabetes”...Wilf

“My dad took insulin so he had the proper diabetes, he was always falling down with hypos, and I don’t do that. I might take it seriously when that happens”...Stuart

The participants offered many reasons as to why they “*just carry on as normal*” and quoted the following”:

- 1. I have no signs or symptoms*
- 2. I do not take insulin*
- 3. I can survive without my medication*
- 4. Surely I would know if it was serious*
- 5. The doctor never mentions it, so it cannot be that serious*
- 6. They don’t let me test my blood sugars so it cannot be that serious*
- 7. Everyone gets it when they are old*
- 8. Everyone is catching it at the moment*
- 9. No one has explained diabetes to me*
- 10. They just gave me tablets, nothing else*
- 11. I feel the exact same as I did before I was diagnosed*
- 12. If I had not had that blood test, I would not know to this day I had diabetes*

Cohen *et al.* (1994) observed 54 patients and reported that more than half felt their diabetes was not severe, with only two considering they were deemed to be ‘*healthy*’. All patients mentioned difficulties they faced in relation to their lifestyle and relationships. Specific problems faced in managing the condition were sexual problems, diet restrictions, loss of self-esteem, and mood swings. When interviewed as part of the study, patients did appear to under-estimate the seriousness of the disease with only a few expressing it would develop into something more serious (Cohen *et al.* 1994).

The overall theory in this study was that the participants placed limited significance on type 2 diabetes and would often compare it as not being as serious as having type 1 diabetes. It is not perhaps necessarily for a person diagnosed with type 2 diabetes to be aware of the exact aetiology of this

disease, however, by obtaining a greater understanding of how type 2 diabetes could affect the body, this may allow a person to address and modify their lifestyle choices.

I also asked the participants to comment on what they felt was important to them in relation to their condition. A summary of the responses are detailed in Figure 11. I entitled the central concept map theme as 'normalisation' as all of the participants had mentioned that they '*just wanted to carry on as normal*' or retain their daily lifestyle routines.

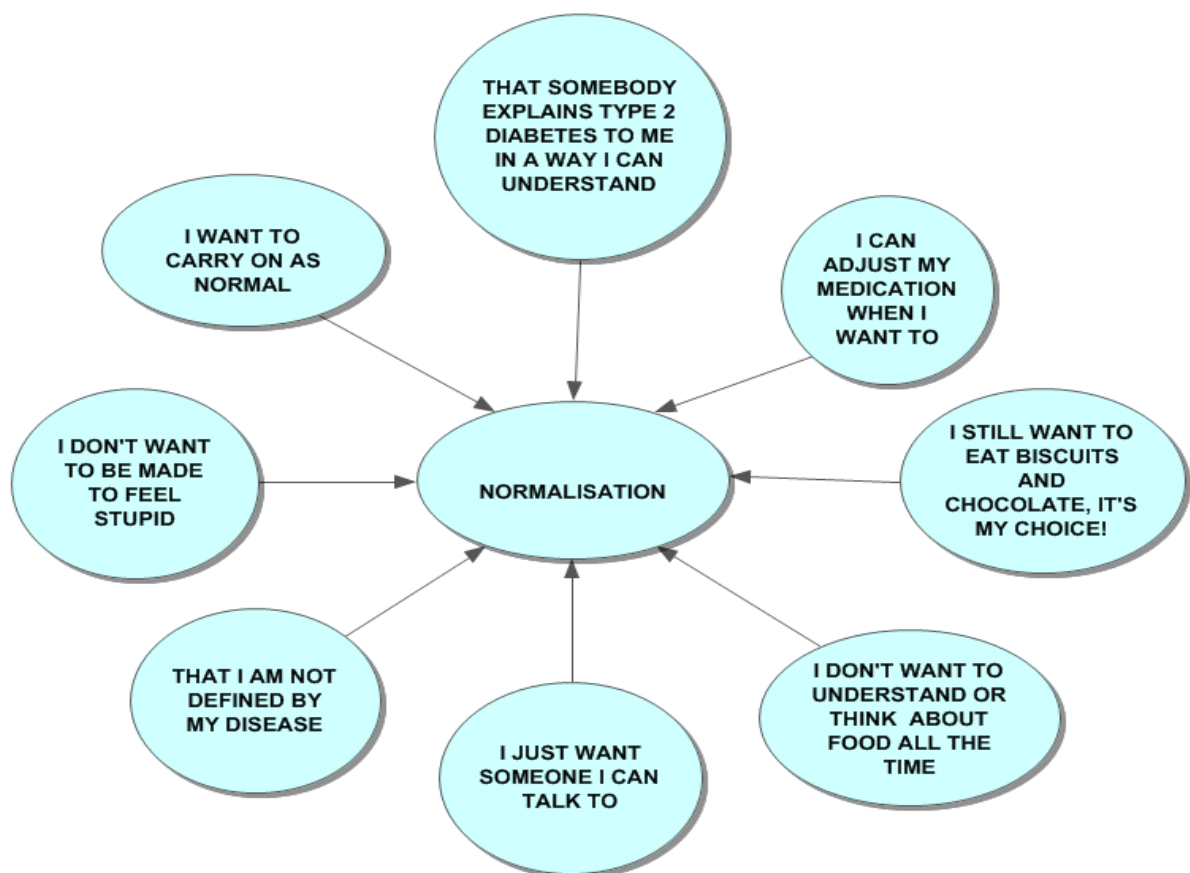


Figure 11: Normalisation

The concept map may offer the impression that participants felt unhappy or miserable during the interviews. This was not the case however, and most individuals were very matter of fact and remained jovial throughout our time together. All of the participants were fully aware that the reason for the interview was to discuss their diabetes. The majority of participants however, wanted to discuss anything and everything except the topic of diabetes. Some

of the participants ate during my visit and some drank (alcohol included) whilst being interviewed. One man sat in his pyjamas and we laughed about the interview dress code. Gail cried all through the majority of her interview but there was also lots of laughter during certain moments. I had dogs sit on my knee, three at a time on one occasion whilst trying to listen and concentrate. Rebecca's children screamed and ran in and out of the room continually during her interview. There were telephones ringing a fire alarm and other distractions. I have looked at more family photos than I have seen in my entire life. I listened to several arguments between Peter and his wife. I was introduced to Stuart and Ruth's partners, who both discussed their cancer diagnosis with me. I struggled to understand some words Ruth said due to her strong accent that would sometimes become a whisper. I had the Jehovah's Witness ideology explained to me by both Pauline and Don. I panicked that my recorder may just stop working, at any time during the interviews. I felt daunted when speaking to Alan. I had to climb over a locked gate to enter Alans house through the back door, he had informed me on the telephone previously that I was not allowed to use his front door. I got lost driving to Jon's house.

I have never cried so much in my entire life, all in the name of research. The process of being immersed in the research development became my normal situation. So when an individual in this study told me they just carry on as normal, who are we as healthcare professionals to take this away from them, by 'telling them what to do' instead of merely asking 'what can we do to help you?'

The health service remains time poor for appointments and this is generally well known amongst healthcare professionals, and recognised by the government and the people using the services that they provide. Due to such resource limitations, it is understandable that a healthcare provider may wish to deliver education or information in an efficient manner but this may be perceived by the receiver as getting told, or instructed what to do, which could be considered as negative. I do believe however, that research undertaken by (Rosenbek Minet *et al.* 2011) may have the answer in stating that, healthcare

professionals may be able to positively influence self-management in individuals by focusing on what the patients deem to be important or appropriate.

Hunt and Arar (2001) illustrate that healthcare professionals base assessments on the achievement of clinical goals whereas the patients consider how they are feeling and how the disease affects their 'normal' lifestyle. Patients are unable to separate the illness and its management as it affects their broader lives and they seek practical methods to apply specific behaviours in order to achieve outcomes.

I asked all of the participants for a final thought they would like to leave me with regarding their diabetes and what they felt were the most important issues for them.

Wilf commented whilst laughing, that he was not taking this diabetes very seriously;

"I think the doctors should give us some information that we can understand and explain to us what this diabetes is, if it is meant to be that important" ...Wilf

Stuart could not understand how both he and his father had been diagnosed with type 2 diabetes, yet his father took insulin and experienced having 'hypos' and always felt ill. Stuart also said that he thought insulin was just a natural progression and he would worry, when he had to take that;

"My dad got diabetes later in life and he went onto injections straight away, they said he had type 2, so I can't have the same as him. He was always ill, I have never been ill" ...Stuart

Winnie believes that her doctor should have spoken to her after she was discharged from the hospital;

"I think there should be something put in place, I mean when you get high blood pressure you are sent to

hospital for all sorts of tests and you get tablets and are tested all the time and yet there is nothing for diabetes. I know someone who stubbed their toe and got gangrene and they kept chopping bits of her leg off, then she ended up dead, she was only forty. She mustn't have been told anything either"...Winnie

Derek associated type 1 diabetes as the serious disease, throughout the interview. Derek assured me that he has never had any symptoms pre or post diagnosis;

"If I ended up type 1 I might start to do something about it, but I have no symptoms. Like I said if that nurse at work that day hadn't told me to go and see my doctor I am convinced to this day I would not have known that I had it. The doctor just gave me diabetes, just like that after that blood test"...Derek

Ruth was confused as to why she could have sugar on one occasion but not the next;

"Well I don't understand it because when I was in hospital and they tested my blood sugar it was 3.2 so the nurse made me drink tea with 2 sugars in. I said I can't, but she said, you have got to have it. The nurse up at that clinic goes mad when my sugars are 6.8 she tells me I can't have anything with sugar in. I wish they would make their mind up, I don't know"...Ruth

Gail already has two other long-term conditions to live with and her husband has cancer. Gail explained that diabetes is very low on her list of priorities, as she has no symptoms and feels that if healthcare professionals took the time to ask her what is important she would not feel so alone;

"I just don't want them to keep telling me what to do and not asking about me, they are paid to help me aren't

they. I know I have cried but no one has ever asked me in ten years about me, you feel like no one cares. I need to be stronger but I know they won't have time to listen to me"...Gail

Angela was diagnosed with type 2 diabetes by her doctor on the same day that she was given the all clear from her breast cancer. She was laughing when she mentioned;

"That doctor had to give me something else. I don't want to go onto insulin because I couldn't do it, I just couldn't"...Angela

Bob explained;

"I am not frightened of my diabetes in any way, but I think that is because I don't think it is that important compared to my other illnesses"...Bob

Jon explained that he will one day just stop taking his insulin altogether as he will no longer need it;

"Diabetes does not hold you back from living in my opinion and you are still able to do what you want at any time, live your life"...Jon

Martin told me he was enjoying his life at the moment with his dog and his caravan holidays to Spain and remarked;

"When I first went to the nurse it was you can't do this and you can't do that but you can't do it all at once, you got to do it slowly. I don't think they realise that you are a person not a machine, and it is a shock when you are first diagnosed and I don't think you accept it. I mean you don't have any illness and you can't see anything, so how do you know there is something wrong with you. They want you to change everything but you don't see or

feel any different, but you can't have anything you enjoy anymore and they don't tell you why"...Martin

Alan mentioned his thoughts concerning the medical bureaucracy and 'red tape';

"I think it is left too much to self-management and that is ok for me because I am intelligent. I can adjust my doses and I just mess around until it is right. Not everyone can do that, not everyone has that frame of mind. I think all diabetic patients and people with long term conditions need more time with the NHS, because there just isn't the time provided. What I am trying to say is more time for people with long term conditions and less time for bureaucracy"...Alan

Peter mentioned his doctor's appointments;

"I am not frightened of speaking to the doctor; no she is not bad actually. I just don't think she has a lot of time to tell me anything or help me"...Peter

Don expressed his approach to teaching;

"I am a Jehovah witness and we are taught to teach not preach, there is a big difference and these people are preaching. Like that woman was preaching to us what to do and she was grossly overweight. People were not listening to her. They don't want to reason with us. They don't see us as individuals they see us as a diabetic. They never ask about me or what concerns me. They never ask you what you want to know and they never ask us what is important to us"...Don

Pauline explained that her doctor ruined her life by diagnosing her with diabetes; she was scared to have any more children post diagnosis in case they 'caught it';

"I have never been told what diabetes is and I don't want to know now, if it is that important they would have told me by now. I am just sad that I was diagnosed with diabetes and put on insulin when I never had it" ...Pauline

Majid expressed;

"I would not go on an education course because I don't want to sit listening to people moaning, you've got diabetes, just get on with it. I will look things up if I need to as I know the doctors and nurses do not have the time to explain it to us" ...Majid

Rebecca states that she needs continual support as a newly diagnosed person with diabetes;

"I am really angry that they let us get like this. I think it is the nurses wanting all the power. They should treat us like individuals. I am sure there are other people out there who don't understand the information" ...Rebecca

Chris just wanted a little information; she explained that she will not be told what to do;

"I have resented having diabetes as I have a quite a few other health problems and to have diabetes as well, I am particularly cross. I still don't know that much about it. I know that I am taking tablets for it and that is about it really" ...Chris

7.9 Conclusion

It is evident from this chapter that although the findings have been able to be formed and presented into categories, patient's perceptions and beliefs in relation to their condition is a web of complex factors and issues. I would personally describe it as being likened to a jigsaw puzzle with many different pieces that are interconnected, and only forming a clearer picture when they all come together. A study by Roberts (2007, p.1) *found that 'the average person with diabetes mellitus will spend three hours a year with a healthcare professional and the remaining 8,757 hours caring for themselves.'*

Clearly the education and information patients receive is a crucial element in enabling individuals to be able to successfully self-manage their condition. Individuals interviewed did not have a good understanding of type 2 diabetes and evidence suggested they had received little in the way of education or on-going support. Participants were not necessarily aware of what they should know about the disease or what questions they should ask of healthcare professionals. It is also not simply a case of being provided with education or information as a form of transaction. Individuals have feelings and emotions and behave differently according to their feelings. I feel therefore that the provision of information or education is not enough in isolation and a deeper level of support and understanding must be taken into consideration.

People do require appropriate education, information and support in order to be able to effectively self-manage type 2 diabetes. It was evident that the various healthcare professionals the patients come into contact with play a significant role in ensuring this takes place. It appears that individuals' felt time restrictions hampered this occurring effectively and their subsequent ability to self-care effectively. Patients expressed a desire to receive education in an easy to understand format, and this may need to be tailored in order to take into account different individuals learning styles or ability to comprehend information or education. A summary of the findings, concepts and overall theory which emerged from the data analysis process is detailed in Table 12.

Table 12: Summary of findings, concepts and theory

Open Coding	Axial Coding	Concepts	Theory
They just give you a leaflet	Patients awareness of what they need to do	Diabetes Education or Information	Limited Significance
I still do not know what diabetes is			
I do not know what I should be asking			
I don't want all the information at once	Patient Education/Information	Patient Empowerment leads to Self Care Management	
Who is supposed to tell me about my diabetes, because no-one does			
If they don't tell me anything then I must be okay			
Why do I need to go on a course	Courses DESMOND, DAFNE, X-PERT		
I have never been offered a course			
I never see the same doctor twice	No information provided from the doctor	Relationship with General Practitioner	
The doctor never mentions my diabetes			
If diabetes was serious the doctor would tell me			
She never explains diabetes to me	Negativity	Relationship with Practice/Diabetes Nurse	
Why should I change my lifestyle			
You are in and out in ten minutes		Relationship with Healthcare Professional	
They never ask about my diabetes			
They give you a diet sheet but you can't stick to it			
I don't think I have diabetes anymore	Participant Beliefs	Patients Perspectives	
The doctor doesn't seem bothered so why should I?			
Type 2 diabetes is not serious	Participant Perceptions		
No symptoms, not changing my lifestyle			
I don't want the nurse to tell me off?	Participant Experiences	Normalisation	
I want to carry on as normal			
I don't want to understand or think about food all the time			

8. Discussion of Findings

8.1 Introduction

Following on from the previous chapter which presented the key findings and concepts from the study, this chapter will further consider and discuss the implications of such findings. This chapter is intended to examine the findings and draw out specific elements in relation to wider research, recent literature or current thinking, whilst incorporating my personal thoughts and reflections. The chapter will also bring to light potential limitations in relation to the study and aspects of my reflective practice observed, whilst undertaking the research.

Figure 12 illustrates the key aspects that will be discussed in relation to the findings. It is aimed to highlight the important aspects that are required to successfully enable self-care management and to also display the apparent barriers and difficulties encountered in achieving this for individuals with type 2 diabetes. The figure illustrates the different priorities and considerations from the healthcare profession and patient aspects and also identifies the issues that have an impact on the successful transfer of education and knowledge to individuals.

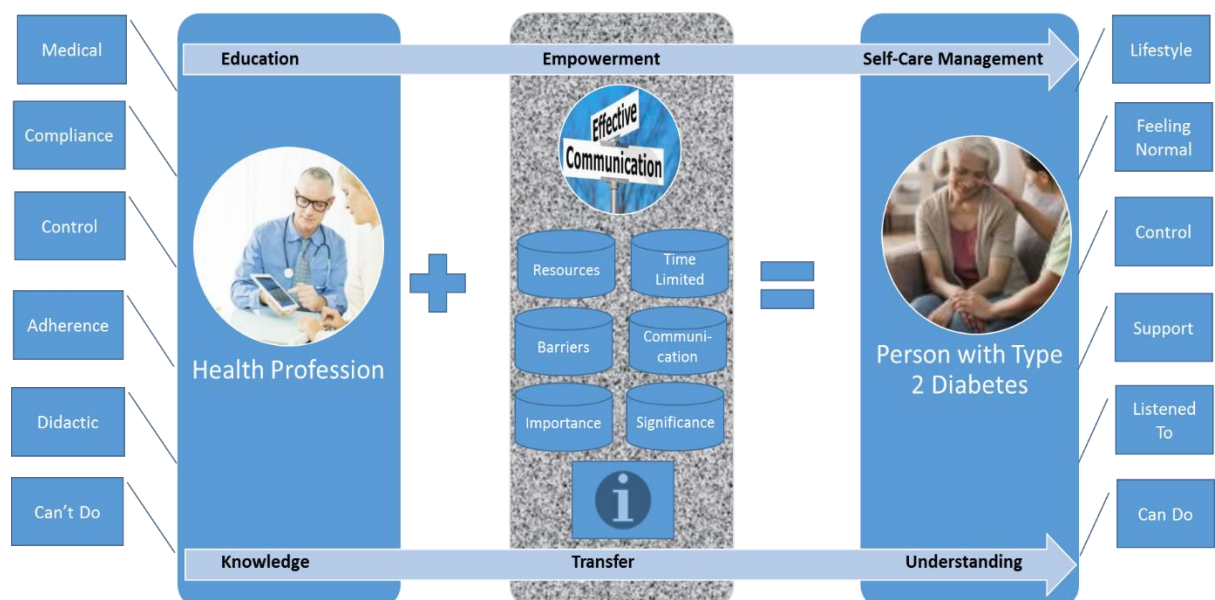


Figure 12: Key aspects from the findings

The key aspects from the findings highlight the participant's experiences, perceptions and beliefs in relation to their diagnosis of type 2 diabetes. The study has revealed that the participants felt healthcare professionals approached diabetes from a medical view point, whereas they preferred to consider the topic from a lifestyle perspective and the issues they face on a daily basis.

