

**How adults with type 2 diabetes and a chronic lower  
extremity wound understand the link between their wound  
and their diabetes management.**

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Lucy Jane Beams

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## **Abstract**

### **Background to the study**

The research question: What do people with type 2 diabetes who also have a chronic lower extremity wound understand about the management of their condition and the complication of a wound?

With the number of people with type 2 diabetes in New Zealand growing so rapidly so are the number of people experiencing complications associated with this condition. High blood glucose levels can contribute to the poor healing of wounds resulting in the development of chronic wounds. This study has investigated the experience of people who are type 2 diabetics living with a chronic wound with a focus on identifying what the participants understanding was of the link between their diabetes and wound healing. This study has also investigated other issues such as foot care, impact on quality of life and educational preferences.

### **Methodology, methods and analysis**

An interpretive descriptive methodology has been used within this study. Semi-structured interviews were conducted to gather data from the nine participants recruited. Thematic analysis was conducted of the interview transcripts and notes.

### **Discussion and recommendations**

Five themes were identified, *'Letting someone else deal with it'*, *'Ownership'*, *'Not making the link'*, *'Coping with it'*, *'Self-care practices'*. It was found that most of the participants were not making the link between how their diabetes management could affect the healing of their chronic lower extremity wound

Efforts need to be made to improve care and education delivered to health professionals and their patients with diabetes and chronic wounds so they are aware of what actions they can take to improve wound healing and also prevent future complications. Further research is needed to identify knowledge levels of both health professionals and patients to ensure appropriate care and information is being delivered. A large scale study on diabetic foot care knowledge and practice would be beneficial within New Zealand; identifying areas that need development will be beneficial for improving patient outcomes in the future and reducing health expenditure.

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## Abbreviations

**AMA** – American Medical Association

**CDHB** – Canterbury District Health Board

**DHB** – District Health Board

**DN** – District Nurse

**DNZ** – Diabetes New Zealand

**DUK** – Diabetes United Kingdom

**Euro** – European

**GP** – General Practitioner

**HbA1c** – Glycosylated haemoglobin molecule

**HDEC** – Health and Disability Ethics Committee

**IDF** – International Diabetes Federation

**MoH** – Ministry of Health

**NZ** – New Zealand

**NZGG** – New Zealand Guidelines Group

**NZHR** – New Zealand House of Representatives

**PAD** – Peripheral Arterial Disease

**QOL** – Quality of Life

**T2DM** – Type 2 Diabetes Mellitus

**UK** – United Kingdom

**US** – United States

**WHO** – World Health Organization

## Chapter One

### Introduction

#### 1.1 Introduction

This research study will explore how people with Type 2 Diabetes Mellitus (T2DM) and a chronic lower extremity wound understand the link between their wound and their diabetes management. In this study, the term chronic lower extremity wound has been used to define the shared characteristic of participants as this covers chronic wounds to the lower legs, feet and toes (New Zealand Guidelines Group [NZGG], 2003). It will investigate how the participants are affected by and what knowledge they might have of their conditions, which will help identify educational needs in order to improve future outcomes. It might be the case, as demonstrated in the literature, that the delayed healing of their wound is related to their diabetes; high blood glucose levels as a result of inadequate diabetes management can contribute to such complications (Diabetes UK [DUK], 2010; Lazar et al, 2004; Patel, 2008; Wang & Hazuda, 2011). By investigating what people know and want to know about their diabetes and wound healing, gaps in knowledge can be identified. This will allow for appropriate education to be delivered which will enable people with T2DM and chronic wounds to self-care appropriately. Self-management may not be something participants want to engage in and they may be more suited to leaving some responsibilities for their health to others such as their district nurse or general practitioner. Therefore it is also important for health professionals to be knowledgeable on diabetes management and its effect on wound healing as well as having an understanding of what patient wishes are in relation to the management of their conditions.

This study has been conducted in a provincial New Zealand city with participants who have T2DM and a chronic lower extremity wound. More information about T2DM and chronic wounds will be discussed later in this chapter. The District Health Board (DHB) covering the area of this study had a regional health plan containing a strategic goal of working towards enabling patients to take an increased responsibility for their own health (Canterbury District Health Board [CDHB], 2011). Previously, the medical model of care delivery was utilised by health professionals where the doctor was responsible for making sure treatment was carried out as prescribed.

However, Anderson (1995) identified this was not the best fit for providing long term condition management in diabetes care. Instead, patients need to be equipped with the required knowledge to enable them to make informed choices and health care professionals need to

talk with patients to make them aware of their responsibilities regarding condition management. A report by the European Commission (2012) found that increasing patient involvement in their own care can lead to increased motivation, understanding of their condition and better monitoring and self-care. Although the report states the process to achieve this may be time-consuming for health professionals, the overall benefits cannot be ignored. Taking increased responsibility for health can be interpreted in many ways. It could be that people ensure they attend regular screening and appointments, but in relation to diabetes it could be that people take control of the management of their condition by implementing lifestyle changes necessary to successfully control their condition. To enable people to achieve this level of responsibility it is necessary to ensure they have the tools and support available to them. This study will go on to identify whether the participants were given all the information they needed to enable them to successfully take responsibility for their health. Identifying what the participants want to know will help in the development of appropriate strategies to overcome gaps in knowledge and lead to better overall outcomes in the health of people with T2DM and chronic wounds.

## **1.2 Background to the study**

This study is based upon the personal experiences and knowledge of the researcher. This section will clarify and explain how this pre-existing knowledge and experience had impacted on the development of this study topic. As this section discusses the author's experiences that led to the development of this study, it will be written in the first person.

As a nurse working in the community nursing setting I visit patients in their own homes and feel I have an opportunity to share my knowledge with my patients to help achieve better outcomes. Over time it became evident to me that many patients with chronic wounds also had T2DM. It appeared to me that some patients were unaware of how their diabetes control could affect the healing of their wound in both positive and negative ways. I would see patients who had a history of poor diabetes control and they often experienced wound infections and suffered complications that sometimes required surgery such as the amputation of toes or limbs, whereas patients with good control were often seen to heal quicker and suffer fewer complications (Patel, 2008). I also became curious about patients' awareness of the actions they could take to protect themselves from serious complications and injury that may lead to the development of chronic wounds to the lower extremities. My experiences and the questions they posed led to the development of the research question this study is based upon.