Foot *et al.* (2014) expressed that despite National Health Service priorities putting people in control of their care it can still feel more like an aspiration rather than a reality and action can lag behind the rhetoric. However, there is agreement that to provide effective and safe healthcare, patients are needed to be present, involved from the point of diagnosis and confident (Berwick 2013).

Table 13 highlights the concepts that emerged from the data analysis process, which led to the substantive theory of limited significance. It was found that the participants placed limited significance on their diagnosis of type 2 diabetes and this is apparent due to a range of underlying reasons:-

Table 13: Concepts leading to limited significance theory

Ref	Concepts leading to limited significance
1	No symptoms pre-diagnosis
2	No symptoms post-diagnosis
3	The way in which patients are diagnosed
4	Limited information provided by the general practitioner
5	Diabetes not being mentioned at subsequent general practitioner's appointments
6	No explanation provided for lifestyle changes
7	Wanting to be seen as a person not a disease
8	Needing to carry on as normal

8.2 Education, Information and Self-Care Management

Funnell and Anderson's considerable research and literature highlights the crucial role of education and appropriate information in order to bring about patient empowerment and effectively enable self-care management. It is as though they are key ingredients in a cocktail recipe and all are required to successfully achieve the outcomes (Figure 13). Although the authors explain '*great strides*' have been made in terms of improving patient education it is clear they also realise that patients do not necessarily receive optimal outcomes due to a constrained health service that is '*poorly configured*' to deliver effective care for chronic diseases (Funnell and Anderson 2004).

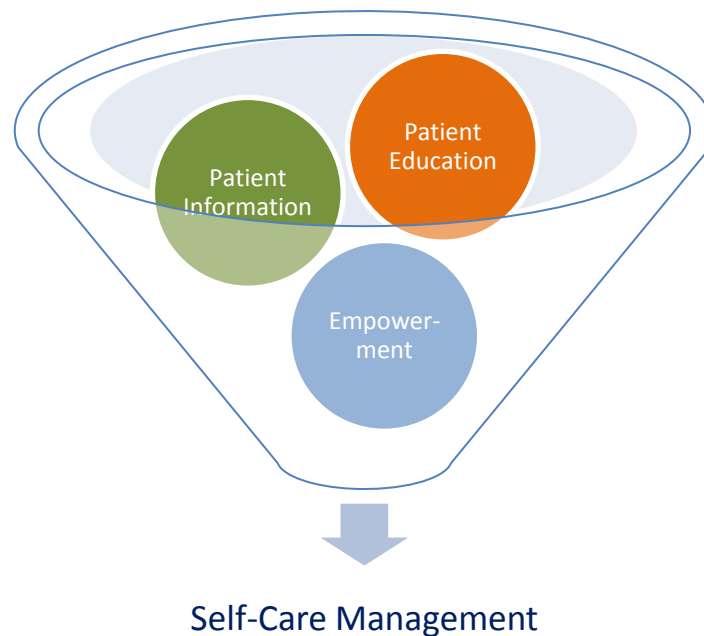


Figure 13: Self-care ingredients model

Hibbard and Gilbert (2014, p.3) describe '*patient activation*' as the '*knowledge, skills and confidence a person has in managing their own health and healthcare.*' Their research suggests that those individuals that are highly activated are more likely to have improved clinical outcomes and report increased satisfaction in relation to the services they receive.

They also report that those individuals with low levels of '*activation*' are more likely to:-

- i) Feel overwhelmed with the task of managing their health
- ii) Have little confidence in their ability to have a positive impact on their health
- iii) Misunderstand their role in the care process
- iv) Have limited problem-solving skills
- v) Have had substantial experience of failing to manage their health, and have become passive in managing their health
- vi) Say they would rather not think about their health

Source: The Kings Fund (2014)

Carvalho de Figueredo *et al.* (2013) indicate the majority of activities involved in diabetes management, such as blood glucose monitoring, medicating, diet and exercise are carried out by the patient. The proportion of treatment time carried out by the patient and their family members has been estimated to be as high as 95 per cent of total treatment time (Heisler *et al.* 2002). However, In order to self-manage effectively, studies have demonstrated that patients do require professional support in assisting with emotional distress, compliance with treatments and behaviour to encourage healthy lifestyles (Thorne and Paterson 2001).

The 'Health Belief Model' advocates that individuals will not be ready to self-manage until they are satisfied in relation to all of the following conditions:-

- i) They are at risk of diabetes complications
- ii) The complications pose a genuine threat
- iii) The complications can be kept under control or ultimately cured
- iv) The psychological, social and financial cost of treatment is less than the benefit

All of the participants in this study have a different story to tell in regards to their life and experiences. A lack of knowledge appeared to influence the participant's feelings of indifference towards their disease and they also viewed some healthcare professionals as displaying indifference also. Few of

the participants obtained general information regarding diabetes from a range of sources, such as friends or family members but commented that they did not know if the information was correct. Due to the fact that diabetes has subtle complications and symptoms individuals do not always appreciate the benefits of adhering to diet, exercise and lifestyle changes. The only link between all of the seventeen participants in this study was that they were diagnosed with type 2 diabetes.

It is evident that patients do not necessarily benefit from a 'one size fits all' approach and interventions need to be tailored specifically to the individual. Some patients may benefit from face-to-face contact whereas others may be more suited to e-health solutions in order to improve their diabetes knowledge and assist them in making informed decisions (Trappenburg *et al.* 2013).

Glasgow *et al.* (2007) has further illustrated that changes to the patient affected by diabetes are dynamic and new issues may emerge over time. In order to be able to deal with emerging issues the patient must develop coping and problem solving skills rather than merely being the recipient of 'education'. Klitzman (2006) undertook research with doctors who had been patients themselves in order that they may draw on their experiences to improve communication and compassion for patients and foster effective relationships. Amongst the findings, doctors stated that information needed to be delivered in ways the patients could understand, they would be less likely to lecture about lifestyle changes having experienced how difficult it was for them, and they would express more sensitivity when discussing adherence and non-medical concerns.

8.3 Relationships with Healthcare Professionals

The study participants expressed feelings of denial, frustration and general indifference regarding the disease and they felt practitioners were not interested in their concerns and would not encourage questions. Patients reported that healthcare professionals did not appear to take their conditions seriously and through this insignificance and silence the patients would subsequently mirror this behaviour and develop an indifference to symptoms

and complications. This research has illustrated that individuals feel the need to 'carry on as normal' and maintain a sense of their lifestyle they experienced prior to diagnosis.

Frosch (2015) explains that there is still progress to be made in changing the attitudes of healthcare professionals. He believes that healthcare professionals need to act with '*respect and humility*' and appreciate that patients do not wish to follow orders or lie about their condition. He also stresses the importance of patients being acknowledged as the 'most important member of the team' due to the fact they know most about having to live with their condition.

The traditional role of the healthcare provider has been compared to the 'parent-child' relationship whereby the doctor knows what is best for the patient in a similar way that a parent would know what is best for the child (Tomasini 2010). The parent role, taken on by the healthcare professional is in a position to impart their exclusive knowledge onto the child, represented by the patient, who is expected to remain obedient and comply. This traditional model does present difficulties for the self-management of diabetes as it implies a hierarchy whereby the patient is treated as a 'child' and does not necessarily accept their maturity or ability to be able to make sensible health choices. Tomasini (2010) illustrated the patient becomes an object of information rather than a subject of communication. Stuart explained;

*"She just talks at you that nurse, all I hear is blah, blah, blah, I just nod my head and then when I leave I just do what I want"...*Stuart

Many of the participants stressed that when they attended appointments at their general practitioners clinic, they felt that the healthcare professionals "*talked down to them*" and made them feel "*inferior*" or "*like a child being told off.*"

Chris remarked;

"I feel I am being told off and I do not like people who talk down to me I REALLY don't"...Chris

Gail commented;

"I just don't want them to keep telling me what to do and not asking about me, they just make me feel stupid"...Gail

Don stated;

"You cannot tell someone off and then expect them to go away and just do as they are told. They don't seem to have time to want to reason with us until we understand what we should be doing. They do not see us as individuals they just see us as a diabetic. They never ask us anything about us or what concerns us. They treat us all as if we are kids who do not know any better"...Don

In order for effective health education to be provided between the practitioner and the individual concerned, both parties must take on the approach of an adult. However, it would appear from the interviews and the information that I obtained, some of the participants felt that they were being treated as a child with the general practitioner or associated healthcare professionals taking on the parent role. Whilst I took into account all of the information the participants provided to me, I also feel it is important to mention that I did not speak to any healthcare professionals or general practitioners to hear their views or opinions, as part of this study.

Figure 14 represents the theory in psychology, examining the transactional relationship between people. This clearly shows the parental aspects of rules, judgements and punishment which have been evident from the individual's transcripts in relation to health care professionals. This also highlights

however the child aspects sometimes displayed by the patients in terms of their self-expression, compliance or rebellion.

TA - the structural model of the psyche

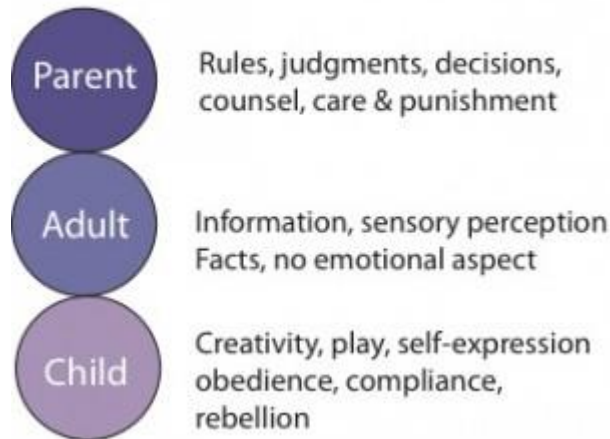


Figure 14: Transactional analysis model

<http://www.ericberne.com/transactional-analysis/>

There are clearly many challenges involving healthcare professionals relationships with their patients and Stilgoe and Farook (2008) indicate that a long term relationship is crucial, where patients are able to access health services despite the fact that responsibility for their health is principally their own. They also point out that patients clearly benefit from personal contact although they may express frustration at the limited time they are able to have with healthcare professionals. There is an appreciation amongst patients of the work that healthcare professionals undertake and that responsibilities are becoming more shared and increased information is now being provided to more demanding patients (Stilgoe and Farook 2008).

Mensing and Norris (2003) explain that health educators and healthcare professionals also have to adopt new learning styles, settings and approaches, along with adjustments in new technology. This research has shown that the participant's relationship with their practice nurse in relation to diabetes education appears to be fragmented. If nurses are to remain the primary contact and provider of diabetes education they must therefore establish what is important to the individual in order for self-care management to be effective. This requires specific training and this standpoint is supported

by Hibbard and Gilbert (2014) who reported that certain health services may possess an overly optimistic view of individual's ability to self-manage their care. They recommended that healthcare professionals require appropriate training and support to be able to assist individuals change their behaviours.

The research has highlighted that the participants did not want to be labelled as mere 'patients' or 'diabetics' and wanted to be viewed as individuals once they walked through the clinic doors. This lack of personal attention created an automatic power imbalance where the health care professional or general practitioner adopted a higher authority. It may be necessary for the health profession to 'assume a degree of control' over patient health visits although the individuals expressed concern over the existing patient/health professional dynamics and relationship. Several participants stated that they no longer attended appointments with the clinic nurse as they always felt they were doing something '*wrong*.' This study also highlighted that participants retain information that is provided in a negative way, but do not necessarily adhere to it. Many study participants appeared to recall specific comments made by the health care professionals and explained how they had ignored or simply not complied with instructions. This may again be a symptom of the parent versus child relationship that is evident in such situations.

A generic approach may sometimes be adopted by healthcare professionals providing information or education and a listening approach that could be developed, tailored and tested, may be more appropriate. The participants sought someone to talk to and listen to the issues that were pertinent to them. If a model could be introduced where the patient's viewpoints and considerations were more integrated into care plans, this would in turn lead to an improved relationship between the individual and the healthcare professional, allowing the person to feel more in control of their self-care management.

In relation to specific information provided by healthcare professionals Jerant *et al.* (2005) illustrated that patients felt they were not able to develop a suitable understanding of their disease, its effects and how they may be best

managed as doctor visits felt '*rushed*'. It was further reported that individuals had concerns about physician's communication styles and experienced frustration with obtaining appointments and receiving test results. A study carried out by Albright *et al.* (2001) appears to reinforce this view as patients were found to be more likely to adhere to specific diets if they were content with the way their doctor communicated with them and were able to answer their questions.

Derek considers himself to be classed as a '*non-compliant patient*', a label which he does not like. He explained this was all due to the fact that he asks questions;

*"The nurse doesn't know the answers and the doctors don't have time to answer them"...*Derek

A study carried out by Agarwal *et al.* (2002) found that administrative and audit requirements have reduced the amount of time general practitioners are able to provide direct patient care.

Funnell and Anderson have published a wide range of articles in relation to the empowerment of type 2 diabetes patients and their works provide an insight into the recent developments that have taken place. Traditional models of care have focused on the patients feeling obligated to follow the healthcare professional's instructions and promoting compliance and adherence was aimed to motivate patients to change aspects of their lifestyle (Funnell and Anderson 2004). Doctors and healthcare professionals have become increasingly frustrated with their inability to achieve success with patient obedience (Funnell *et al.* 1991) and 'non-compliance' is viewed as a serious problem by many (Anderson 1995). Funnell and Anderson (2004) later explained the complex situation and tensions that may exist, where the patient may be viewed as 'non-compliant' and providers struggle to deal with their chronic condition as the responsibility for day to day management lies in the hands of the patients.

Foot *et al.* (2014) observed that many patients with a long term chronic condition do not necessarily see a role for themselves in managing their own health or they appear to be ineffective due to a lack of confidence or deficiency of skills. They also recognise that a 'tailored' approach to support for individuals and care delivery is likely to maximise patient outcomes. It is worth considering however, that an individual patient's self-image and confidence may be affected by diabetes and this may have an adverse effect on their ability to self-manage and with their relationship with healthcare professionals (Hibbard and Gilburt 2014). Each individual's ability to listen and learn may vary considerably and Assal *et al.* (1997, p.63) identify that individuals may progress through five stages:-

1. **Denial of reality** – *patients are unlikely to listen as they have no concern of the disease*
2. **Revolt** – *patients tend to ask why the disease is happening to them*
3. **Bargaining** – *patients often distort and misinterpret the information and education they receive. Healthcare professionals may become frustrated with the patients inability to understand*
4. **Depression with hope** – *patients express a desire to learn that is not always appreciated by healthcare professionals who have just experienced the 'revolt' and 'bargaining' phases*
5. **Acceptance** – *patients become receptive whereby treatments plans are put into practice and suggestions are accepted*

Healthcare professionals should become aware of patient's psychological status in order that appropriate skills may be adopted, enabling patient's to be able to come to terms and manage their condition.

In order for there to be an effective healthcare professional/patient relationship and for self-management to be embraced successfully, the traditional model is required to adapt to a more flexible model of collaboration, where communication, joint problem solving and shared decision making are possible (Heisler *et al.* 2002). This paradigm shift to enhance such relationships would ultimately aim to increase patient satisfaction, improve adherence to treatment plans, reduce complications and improve health

outcomes. Thorne and Paterson (2001) explain that although the role of healthcare professionals in supporting diabetes self-management is crucial, the nature of such support is not particularly understood.

Healthcare professionals must have the personal characteristics to be able to develop relationships with patients in order to foster a culture of trust, respect and acceptance (Anderson and Funnell 2008). Further research indicates that many healthcare professionals are trained in a traditional approach to education that does not always prove effective. The act of instructing patients what to do, merely based on their clinical understanding of the disease cannot be expected to meet the unique challenges that diabetes presents (Brackenridge 1999). Certainly evidence suggests that those healthcare professionals that are able to understand their patient's health beliefs should be in a better position to suggest treatments that are more suited to their personal circumstances and requirements (Funnell and Anderson 2010).

In addition to these obstacles, there are also indications that healthcare providers are often not proficient at communicating or providing information to patients (Carvalho de Figueredo *et al.* 2013). Thorne and Paterson (2001, p.82) state that those healthcare professionals who are most able to support patients with self-management are those who accept the view that '*the patient is the most reliable and accurate source of information*' and that an on-going partnership is required. They also highlighted the fact that the supply of information alone was not adequate enough and patients had to be able to appreciate and understand how to use such information to be able to self-manage. Findings from a study conducted by Heisler *et al.* (2002) suggest that those healthcare professionals who provided suitable information to their patients and involved them in decision making, established a greater understanding of diabetes by encouraging patient motivation and treatment engagement. Figure 15 developed by Heisler, illustrates the importance of the provision of information and self-efficacy to enable successful self-management and ultimately achieve improved clinical outcomes.

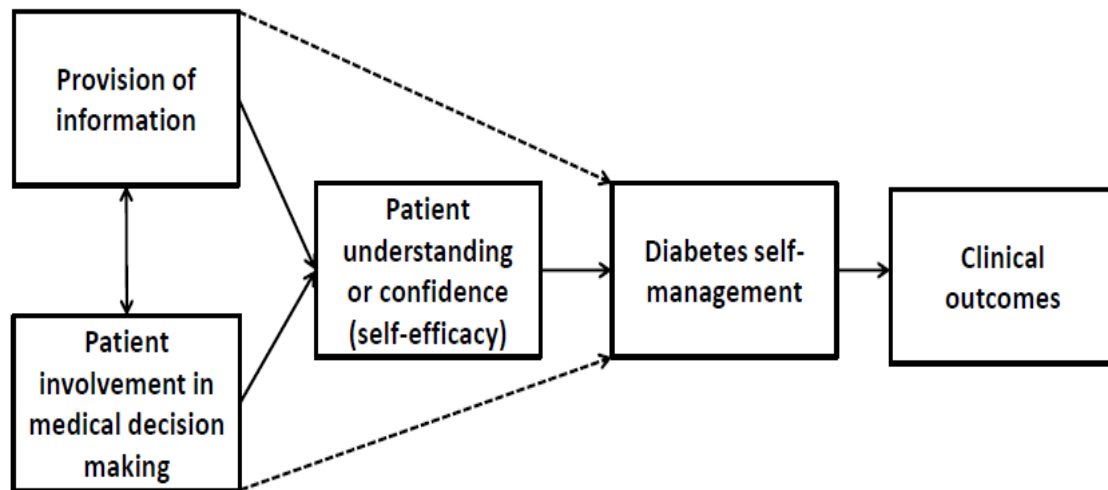


Figure 15: Conceptual model diabetes self-management

Source: Heisler *et al.* (2002)

Alazri *et al.* (2007) highlight that type 2 diabetes patients may visit several healthcare professionals who can provide conflicting advice or incomplete information in the management of their disease. Patients had also expressed confusion at having to consult with several team members. They identified in their research that general practitioners and nurses felt that trust, confidence and a good rapport with patients was deemed to be important in providing health continuity. They also stressed that a patient's background needed to be understood in order to manage their current and future condition.

Hibbard and Gilburt (2014) illustrate that patient responsibility may take different forms and operate at various levels where individuals can take prescribed medication or can change their long-term behaviour in specific ways. They also indicate that this can be dependent upon a range of factors, including an individual's motivation and capability. Foot *et al.* (2014) also advocate that clinicians and patients possess different expertise and information exchange and shared decision making is important to lead to better adherence to treatment and medication. Clinicians are familiar with diagnosis, prognosis, treatment options and outcome probabilities, whereas patients are more acquainted to experience of illness, social circumstances and their values and preferences (Hibbard and Gilburt 2014). Research has found that clinicians may feel that they share information and knowledge more

than patients and dissatisfaction amongst patients is predominantly caused by not being adequately informed about their illness and treatment options (Grol *et al.* 2000).

Although the research has investigated the areas of patient self-care management and diabetes I feel it could be transferable to other global areas of research as it is more relevant to the relationships between healthcare professionals and the individuals living with a chronic long-term condition.

8.4 Normalisation and Limited Significance

Having conducted the interviews, transcriptions, coding and data analysis it appears from the findings that participants valued having a sense of 'normalisation' in relation to their daily lives. This research has found that the individuals also placed limited significance on the diagnosis of type 2 diabetes and did not appreciate the seriousness or risk of complications caused by the chronic condition. This may be present due to a summary of key factors identified in Figure 16.

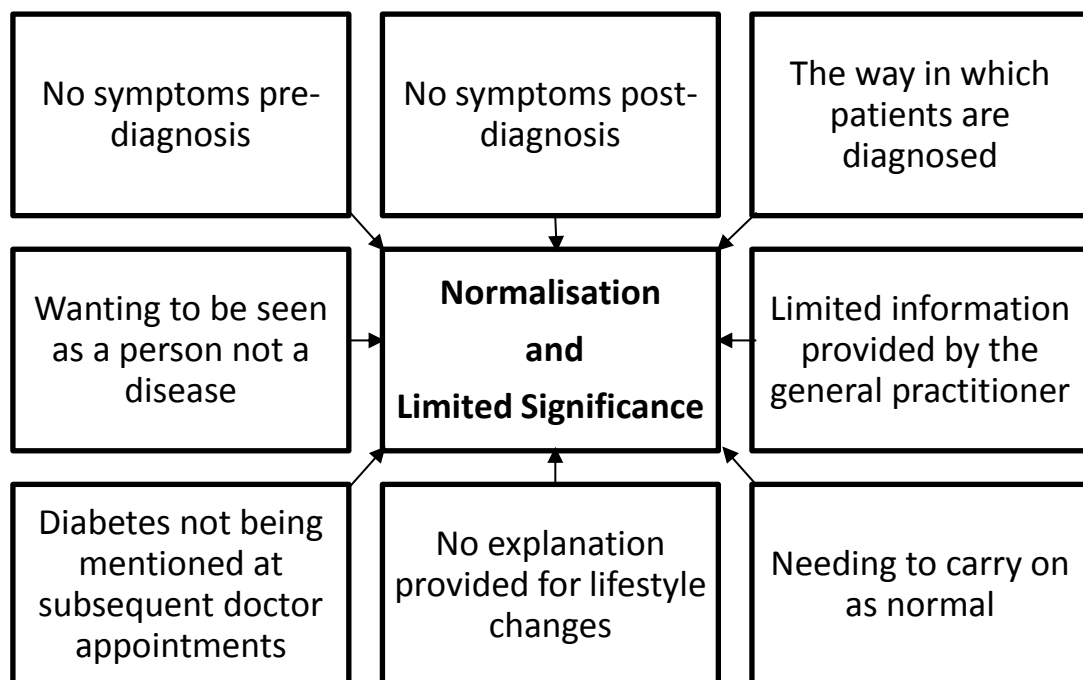


Figure 16: Normalisation and limited significance diagram

The participants wanted to '*carry on as normal*', whether this manifested itself in being able to continue specific lifestyle choices or consume their usual food or drink. The aspects of being able to maintain normal activities and make decisions were key concepts that emerged from the study. For the participants, the focus appeared to suggest they were interested to talk about the 'things they could do' rather than listen or accept the 'things they were no longer advised to do' by the medical profession. From the interviews and emerging concepts this appeared to be a consistent theme and certainly became apparent following the undertaking of coding and the formation of categories and sub-categories. It appears from the study that the participants were being instructed as to what they could not do, rather than being advised what they could do, or at least be provided with explanations behind the reasons for adherence.

Despite having a chronic condition the patients want to maintain a sense of feeling normal and in certain circumstances they have not necessarily admitted or accepted the seriousness of the disease. The findings certainly suggest that it is important for individuals to be in control of their daily lives and to be able to make decisions.

8.5 Study Limitations

Simon and Goes (2013) identify limitations as matters or incidences that occur during the course of research that are out of the researcher's control and limitations with qualitative studies may potentially affect their validity or reliability. In determining potential limitations in relation to this particular research study I considered it would be valuable to use a three-phase framework to present important areas that could be interpreted as potential limitations;

1. **Announcing** – Identification and explanation of important areas
2. **Reflecting** – The nature of the limitations and justification of my decisions or choices
3. **Forward looking** – Assessing how the limitations may be overcome or addressed for future research

Although limitations may be viewed subjectively, it is generally considered that limitations exist within research projects and this study is indeed no exception. I felt that the main limitations may be in relation to the research sample selected for the study being viewed as too generalised and the lack of triangulation as a sole researcher.

Research Sample – the individuals were not pre-screened or selected by way of certain characteristics and were only asked to participate if they had type 2 diabetes. I therefore felt that I had little control over those who came forward and would also not be able to initially ensure that enough individuals were involved to necessarily fully inform my findings or adequately represent a sample of the wider community of people with type 2 diabetes. I did however select representatives with similar conditions and associated variety of experiences with a chronic condition. The individuals were also selected from a relatively small geographic region and it could be argued that they may not necessarily be representative of the United Kingdom population. Despite these limitations I did manage to perform constant comparisons and coding methods to ensure that '*data saturation*' was reached and I did not feel that any further interviewees would add much more new information or 'emerging concepts' to the research process. Further research projects may be carried out in other jurisdictions or over wider areas to obtain a wider geographic sample although it is notoriously difficult to duplicate qualitative research projects of this nature. It is also important to recognise that limitations cannot necessarily be corrected by the researcher and I would have found using an increased and wider cross section of participants difficult to manage. This may in turn have produced further limitations in terms of time and labour resource issues. The method of sample selection would certainly be transferable to other areas of research for the same disease group or for other long term conditions.

Triangulation – Although during the research process I had contact with my supervisors, the participants and student colleagues, I did feel the experience was predominantly a solitary journey. Despite challenging and querying aspects of the research with my supervisors, colleagues and fellow

researchers I found the majority of testing assumptions and findings involved a considerable sense of personal reflection. This led me to question, because I had conducted the research activities on my own, was there sufficient rigour, confidence or reliability in my work? I struggled with this doubt on a few occasions during the course of my research and considered if a lack of 'triangulation' could be considered a potential limitation to my findings.

Creswell (2003) explains that triangulation involves the use of multiple or different sources, in terms of methods, investigators or theories, to '*shed light on concepts*' or corroborate evidence. I had on reflection, used a single methodological grounded theory approach to conduct the research and had performed the principal activities of interview, transcription, coding, analysis, and thesis writing alone. Although I was confident I had undertaken the various activities in a professional, ethical and appropriate manner I did question whether further triangulation would have provided further credibility to the research findings. Lincoln and Guba (1985) discuss the importance of trustworthiness and credibility when conducting qualitative research in order to maintain quality and rigour.

I felt that the use of one methodological approach was fundamental to the research and the grounded theory method suited my line of enquiry and my area of research. The addition of quantitative methods would not have added any additional context or richness to the findings in my opinion. Much research has been undertaken and certain academic literature promotes the use of a '*mixed methods*' approach by combining qualitative and quantitative approaches. Despite Morse *et al.* (2009) indicating that mixed methods research can have numerous meanings it is generally interpreted as the addition of high-level quantitative methods of data collection and analysis to supplement and improve the overall quality of qualitative research (Johnson *et al.* 2007). It is unclear how quantitative research would have enhanced my findings in any way and I do believe that the grounded theory methodology suited the research purpose and aims by allowing the rich contextual information to be obtained directly from the participants.

I also contemplated if seeking corroboration from other researchers in order for emerging concepts or concepts to be subject to further testing would improve quality or rigor. It may have been considered beneficial to gain other individuals thoughts and opinions for useful comparisons, ideas and increased subjectivity. Although I did consider that undertaking the interviews, analysis and review work independently to be a potential limitation it would have not been possible or practical to conduct the work with another researcher. This is due to the ethical principle that the PhD research should be undertaken independently and I felt that the process of interviewing participants, performing the development of coding, formation of categories and identification of emerging concepts were activities that needed to be executed appropriately by the same person. I do believe that by sharing my thoughts and progress with my supervisors and also regularly reflecting on my research I did add sufficient rigor and credibility to the process.

8.6 Reflective Practice

Boud (2001, p.10) explains that reflection involves '*Taking the unprocessed, raw material of experience and engaging with it as a way to make sense of what has occurred.*' Finlay (1998, p.454) adds that reflexivity is '*continual evaluation of both subject responses and research methods*', by adopting a self-conscious critical, systematic and analytical approach to capture subjective and inter-subjective dimensions.

I reflected throughout the entire duration of this study. I have also questioned myself many times as to which role or part I had to play in order to receive the information I required. Silverman (2011) reinforces the importance of constant reflexivity is necessary due to the fact that the researcher becomes intrinsically involved in the world they are studying and there is therefore a need to question the way observations are drawn and interpreted.

I reviewed the work I had written so far and I reflected back to my first interview with Wilf three years ago. Wilf explained he had a '*good innings*' and is in his early sixties, admitting that diabetes '*plays no part*' in his life. He commented all the way through his interview that he feels he has been

misdiagnosed by the doctors and would like a second opinion. He laughed at the end of the interview and said;

“Maybe I am just kidding myself”.....Wilf

This made me smile at the time, however, at this point whilst I am writing this into my thesis I am actually crying because I feel I have let Wilf down. Maybe I am thinking about my dad George, maybe I am thinking that there was someone like me out there who could have helped him but didn't. When I started this research, my paradigm was that people with a chronic disease were given education, but for whatever reason they chose to ignore it or embrace it. That is after all their choice; this is their life, and who says that by having all the facts in front of you, will make your life any better. I encountered Wilf from time to time during this study and I always made a point of stopping to speak to him no matter how busy I was. He would mention concerns such as, pain in his calf's when walking and I would subtly try and obtain more information from him. I would then suggest a referral to a podiatrist, for Wilf to mention his concerns to the doctor the next time he visits. He would always laugh and put his condition down to his age. The last time I saw Wilf was May 2014 and I gave him a big hug and told him to look after himself. I felt the system had perhaps let him down and I also feel as though I have let him down due to the fact that I am a healthcare professional and am there to assist and help individuals.

I have read many papers concerning patient education, with some dating back to the 1950's, and feel this should not be a new concept, and is not new knowledge. If we as healthcare providers and researchers contributed so much literature relating to the subjects of patient education and chronic disease management, why were only two people in my study ever given any education regarding a disease that they will have to live the rest of their lives with? I am certainly not proposing that by providing education this will ensure people will necessarily change their lifestyle or habits. I am suggesting however, that by providing information in a way that a person understands allows them the choice as to how they wish to use it. I did initially feel I would

conclude this study with answers, although I have instead burdened myself with many more questions. The questions raised however may be useful as potential indicators for future research possibilities.

Corbin and Strauss (2008) explained that self-reflection felt a necessary and natural process and by writing memos they were able to see themselves in the analysis and how they may '*slant the data*'.

During the analysis process, I tried to put all of my previous experience as a podiatrist and any personal thoughts to one side. Data analysis in grounded theory is difficult enough without allowing my previous and personal thoughts and reflections into the process. At times during the analysing process I became extremely critical with myself and often questioned my own thoughts. Holloway (2008) has found that critical reflexivity is considered a significant aspect of health research involving the researcher adopting a critical stance in order to include personal thoughts and observations and how they may affect the particular study.

There were times throughout this research that I questioned my role as a researcher, and as a healthcare professional asking myself; what I was doing, what have I taken on? During the time I spent with the participants I was aware that I was carrying out research, I asked questions gathering information whilst picking up on cues from the participants. I reflected on my role as a practitioner where I strive to provide an excellent service to the patient. In order for me to achieve this goal I ask open questions and gathered information, enabling me to make informed decisions, and further provide the relevant information to an individual or refer to other healthcare professionals. I have always enjoyed this aspect of my role as a podiatrist and feel the people I have treated over the years have benefited from this service. I did struggle however, with the concept of being a practitioner taking on a researcher's role. This was an aspect that I had not taken into consideration prior to the research taking place. On reflection I feel I was merely shocked by some of the replies I received during the interviews and also the emotions that some of the participants expressed. I was not expecting to become as

involved as I did during the analysing of the data and it often felt difficult to take a step back. Findlay (2002) found that reflective practice can be introduced using a range of methods and can be conducted at many levels, from acknowledgment of researcher bias to consistent and comprehensive, self-awareness and subjectivity throughout the entire research process

Transcribing Rebecca's interview was also challenging for me, as she was not aware that her general practitioner was also my general practitioner. I have attended his clinic for twenty five years, and the two nurses at the practice she specifically mentioned are the nurses that I also visit. I reflected on the service that I have received from my general practitioners surgery and I analysed the transcripts of the service that Rebecca had received and this an area where I am confident I have not brought any of my own personal views into the research. I reflected on my thoughts and on the words that Rebecca had said and I became all too aware that this research presented Rebecca's perceptions, thoughts and beliefs and not mine. Leonard and McAdam (2001) emphasise that reflective practice by the researcher is a critical grounded theory activity in order to build and test theory, '*make sense of the literature*' and to question underlying assumptions and preconceptions. Finlay (2002) recognises that the practice of self-reflection has a recognised place in qualitative research due to the fact that the researcher is a '*central figure*' that influences the data in terms of its selection, collection and ultimate interpretation.

Activities such as observing, describing, recalling, questioning, note taking and providing or receiving feedback can be used to aid reflective practice and Gibbs reflective cycle (1988) provided a useful model in order to ensure that as a novice researcher I followed a process for self-reflection. The model illustrated in Figure 17 proved useful in analysing and evaluating my feelings following interviews and other aspects of the research process.

There a range of reflective models that may be used in order to undertake and support self-reflection and Donald Schon introduced a 'reflection-in-action' approach that enabled practitioners to reflect and learn from their on-going

experiences. The model incorporates self-reflection before, during and after events and enables increased awareness and consciousness of one's own actions and the effect these may have on events. The approach allows increased scrutiny of events and assumptions whilst enabling new perspectives to be established (Boud 2001).

Following careful deliberation of a number of approaches and background reading in relation to the practice of self-reflection I decided I needed to use a model in order to reflect whilst having a structure to adhere to. As a novice researcher I believed that the model that suited me best was the Gibbs' reflective cycle (1988) by following the model this allowed me to adopt a specific cycle to ensure I asked the appropriate questions and covered all aspects in assessing my feelings and actions whilst evaluating the research process effectively.



Figure 17: Gibbs reflective cycle

<http://www.northallertonvts.org.uk/eportfolio/reflection>

Finlay (2002) continues to illustrate that self-reflection was an important element of the early development of symbolic interactionism where Mead (1934) observed that individuals gained self-awareness by interacting with others. The author also considers that by carrying out the practice of careful and systematic self-reflexivity, the researcher is adding a level of integrity to the research.

8.7 Conclusion

This chapter has highlighted the concepts that emerged from the data in order to find an overall substantive theory. It was found that the participants placed limited significance at the point of diagnosis and have continued with this

theme due to a number of reasons. The participants in this study reported that visits to the healthcare professionals were short in duration and did not support enough time for effective patient education. They had little knowledge of their disease, had indifferent attitudes towards their symptoms and did not realise the seriousness of their condition. Many of the participants stated that they would only see a certain healthcare professional once a problem had arisen. This aligns with work by Nesbeth *et al.* (2009) who identified that a number of barriers to effective blood glucose control were a lack of awareness of their HbA1c levels, a lack of consultation time in order for information to be provided. Nurses can provide an additional level of support to the patient as well as the general practitioner but they must have appropriate education along with the patients in order to prove effective (Holt *et al.* 2013).

This study may be interpreted or suggest that health services are failing patients in some way by healthcare professionals not realising individuals' lack of understanding or knowledge. I believe that the value of this research is that despite the services healthcare professionals are providing, the patient's appear to be forming their own perceptions based on a different set of values and beliefs. It is evident that the participants see healthcare professionals in a specific role of those holding the medical knowledge and they may be reluctant to admit their lack of understanding or be able to converse appropriately with health professionals due to the limited time available or the medical terminology used. Having been employed as a healthcare professional, providing advice to 'patients', I always viewed that as a profession we were extremely patient focused and we successfully 'entered the patient's world' and understood their specific needs. This research has shown however, this is clearly not taking place and there is a disconnect that exists between the aims and objectives of the health profession and the individuals requiring support and education. I firmly believe I would not have gained this insight acting merely as a healthcare professional, whereas operating as a researcher has enabled me to obtain a greater understanding of the experiences, perceptions and beliefs of individuals living with a chronic disease.