### 1.3 The research question

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*What do people with Type 2 Diabetes Mellitus, who also have a chronic lower extremity wound, understand about the management of their condition and the complication of a wound?*

### 1.4 Aims of the research

The overall aim of this study was to learn how the participants understood the relationship between their T2DM management and how it affected their chronic wound. This study also intended to identify the self-care practices of the participants in relation to diabetic foot care. Learning what people do and do not understand about this will identify what further knowledge or information would enhance their ability to effectively manage their diabetes and improve wound healing outcomes. By identifying what people know and want to know, the current study may help improve patient outcomes. Identifying the method of delivery people prefer for health information/education and what goals they have regarding their health which was also an aim of this study. Diabetes and chronic wounds, individually and combined, can have a negative impact on quality of life therefore it was also an aim of this research to explore the impact of having a chronic wound, for people with diabetes (Armstrong, Lavery, Wrobel, and Vileikyte, 2008; Goodridge, Trepman, and Embil, 2005; Goodridge et al., 2006; Wexler et al., 2006). If achieved, the study's aims could lead to improved outcomes for people with T2DM and chronic wounds, and ultimately decrease health expenditure.

### 1.5 The impact of diabetes

The number of people with T2DM is increasing in every country in the world, making it a pertinent issue for further research (International Diabetes Federation [IDF], 2011; World Health Organisation [WHO], 2012). In general terms the incidence of T2DM is increasing globally and the New Zealand statistics reflect this with 189,737 people being diagnosed with diabetes (both Type 1 and Type 2) by the end of 2010 (Diabetes NZ.[DNZ], n.d.a) By June 2012 this had increased to 208,076 people, constituting an increase of over 18,000 people in less than two years, (DNZ, n.d.b). As 90% of all people with diabetes have T2DM, this suggests T2DM and its associated complications are affecting many of the people of New Zealand. As the current study focuses on both diabetes and a complication, it is hoped it will help address the problems faced by this particular group (McCance, Huether, Brashers, and Rote, 2010).

Costs for diabetes care are escalating. In the Western Pacific region, an area that includes New Zealand, it was estimated that 72.2 billion US dollars would have been spent on treating diabetes in 2012 (International Diabetes Federation [IDF], n.d.). With the current exchange rate, that equates to about 86.3 billion New Zealand dollars (Currency converter widget, n.d.). Looking at New Zealand (NZ) specifically it is expected that by 2021 it will cost 1.6 Billion New Zealand Dollars each year to treat people with T2DM (Fight The Obesity Epidemic, 2007). Ultimately these costs will become prohibitively expensive for healthcare services to absorb and therefore more action is needed to prevent this anticipated expense becoming reality (Sheerin, 2009).

As obesity is listed as one of the key reversible factors that can contribute to a person developing T2DM, it is becoming an ever growing problem for the population of NZ (New Zealand House of Representatives [NZHR], 2007). The latest New Zealand statistics state that 28% of the population are classified as obese, which suggests a large section of New Zealanders are at risk of developing T2DM, (Ministry of Health [MOH], 2012). More effort needs to be made to help reduce obesity in the New Zealand population. This, in turn, will help to reduce the number of people developing T2DM (NZHR, 2007). To achieve this requires the participation of many organisations within our society as well as the individuals affected. As nurses, we can help to reinforce healthy lifestyle options but ultimately it is up to the individual to take action (NZHR, 2007). The ideal would be to prevent people developing T2DM, but in reality there are already many people with the condition. Strategies to reduce the burden of the complications of diabetes will be beneficial to patients, their families and health services as well as helping to reduce the long term costs of diabetes care for the people of New Zealand (Sheerin, 2009; NZHR, 2007).

In the region where this study was conducted, there were 19,439 diagnosed diabetics at the end of 2011 (DNZ, n.d.b). Furthermore, for the 2005/06 period, in this region the cost of diabetes-related hospital admissions as both primary and secondary diagnosis was 10.1 million dollars. This does not include the care delivered in the community setting which would increase this amount further (Sheerin, 2009).

This study focused on people with T2DM because of their growing over-representation and the growing burden of this disease on the quality of life experienced by people with such a diagnosis (McCance et al., 2010). To further explain the rationale of having only Type 2 diabetics participating in this study, the different types of diabetes will be explained. The two most common types of diabetes are Type 1 and Type 2; others include gestational diabetes, which occurs during pregnancy, and drug-induced diabetes which can often result from

prolonged use of steroids (O'Toole, 2003). Type 1 Diabetes Mellitus is an auto immune condition that results in no insulin being produced, whereas Type 2 Diabetes Mellitus (T2DM) causes insulin resistance and reduced insulin production (O'Toole, 2003). Type 1 diabetes, whilst being a life-long condition, affects only 0.3% to 0.5% of the population globally, whereas T2DM affects 10% to 20% of the general population and is on the increase.

## **1.6 Diabetic complications**

Diabetes has many associated complications that can affect a person's wellbeing. This study focuses on T2DM and its association with wound healing; the development of a wound and delays to healing can be associated with many of the complications discussed below. For the purposes of this study the terms delayed healing and chronic wound refer to wounds of more than 30 days duration, (US Department of Health and Human Services, n.d). T2DM has many complications which can be prevented with good management of the condition. These complications are classified as micro vascular and macro vascular disease; both are caused by hyperglycaemia, which is an elevated blood glucose level (Fowler, 2008).

### **1.6.1. Micro vascular complications**

Micro vascular complications include retinopathy, which can lead to deterioration in eyesight and blindness; nephropathy, which causes chronic renal failure, can lead to the need for dialysis treatment and ultimately the need for a kidney transplant; and neuropathy, which is damage to nerves causing decreased or total loss of sensation, especially to the lower limbs (Fowler, 2008).