9. Conclusions and Recommendations

9.1 Introduction

The purpose of this research was to gain an in-depth understanding in respect of individual's experiences, perceptions and beliefs in relation to type 2 diabetes. In order to achieve this aim a grounded theory approach was undertaken. The research methodology enabled the participants to have a voice at a time and place of their choosing and their contributions therefore formed the basis of the study findings.

9.2 Thesis Conclusions

The study has revealed a wide range of emerging concepts through the interviews that took place with the various participants. It is evident that insufficient information and education is provided to individuals and information that is available, is not necessarily in the correct format or offered at the most appropriate time for patients. The limited information provided to the participants appears to have a marked impact on their lack of understanding or knowledge of their chronic condition.

The individual's relationship with their health care professionals or general practitioners appears fragmented and principally remains focused on the traditional didactic model of care. It was found that the participants may be instructed or informed of aspects affecting their lifestyle that they can longer partake in, rather than being encouraged in terms of elements they may continue or marginally adapt. This approach appears to be in stark contrast to a model that provides information and education to empower patients, enabling them to effectively self-manage.

The key experiences of the participants may be compared to the stages of the Kubler- Ross change model (2009);

- i) **Stage 1 - Shock and Denial** – The shock may have often been felt following diagnosis and may continue for a considerable period for certain individuals. This may manifest itself where participants could be fearful of doing or saying something wrong, display a fear of the

unknown or suffer due to a lack of information. During this stage the participant's may continue on as normal as if the change does not affect them.

- ii) **Stage 2 - Anger and Depression** - During this stage a 'scapegoat' may be found by the participants and blame may be aimed at healthcare professionals or organisations. Individuals also appeared to carry on as normal despite the fact that existing behaviour may not necessarily be the most appropriate option.
- iii) **Stage 3 - Acceptance and Integration** - It is evident that many participants are yet to achieve this stage in relation to their knowledge of type 2 diabetes. This stage is dependent upon effective communication and this did not appear to be evident on the basis of the participant's information.

As the study has demonstrated, individuals may react differently to their specific situations and may remain in certain transitional stages for some time, before ultimately gaining acceptance and integration.

The participant's experiences, perceptions and beliefs indicate a limited significance placed on their condition and this is manifested in a variety of different ways. A major challenge exists whereby individuals tend to focus on their daily lives and factors that are important to them, whereas the medical profession in contrast are principally focused on patient compliance and adherence. Individuals do not necessarily experience symptoms in relation to type 2 diabetes and express a desire to retain 'normality' of their lifestyle. The factors and issues appear to be numerous and complex resulting in individuals placing limited significance on their chronic illness.

9.3 Recommendations

9.3.1 Introduction to Recommendations

It became apparent during the undertaking of the research and more recently upon reflection of the findings and theory generation process; there are a variety of implications for future clinical practice and potential considerations for further research possibilities. The key concepts and recommendations are detailed below and reflect the areas of opportunity I believe would benefit most from future consideration and attention.

9.3.2 Recommendations for Clinical Practice

a) Evaluation of patient's perceptions – The research has demonstrated that whatever healthcare professionals feel they are providing, the patients will generally formulate their own ideas and perceptions regarding their chronic illness. A feedback mechanism is therefore required in order to capture patient's perceptions and beliefs with the ultimate aim of improving individual's understanding in order to self-manage their condition. The assessment of an individual's comprehension or understanding of their situation or facilitation of feedback in relation to areas they do not understand would be beneficial in appreciating causes of 'non-compliance' or individuals not placing appropriate significance on their condition.

Recommendation – A feedback mechanism is required in order for a healthcare professional to gain an improved understanding of an individual's self-care knowledge.

b) Healthcare professional roles and appropriate training – The research indicates that individuals place considerable emphasis on the healthcare professionals they come into contact with during their daily lives. The majority of individuals within the study saw general practitioners or practice nurses and I feel that these medical representatives almost represent a symbol of the disease to patients and this label reinforces the fact the individuals have a chronic condition. The patient's perceptions of healthcare professionals play a

key role in the education process and in ensuring the patient feels empowered and confident to be able to self-manage their condition on an on-going basis.

It is without question that medical professionals are required to maintain a role of providing expert medical advice to patients but there is also a level of support and knowledge transfer that is essential. I do not believe this should necessarily take place in a medical setting or be provided by a medical professional in a didactic manner, within a short restricted timeframe. Patients are aware that current appointment times are limited and that medical professionals are under pressure within such short timed visits. Specific supportive training could be provided to other individuals (i.e. health counsellors, health friend, lay people, educators) in order that they are able to transfer knowledge to patients in a more appropriate setting, either individually or by group sessions and break down the barriers that currently exist between patients and healthcare professionals.

Diabetes UK and Tesco have recently formed a national charity partnership and have provided group meetings for individuals who have type 2 diabetes. They provide information and education in a casual, informal setting where individuals are encouraged to ask questions, share their stories and experiences and meet other people who are 'on the same journey'. This social interaction, joint learning and educational support may be more beneficial to communicating the important messages to individuals from lay people who do not directly represent the disease or medical profession. The model involves more about support to encourage behavioural change rather than specific education provision and this could be adopted more in the future. Further consideration regarding the most appropriate forms of education and their settings should be taken into account when developing strategies to provide education and knowledge to patients. Older patients for example may have difficulties with accessing support via the internet and may prefer individual or group face-to-face support; although this may not always be the case and each person should have education tailored to their individual needs.

Hibbard and Gilburt (2014) suggest that lay and peer support may be beneficial in a range of formats in order to improve tackling lifestyle risks. The independent charity, report that tailored advice, motivation and practical support to promote behavioural change, can be delivered by local community representatives and examples of health trainers or champions have proven to be successful and cost effective.

Recommendation - Careful thought should therefore be given to the most appropriate individuals to provide patient education and what their role should involve.

c) Spreading the success – Although it appears that there are many complex issues involved with enabling patients to become empowered to successfully self-manage their conditions, there are certainly examples of successful strategies or best practice that has been introduced. It is extremely difficult to monitor or adhere to standards in an area that may be deemed subjective and dependent upon many factors for different individuals, nevertheless stories of success or innovation should be shared and promoted. Whether it is the introduction of a multi-disciplinary team approach to encourage and support individuals self-manage or a model of care that improves patient's understanding of their condition, their approach, methodology and successful outcomes should have a platform that enables other individuals or organisations to consider their adequacy or potential use.

Recommendation – The sharing of best practice in order to achieve successful self-care management should be promoted.

d) Changing emphasis of education / “can’t do” to “can do” – This research indicates that instances of practitioner and patient interaction predominantly still occur in a didactic fashion with individuals commonly being instructed as to what they are no longer able to do as a result of the condition. The healthcare professional can be seen as a ‘messenger of bad news’ and individuals may feel a lack of power and control. By changing the emphasis to one of support and advising an individual of what they are able to do, rather than what they are no longer able to do, would potentially shift the balance of power and enable them to become more empowered to make lifestyle

choices. Foot *et al.* (2014) highlights that maximising the value of doctor's appointments whilst suggesting that trained medical assistants aid individuals with questions or concerns prior to appointments and meet to follow up medication and queries afterwards. The information or education provided to a person with diabetes should be an integral part of the appointment with a healthcare professional and not just merely seen as an add-on, which again may limit the person's significance of the disease.

Recommendation – The emphasis of education and information provided to an individual needs to be provided in a consistently positive and collaborative manner.

e) Type 2 diabetes growth trajectory and resources – The forecast global growth rates, as detailed in Chapter 2, are due to rise considerably in the foreseeable future due to a range of factors, including an increase in the ageing population and lifestyle changes. It is unlikely that current resources such as staffing or finance will be able to appropriately deal with this widespread epidemic. It is therefore crucial that methods of future healthcare delivery are assessed, developed and improved wherever possible in order to ultimately improve patient outcomes. Further recommendations would involve an increase in health promotion activities and general public awareness targeting those who have been newly diagnosed or particularly those individuals who are at risk of developing type 2 diabetes. The serious nature and associated risks of diabetes are not necessarily widely known by the public and by increasing awareness and promoting healthy lifestyles could assist in reducing the projected increase in numbers of people with type 2 diabetes.

Recommendation - The shift in focus to prevention, early detection of potential symptoms or signs and school awareness sessions would be beneficial in attempting to curb the forecast rises of individuals with type 2 diabetes.

f) Equipping the educators – A further recommendation would be to ensure that the educators or those providing support to individuals are adequately equipped and informed to be able to 'support the individuals' rather than

merely treating the disease itself. The method of their approach and the appropriate way of dealing with individuals with a chronic disease would be crucial to enabling successful self-management. Hibbard and Gilbert (2014) also raise the importance of '*reframing professional education and training*' to ensure models are based on healthcare professionals providing support to patients, rather than assuming superior expert knowledge. They do however advise that national support for healthcare professionals will be required in order that they have the relevant high-quality tools to provide appropriate care-planning and decision making conversations. A common theme within the findings was that patients wanted to be seen as individuals and helped and assisted when required rather than being seen as a disease that needed to be managed or controlled.

Recommendation – Health care professionals should place importance on considering the individuals and their circumstances as well as treating the disease.

9.3.3 Recommendations for Further Research

a) Transferability to other subject areas – Although the focus of this research has been in relation to the topic of type 2 diabetes, patient education, self-care management and the ways in which individuals perceive their chronic condition, I do feel that the method of investigation and methodological framework could be transferred to other areas of the health arena or to other jurisdictions. The subject matter could potentially be deemed irrelevant as the important aspects relate to the global concept of the relationship between the healthcare professional and an individual living with a chronic condition. The crucial spotlight concerns people being in control of their daily lives and making informed decisions by themselves or with the support of the healthcare profession.

Recommendation – The research could be replicated for practice in other areas of chronic disease self-care management.

b) Medical practitioners' views and education providers – The focus of this research study has involved extensive input and analysis of the

experiences, perceptions and beliefs of type 2 diabetes from individual's perspectives. It could be argued therefore that the research does in fact only assess 'one side of the story' and does not take into consideration any of the views of medical practitioners or healthcare professionals. The research could incorporate the findings from this particular study or could approach the research topic using a similar grounded theory methodology. It would be advantageous to investigate the medical professional views in order to obtain a more balanced and considered opinion of any aspects, factors and potential barriers to successful self-care management.

Recommendation - Further research could potentially investigate the perceptions and thoughts of medical professionals in respect of education, empowerment and self-care management.

c) Best practice and areas of success – As mentioned in the previous section it is likely that there are specific examples of patient education and support that have been successful in enabling behavioural change and achieving successful self-care management. Although this is likely to be dependent upon a range of complex factors and may not necessarily be able to be successfully replicated for all individuals. I feel this area of research could warrant further attention, although it would be dependent on a range of potential questions.

Recommendations – Further investigation could be undertaken to identify examples of self-care management 'best practice' and to establish how they are being achieved.

d) Factors leading to limited significance – This research study has found that individuals with type 2 diabetes place limited significance on their chronic condition. Further research to build on this theory could investigate the reasoning and test the hypothesis in relation to limited significance. By creating an awareness of the causes of placing limited significance on a chronic condition this research could assist future education programmes and ultimately improve models of self-care management for individuals.

Recommendation - The associated and complex reasoning behind the theory of limited significance could be further researched and

investigated in order to gain a better understanding and appreciation of the factors leading to this conclusion.

e) Barriers to education and self-care management –Research has indicated that the medical profession may consider patients to be ‘non-compliant’. There are also suggestions that barriers exist in adequately educating patients with type 2 diabetes or not making them aware of the importance of following a healthy lifestyle. Assessing the most important aspects from a patients’ perspective and research identifying what patients are advised upon diagnosis, and shortly afterwards, could potentially aid understanding as to the barriers that may currently exist.

Recommendation - Further research could also investigate the specific reasons as to why self-care management is not being successfully undertaken by patients.

9.4 Overall Conclusion of the Thesis

The completion of this research achieved insight into the experiences, perceptions and beliefs of participants who contributed to the thesis. This has provided a unique opportunity for clinicians, researchers and others to understand the ‘world’ of people who live with a chronic disease.

This novel work has identified that whatever healthcare professionals feel they are providing in relation into health care and advice, people with chronic conditions will formulate their own interpretations, perceptions and ultimately health behaviours. Until clinicians gain insight into the individuals’ world, an opportunity to improve health behaviours and effective self-management is lost. This lost opportunity has consequences for the person in relation to morbidity and mortality and for health services in relation to the financial cost of professional care.

Further research needs to focus on communication between the person (patient) and the professional (clinician) and the strategies which need to be developed in order for patients to effectively self-manage their chronic condition.

'The doctor of the future will give no medicine, but will interest his patients in the care of the human frame, in diet and in the cause as well as the prevention of disease.'

Thomas Edison (1894)

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APPENDIX I
NICE clinical guideline 87
(2014)

1.1	Patient education
1.1.1	<p>Offer structured education to every person and/or their carer at and around the time of diagnosis, with annual reinforcement and review.</p> <p>Inform people and their carers that structured education is an integral part of diabetes care.</p>
1.1.2	<p>Select a patient-education programme that meets the criteria laid down by the Department of Health and Diabetes UK Patient Education Working Group.</p> <p>Any programme should be evidence-based and suit the needs of the individual.</p> <p>The programme should have specific aims and learning objectives, and should support development of self-management attitudes, beliefs, knowledge and skills for the learner, their family and carers.</p> <p>The programme should have a structured curriculum that is theory driven and evidence-based, resource-effective, has supporting materials, and is written down.</p> <p>The programme should be delivered by trained educators who have an understanding of education theory appropriate to the age and needs of the programme learners, and are trained and competent in delivery of the principles and content of the programme they are offering.</p> <p>The programme itself should be quality assured, and be reviewed by trained, competent, independent assessors who assess it against key criteria to ensure sustained consistency.</p>
1.1.3	Ensure the patient-education programme provides the necessary resources to support the educators, and that educators are properly trained and given time to develop and maintain their skills.
1.1.4	Offer group education programmes as the preferred option. Provide an alternative of equal standard for a person unable or unwilling to participate in group education.
1.1.5	Ensure the patient-education programmes available meet the cultural, linguistic, cognitive and literacy needs in the locality.
1.1.6	Ensure all members of the diabetes healthcare team are familiar with the programmes of patient education available locally, that they are integrated with the rest of the care pathway, and that people with diabetes and their carers have the opportunity to contribute to the design and provision of local programmes.
1.2.1	Dietary advice
1.2.1.1	Provide individualised and ongoing nutritional advice from a healthcare professional with specific expertise and competencies in nutrition.
1.2.1.2	Provide dietary advice in a form sensitive to the individual's needs, culture and beliefs, being sensitive to their willingness to change and the effects on their quality of life.

1.2.1.3	Emphasise advice on healthy balanced eating that is applicable to the general population when providing advice to people with type 2 diabetes. Encourage high-fibre, low-glycaemic-index sources of carbohydrate in the diet, such as fruit, vegetables, wholegrains and pulses; include low-fat dairy products and oily fish; and control the intake of foods containing saturated and trans fatty acids).
1.2.1.4	Integrate dietary advice with a personalised diabetes management plan, including other aspects of lifestyle modification, such as increasing physical activity and losing weight.
1.2.1.5	Target, for people who are overweight, an initial body weight loss of 5–10 per cent, while remembering that lesser degrees of weight loss may still be of benefit and that larger degree of weight loss in the longer term will have advantageous metabolic impact.
1.2.2	Management of depression
1.2.2.1	Recommendations for management of depression, detailed in primary and secondary care clinical guidance (NICE clinical guideline 23).
1.3	Glucose control levels
1.3.1	<p>When setting a target glycated haemoglobin (HbA_{1c}):</p> <ul style="list-style-type: none"> involve the person in decisions about their individual HbA_{1c} target level, which may be above that of 6.5 per cent set for people with type 2 diabetes in general encourage the person to maintain their individual target unless the resulting side effects (including hypoglycaemia) or their efforts to achieve this impair their quality of life offer therapy (lifestyle and medication) to help achieve and maintain the HbA_{1c} target level inform a person with a higher HbA_{1c} that any reduction in HbA_{1c} towards the agreed target is advantageous to future health avoid pursuing highly intensive management to levels of less than 6.5 per cent. The new guideline for the measurement of HbA_{1c} is anticipated to be published in August 2015
1.3.2	Measure the individual's HbA _{1c} levels at: 2–6-monthly intervals (tailored to individual needs) until the blood glucose level is stable on unchanging therapy; use a measurement made at an interval of less than 3 months as an indicator of direction of change, rather than as a new steady state 6-monthly intervals once the blood glucose level and blood glucose-lowering therapy are stable.

APPENDIX II

Academic audit and governance ethical approval

Academic Audit and Governance Committee

Research Ethics Panel
(REP)



To Mandy Turnbull
cc: Danny Meetoo, Tony Warne
From Jayne Hunter, Contracts Administrator
Date 15th July 2011

MEMORANDUM

Subject: Approval of your Project by REP

Project Title: What are the perceived determinants of self-care knowledge among people with type 2 diabetes; A grounded theory approach.

REP Reference: REP11/105

Following your responses to the Panel's queries, based on the information you provided, I can confirm that they have no objections on ethical grounds to your project on condition that documentation is amended to state what will happen to any data already collected should a participant choose to withdraw and it is made clear when the data is to be destroyed.

NRES approval must also be granted prior to the commencement of the research. Please provide copies of these documents when available, for our records.

If there are any changes to the project and/or its methodology, please inform the Panel as soon as possible.

Regards,

Jayne Hunter
Contracts Administrator

APPENDIX III

NRES committee North West ethical approval



Greater Manchester **NHS**

NHS SalfordR+D
Acute & Primary Care Research

NHS SalfordR+D Director:
R&D Associate Director:

Professor Bill Ollier
Rachel Georgiou

SalfordR+D web address:
ReGroup web address:

<http://www.nhssalfordrd.org.uk/>
<http://www.gmregroup.nhs.uk/index.html>

22nd March 2012

Mrs Mandy Turnbull
PhD student
Salford University
Allerton Building
Frederick Road
Salford
M6 6PU

Dear Mandy,

Study Title: What are the perceived determinants of self-care knowledge among people with type 2 diabetes: A grounded theory approach

REC Reference No: 12/NW/0182
R&D Reference No: 2012/045

Thank you for forwarding all the required documentation for your study as above. I am pleased to inform you that your study has been registered with NHS SalfordR+D. We agree that the following NHS Trusts can be involved as **Patient Identification Centres (PICS)**:

- NHS Stockport (PCT)

Yours sincerely,

Sue Gowland
R&D Manager

Cc File

3rd Floor Mayo Building SRF-T, Stott Lane, Salford M6 5AP

APPENDIX IV

Letter to general practitioner



University of Salford
A Greater Manchester University

Dear (contact name)

Following our telephone conversation, I am writing to you to further confirm your interest and offer you further information into the project.