Retinopathy is the result of micro-vascular disease causing blood vessel changes in the eye. Haemorrhage can occur in the small vessels of the eye and inflammation and ischemia can also occur, leading to visual disturbances and eventually blindness (McCance et al., 2010). High HbA1c levels, (described further in 1.6.4), being a diabetic for a long time and high blood pressure can all contribute to the occurrence of retinopathy. If improvements are made to these contributing factors, the severity of retinopathy can be reduced (Zhang et al., 2010).

In New Zealand, over one third of all cases of chronic kidney disease are related to diabetes. This is associated with prolonged periods of elevated blood glucose levels leading to damage to the micro vascular system within the kidneys (Endre, Beaven, and Buttimore, 2006; McCance et al., 2010). The costs of treating nephropathy as a result of diabetes are at least \$36 million NZD a year, (Endre et al., 2006). If T2DM is not well controlled, it will lead to

nephropathy in 40% of this population group. As it can show no symptoms initially, it may have been present for many years before diagnosis (McCance et al., 2010).

Chronic or prolonged episodes of hyperglycaemia can lead to damage to the nerves. Slowed, impaired or absent nerve conduction can lead to reduced or absent sensation (McCance et al., 2010). Different degrees of neuropathy exist, causing pain, altered sensation, weakness, altered gait, gastrointestinal, cardiovascular, genitourinary and sudo-motor problems. Neuropathy can also lead to carpel tunnel syndrome, wrist drop, foot drop and lower limb weakness (McCance et al., 2010).

Retinopathy and neuropathy are of particular relevance to the development of wounds in people with diabetes as sufferers may not see or feel potential hazards, leading to injury. These complications may result in delayed realisation that injury has occurred. The cost of treating wounds in people with diabetes is great. Tennvall and Apelqvist (2004) suggested it costs US\$17,500 to heal a diabetic foot ulcer; this converts to about NZ\$20,900. Although this data was from a 2004, it quotes 1998 numbers so this figure is likely to be much greater in today's terms, (Tennvall and Apelqvist, 2004; XE Currency converter widget, n.d.).

### **1.6.2. Macro vascular complications**

Macro vascular complications include: coronary artery disease that can lead to heart disease and myocardial infarction; peripheral arterial disease that causes poor circulation and can ultimately lead to lower limb amputation; and cerebrovascular disease, which can cause strokes to occur (Fowler, 2008).

Coronary artery disease is the leading cause of death in people with T2DM. Oxidative stress caused by hyperglycaemia leads to dysfunction of the endothelial tissue of the arteries; this, in turn, allows for the deposit of atherosclerotic plaques in the arteries and can lead to heart attacks and strokes (McCance et al., 2010). People with T2DM are twice as likely to suffer a stroke (usually ischemic) than non-diabetic people, while high blood pressure, elevated blood glucose levels and high cholesterol can all increase the risk of stroke (McCance et al., 2010).

Peripheral arterial disease is a result of atherosclerosis occurring in the arteries and arterioles of the lower limbs. This causes blockages and can restrict or prevent blood flow reaching areas of the lower limbs (McCance et al., 2010). This restricted or absent blood flow can result in ischemia. When tissues do not get nourished with oxygenated blood, cell death occurs which leads to the breakdown of tissue and wound formation. Ultimately this can lead to amputation being required (McCance et al., 2010).

### **1.6.3. Infection**

People with diabetes are at a higher risk of infection than the general population (McCance et al., 2010). Impaired vision and touch, caused by retinopathy and neuropathy respectively, can lead to delayed identification of an injury and as the inflammatory response to infection can be decreased in people with diabetes, infection may be more advanced before it is detected (McCance et al., 2010). As micro and macro vascular changes can lead to decreased oxygen in the tissues, and glucose attached to the red blood cells may also decrease the availability of oxygen, this may increase the likelihood of infection developing (McCance et al., 2010). Another factor working to the disadvantage of people with diabetes is the excess glucose circulating in the blood stream when hyperglycaemia occurs, Glucose is a good source of energy for bacteria; if they get into the wound of a person with high blood glucose levels, they will be able to proliferate rapidly and cause infection (McCance et al., 2010). Infection is a known factor contributing to the delayed healing of wound, (McCance et al., 2010).

### **1.6.4 Glycaemic control**

Good glycaemic control by people with T2DM can help improve outcomes and reduce the incidence of complications (DUK, 2010; Lazar et al., 2004; Patel, 2008; Wang and Hazuda, 2011). Both Lazar et al. (2004), and Wang and Hazuda (2011) conducted quantitative studies looking at good glycaemic control and improved outcomes for diabetic patients. They took different approaches, with Lazar et al. (2004) doing a randomised control trial with two groups, one group receiving tight glycaemic control and the other, usual care; Wang and Hazuda (2011) focused on education to improve glycaemic control and monitored the outcomes over a 36 month period. Their study emphasised the importance of providing good education to patients to enable them to have good glycaemic control and prevent diabetes-related complications, whereas Lazar et al. (2004), provided more of a medical intervention to achieve tight glycaemic control. Both studies concluded that achieving optimum glycaemic control could help improve outcomes and prevent complications in patients with T2DM (Lazar et al., 2004; Wang and Hazuda, 2011). These two studies confirm the findings of a literature review by Simms and Ennen (2011) that aimed to define the best nursing practice for leg ulcer care and suggested good blood glucose control can help improve wound outcomes.

This understanding, of how diabetes and the development of and problems associated with chronic wounds are intertwined, has led to the development of this research. It may be that participants do not understand how their glycaemic control affects their healing. If this is the case, more emphasis needs to be made regarding this link, in the development of new patient

education. If people have a clearer understanding of how high blood glucose levels may impede healing and contribute to other complications, they may be more likely to take action to gain better control. The current study has gained an insight into the patient experience and more understanding of what improvements in care delivery are needed in the future.

When haemoglobin and glucose combine, this leads to the development of a glycosylated haemoglobin molecule; this is known as HbA1c (DUK, 2011). HbA1c is often used as an indicator of glycaemic control. Although not recorded in the data collection for this study, it was anticipated that participants might discuss it in relation to their condition management, so this term will now be explained in more detail. Haemoglobin is part of the red blood cell and it can live for eight to twelve weeks, a test for HbA1c can give an indication of average blood glucose levels for that period (McCance et al., 2010). An optimal HbA1c level would be 6.0-7.0%, 42-53 mmol/mol or a fasting blood glucose level of 6.0mmols (McGill and Felton, 2007). There were recent changes to the method of recording HbA1c going from % to mmol/mol therefore both have been mentioned throughout this thesis depending on the source of information, (New Zealand Society for the Study of Diabetes, 2009). Nathan et al. (2009), state that an HbA1c level greater than 7% indicates a need for a review and change of treatment. HbA1c can be tested 3-6 monthly to monitor diabetic control and it gives a good indication of how well-managed the condition is. A reduction in HbA1c level of just 1% can lead to improved outcomes for people with T2DM (DUK, 2011).

### **1.7 The incidence of wounds in people with T2DM**

This study focuses on people with T2DM and wounds all participants will have both conditions; therefore it is important to understand how wounds occur in diabetes and the incidence of such a complication. Foot ulceration occurs in 2 to 5% of the diabetic population each year (Golinko et al., 2009). Singh, Armstrong, and Lipsky (2005), state 4-10% of people with T2DM will develop foot ulcers in their lifetime. In contrast, Boulton, Vileikyte, Ragnarson-Tennvall, and Apelqvist (2005) state that there is up to a 25% risk of developing a foot ulcer over the lifespan of a person with T2DM. Wounds suffered by people with diabetes are prone to infection due to impaired cellular and immune function, so this can increase the likelihood of problems for diabetic patients (Sheetz and King, 2002; Singer & Clark, 1999). Other factors that contribute to poor or delayed wound healing in diabetes include elevated blood glucose levels, which causes impaired blood flow and rigidity to cell walls, and impaired oxygen flow (Ekmektzoglou and Zografoz, 2006; Sheetz and King, 2002). T2DM is associated with many complications, including slow-healing chronic wounds that can affect the wellbeing of people with T2DM.

In New Zealand between 1980 and 1993, hospital admissions for diabetic foot disease increased. Although this is older information, it illustrates that the problems faced by diabetic people are not new and more research is still required to help improve outcomes (Boulton et al., 2005). It is well documented that diabetic ulcers/wounds can lead to amputation, and Schaper, Apelqvist and Bakker (2012, p1869), describe it thus: "Amputation of the lower limb is one of the most feared diabetic complications". It is anticipated that the current study will help lead to better outcomes for diabetic patients and ultimately prevent this fear becoming a reality.

A study discussing the incidence of amputations in diabetic foot disease concluded that whilst minor amputations increased over their ten-year study period, major amputations decreased (Margolis, Allen-Taylor, Hoffstad and Berlin, 2005). This finding may be indicative of improvements to care and knowledge decreasing the severity of wounds experienced by patients. However, occurrence of foot ulcers in people with diabetes is usually preventable and appropriate education and support are still needed to help achieve better outcomes for patients (Boulton et al., 2005; Margolis et al., 2005). In New Zealand the occurrence of non-traumatic amputation is overrepresented by people with diabetes, who account for half of all of this type of amputation, (NZGG, 2003).

### **1.8 Improving outcomes in diabetes**

Simply maintaining blood glucose levels within safe limits will help to reduce the impact of complications from diabetes. However, strict diabetic diet and exercise may be difficult for some people to maintain, so support is needed (McGill & Felton, 2007). In the community nursing setting, nurses visiting patients' homes for wound care may have the opportunity to provide such support. Participants of the current study may receive support from their community nurse, practice nurse and GP, amongst other health professionals involved in their care. Heisler (2009) suggests the need for support from family and friends if people with T2DM are to successfully manage their condition. Multidisciplinary care led by nurses has been shown to improve HbA1c levels by over 1% and reduce hospitalisation by 80%; this would be suggestive of a reduction in severe complications (McGill & Felton, 2007). The participants recruited for the current study were seen by a Community Nurse at least once a week for wound care. These nurses have the opportunity to lead the way, improve care and make a positive difference to patient outcomes. In the interview process, participants were asked about education and information they have received from health professionals involved in their care. This indicated the sources of support and information available to this group.

## **1.9 Community nursing**

There are many people, within every community, living with T2DM who self-manage their condition from day to day with support and direction from health professionals (Emerson, 2006). This study was conducted within a patient group of a community nursing service; therefore, an overview of community nursing in relation to this study will now be given. Historically, community nursing research has focused on the definition of the role of the nurse and tasks they complete, such as wound care, rather than placing the focus on patients and the outcomes of care delivery (Goodman, Ross, Mackenzie and Vernon, 2003). The current research was conducted in the community where many patients are seen who are both diabetic and suffering a wound that may be slow to heal. Community nurses can create opportunities to provide long-term condition management, education and support to their patients with the aim of preventing hospital admissions (Flood, 2009; Mackie, 2006; Roberts & Newton, 2011). However, Haycock-Stuart, Jarvis and Daniel (2008) identify that community nurses often provide task-orientated care with focus on a specific ailment, over the holistic care e.g. (which would view the whole person) that is required for care to be successful. But perhaps this may be difficult to achieve due to factors that may include insufficient time or knowledge. Community nurses need to understand the importance of looking at the whole person, not just a specific problem, as this will help identify and address other factors that may be contributing to the problem (Haycock-Stuart et al., 2008). In terms of the current study it may be the case that some participants are seen by nurses who are focused on the task at hand, e.g. wound care, as they may have insufficient time or knowledge to realise the importance of the bigger issue of diabetes management which is actually contributing to poor wound healing.

The current study was designed to gain a greater knowledge of patient understanding of how their diabetes may be linked to their chronic wound and aimed to help inform future care delivery.