I am a PhD student undertaking a Doctoral programme at the University of Salford. Currently I am interested in exploring the amount of knowledge or understanding that people with type 2 diabetes have of their medical condition. The purpose of the study is to gain a better patient perspective of their understanding of this chronic disease. This may enable diabetes educators in the future to tailor education services around what the patient requires in order to self-manage their type 2 diabetes.

Prior to undertaking the study consent is needed by your organisation to approach the following: participants with Type 2 diabetes, aged 25 or over, both male and female.

I will recruit people by displaying an A3 poster in your surgery. The total number of participants cannot be known in advance. Although no more than 12 participants may be required. I will be using grounded theory as a methodological approach as this will allow the participants to freely express their views about their self-care management.

I would like to assure you that this study will not disrupt your working environment in any way and the data collected will remain confidential. I am applying for ethical approval for the study from the University of Salford, Governance and ethics committee and also through IRAS, NHS research ethics committee.

My research is being supervised by: Professor Martin Johnson and Dr. Anita Williams

Yours Sincerely

Mandy Turnbull

m.turnbull@edu.salford.ac.uk

APPENDIX V

Information sheet



University of Salford
A Greater Manchester University

A QUALITATIVE INVESTIGATION INTO THE EXPERIENCES, PERCEPTIONS AND BELIEFS OF PEOPLE WITH TYPE 2 DIABETES AND THEIR SELF-CARE MANAGEMENT

Introduction

You are being invited to take part in a research study. Before you decide whether to take part it is important you understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or you would like more information about. Take time to decide whether or not you wish to take part.

Who is organising and funding the research?

My name is Mandy Turnbull and I am a PhD student researcher based at the University of Salford in the School of Nursing, Midwifery and Social Work. I am leading this project and the research is being funded solely by me. This study has been approved by the University of Salford Research Ethics Panel and by the NHS Research Ethics Panel.

What is the study about?

The study will be looking at information gathered from a patients perspective on how best to educate and support people with type 2 diabetes to ensure they remain healthy for as long as possible. Often, for people with diabetes it can be difficult to establish healthy routines such as regular mealtimes, menu planning and exercise. For this reason, I am collecting detailed information from participants such as yourself about the difficulties you might have when trying to establish and maintain healthy routines in order to self-manage your diabetes.

Why have I been contacted?

You have been contacted to take part in this study as I am asking for participants aged 25 years and over, male and female who have been diagnosed with type 2 diabetes to give their individual insight into the education they have been given in regards to type 2 diabetes.

Do I have to take part?

It is up to you to decide to join the study. I will describe the study and go through this information sheet. If you agree to take part, I will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive.

What will happen/what will it involve for me?

I will be gathering information by interviewing people on a one-to-one basis which will be audio recorded. The interview will take between 60 and 90 minutes. A follow up interview may be required, but no more than two interviews will take place for this study. The interview/s can be conducted at your home or at a place of your convenience. The interviews will be recorded on audio tape with the participant's permission.

There will be no pre-set questions for you to answer. Instead there will be some broad open-ended questions related to the general topic area.

If you decide to take part in the study I will contact you to arrange a time and place of your choice at your earliest convenience. Any travelling expenses incurred by you cannot be reimbursed.

Obviously, I would like to take up as little of your time as possible as I realise that you might be very busy with work, other responsibilities, and also looking after other family members. The interview will be very flexible and we will discuss only the issues that are of concern to you. I also ask permission to inform your GP of your participation in the study.

What are the potential benefits?

Very little is known about the types of difficulties that people face when coming to terms with conditions such as yours and how these difficulties might prevent people with diabetes from having healthy routines. That is why I would like ask you about any difficulties you might have experienced or do experience. I hope to then use this information to find ways of helping people with diabetes who might need education or extra support when trying to establish routines with their diabetes management.

My wish for the future is that the correct support and education is provided to all people with diabetes to help self-manage their care in order for them be as healthy and happy as possible. I would like to find ways of identifying people who would benefit from extra support, education, and guidance when they are trying to establish healthy routines with self-care in regards to their diabetes. The information I gain from this study will enable me to design ways of identifying such people.

What are the risks?

There will be no risks involved in this research. You will be asked a question relating to your diabetes, from the answer given you may be asked further questions. You will lead the interview. Only topics that you have mentioned will be discussed. If you become upset when talking about your diabetes, I will stop the interview and only continue if you are ready to do so.

What if there are any problems?

Any complaint in relation to the way you have been dealt with during the study or any possible harm you might suffer will be addressed. **Will my taking part be kept confidential?**

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The only time the researcher would have to break confidentiality is if you disclose harm to self or others.

What will happen if I don't want to continue with the study?

If you wish, you can withdraw from the study at any time without giving a reason. Any information I have collected from you will be destroyed and not used in the study.

What do I do if something goes wrong?

If you have any questions or concerns you are welcome to ask the researchers or advisors whose contact details are listed at the end.

If you are harmed by taking part in this research study, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, then in the first instance please contact:

Mandy Turnbull
Telephone Number 07525464416
Email m.turnbull@edu.salford.ac.uk

Will my taking part be confidential?

If you agree to take part in the study, any information you give the researcher will be kept strictly confidential and will conform to the Data Protection Act of 1998 with respect to data collection, storage and destruction. Your name will not appear on any of the forms, you will be assigned a study number instead. All information about your identity will be stored separately from data gathered during the study. All data may be held for up to 3 years before it is destroyed. This is following recommendation by the Medical Research Council. Any information you give to the researcher will not be shared with anyone outside the research team without your consent, unless the researcher feels that either yourself or others are likely to be harmed.

What will happen to the results of the research study?

It is intended that the results of this study will be published in a Diabetes and Nursing journals. If you take part in the study you will be informed of the overall results by feedback in person, in a group or by a written summary.

Who has reviewed the study?

All research in the NHS is looked at by an independent party called a Research Ethics Committee in order to protect your safety, rights, well-being and dignity.

The University of Salford ethics Committee has also reviewed this study for approval.

Further Information

If you would like any further information or have any questions about the study, please contact:

Mandy Turnbull
Telephone number: 07525464416
Email m.turnbull@edu.salford.ac.uk

Dr. Anita Williams
Telephone number: 0161 295 7027
Email a.e.williams1@salford.ac.uk

If you would like any other general advice or information about taking part in research, please contact:

Patient Advisory and Liaison Services (PALS)
Stockport PCT
Floor 7
Regent House
Stockport
Cheshire
SK4 1BS

APPENDIX VI

Recruitment poster

PARTICIPANTS NEEDED

Do you have Type 2 Diabetes Mellitus?

- **Would you be interested and willing to take part in a research study which looks at your understanding and self-care management of your condition?**
- **If you are aged 25 and over and have type 2 diabetes, then I would like to hear from you.**

Taking part in the study will involve an audio recorded interview at the time and place of your choice. A follow-up interview may take place. Participation is voluntary. The details are included in the Participant Information sheet which will be issued and discussed when potential participants contact the researcher.

If you would like any further information about the study, please contact the researcher

Mandy Turnbull

m.turnbull@edu.salford.ac.uk

podmandy@yahoo.com.au

0161 427 2613

07525 464416

- OR -

Collect a leaflet from reception with the above details.



APPENDIX VII

Consent form

Centre Number:
Study Number:
Patient Number for this study:

CONSENT FORM

Title of Project: A Qualitative Investigation into the Experiences, Perceptions and Beliefs of
People with Type 2 Diabetes and their Self-Care Management

Name of Researcher: Mandy Turnbull

Please initial box

1. I confirm that I have read and understand the information sheet dated 15/07/2012 version 3 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.
3. I understand that relevant sections of any of my medical notes and data collected During the study, may be looked at by responsible individuals from the University of Salford, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
4. I agree to my GP being informed of my participation in the study.
5. I agree to take part in the above study.
- I agree for the interview to be audio taped
- I agree for the interview to be transcribed
- I agree for anonymised direct quotations to be used

Participant

Date

Signature

Researcher

Date

Signature

APPENDIX VIII

Demographics questionnaire

<p>My name is Mandy Turnbull. I am undertaking a research study for my Doctoral thesis which looks at perceptions of self-care knowledge by people who have been diagnosed with type 2 diabetes. The information which will be gathered will take 2 forms: a questionnaire and an interview. As you have kindly agreed to take part in this study, I would be most grateful if you would complete this short questionnaire which contains 12 questions.</p>	DO NOT WRITE																								
<p>Question 1: Please indicate your gender:</p> <table border="1" style="margin-left: auto; margin-right: auto; border-collapse: collapse;"> <tr> <td style="text-align: center; width: 50px;">1</td> <td style="text-align: center; width: 50px;">2</td> </tr> <tr> <td style="text-align: center;">Male</td> <td style="text-align: center;">Female</td> </tr> <tr> <td style="height: 20px;"></td> <td style="height: 20px;"></td> </tr> </table>	1	2	Male	Female																					
1	2																								
Male	Female																								
<p>Question 2: Which age range applies to you?</p> <table border="1" style="margin-left: auto; margin-right: auto; border-collapse: collapse;"> <tr> <td style="text-align: center; width: 50px;">1</td> <td style="text-align: center; width: 50px;">2</td> <td style="text-align: center; width: 50px;">3</td> <td style="text-align: center; width: 50px;">4</td> <td style="text-align: center; width: 50px;">5</td> <td style="text-align: center; width: 50px;">6</td> <td style="text-align: center; width: 50px;">7</td> <td style="text-align: center; width: 50px;">8</td> </tr> <tr> <td style="text-align: center;">25-32</td> <td style="text-align: center;">33-39</td> <td style="text-align: center;">40-47</td> <td style="text-align: center;">48-55</td> <td style="text-align: center;">56-63</td> <td style="text-align: center;">64-71</td> <td style="text-align: center;">72-79</td> <td style="text-align: center;">80+</td> </tr> <tr> <td style="height: 20px;"></td> <td style="height: 20px;"></td> <td style="height: 20px;"></td> <td style="height: 20px;"></td> <td style="height: 20px;"></td> <td style="height: 20px;"></td> <td style="height: 20px;"></td> <td style="height: 20px;"></td> </tr> </table>	1	2	3	4	5	6	7	8	25-32	33-39	40-47	48-55	56-63	64-71	72-79	80+									
1	2	3	4	5	6	7	8																		
25-32	33-39	40-47	48-55	56-63	64-71	72-79	80+																		
<p>Question 3: Are you: (please tick only one)</p> <table border="1" style="margin-left: auto; margin-right: auto; border-collapse: collapse;"> <tr> <td style="text-align: center; width: 50px;">1</td> <td style="text-align: center; width: 50px;">2</td> <td style="text-align: center; width: 50px;">3</td> <td style="text-align: center; width: 50px;">4</td> <td style="text-align: center; width: 50px;">5</td> <td style="text-align: center; width: 50px;">6</td> </tr> <tr> <td style="text-align: center;">Married</td> <td style="text-align: center;">Single</td> <td style="text-align: center;">Separated</td> <td style="text-align: center;">Divorced</td> <td style="text-align: center;">Living with Partner</td> <td style="text-align: center;">Widow</td> </tr> <tr> <td style="height: 20px;"></td> <td style="height: 20px;"></td> <td style="height: 20px;"></td> <td style="height: 20px;"></td> <td style="height: 20px;"></td> <td style="height: 20px;"></td> </tr> </table>	1	2	3	4	5	6	Married	Single	Separated	Divorced	Living with Partner	Widow													
1	2	3	4	5	6																				
Married	Single	Separated	Divorced	Living with Partner	Widow																				
<p>Question 4: Which chronic condition have you been diagnosed with? (please tick as appropriate)</p> <table border="1" style="margin-left: auto; margin-right: auto; border-collapse: collapse;"> <tr> <td style="text-align: center; width: 50px;">1</td> <td style="text-align: center; width: 50px;">2</td> <td style="text-align: center; width: 50px;">3</td> <td style="text-align: center; width: 50px;">4</td> <td style="text-align: center; width: 50px;">5</td> <td style="text-align: center; width: 50px;">6</td> </tr> <tr> <td style="text-align: center;">Type 2 Diabetes</td> <td style="text-align: center;">Type 1 Diabetes</td> <td style="text-align: center;">High Cholesterol</td> <td style="text-align: center;">High Blood Pressure</td> <td style="text-align: center;">Heart Disease</td> <td style="text-align: center;">Lung Disease</td> </tr> <tr> <td style="height: 20px;"></td> <td style="height: 20px;"></td> <td style="height: 20px;"></td> <td style="height: 20px;"></td> <td style="height: 20px;"></td> <td style="height: 20px;"></td> </tr> </table>	1	2	3	4	5	6	Type 2 Diabetes	Type 1 Diabetes	High Cholesterol	High Blood Pressure	Heart Disease	Lung Disease													
1	2	3	4	5	6																				
Type 2 Diabetes	Type 1 Diabetes	High Cholesterol	High Blood Pressure	Heart Disease	Lung Disease																				
<p>Question 5: Do you know the medical term that has been given to your heart disease or lung disease?</p> <p>Type of Heart Disease: </p> <p>Type of Lung Disease: </p>																									
<p>Question 6: In the box below, please include any other chronic condition you may have:</p> <div style="border: 1px solid black; height: 50px; width: 500px; margin-top: 10px;"></div>																									

Question 7: How many years is it since you have been diagnosed with diabetes?							
1	2	3	4	5	6	7	
Less than 1 year	1-2 years	3-4 years	5-6 years	7-8 years	9-10 years	Over 10 years	

Question 8: Do any members of your family have diabetes?			
1	2	3	
Yes	No	Don't Know	

Question 9: Please indicate your educational attainment (tick all those relevant to you)					
1	2	3	4	5	
No Formal Education	Primary School	Secondary School	College	University	

Question 10: In the box below, please state your occupation	

Question 11: In the box below, please indicate your ethnic origin?	

Question 12: I would rate my health to be:					
1	2	3	4	5	
Excellent	Very Good	Good	Fair	Poor	

Thank you very much for completing this questionnaire.	
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APPENDIX IX

Initial concept map

ATF

Action

Thoughts

Feelings

Name: _____

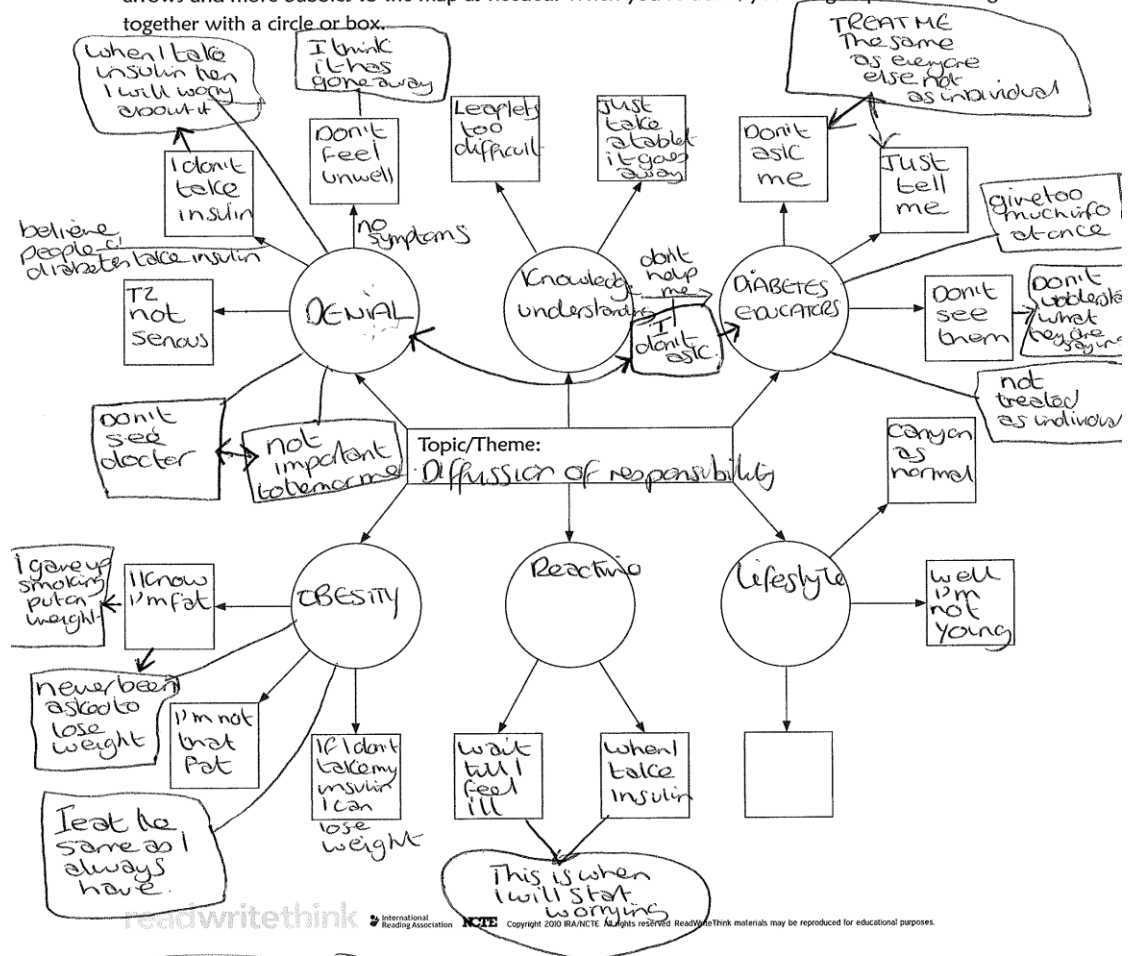
Date: _____

equality

consistency

Concept Map

The concept map below is a way for you to show relationships between words and concepts. An arrow connecting two words shows that those words are related in some way. You can add more arrows and more bubbles to the map as needed. When you're done, you can group words that go together with a circle or box.



APPENDIX X

Introducing the participants

Wilf

Wilf is male and he is 62 years of age. He states that he was educated up to college level and currently works as a Handyman/Porter at a University. He has been living with type 2 diabetes for nearly eight years and controls his condition with tablets. When asked how he felt about his health status he replied '*very good*'. Wilf indicated strongly that he was not going to change his lifestyle and enjoyed a bottle of wine with a few beers every night. He also felt that at his age he had had a '*good innings*.'

Wilf stated on several occasions that he felt he had been misdiagnosed and did not appear to be accepting of his condition. He stated, '*I think doctors get it wrong but could not go back on their word once they have diagnosed you with something*.' He emphasised throughout the interview that he thought he was wrongly diagnosed although admits he was told his blood sugar levels were 30 at the time of diagnosis. He puts this down to having a Chinese meal and lots to drink the night before he had his blood tested. Wilf stated, '*I don't go and see that practice nurse anymore, she told me I had to have toast with no butter on and that I couldn't eat anything that had sugar in it, I said, I might as well be dead as listen to you and she said, you are a diabetic you can't have any sugar*.'

Wilf admits that he has forgotten to take his medication on many occasions and that '*I have never died yet*.' Interestingly however, despite his protestations, he states he would like some further information around type 2 diabetes.

Wilf remained cheerful often laughing throughout both the first and second meetings that we had together. He was incredibly laid back during the interview and stated that he loved his social life; his holidays and was incredibly proud of his family. When speaking with Wilf he said he would listen to any information that he was given about diabetes but stated that until he was certain he had diabetes, or until something serious happened, he would not go out of his way to search for information as he was not concerned about the disease.

I realised by listening to Wilf and reading through his transcript numerous times that having diabetes did not affect Wilfs' outlook on life in anyway. I considered this may be due to the fact that he felt he was not displaying any signs or symptoms of the disease. Wilf admitted on several occasions that he would not do anything to change his lifestyle unless something drastic happened.

Wilf did make it quite clear that he was not going to worry about his diabetes or let it stop him living his life in any way.

Stuart

Stuart is male and is 54 years of age. Like Wilf he is educated up to college level and is currently a self-employed company director. Stuart has been living with his condition for six years, which is controlled by tablets. He admitted that prior to his diagnosis of type 2 diabetes he had symptoms of constant thirst and excessive urination but states that after taking his prescribed medication for diabetes his symptoms had disappeared. This has currently led him to believe that he no longer has diabetes.

He has also expressed that he felt his health was '*very good*,' and despite acknowledging that he is '*morbidly obese*', he informed me that his wife does all the cooking so it is not his fault he is overweight, although he does admit he has a sedentary lifestyle but is too tired after work to exercise. Like Wilf, Stuart drinks alcohol every evening and stated that he '*would not stop, not at his age, no matter what.*'

He articulates that his father, who had developed diabetes in later life and was prescribed insulin, frequently collapsed, this is something which he does not do, therefore feels he does not have diabetes, he comments throughout the interview '*If I do have diabetes it is not the serious type of diabetes.*' Stuart remarked, '*Everyone catches diabetes eventually don't they, I mean everyone I speak to has it, so it must be catching.*'

Stuart mentioned that several of his toes have no sensation but feels this has no connection to his diabetes. He has never been referred to see a podiatrist

or a dietician and can't remember the last time he had a blood test. Stuart says *'I have no time to go and see that diabetic nurse; I run my own business and the doctors is closed when I get home, plus that nurse only works there one day a week.* In regards to the practice nurse he remarked, *"The last time I went she tried to have a go at me so I will not be going again.'*

Stuart also stated that he would like further information around this condition, so he can discover for himself whether he feels he actually has type 2 diabetes.

Stuart was extremely easy to talk with during both of our meetings. I was introduced to his wife, two of his three sons and his grandson during our first meeting. Stuart lives with his wife in a large house with acres of land, paddocks and several horses, and commented that he has a wonderful life.

During our interview Stuart drank 6 bottles of beer, which he informed me he does most evenings. He loves his lifestyle and cannot see how he can adapt it in any way due to his social circle. Stuart and his wife eat out at expensive restaurants up to five times a week and have long holidays often in Italy or other European destinations. Stuart told me that he acts as if he has not got diabetes because he has never thought about it. He made it clear that due to work commitments he does not go to see the nurse or the doctor as all the appointments are during working hours. He states that if he does have diabetes it does not affect his life in any way.

Stuart has been given a testing kit from his local practice in order to check his own blood sugar levels but told me that, it is still in the box. He said he has never felt the need to check his sugar levels because he has never felt *'wishy washy'* like his dad used to. He commented that when he has to take insulin he will test his sugars, but only if he has to.

He explained that the nurse at the clinic told him he would *'have hypos'*, when he asked her about this, she informed him that everybody with diabetes has hypos, she told him he has to keep his blood sugars up. Stuart explained that

during the day he eats on a four hourly basis as he does not want to have a hypo.

At the end of the interview I asked Stuart if there was anything that I had missed and that he would like me to know. He commented, *'I know I am well overweight, but then I am not going to starve myself. The nurse said, if I start starving myself I will feel shitty, and you need to have food to stop the shittiness, so you can't win. She tells me I am fat and then she tells me to eat, which one is it? She has never once asked me if I am alright so I just let her go on and on, she tells me I should be doing this and I should be doing the other, I just walk out of there and do what I want.'*

'I think I am denying it to myself aren't I. Until the day comes that it gets serious and I have to start injections. I have never felt any difference once I started taking the tablets, so I do not let it affect my life. If I have to start taking insulin I might start worrying about it.'

Winnie

Winnie, the oldest participant is a 92 year old female who lives with her daughter, she left school at 14 and worked as a receptionist most of her life. Winnie was diagnosed with type 2 diabetes four years ago during an inpatient stay in hospital for a broken bone and pneumonia. Barbara explained that the doctor in the hospital just came up to her and said, *'How long has your mother been a diabetic and why didn't you put it on her admission form.'* Barbara stated *'I never knew my mum had diabetes, how would I know that, I felt dreadful as if the doctor was accusing me of abusing my mother, she is so thin and underweight I only thought fat people got diabetes, I do feed her but she doesn't have much of an appetite.'*

Winnies' condition is not currently being controlled with medication and she has not been advised to modify her diet or change her lifestyle in any way. Winnie also states that she feels her health is *'very good'* for her age. Both Winnie and her daughter are in doubt as to whether Winnie has diabetes as there has been no input from her general practitioner or any other healthcare

professional regarding her diagnosis, since her discharge from hospital. Winnie stated *'If I do have diabetes it is because of my age, and that is why the doctors are not bothering to treat me, because I am too old.'*

Both Winnie and her daughter felt that they would benefit from having type 2 diabetes explained to them, particularly Winnie's daughter who was concerned that she may also be at risk due to having a similar lifestyle to her mother.

Winnie was a delightful lady to interview she told me stories about the war and made me feel most welcome in her home. Barbara, her daughter also participated in the interview as she is the sole carer for her mother and they both live together.

Winnie said that she was shocked when diagnosed with diabetes as she *'Never felt it coming on as you do with a cold.'* She still thinks that they must have got her results mixed up with somebody else as she has never been given any advice and has not been asked to modify her diet or take any medication.

Throughout the interview it was clear that Winnie was not that concerned about her diabetes and appeared more pre occupied about her painful chilblains, commenting that she has always had poor circulation. I gave them both advice in regards to the chilblains, I would not have forgiven myself if something had happened to her feet and I had just ignored it in my pursuit to train as a researcher. It was during times like this I found it incredibly difficult not to revert back to my profession. I never told them I was a podiatrist and they never asked.

On my second visit I was glad to see that they had listened and acted on my advice, and Winnie seemed a lot happier. When I asked Winnie who she had been referred to in the care team, they both laughed and commented *'Care team, what care team, I never knew anything like that existed.'*

Barbara was told by the local podiatry service that they do not have time for home visits and that Winnie would have to go onto a waiting list.

Since my first visit Barbara had tried to get some information from the doctors regarding diabetes but had so far been unsuccessful, but she managed to pick up a leaflet from her local supermarket about food. At the end of the second meeting Winnie thanked me for speaking with her and commented,

'Really I do not think I have got it because no one ever talks to me about it, you are the first.' Winnie then followed this by stating, *'When you get high blood pressure you are whisked off to the hospital and you have all sorts of tests and you get tablets. Yet you do not get anything for diabetes it is just not as serious as blood pressure.'*

Derek

Derek is a male who is 51 years of age. He explained to me that he was one of eleven children and was only educated to secondary school level although felt that he could have gone on to University given the opportunity. Derek is currently self-employed as a pub landlord. Derek was diagnosed with type 2 diabetes eight years ago during a routine urine test at work and stated very strongly, *'I would not know until this day that I had diabetes as I have never experienced one sign or symptoms.'*

His condition is controlled by tablets and whilst he described his current health status as *'fair'* he admits he has a very poor diet often consisting of eating pies from the local chip shop, due to his long unsociable hours of work. Derek commented that he does not keep his diabetes check-up appointments with his practice nurse as he feels he is judged by her and does not want to be told to restrict his diet as this would not fit in with his lifestyle.

He admits that he is overweight and when he first asked the practice nurse to see a dietician she informed him, that it would not be necessary. He commented that *'Her credibility had gone out of the window as she was at least four stone overweight and bursting out of her uniform.'* The attitude of the practice nurse frustrated him as he has a stutter and he cannot find the appropriate words to argue his case. Derek has tried to look on the internet for more information but states that the websites just scare him and the

information is too complicated to understand. In addition he acknowledged his need for more information regarding his condition.

Derek was very frustrated throughout the interview and said that his local doctor's practice 'Was a joke', stating '*The receptionists talk to you as if you are a piece of shit, they are rude and don't understand that you have a life and that you have to move your appointment sometimes.*' He also commented that the receptionist speaks to him as if he is an idiot; he noted this may be down to his nervous stutter; he called them rude and said that their attitude stops him calling for appointments.

He gets very exasperated by the system and mentioned that, '*I still think I was wrongly diagnosed with diabetes as I have no symptoms, and they don't allow you to test your own sugars and they never tell you the results of any tests, so you just have to take their word on one simple test that you have diabetes.*'

During the interview Derek would bang his fists and lower his voice and speak with an angry growl, then he would look at me and say '*what am I supposed to do, who can I turn to*' in a calm manner. Sometimes he would shake his head as if in disbelief, or put his head in his hands, when he was talking to me. He would also ask me a question and then he would answer it himself. I sensed that Derek was frustrated by the whole system throughout the interview and just wanted someone to talk to, and who would listen to him.

At his request he was interviewed at my home, he explained that we would probably have constant disruptions at his house as he lived above his pub. He was extremely talkative and I sensed we could have spoken all night and still not have finished the conversation. The main theme I found with Derek was that he just wanted answers but did not know who to turn to or who to ask. He said even though he is not a stupid man he was made to feel stupid and often felt he was being told off at the doctors surgery but he did not know what for, as he was just living his life, just the same as everyone else and he could not see what he had done that was so wrong to be treated in this way.

Derek commented that he felt intimidated by the receptionists at his local doctors practice, he mentioned that he does not feel comfortable talking on the telephone this tends to make him panic which then causes him to stutter. I am happy to say that Derek never stuttered once during our interview, he drank several glasses of water and was very relaxed. At the end of our conversation he asked me for help regarding losing weight and gave me his email address and asked if I knew anyone who could send him some information regarding diet and healthy eating. I passed his details on to an ex colleague of mine in Australia who is a senior dietician, they have conversed via email and Derek has currently lost over three stone. At our second meeting Derek expressed his joy at losing weight and said he felt a lot better for it.

Derek didn't understand why a colleague who took insulin was allowed to test her blood sugars yet he wasn't. He commented, *'I am either diabetic or I am not why is there one rule for one and one for another.'*

Ruth

Ruth is a female and she is 72 years of age. She stated that she was educated to secondary school level and is a retired National Health Service receptionist. Ruth was diagnosed with type 2 diabetes over fourteen years ago and was originally treated by tablets. She informed me (on my second visit) that after twelve hospital inpatient episodes which spanned two years, and were directly concerning her diabetes, she was finally given insulin, much to her relief, in order to control her blood glucose levels. For the first time in fourteen years she felt that she had been allowed to test her blood glucose levels and currently feels in control of the disease.

Ruth described her current state of health as *'fair'* and acknowledged that she was overweight but commented *'What can I do?'*

Whilst having always accepted her diagnosis of type 2 diabetes, she also informed me that she had not changed her lifestyle in any way and put this

down to never having received any information or guidance from her general practice.

Ruth sounded sad throughout the interview and commented, *'I would welcome the opportunity to speak to someone in order to understand more about my condition but I appreciate that no one really has the time. Doctors are far too busy nowadays to spend any time with you; they only put me on insulin a month ago after I kept requesting blood tests, so I know they are too busy.'*

Ruth's interview was a little challenging to me at first, primarily because she had a very strong, quiet, welsh accent. During the introductions and for the first couple of minutes I struggled to understand what Ruth was saying, I need not have been too concerned because she was a lovely speaker and spoke very slowly, although a little too quietly, once the interview started. I did squint my face a few times during the transcribing when Ruth's voice almost became a whisper. I did not notice her voice gradually lowering as we spoke it was only when I played the recording back and I heard the sadness.

During the meeting with Ruth her husband popped in and out, he was very friendly and extremely interested in this research. Ruth has been happily married for 52 years and has two grown up sons.

At the first meeting Ruth told me all about her inpatient hospital stays and the food she was given to eat, this I soon realised was to be the main theme throughout her interview. Ruth described in great detail the food that she ate on a daily basis and I found when I looked at the transcript that over three quarters of it was discussing food and meals so much so that it almost looked like a cook book. I realised that this was an important part of Ruth being able to live her life normally, having full control over every single bit of food she ate, whether at home or visiting friends.

At the second interview Ruth informed me that she had recently been prescribed insulin for her diabetes and was finally allowed to test her own blood sugars. This gave her a huge sense of relief as she was now able to appreciate and understand the effect that the food she ate on a daily basis

was having on her blood glucose levels. She also informed me that her sugar levels were the lowest they had been in years, she tested them meticulously four times a day whilst her husband wrote all the figures down in a log book in order to present to the practice nurse.

Ruth did not like the annual visits to the podiatrists in the park and was frustrated with the service that was provided. She commented that she is always in and out in ten minutes and she knows that a thirty minute appointment is allocated for a diabetes foot check-up. She was frustrated that the podiatrists do not cut her toe nails or take her corns out which are extremely painful. She has grave concerns as to whether her feet are checked properly, and commented that her feet are always very cold but she has never once been asked any questions regarding this.

On the other hand Ruth loves the optician as he shows her pictures of her eyes and has all the time in the world for her and explains everything that she needs to know. The optician is local and she has been going there for years and always looks forward to her check- ups as she knows she is in “safe hands”, and she trusts them.

Ruth informed me that she is not restricted in anyway with her diabetes and said that she just lives a ‘normal life.’ She states, ‘*I know I have diabetes and I know that I mustn’t have this and I mustn’t have that*’, so that is just what I do. ‘*I feel more in control now that I have the serious diabetes, you get more care with this one.*’

Gail

Gail is a female who is 60 years of age. She states that she is educated to college level and is currently in full-time employment as a deep cleaner. Gail has been living with type 2 diabetes for two years and was diagnosed during a routine blood test for her epilepsy. She had no signs or symptoms prior to diagnosis and her diabetes is currently being controlled by tablets. Gail noted that at the time of her diagnosis she did not think about it because she had enough going on in her life.

At present she does not see type 2 diabetes as a serious condition in comparison to her epilepsy or her husband's cancer. When asked about this aspect Gail informed me that *'I have regular check- ups for my epilepsy but I have never had a check-up for my diabetes.'* Gail described her health as *'very good'* and acknowledged that she was extremely overweight and stated *'I have never been told to lose weight by the doctor even though I struggle to walk without losing my breath at times, he has never told me anything about diabetes and he doesn't send for me.'* As Gail does not take insulin for her condition she feels that this has re-affirmed to her that *'type 2 diabetes is not that serious.'*

Gail states that her work colleague has diabetes and commented, *'I will listen to any education, but my friend who has type 1 diabetes tells me all I need to know. When I was first diagnosed the doctor sent me to the nurse and she is just spouting all this out an I thought I am not even taking this in, and she is reeling all these papers off and I thought I'm not even going to read them. She never once asked about me not once.'*

Gail cried throughout the entire interview and when I asked if she wanted to continue she stated *'I am fine it is just that no one has ever asked me how I am feeling, you are the first person in years to ask about me, it has just made me very emotional but I am okay.'*

Gail was very open during our time together; she talked about her children how they have all grown up and left home to start families of their own. She talked about her husband and how she has always had to be the strong one and looked after him on several occasions none more so than when he was diagnosed with cancer.

It soon became clear during the conversation that Gail was on a treadmill with her life and although in despair, Gail commented that she did not know any different. She was diagnosed with epilepsy many years prior to her diabetes and one of the words that she used often during the interview and probably without realising it was *'coping'*, she stated how she often just *'coped with it'*, this was in reference to numerous situations.

There were also several times during the conversation that Gail became annoyed and frustrated often raising her voice when she discussed the doctor and the practice nurse, but to my relief and delight she laughed when she was angry and it was a lovely sight to see her laughing loudly even though she was crying at the same time. I laughed along with her and this seemed to make her laugh more.

Gail said she was unhappy when she expressed how she felt when one day the nurse, without any explanation, just told her to *'lose weight.'* Gail observed *'I know it is her job but why couldn't she just be nicer about it, it is not as if I am sitting at home stuffing cakes down, I am not a binge eater.'* It was clear from speaking to Gail that she worked all day in a manual job, she then returned home to look after her husband which she described as *'starting work all over again for the second time in one day.'*

I remember sitting for many hours reflecting and making notes after this interview and wishing that I was part of a team undertaking this research instead of being autonomous. I had interviewed six people and I had this wealth of information that they had given to me so generously, and I recall thinking, the participants have all been able to speak to me, but who could I speak to in order to get this process right?

I still feel incredibly sad and inadequate as a healthcare professional when I read Gail's transcript but I am grateful that she took part in this research.

Angela

Angela is a female and who is 68 years of age and like Ruth and Gail she also mentions that she is overweight. She stated that she was educated to secondary school level and is a retired office worker. Angela has been living with type 2 diabetes for six years and was diagnosed whilst receiving her final check- up for breast cancer. Her initial thoughts were *'what next, do you not think I have enough to contend with'* and this was in addition to her existing conditions of angina and asthma.