## **1.10 Structure of the thesis**

This thesis is divided into six chapters. Chapter One serves to introduce and give a background to the topic of diabetes and chronic wounds by explaining the incidence, prevalence and significance of this phenomenon, emphasising the need for and importance of research on this topic in nursing. The research question and aims of the research are outlined. Chapter Two explores the literature relevant to diabetes and chronic wounds; various categories have been identified and discussed, including those relating to quality of life, education and knowledge.

Chapter Three contains a description of the methodology used to underpin this research, the methods used to gather the data and the associated ethical issues, analytical concepts, and cultural considerations. Chapter Four describes analysis of the data gathered during the study, and explains how the themes were identified from the data. Chapter Five is a discussion of what has been learnt from interpreting the information gathered and the themes identified are explored in more detail. What has been learnt in relation to the literature review, as well as further reading undertaken following the analysis, all form part of this chapter. Chapter Six identifies the implications for nursing practice and recommendations for improving the care of people with T2DM and a chronic wound.

## Chapter two

### Literature Review

This literature review was conducted to identify what is already known about diabetes management and its relation to wound healing, as well as gaps in knowledge on this subject. This review helped to develop the questions for the interviews that were conducted as part of this study.

The literature for this review was found using the Eastern Institute of Technology (EIT) databases that included CINAHL, Science Direct, EBSCO Host and ProQuest. Google Scholar was also used, linked in to the EIT database to make searching easier and to search scholarly articles on the internet to ensure a wider search was conducted.

Numerous searches were necessary as diabetes is a well-researched health issue with complications, effects of the condition and education strategies to improve outcomes covered by a wide variety of literature. Therefore, multiple different searches were conducted using a variety of search terms to ensure the information required was found. The searches included phrases such as “Diabetic complications; nurse-patient communication; diabetes health education; health literacy; Diabetic wounds; Diabetic ulcers; Diabetic foot ulcers; Diabetic chronic wounds; Diabetes and Quality of life; Diabetic ulcers patient experience”.

Many articles were found relating to diabetes and wounds and all relevant articles have been discussed in the literature review. The date range was variable, with the initial search covering the last ten years. If insufficient information was found, this range was opened to any time, with the publication dates ranging from the 1980’s to the present. All studies included in this literature review had only human subjects as animal studies were not relevant to this study.

The majority of articles found were research articles; however, some included discussion of issues relevant to the study and, although not original research, included subjects of importance. Studies were included from all over the world as the range of New Zealand-based literature was limited, perhaps due to the small population. Not all articles included research relating specifically to wounds or diabetes. In some cases it was one or the other, and many discussed education and knowledge in relation to diabetes management. Where articles have been discussed in relation to the current study, (e.g. how the article relates to the current study) it will be referred to as “the current study”.

Diabetes and wounds are multifaceted with many implications for patients, the way they live and experience the world and the care they receive from a variety of health care professionals.

For this reason, the literature review has been broken down into categories. Quality of life will be discussed as diabetes, a wound, pain, mobility and cultural issues which can arise and affect the quality of a person's existence. The experience of being a diabetic person with a chronic wound is important to the current study as it was intended that insight be gained into how people understand their diabetes and chronic wound; therefore, patient experience is the second category for discussion. This is followed by communication, as effective communication between patients and their healthcare providers is vital for successful outcomes to be achieved; if information isn't delivered in an appropriate manner it will not make any difference to the patient. Knowledge and the most up-to-date information is needed to help patients and health professionals make the right choices, be it lifestyle education for a patient, or education on the most recent evidence-based practice for health care providers so they can deliver the best care possible. However, health education does not always work and it is not always effective.

The knowledge people have can have an impact on their self-care practices which are an important part of diabetes management. This is discussed in detail. As there is evidence of disparities in health outcomes for some ethnic groups within New Zealand, and barriers to care may also be evident due to location or lack of appropriately qualified professionals to deliver care, both issues are discussed.

### **2.1 Impact on quality of life and life expectancy**

The impact of diabetes and its associated complications can be severe (Robbins, Strauss, Aron & Kaplan, 2008; Armstrong, Wrobel & Robbins, 2007). A range of factors can impact on quality of life, with diabetes and wounds affecting the quality of life of the person experiencing the phenomenon (Goodridge, Trepman & Embil, 2005). People with diabetes and a wound have many things to contend with, amongst them pain, dietary limitations, constraints with movement and activity, contending with medication regimes, impacts on lifestyle and employment, the need for regular contact with health professionals for wound care and the increased risk of complications, to name a few. There are a variety of quality of life (QOL) assessment tools available to measure the effect of diabetes on QOL, such as the generic Rand Short Form 36 which has 36 questions that cover issues relating to mental and physical wellbeing (Reiber, Libsky & Gibbons, 1998). The Cardiff Wound Impact Schedule is also available, which was developed to assess how chronic leg and diabetic foot ulcers impacted on health-related quality of life (Price & Harding, 2004). Both of these tools are more suited to a quantitative study. The current study is taking a qualitative approach, therefore it does not use

a QOL tool; rather, it enquires about how the participants feel their conditions (diabetes and wound) effect their QOL. This will contribute to the discussion.

A study conducted by Gurková, Čáp and Žiaková (2009) aimed to identify and compare the factors affecting quality of life and treatment satisfaction in insulin-dependent diabetics attending an education programme. Although this is not wound related, the study looks at education in relation to diabetes management and insulin therapy (Gurková et al., 2009). The researchers found that the number of complications experienced, the intensity of the person's insulin regime, age and the length of time the person had been a diabetic all had an impact on the quality of life of people with diabetes.

It was noted that Gurková et al. (2009) excluded participants with significant complications such as foot ulcers. If a true reflection of quality of life was being sought they should have included participants with these significant complications. One study found that there was no significant difference in quality of life associated with differing wound severity (Jaksa & Mahoney, 2010).

Ghanbari, Yekta, Roushan, and Lakeh (2005) identified that assessing quality of life is an important way of quantifying the success of treatments and education that patients receive. Health professionals need to work towards improving QOL as well as health status, which suggests a need for a more holistic approach to diabetes care than the problem solving approach adopted by many health care professionals (Ghanbari et al., 2005).