Her diabetes is being controlled with tablets and she was frustrated that she was not allowed to test her own blood glucose levels. Angela's son in law has type1 diabetes and has informed her that she has '*nothing to worry about until she has to take insulin*'. This makes Angela feel better as she now knows that her diabetes is '*not that serious*.'

Angela thought that her health status was '*fair*' and that her condition did not necessarily affect her lifestyle. Angela remarked, '*I don't think about my diabetes, if it was that important the doctor would have told me*.' When asked if she would like any information or education regarding type 2 diabetes, Angela advised, '*I can't get to the doctors and have to rely on my daughters to take me, and the doctors only give you five minutes so that is a waste of time, If they gave me a diet sheet I would be happy*.'

Angela informed me that her blood sugars have never been under control, but stated '*what am I supposed to do they don't let you test your own blood sugars, and they never tell me what mine is they just say they are too high. Well what am I supposed to do about it they haven't given me any help. I am just waiting for the next thing which will be insulin, well I am afraid of needles but I suppose I will have to take it*.' Angela explained how annoyed and upset she was with her doctors' practice, '*they just don't tell you anything*." She further commented that she did not ask questions at the doctors or with the nurse but she said, "*I do not know the right questions to ask*.'

Angela was very nervous when we first met and informed me that she was frightened of getting all the answers wrong as she did not know anything about diabetes. We sat and discussed the information sheet together and the purpose of the study; this allowed Angela the time to ask any further questions prior to signing the consent form. This seemed to put Angela's mind at rest, and she soon relaxed, but still mentioned that she did not think she had anything of value that she could contribute to the study as she did not know what diabetes was.

We sat for a while and Angela explained that she was initially going to cancel the interview as she felt embarrassed about her illnesses. She said that she

never asks the doctor about her diabetes as she does not want to '*hear bad news or be put on insulin.*' She feels that every time she goes to the doctors it will always be bad news. The last time she went to her doctors they doubled her tablets, so she doesn't want to go again.

Angela laughed when she told me that it was her final check-up for breast cancer and the doctor, '*gave me diabetes*'. Angela commented, '*you would have thought I could have had a day off from being ill wouldn't you.*' She had a lovely bright disposition and just said well I just have to get on with it.

On my second visit Angela informed me that she had bought her own blood testing machine and strips, she said '*I got sick of asking at that doctors, they give you nothing to help you look after yourself. I had no idea what my blood sugars were from one day to the next and I kept getting infections down below and I know it is all related. My son in law tests his blood sugar every day, so why is he allowed and I wasn't?*' Angela said that she still takes sugar in her tea, although she has been told by the '*diabetic nurse*' that she is not allowed any food with sugar in it.

When asked about education Angela said that she would love to go on an education course if she was able to get there. She has never discussed diet with the nurse and says that she would go on a diet but is not sure of the right things to eat. She would also like to know why some people take insulin and some people do not. Angela was annoyed when she told me that her daughter shouts at her and tells her '*your diabetes is nothing, wait till you have to take insulin like my husband does*', this upsets Angela because she does not want to take insulin. She explained that no one in her family takes her diabetes seriously, unlike when she had cancer. Angela says, everyone knows cancer is serious and my diabetes is not.

Bob

Bob is a male he is 49 years of age. He was educated to college level and was diagnosed with type 2 diabetes four years ago. His diabetes is controlled by tablets and when discussing his health status he described it as '*poor*'. Bob

works full time as a care worker and often works excessively long hours. He was diagnosed during an inpatient hospital stay. Bob asked the doctors to test him for diabetes as he felt he had symptoms of the disease which he knew were being ignored by the hospital staff.

He admits that although he took his medication for diabetes he did not understand what he was being told in regards to the disease for the first two years because he had *'other more pressing issues in his life to deal with'*. He feels that he has never been treated as an individual and that *'doctors were more interested in treating the disease'*. He said at one stage he was taking so many tablets that he did not have a clue what he was doing, and felt there was no explanation given by his doctor.

Bob eats fast food and take-out meals every day and blames this on his workload as he is too tired to prepare meals after work. On the first visit he insisted that he did not want to change his diet on his own and wanted the doctor to tell him what he could and could not eat. Bob stated that when he hears advice from the doctor that is when he will make the changes in his life. He also felt that education at the time of diagnosis would not have helped him as it took him two years to come to terms with his diagnosis. He did say however that he had recently asked his doctors practice for some information on diabetes and has not yet received any.

Bob originally came to the conclusion, *'type 2 diabetes is not that serious because it is never mentioned when I go to see the doctor.'* At the end of the first interview, Bob informed me that after speaking with me he was going to ask the nurse to refer him to a dietician. He explained that talking to me had actually made him think about his diabetes.

It was made clear from this interview that diabetes was the least of Bobs' worries when he was diagnosed, he referred to the fact that he did not come to terms with his diabetes diagnosis at first, in fact he totally ignored it. He was aware that he had all the symptoms but this did not stop him putting the diagnosis to the back of his mind as he was more concerned with his private and work life getting back on course.

Bob was upset and explained some of the heartbreak that had happened to him up until the point of being hospitalised and diagnosed with diabetes, he was annoyed when he described *'In the beginning they give you so much information and they never ask how you feel, they just treated me as having another complication that they had to deal with, that is how I felt at the time'*, this made him upset and he pushed the diabetes to the back of his mind.

He explained that at first he never thought diabetes was a permanent thing and just thought once he took the tablets it would go away. When originally diagnosed Bob was offered an education course but explained it was not the right time due to several factors. Bob believes that his diabetes was caused by stress and being a little overweight. His brother had recently been diagnosed with diabetes and Bob commented that, *'he is dead skinny, so that goes against the norm doesn't it.'*

Bob only started to take his diabetes seriously when a colleague at work told him that it was classed as having a disability. He remarked *'I was in shock when he told me that.'* This started to make him think that diabetes maybe a bit more serious than he first thought.

Bob made it clear after the first interview that he was in no fit state after diagnosis to go on a diabetes education course as he would not have taken any information in. He did however remark that he would welcome a course at the present time as he has started to come to terms with his diagnosis.

On my second visit Bob informed me that he was currently only eating 500 calories a day and that he had stopped taking his diabetes medication. In regards to this low calorie diet he told me, *'I know that it will cure my diabetes, I have tested my blood sugars every day and they are down to 6.3.'* He proceeded to tell me that *'seven out of eleven people in a Newcastle study were cured of type 2 diabetes by eating 500 calories a day.'* He carried on by telling me that he had lost 2 stone in the past 6 weeks and that he would *'eat normally again when his diabetes had gone.'* I asked if his doctor was aware that he had stopped taking his medication and he answered, *'Yes, he knows what I am doing.'*

His final comments to me were *'I am not frightened of my diabetes in anyway, but I think that is because, I do not think it is that important compared to my other illnesses.'*

Jon

Jon is a male and is 42 years of age. He stated that he is educated to college level and works as a prison officer in a female prison. Jon was diagnosed with type 2 diabetes four years ago and initially it was controlled with tablets, but it is more recently being controlled by insulin. Jon goes to the gym several times a week and rated his health as 'good'. In his own words Jon stated *'I received excellent education, help and support when I was first diagnosed in fact it was brilliant'*. Much to Jon's delight this help and support was implemented by his practice nurse and lasted almost one year. Unfortunately his nurse left the local practice to return to her homeland Spain and Jon stated that he had never received any further information or guidance from his local general practitioners practice since, *'I have never even met the new diabetes nurse at the clinic, there was no handover or anything like that, I was just left on my own.'*

Jon commented *'I like to push the boundaries to see how far I can go with my medication'* and informed me that on several occasions he would, stop taking insulin to see how long his body could last without it. He was upset when he told me *'I want to go back to just taking my tablets, I don't like taking insulin so I am going to keep trying until one day I no longer have to take the insulin.'* Jon also realised by not taking his insulin for prolonged periods of time he could lose weight quickly and he often, deliberately, missed taking his medication before holidays in order to *'look good'*. Jon stated that he would not tell his doctor he skips his insulin for weeks at a time as he feared *'being told off.'*

Jon states that he knows he has diabetes, however, he is unable to come to terms with the fact he has erectile dysfunction. He mentioned that he would like to speak to a *'diabetes specialist about this condition'*, he commented that he did not want to speak to his doctor about this condition as he did not want

to be given more tablets, and wanted '*his body to react naturally*'. He said '*I just want everything to come back how it was I just want to be normal again. If I can stop taking the insulin, my body will go back to normal*'

Jon has attended his local podiatry clinic and was told that he has 40 per cent nerve damage to his feet, he was then informed by the hospital that if he can get his blood sugars under control the sensation in his feet will come back over time. Jon enjoys going to see the optician and says '*they are brilliant; they show you all the pictures and put your mind at rest.*'

Jon informed me that he has stood on stair rods and felt no pain but that blood was gushing from his feet. Despite this fact Jon still believes that his diabetes is reversible and that once his blood sugars are under control he will no longer have to take insulin or any other medication. Throughout our meeting Jon described his diabetes as '*just temporary*', and believes that his body will one day go back to '*normal*'.

Jon has attended the DAFNE course and commented that it was 'brilliant.' He loved the interaction with other people who were in the same boat as him and he loved speaking to them about their experiences. He said he never learnt much from the course but enjoyed meeting other people. Jon said he would go on any further education courses if he was allowed.

Jon admits that when he was diagnosed it was a novelty at first because he could get free prescriptions so he said he went to the doctors with the slightest problem just to get free medication. He admits that he just used to stockpile it and then the novelty wore off when he realised that diabetes can take between 10 and 15 years off your life. However, even though this thought frightens Jon he states that he is '*still honeymooning even after all this time and I still skip all my insulin for up to 4 weeks at a time.*' Jon feels that he was wrongly diagnosed as he believes that his body is still producing insulin, he noted '*I think I must still be producing insulin, for me to go so long without injecting.*'

Jon was very sad and unhappy when he explained that he is only 43 and had recently got married to his husband but unfortunately his sex drive has, *'Gone through the floor, there is nothing it has completely gone. I just can't get an erection.'* Again he explains that he does not want to take any medication for this or speak to his doctor, he just wants his body functions to come back normally.

Jon ended the interview by stating, *'I would like a nurse my old nurse to come back, I would like a pancreas transplant, I would like health advice on tap where you do not have to go to the doctors you could just ring somebody up like my nurse who would explain diabetes to you in words that you understand and I would also like to speak to somebody else with diabetes so I do not feel alone.'*

Martin

Martin is male and is 69 years of age. He stated that he was educated up to college level. Martin qualified as an electrician when he first left school, but from his early twenties he became a long distance lorry driver. Martin and his wife would often work together staying in his truck for many days at a time, which in Martins words *'led to a very unhealthy lifestyle for both of us.'*

Both Martin and his wife were diagnosed with type 2 diabetes almost twenty years ago, which at the time was controlled by tablets and diet. They were both referred to the dietician when first diagnosed but Martin said that *'The dietician gave us certain things to eat and just told us to both lose weight. She just gave me a diet sheet and never asked me if I could follow it, well you just couldn't it was impossible, so in the end I joined weight watchers and lost four stone.'* Martin also gave up smoking which was a habit he had since childhood. He rates his health as *'good'* and has controlled his condition with insulin for over ten years.

Martin spends six months of the year in Spain in his caravan and admits, *'I am healthier there as it is flat and I walk my dog Millie in the sunshine most days.'* He pre packs all of his insulin in ice cream tubs and puts it in his fridge in his

caravan ready to drive over to Spain. He expressed the sadness he felt when he explained to me that *'I was never told how serious diabetes was when I was diagnosed; they just gave me tablets and told me to lose some weight. They never explained anything to me about complications. When I had to go on insulin I had to give up my HGV licence so I could no longer work in the job I loved, why didn't they tell me it was serious.'*

Martin made it very clear that at this point in his life he did not want any education regarding his diabetes, stating *'What do they know about it? I could teach them, I have done it all on my own so far without any of their help and I live with it every day. If they knew so much about it why didn't they tell me years ago?'*

Martin was a very quiet gentleman, he never raised his voice once, only lowered it. He showed me his wedding pictures and spoke with great fondness of the times he and his wife went out on the road together. He was absolutely devastated when his HGV licence was taken from him due to his diabetes and he said it was the second lowest point in his life after his wife's death. Martin was extremely organised when it came to his medication and his diet. He said of course I am aware I have diabetes, I have to inject myself everyday but I do not let it stop me doing anything. Martin moves his diet around and his insulin depending on how he is feeling. He says he does not follow the instructions that his nurse gives him because that would not suit his body and would make him feel ill. He clarified that she tells him to eat three meals a day and have snacks; he explained that would not suit him as he has hypos if he eats late at night because his blood sugar drops in his sleep, so he just listens to his body and follows that.

Martin has never been referred to the optician or the podiatrist and commented that he has got nothing wrong with his eyes or his feet. He also said that he would not go and see the dietician or go on any education that was offered as, *'Once you get used to it you work it out for yourself, and you know what you can eat and what you can't.'*

Martin told me that if he had the chance to live his life over again he would 'do it all differently next time, he said very sadly *'I would not get diabetes, next time.'*

Alan

Alan is male and is 58 years of age. He stated that he is university educated and has taken early retirement from a research department. When Alan was first diagnosed over ten years ago the disease was *'Initially controlled by way of diet that did not necessarily work.'* The next course of action was to administer tablets, although this could not bring the disease under control either.

Alan explained that his biggest fear was injections although due to the previous unsuccessful attempts at controlling the disease he now required insulin to achieve appropriate control of the condition. Eighteen months ago on the advice of a temporary locum doctor, Alan was also prescribed additional tablets to take alongside his insulin. This course of action made Alan *'angry with the medical profession'* and he felt he *'Never received the correct information from successive doctors.'* He was also *'extremely frustrated'* that he has to self-manage his condition and feels that this should be the responsibility of the medical professionals and not his.

Alan also expressed how annoyed he was upon taking early retirement from his desk job, and explained that *'My lifestyle totally changed I became far more active and yet my insulin and medication were never reviewed, not once'*, he explained that the medical profession *'Just leave you to your own devices.'* Alan made a strong point of saying *'Whilst this is ok for me, as I am an educated person, but what about the people who are not clever, how do they manage their medication.'*

He maintains a logbook with his diet and blood glucose levels detailed, and again stated that he is *'Frequently disheartened when no medical professionals show an interest.'* This makes Alan's efforts feel wasted and he comments *'I feel alone and let down by the entire system.'* Alan emphasised,

'Doctors should be more pro-active in dealing with people with diabetes.' He adjusts his own insulin as feels *educated enough to do this* and admits that his lifestyle is far more active now that he has retired.

Alan was the only participant to rate his health as *'excellent'*. Recently he was given a book from his local hospital called *'The Complete Guide to Type 2 Diabetes'* and much to his amusement he told me *'I think they are ten years too late with this, I don't see any point in reading it now.'*

When I asked Alan the initial question that was asked of everyone which was, to tell me a little about themselves in order to create a picture of who they were, Alan then spoke for three and a half pages of transcript about his medication and how the doctors or nurses had never got it right since his diagnosis. Alan answered the questions with long almost scripted answers and I felt he had a lot of information that he wanted to relay to me.

I realised whilst I was reading through his transcript, which I did on numerous occasions, he was just merely frustrated by the whole system including the red tape, and the bureaucracy that went with it, which he mentions constantly throughout the interview.

I felt Alan wanted more of a questions and answers session from me, with him asking the questions, and me answering them. If this would have been my first interview, it may have been my last as a researcher in training.

Alan explained that when he visited his doctor or the nurses at the hospital, regarding his diabetes, he only got answers because he knew which questions to ask. He explained that his experience as a researcher had taught him to ask questions and get answers. Alan then started asking me questions such as, *'What about the people who do not know the right questions to ask, how do they look after their diabetes, because the doctors are not doing it.'*

Peter

Peter is male and he is 77 years of age. He stated that he was educated up to college level and worked as a surveyor until his retirement. Peter was diagnosed with type 2 diabetes over forty years ago during a routine blood test at work. He was glad that the blood test took place, as he was not aware of any signs or symptoms prior to diagnosis. For the first five years the condition was treated with tablets although this did not appear to control his blood glucose levels and Peter stated *'I was always lethargic and out of sorts, so the doctor put me on insulin.* Peter explained, *'I am currently experimenting with my insulin on a daily basis.'* He maintains *'I no longer eat a big lunch therefore I have decided not take my prescribed insulin at lunchtime.'*

He has had two hypoglycaemic episodes both resulting in him being taken to hospital for a period of recovery. He rates his health as *'fair'* and admits that he does not exercise because it makes him feel hungry. Peters' biggest regret was no longer being able to have sexual intercourse due to having diabetes and feels this has caused a rift in his marriage. Peter added that *'I would like my diabetes to be better controlled in order that I would be able to have sex again, I would feel a lot happier, I know that I would.'*

He states that his diabetes makes him irritable, grumpy and bad tempered and says his wife would agree. He admits that he has too much time on his hands and dwells on his illnesses and is frustrated by all the things that he is no longer able to do. He is predominantly housebound due to being overweight and his inactive lifestyle. Peter laughed when he told me *'I suppose you have to die of something so I might as well die of diabetes.'*

Peter's wife joined us half way through the interview and it was obvious that she loved him but was frustrated with him in equal measures. His wife explained that she knew nothing about his condition and that it frustrated her as she made all his meals and was not sure what he should be having. She explained that he had a sweet tooth and would often eat a full box of chocolates in one day. There should be more talk around the diet she explained, I want to know what he can and cannot eat. He is grossly

overweight but will not do anything about it and just blames the insulin for making him fat. He has never seen a dietician and neither have I, they just do not involve the family. I know your health care is personal but surely doctors must know that we do the cooking. Peter then proceeds to argue with his wife about his food intake and says *'I do not eat a lot of food, it is not my fault I cannot exercise, because my blood sugar drops and there is nothing I can do about it.'*

Peter was annoyed when he said that he had never received any diabetes education, he said *'A couple of years ago when they changed my insulin they told me when to take it and that was it. I still have no idea what diabetes is, I just know I have to take my insulin, although I don't take it a lot of the time, I just take my tablets instead.'*

Throughout this interview Peter played down his diabetes whilst his wife pointed out all his shortcomings. Peter said that he felt his eyes go a bit blurry so he went to hospital and then explained, *'Oh! They kept me in for a couple of days and said everything was okay.'* His wife then said *'No they called it a mini stroke and something else that you did not listen to.'* Peter just shrugs this off.