As previously discussed in the Introduction, diabetes and the complication of a wound can result in infection, pain, decreased mobility and, in the worst case, amputation of lower extremity and/or limb. Diabetes-related wounds and the consequential amputation have a high five year mortality rate. Of the patients having diabetes-related amputations, about half of them will not be alive after five years (Armstrong et al., 2007). Sohn, Lee, Stuck, Frykberg, and Budiman-Mak (2009) and Armstrong et al. (2007) both discuss how diabetic ulcers and resultant amputations can be considered worse than cancer in terms of mortality. Sohn et al. (2009) carried out a retrospective analysis of mortality statistics for people with diabetes and a variety of associated complications, taking into account multiple co-morbidities. Armstrong et al. (2007) compared the mortality statistics for people with diabetic wounds and different cancers. People who have prostate, breast cancer or Hodgkin's disease have a better five year mortality rate than those experiencing amputation and/or neuropathic or ischemic ulcer due to diabetes (Armstrong et al., 2007). In people with newly-developed diabetic foot ulcers, the five year mortality rate is 43-55%; if a person undergoes an amputation, this rate jumps to 74%

(Robbins et al., 2008). This varies from Armstrong et al. (2007), however both sources clearly emphasise the serious impact diabetic ulcers and the associated complications have on the sufferers. Sohn et al. (2009) investigated mortality further, comparing the mortality rates of people with just diabetes, Charcot arthropathy and diabetic foot ulceration. They found that the group with foot ulceration had the highest incidence of death. During the five year follow-up of the study of 1050 total participants, 28% died. The patients with foot ulcers had the highest mortality, representing 37% of the deceased, 18.2% more than those with diabetes alone and 8.7% more than those with Charcot arthropathy (Sohn et al., 2009). Faglia et al. (2006) continue to discuss mortality, finding that after major limb amputation in diabetic people, the five year survival rate is as little as 31%.

The mortality statistics for people such as those in the group being studied are worrying. However, it must be noted that diabetic foot ulcers are an indicator of poor glycemic control. Prolonged episodes of hyperglycaemia increase the risk of micro and macro-vascular complications which can result in increased risk of cardiac problems, stroke and renal failure which can all negatively impact on mortality (Endre et al., 2006; Fowler, 2008; McCance et al., 2010). Also, whilst it is important to know the associated risks when imparting information to patients, communication needs to be done sensitively (Sohn et al., 2009). Giving information on the right things to do does not always work alone; factors such as patient motivation need to be worked with. Although patients are assumed to be motivated to do what is best for their health, this is not always the case (Robbins et al., 2008). It may be that patients' priorities vary somewhat from those of the health professionals working with them because they are more focused on living their life than on meeting targets such as an ideal HbA1c.

## **2.2 Patient experiences**

Patient experience of being a diabetic with a wound can vary greatly, often depending on the severity of the wound, how their diabetes is managed and the interventions they require. Wellard, Rennie and King (2008) conducted a qualitative study with four participants. Although this was a small study and cannot be applied at a general level it does provide an insight into patients' perceptions about their T2DM self-management and the community-based care they received. Their study identified that health professionals need to be working towards improving diabetes management services in the community. The researchers also found that the participants felt that health professionals failed to acknowledge the knowledge that the participants held, when planning and providing their care. Kielmann et al. (2010) agreed with this finding, stating that health professionals need to respect their patients' knowledge about the condition that they live with every day. The reverse was identified in the Matthews, Peden

and Rowles (2009) study where participants felt health professionals were making assumptions that the participants knew things about the management of diabetes when in actual fact they did not have this presumed knowledge.

Wellard et al.'s (2008) study was very small, with only four participants; ideally, at least ten participants are required to help ensure the rigour of the data gathered in qualitative research. Wellard et al.'s (2008), study served to confirm what is already well known about diabetes services, in that diabetes care needs great improvement on a global level.

A study on patients' reflections and experiences of their diabetes care found that autonomy and equality are important for patient compliance and empowerment with diabetes care (Hornsten, Lundman, Selstam & Sandstrom, 2005). Hornsten et al. (2005) and Kielmann et al. (2010) have both identified that there is a need for health professionals to understand and respect the goals that patients have regarding their health, however it is also necessary to respect patients' wishes if they don't have goals or the desire/ability to self care (Hornsten et al. 2005; Kielmann et al. 2010). Hallett, Austin, Caress and Luker (2000) suggest that knowledge and understanding on the part of the patient can affect compliance. If a patient does not know or understand why they must do something, they are less likely to do the activities that will help them. This suggests a need for better education to help improve patients' participation in their own care.

Oftedal, Karlsen, and Bru (2010b) conducted a descriptive, explorative qualitative study to identify how people with T2DM perceive the support offered to them and how the knowledge and skill of the healthcare professionals working with them can affect their ability to self manage their condition. They conducted focus groups with nineteen people with T2DM and following qualitative content analysis found that the actions of healthcare practitioners can help improve patients' motivation for self management (Oftedal et al., 2010b). These authors also suggested the need for healthcare practitioners to provide on-going individualised empathetic care and education to their patients, to deliver the support required. They further suggested that patients needed individualised care with practical and ongoing support. However, it appears that while this can improve outcomes for people with diabetes, this does not necessarily offer any more benefits than group based interventions (Duke, Colagiuri, & Colagiuri, 2009; Rickheim, Weaver, Flader & Kendall, 2002).

Duke et al. (2009) found that individualised education can be of benefit to people with higher than optimal HbA1c levels; however, there was no clear evidence of an overall difference between individualised and usual care groups. Rickheim et al.'s (2002) findings agreed with

Duke et al. (2009), in that group interventions and individualised education showed similar effectiveness at improving diabetes management, using HbA1c as an indicator of control. Rickheim et al. (2002) also identified that group interventions would be more cost effective to deliver than individualised interventions. There are group-based education courses offered as well as individual one-to-one information delivery within the region of the current study,(CDHB, 2003). The current research asked participants what information or education they have received and identified whether patients felt they were receiving appropriate care and education, and what patients actually wanted in terms of care and education surrounding their diabetes and wound management.

Livingstone, Van De Mortel and Taylor (2011) used a qualitative approach to explore the experience of people who have had an amputation due to the complications of diabetes. Whilst amputation is different to having a wound, it is usually preceded by a wound in people with diabetes (Livingstone et al. 2011). Five participants were recruited to this small study. The findings identified that poor care delivery was associated with a lack of knowledge. The researchers also found that if patients were not fully aware of the risks they faced, such as the risk of amputation as a consequence of poor diabetes management, they were fearful and uncertain. However, it could be said that such knowledge may result in patients being scared into complying with treatment and may not necessarily be a positive thing. So, patients being aware of potential outcomes, good and bad, may give them more control and confidence with managing their conditions. However this awareness may also have a negative impact on the patients' experience of being a Type 2 diabetic with a wound.

Although not diabetes-specific, Byrne and Kelly's (2010), qualitative study investigated the impact for older people living with a chronic leg ulcer and identified that living with an ulcer is a complex experience. Byrne and Kelly, (2010) reported pain as the worst symptom to cope with and having a significant and negative impact on people with leg ulcers, followed by issues such as reduced mobility and embarrassment due to odour. As well as physical complications, psychological complications can arise and range from depression to suicidal thoughts (Byrne & Kelly, 2010). For people with diabetes this becomes even more complicated, with the lifestyle changes and medications required for successful diabetes management also having to be taken into account. Hallett, Austin, Caress and Luker (2000) conducted a study of nurse and care assistant perceptions which indicated that non-compliance with treatment was an issue in problematic wound healing. Therefore, taking a different perspective and asking patients about their experiences might help address this issue.

### 2.3 Communication

Effective communication between health care providers and patients can help contribute to successful health outcomes. Flood (2009) conducted a study looking at nurse-patient interactions in relation to diabetic foot care. Flood's research focused on the nurses' perceptions of the experience of interacting with patients regarding foot care and assessed this experience against the nurses' knowledge of diabetic foot care. Flood (2009), reported that more interactions were occurring in the community nursing setting than the acute hospital setting and the community nurses were having interactions that were more effective. Flood's research indicated that heavy workload and patients unwilling to learn or enter into dialogue about diabetic foot care negatively impacted on interactions in the acute nursing setting.

Roberts and Newton (2011) identified that in some cases it may be difficult to communicate effectively due to fear of causing distress. In diabetes care the potential severity or consequences of a diabetic wound should be discussed early in the treatment but this can be hard to achieve without causing distress. Bearing this in mind it is still necessary to ensure patients are fully informed of the complications and consequences of decisions they may make relating to their diabetes management, to enable them to make the right choices for themselves. However, for this to be achieved without causing distress, those delivering the information would need to be effective communicators equipped with the most up to date information, and able to provide the appropriate support. Education and information available to patients should make the risks of complications such as amputation clear.

A study by Spikmans et al. (2003) included questions to ascertain how patients understood the severity of their diabetes, in their data collection tool, in order to identify the reasons why people did not attend their diabetic nutrition appointments. After all, if people do not realise how serious diabetes and its complications can be, they may not be serious about the management of their condition. This may be evident from failure to attend appointments or participate in activities that will protect their health.

Babwah's (2011) study, although not specifically about communication, showed there is benefit from allowing time for extended interactions between patients and health professionals. Babwah set up a specialist clinic for people with diabetes in Trinidad. The clinic had been established for patients with no major macro or micro vascular complications and outcomes were reviewed to establish whether the new clinic was worthwhile. The specialist clinic allowed for longer consultations, more frequent visits and more lifestyle advice than the

general chronic illness clinic available in the area. Eighty-six of the 101 volunteers completed the full study and results showed an improvement in mean HbA1c from 9.44 to 7.96%. This would suggest a reduced risk of complications from diabetes when there is more time allowed for health interactions between health professional and patient and may be because more time was allowed to address issues being faced by the patients.

The project excluded participants with major diabetic complications. However, it could be assumed that the group with complications might also find frequent visits to a diabetes clinic with longer appointment times beneficial (Babwah, 2011). It may have been useful if the authors had included participants with any diabetes-related complication to see if HbA1c improved and if complication severity reduced. The current study includes participants with diabetes and a chronic wound; however, identification of other possible complications of diabetes was not necessary for selection in this study and it may be that participants have a variety of complications that have not been discussed.

#### **2.4 Knowledge of diabetes**

The level of knowledge and understanding a person has of their condition can greatly affect the outcomes they experience. Tang, Pang, Chan, Yeung, and Yeung (2008), conducted a quantitative study to examine health literacy in people with T2DM. Health literacy is the ability to read and have sufficient numeracy skills to function in relation to health (American Medical Association [AMA], 1999, cited in Tang et al., 2008). Tang et al. (2008) were looking at how patients manage the condition and the complications experienced. The researchers used a questionnaire to gather information and analysed participants' HbA1c blood tests to ascertain diabetes control. The study found there was a negative correlation between health literacy and diabetes management

Health professionals need to be able to assess health literacy to ensure their patients receive appropriate education that they will understand and be able to act upon, (Tang et al., 2008). In some cases people can have satisfactory knowledge of diabetic foot care and the consequences of poor management, yet their preventative self-care techniques can remain poor (Jinadasa & Jeewantha, 2011). Jinadasa and Jeewantha (2011) state that regular reminders of the principles around diabetic foot care may increase patient motivation to carry out the activity. However, in reality patients may not necessarily appreciate this.

Gazmararian, Williams, Peel and Baker (2003) conducted a study looking at health literacy in relation to chronic conditions. Participants included people with diabetes. The researchers found that when developing education, awareness is needed of the health literacy of the

target group They also noted that as doctors and nurses have less and less time for prolonged interactions, it is important to allow sufficient time for patients with poor levels of health literacy to allow the best chance for good outcomes. The authors suggested that allowing support people in the form of a friend or a family member to attend education sessions may be beneficial for patients with poor health literacy. In reality this may be prohibitively expensive for already over-stretched healthcare services to provide service that accommodates both patients and their support person.