In regards to education Peter said that he would like a video with subtitles, he explained that he is very hard of hearing and would like to read the information on the screen. He explained, *'I would enjoy this because I could watch it at my leisure and I would not be holding the class up.'* He sounded defeated and commented that he knew they did not have videos for him to watch, but explained that he would not be able to hear if he went on a course.

He ended by saying, that no matter what the doctors or nurses told him to do he was going to live his life the way that he wanted anyway. He then went on to say, *'I mean I am a diabetic and there is nothing I can do about it, the thing that annoys me the most is that I know I have got to lose weight.'* His wife comments, *'You can do it; Stop blaming your illnesses for everything, I have just lost a stone.'*

Don

Don is a male and is 78 years of age. Don did not start school until he was eleven and a half years old and when he left at fifteen he was unable to read or write. It was not until he returned to college in later life and eventually learnt to read and write at the age of seventy-four. I mention this because it was something that Don was extremely proud of.

He worked as a bricklayer until an accident forced his doctor to retire him early at age fifty. Don was a sub deacon in the Church of England most of his adult life and is currently a full time minister for Jehovah's Witnesses.

When Don was diagnosed with type 2 diabetes fourteen years ago he was constantly feeling thirsty and drinking water all through the night. After a visit to his general practitioner and a referral to the nurse his blood results returned two weeks later and he was told, '*You are a diabetic*', a label that he states, '*I did not like.*'

For the first five years his diabetes was controlled by diet only and he admits, '*I lost a lot of weight in that time.*' Don stated however '*I have since put it all back on and more.*' His condition is currently being treated with tablets although his doctor is debating whether he should be put onto insulin. Don rates his health as '*poor*' but puts this down to having a recent cataract operation (the day before this interview).

Don previously attended a diabetes education course, which was organised by his practice nurse. The course lasted six weeks and Don attended for three hours each week. The main focus of the course was on weight loss and diet and Don admits '*I knew a lot of it but it does no harm learning a bit more and I never missed a session.*' Don was very vocal about his eighteen hours of education and admitted that he had a few '*lively discussions with the diabetic nurse.*'

Don was angry that he was never told to lose weight prior to his diabetes diagnosis and said *'They tell you nothing; surely the doctor could see I was fat.'* Don has never felt in control of his diabetes and remarks, *'You can never get control of it, it controls you.'* He expressed that the diabetes nurse, *'Preaches not teaches'* also commenting *'They never ask you what you want to know or what is important to you; it is as if we are an inconvenience.'*

Don spoke in great detail regarding the six week DESMOND course that he attended and most of it was with fondness. He enjoyed the interaction with the other attendees but commented, *'They dropped off week by week.'* He had what he noted as a *'Disturbing conversation'* with the nurse who was overseeing the course, it went as follows:

(Don) *'It made me laugh, the diabetic nurse, you won't believe this she was over 21 stone, honestly you won't believe this the diabetic nurse who was taking the course was over 21 stone (spoke with absolute disbelief). You would think that she would know flaming different wouldn't you. I said to her physician heal thyself. I said to her, you being that weight, we had an excuse we had no education and we are not medical, where as you know all about this so you should be losing your weight. She just looked at me.'*

He was further surprised when he commented,

'They kept giving us cups of tea and biscuits all through the day, now we are diabetics and they kept giving us biscuits. I mean I am not surprised that they are overweight these nurses, she never stopped eating. I asked the nurse I said, have you got diabetes? She said, not yet, I said, you will have very shortly. Can you believe (sounded exasperated) she said, not yet, I mean she has gone to university and she is taking the course.'

'Now the other woman who was in charge of diet, she was as thin as a rake, and she was laughing at what we were saying about the nurse and she said to her, they are right you know, she said to her, they are right you know you are grossly overweight. In fact she could have weighed a lot more than 21 stone she was huge, the chair used to creak when she sat on it, ours didn't. Her

flaming chair used to creak (raised voice). I mean she was trying to tell us what to do and she couldn't tell herself. She should practice what she preaches or stop preaching.'

'She gave us a book but you couldn't follow it, I just couldn't live like that. The nurse that was teaching it doesn't follow it. Wouldn't you have thought that they would have picked a better candidate to teach us (laughing and shaking his head) was there no one slim who could do the job?'

Don struggled throughout the interview with the concept that the nurse teaching the DESMOND course had the audacity to tell him to lose weight and she was heavier than him. He commented that people on the course were just not listening to her as she did not set a good example. He was shocked that *'She was educated and should know better than me because I have not had an education.'*

I asked if maybe he had considered that the nurse had made the choice to be the weight she was, and his reply was *'Well she shouldn't be educating people to lose weight if she can't do it herself, she shouldn't have been given the job and she should know better.'*

Don felt very sad that he had missed out on education due to the second world war, he was unable to read until he was 74 having returned to college aged 69, he left college at 76 and was very incredibly proud when he showed me his 8 certificates that he had achieved for reading.

Don spoke with great enthusiasm about education and said that he would love to go on another course. He is annoyed that the doctors never explained diabetes to him either before he was diagnosed or after. Don told me that he had a great memory; he put this down to not being able to read until recently so he had to remember everything that he was told. Don explains that he knocks on doors as a full time minister and he loves educating people, so in turn he loves to be educated. Don realises that his diabetes was brought on by his weight, but this did not stop him being annoyed at the fact it was never mentioned prior to diagnosis. He says that the health system is totally

reactive, they let things happen *'They don't educate you and they are they are supposed to be the clever ones.'* Don explained that if he is not hungry or doesn't feel like eating then he will not take his tablets for his diabetes.

He explained that four other people also had an eye operation alongside him yesterday, and he laughed when he said *'we all had diabetes, can you believe that.'*

Pauline

Pauline is female and is 75 years of age and is married to Don. Pauline stated that she was educated to secondary school level and prior to her early retirement she worked as a telephone operator. Pauline has been housebound for ten years and rates her current health status as *'poor'*. She was diagnosed with type 2 diabetes forty-two years ago and maintains *'I am very unusual as the doctor got the diagnosis wrong.'*

Her diabetes was initially controlled by diet, although she found this strange, as she was already extremely underweight. Pauline explained that many years ago whilst in hospital she was diagnosed and told over the telephone that she now had to take insulin. She further clarified, *'I woke up in the hospital and my sugars were sky high. The doctor just rang them and instructed the nurses to put me on insulin and tablet there were no tests done.'* This was something that Pauline said she had never forgotten and was annoyed when she said, *'they told me nothing, nothing at all.'*

Several years later Pauline forgot to take her insulin one evening, however, when she tested her blood sugar levels the next day they were in the normal range. Pauline said *'I never took any insulin for three weeks and I tested my blood twice a day and I had been alright so I decided that I was not taking insulin anymore.'* Pauline has never taken insulin since.

Pauline said that she wishes she would have queried her diagnosis all those years ago, she explained that in them days you just did what the doctor wanted, you never asked questions. She explained, *'When I was initially diagnosed all those years ago, I was in shock as I did not fit the stereotype. I*

never took anything in at all that the doctor said, and you need time to absorb the shock before you can understand what you are being told.'

Although Pauline maintains that her initial diagnosis was wrong, she said, *'Diabetes controls your life, it affects everything inside you and you can never live a normal life. I could never be just one of the girls and my biggest regret is that I never had any more children after I was diagnosed. Diabetes has always played a major part in my life and it has always been in the background.'*

In reference to her education Pauline relies on Don for any information she might need. She says that she trusts him more than anyone and can't remember the last time the doctor mentioned her diabetes to her.

Pauline said that the chiropodist from the clinic in the park used to come out every now and then to cut her nails, but she has not seen them for years. She said they just forget about you when you are housebound, if you are not causing a fuss they don't know you exist.

Majid

Majid is male and he is 55 years of age. He states that he was educated to university level attaining a master degree. He recently set up his own company and currently works from home. Majid was diagnosed with type 2 diabetes three years ago during a routine check-up, initially he requested a second opinion, and when the same diagnosis came back he accepted that he might have diabetes. He admits that prior to his diagnosis he was feeling thirsty and tired and was getting short tempered very quickly. His diabetes is currently being controlled by tablets and Majid admits that he looks after his condition by predominantly controlling his diet.

On diagnosis he initially received a diet sheet and was informed by his doctor that this was merely a guide. Majid was glad to be told this as he commented, *'To be frank the diet sheet excluded just about everything except for oatcakes and all the boring stuff.'* Regarding any further education Majid explained that he relies on the internet for information regarding diabetes and understand that his doctor does not have the time to explain in detail his condition to him.

He describes himself as active and likes to play five a side football every week, rating his health as 'very good' he has also reduced his blood sugars from a level of 11.5 to a more acceptable level of 6.5, which he credits chiefly to his diet. Majid explains that he looks after his sugar intake and that he knows how his own body is feeling. Majid has been given a self-testing machine from his local doctor's practice but has said that he has not had the need to use it because he is very self-aware, so as a consequence he knows when his blood sugars are getting low. He explained *'From time to time I feel that you do need a little bit of sugar to prop me up because I feel so tired or so irritable, I have a biscuit or a banana or anything with just a tiny bit of sugar in and I come back to life again.'*

Majid explained that it took him a while to come to terms with his diagnosis having had to research information on the disease for himself. Majid commented, *'You are bombarded with information when you are first diagnosed and you do not take any of it in. I sat in the doctors thinking why me? He must have got this diagnosis wrong and from that point on I never listened to another thing the doctor said.'*

He has previously declined a group education session, as he did not want to sit and listen to other people moaning about their chronic disease. He remarked *'I don't want to be any more depressed than I already am, listening to them, I do not want to hear negative stuff in regards to diabetes, only positive stuff.'* Majid did comment however that this research process and interview conducted allowed him the opportunity to discuss his feelings about his long-term condition.

Majid was the only participant who expressed that he felt better for being diagnosed with diabetes. He has lost half a stone and reduced his trouser size. He says *'To be honest we all eat too much rubbish most of the time without realising it.'* Majid explained that the time when he would have benefitted most from education was in between being diagnosed and finally accepting that he had diabetes. He said that once you have accepted you have diabetes it gets easier from there because you can start to control it. He

says that it took him over three months from diagnosis to come to terms with it but from that point onwards he has accepted it fully.

Majid said that he would not attend any formal education course, as he has come to terms with his diagnosis, but would be happy to speak to someone one to one. He has never been to see a podiatrist or an optician and says that he will only go if any problems arise, but he is fine at the moment. Majid was extremely pleased when he informed me that he has turned his diabetes on its head and he sees being diagnosed only as a positive thing in his life and not a negative thing. He feels that once people accept that they have diabetes they may lose a bit of weight, feel better for it and then just get on with it.

Rebecca

Rebecca, is female and was the youngest participant in this research she is 27 years of age. She stated that she was college educated and qualified as a beauty and holistic therapist. Rebecca is currently in receipt of disability allowance and is a full time mother. She was diagnosed with psychotic bipolar disorder in 2005 and suffers from severe anxiety and depression. Rebecca explained *'At the time I weighed ten stone but after taking my psychiatric medication I just put more and more weight on until I became morbidly obese. It is horrible and I hate it!'* Rebecca has previously been refused a gastric bypass operation. Rebecca expressed her frustration in being recently diagnosed type 2 diabetes, stating *'This would have been avoidable if they had given me the bypass, now I am morbidly obese and I have type 2 diabetes to contend with.'* Rebecca is currently taking tablets but is disheartened as her blood sugar levels are not under control or responding to the treatment. She has recently discovered that due to being diagnosed with type 2 diabetes her gastric bypass operation has been granted by her NHS trust. Her doctor has informed Rebecca that no matter how much weight she loses in the future her diabetes is not going to go away. Rebecca rated her health as *'poor'* as she is due to undergo a back operation but has been informed that her diabetes has to be under control before this can take place. Rebecca commented that she did not want to end up like her mother who was

diagnosed with type 1 diabetes forty two years ago. She further expressed '*I do not want to inject insulin every day but that is what the doctor has told me will happen next.*' She is unhappy and feels that the diabetes could have been avoided if she had not gained all the weight. Rebecca stated '*I would like to have a one to one session with a diabetes specialist but not a nurse and I want to go through everything. I just want someone that I can go to for information and ask questions.*' Rebecca has a dislike of the nurses at her medical practice as she says '*They talk to me as if I am stupid or a child, they often just tell me off, and well that is how it sounds to me*' and states that she is going to lose weight and get her diabetes under control.

Rebecca spoke with utter disbelief as she conveyed a conversation that had recently taken place with the practice nurse; Rebecca told me that she had asked the practice nurse for a glucose machine to test her blood sugars. The nurse informed her that she did not need one and that the clinic would test her blood sugars every three months and that there was no need for testing in-between appointment. Rebecca was astonished by this as her blood sugar levels were 22.1 first thing in the morning and the nurse was aware of this.

The interview with Rebecca is one that I shall never forget, and one that almost never took place. Picture the scene; On arrival for the interview Rebecca led me into a tiny room inside her cottage, already inside this room were, her mother, her two children, her five dogs, her three cats and her three rabbits all creating havoc, well not her mother, she was lovely. After the interview started one of the dogs took it upon themselves to sit on my knee, another sat on my feet and as I leaned forward hoping they would move another sat on my back. Rebecca then pointed out that it was best to leave the dog sat on my back where it was as it normally bites strangers! The dog who was still sitting on my knee barked all the way through the interview and I remember thinking very clearly, if I get out of this house without being bitten, I do hope I can hear the recording over that very loud bark. The first thing I wrote when I left the house and sat in the safety of my car was 'Funny how some peoples normality is another person's nightmare'.

Chris

Chris is female and she is 69 years of age. She stated that she was educated to university level and prior to her retirement she worked as a head teacher in a secondary school. Chris has also been a local councillor and still sits on many school boards. When first diagnosed with type 2 diabetes over ten years ago she was initially relieved as she was suffering from severe symptoms at the time. Her diabetes is currently being controlled by tablets although her general practitioner has mentioned that she may have to start taking insulin as her blood sugars are high and her weight is presently not under control.

Chris is concerned by this potential change in treatment and commented that she, tries to carefully control what she eats. She does state however, *'The nurse wants me to walk everywhere and cut out all of my sugars but I am not prepared to do it. Yes I have got diabetes but this is my choice and I have to decide what quality of life I want.'* Chris said that she likes to eat a biscuit in the afternoon as she feels this is when her blood sugar levels start dropping, but is aware that the nurse frowns upon this practice. Chris was very annoyed at the nurses attitude and declared that it was not as if she ate the whole packet, she was extremely frustrated with the practice nurse and stated, *'She has no qualifications in diet or diabetes so what would she know about anyone's blood sugars, she won't let me test my own blood sugars, surely that is saving her a job, it is all tick boxes every appointment.'*

She rates her health as 'good' and admits that she is extremely overweight and not as active as she used to be, and she 'enjoys taking several holidays abroad each year. In terms of education Chris would prefer a leaflet to read at her leisure in order to absorb the information over a period of time. She also expressed that she would not be interested in going on a course and commented that she would just dismiss that after all this time.

Chris stated that she is sick of the guidelines changing she said *'I get my cholesterol down and they want it lower, I get my blood sugars down and they want it lower, well it is just impossible.'* Chris was furious when she explained that she used to test her own blood sugars up until six years ago at that point

the local clinic then refused to give her any more testing strips. Chris commented that at the time of self-testing her blood sugar levels they were stable at around 7 or 8, and that she feels they are a lot higher now she is no longer able to keep her eye on them. She further commented *'You just have to do as they say, they have all the power that is the way that they like it, I mean it is my diabetes and I wanted to keep it under control but I am no longer able to, it is the tick boxes you see, that is all I am to them a tick box not a person.'*

When asked why she would dismiss any education around her condition Chris said *'I have had it for ten years and I am at the point where I do not want to be told the same information by them again and again and again, they treat us all the same you see, they would never see me as an individual so what is the point.'*

She explained that she would also like to be able to, ask questions at her check-up appointments but stated *'I feel that the nurses would just give me negative answers, she has in the past.'* Chris said that there is too much negativity from the health service and does not see why education cannot be given in a positive way she commented *'Every time I see that nurse it is always, you cannot do this and you must not do that, so in the end I just stop telling her what I do, no one liked to be spoken to in that way.'*

She does not sense that the people giving the diabetes education are qualified enough to understand about each individual person's needs. Chris was originally given a leaflet from the dietician over ten years ago and remarked *'I am intelligent enough to understand what I should be eating and I do not want to be told what I can and cannot have. Why can't they just ask us what we want and then help us with that and stop telling us what to do? I feel I am being told off when I see the nurse and I do not like people who talk down to me, I REALLY don't.'* Chris also commented that *'There is no health in healthcare anymore, they just tick their boxes and we are left to suffer the consequences.'*

Chris loves her yearly appointment with the optician and looks forward to it, she does not understand how this service can be so proactive and organised

and yet the nurse and the podiatry services are not. She commented that the optician she attends arrange her appointment and speak to her like an adult and explain everything she needs to know. Chris commented that this was the only service where she truly understood about diabetes and the complications, and they did not speak to her as if she was stupid.

Chris was frustrated at the bureaucracy of trying to book an appointment with the local podiatry service, remarking *'I have given up trying to get my feet done, you are in and out in five minutes and they expect you to call them every year for an appointment. How are you supposed to remember if you are old?'*

APPENDIX XI

Gantt Chart

Gantt Chart	2010				2011				2012				2013				2014				2015			
	Oct-Dec	Jan-Mar	Apr-Jun	Jul-Sep	Oct-Dec	Jan-Mar	Apr-Jun	Jul-Sep	Oct-Dec	Jan-Mar	Apr-Jun	Jul-Sep	Oct-Dec	Jan-Mar	Apr-Jun	Jul-Sep	Oct-Dec	Jan-Mar	Apr-Jun	Jul-Sep	Oct-Dec	Jan-Mar	Apr-Jun	Jul-Sep
Activity																								
Diabetes Study Research																								
Research Methodology																								
Research Preparation Paperwork																								
Ethical Approval (IRAS)																								
Interviews and Transcribing																								
Data Analysis																								
Literature Review																								
Writing Up Thesis																								
Conclusions and Recommendations																								
Proof Reading and Review																								
Academic Break																								
Major Milestones																								
Interim Assessment																								
Internal Evaluation																								
Final Thesis Submission																								
Vive Voce																								