However, Boren, Fitzner, Panhalkar and Specker (2009) conducted a literature review that found that the benefits of providing education to patients, on what they can do to improve their health, far outweighed the cost of providing the education. Tying in with health literacy, Hibbard (2003) discusses how it is important to make sure patients have the skills necessary to achieve their goals, so as well as assessing their knowledge it is important to assess what they understand. Hibbard (2003) talks of patients as co-producers in their own care. This involves working with the health professionals towards positive outcomes. However, to develop the patients as a co-producer in healthcare, Hibbard says it would be necessary for major changes to occur within the healthcare system as it is currently more focused on allowing for informed choices. Changes such as this would require great motivation from both the patient and the health professionals to achieve improvements in the outcomes for diabetic patients (van Dam, van der Horst, van den Borne, Ryckman, & Crebolder, 2003).

Seale et al. (2008) conducted a comparison study to compare the beliefs of three groups of participants, all of whom were people with T2DM. One group had a foot ulcer, the second group had retinopathy and the third group were experiencing no diabetes-related complications. Searle et al. (2008) concluded that if people have a better understanding of diabetes, this will lead to improved diabetes management. Searle et al.'s (2008) study also confirms the findings of Spikmans et al. (2003) that state people with diabetes who have little or no experience of the complications of the condition may not always feel that education and preventative interventions are relevant to them.

Ho, Berggren and Dahlborg-Lyckhage (2010) conducted a meta-synthesis of the research available on the topic of patient empowerment in relation to a health promotion model. The meta-synthesis included nine qualitative research studies that in total had 197 participants. The researchers identified four metaphors: a patient's trust in a nurse's competence; control; eagerness to share experiences; and a nurse's ability to personalise patient care. The researchers also concluded that diabetes management requires commitment to self-care on the part of the patient and on-going input from the multidisciplinary team.

Patient trust is very important. However, it can have good and bad outcomes depending on the level of competence of the nurse providing care (Bell & Duffy, 2009). There is always a risk involved in trusting someone; patients usually trust that nurses know what they are doing and will do what is in their best interest (Bell & Duffy, 2009). However, this is a two way thing and nurses can and do put their trust in their patients to make the right choices in relation to their health, but patients need to be fully equipped with all the necessary information to achieve this (Bell & Duffy, 2009). Hornsten, Lundman, Selstam, and Sanstrom (2005) found that patients' confidence in the care they receive could be affected by the knowledge of the health professionals involved in their care. If patients see the health professional is offering nothing new or of any use to them, they may see the interaction as pointless and it may act as a deterrent to participating in health-related activities.

Atak, Gurjan and Kose (2008) took a different perspective in their research to assess the effect of patient education on diabetes management and patient knowledge. They conducted a randomised single blind control trial with an intervention and control group. Eighty patients were split into the two groups and questionnaire responses, diabetes knowledge and self-management skills were assessed for both groups. The intervention group received health education and the control group normal care. The questionnaires and skills assessments were repeated two weeks after the intervention for both groups and it was found there was some improvement in the knowledge and behaviours of participants in the intervention group. These improvements included increased exercise activity, awareness of appropriate diet and taking action to ensure good glycaemic control to prevent complications.

Two international studies showed that in some cases people do know what they should be doing to manage their condition successfully, but make a conscious decision not to do what they know to be for the best for their health (Lawton et al., 2008; Oftedal, Karlsen, & Bru, 2010a). They both found that culture and/or religious beliefs can influence how successful a person is at self-managing diabetes, regardless of their level of knowledge. Another study found that people with previous experience of wounds and or neuropathy were shown to perform better standards of foot care; however it could be the case that these people know what the 'right' answers are (Johnston et al., 2006).

## **2.5 Self-care practices**

A fundamental part of diabetes management is self-care. While patients are having interactions with a variety of health professionals during the course of their condition, in most cases each patient is caring for themselves the majority of the time. To enable people to

successfully self-care they need to be equipped with the tools to do this. Jinadasa and Jeewantha (2011) conducted a descriptive cross-sectional study of patients with diabetic foot ulcers to find the level of knowledge regarding diabetic foot care. The researchers used an interviewer-administered questionnaire to gather data. The study found that although participants had satisfactory knowledge of diabetic foot ulcers, preventative self-care techniques were poor. Abu-Qamar and Wilson (2011) also looked at the patients' perspective of diabetic foot care in their qualitative study where they interviewed seven patients; all were diabetic with a foot burn injury. It is unclear why researchers required patients to have a foot burn injury over any other kind of wound. The study identified a lack of knowledge on the part of the health professionals involved in the care of the participants, and that patients felt that routine foot examinations were not necessary even though they were diabetic.

Lavery, Peters and Armstrong (2008) identified the need for diabetic foot care education to prevent ulceration as being very important and Roberts and Newton (2011) described education on diabetic foot care for patients as the most complex part of managing diabetic feet. There are many different ways of providing education to patients with diabetes who are living with the associated complications. These include one-to-one sessions, group sessions, informative literature (booklets/leaflets), and online resources. All have differing impacts and depend very much on the appropriate delivery method being selected for the target group. Interestingly, Lavery et al. (2008) point out that although health professionals may know the risks for their diabetic patients, they may not necessarily act upon this. Roberts and Newton (2011) state that community nurses are in a good position to build therapeutic relationships and provide education and information regarding diabetic foot care.

However, in practice this may not happen, with lack of time and knowledge possibly being factors affecting this. The current study interviewed patients of a community nursing service to find out if patients feel these interactions are occurring. Although the current study's focus is on patient understanding of their conditions, the interview questions include an enquiry asking how the participants feel about the information they receive from health professionals involved in their care.

Moriyama et al. (2009) conducted a randomised control study with two groups, one receiving a 12-month diabetes self-management education programme, while the others were given a textbook and some guidelines to follow. The intervention included fortnightly phone calls for support and monitoring of blood pressure, body weight, and abdominal circumference. The participants in the intervention group participating in the education programme were found to take more actions to prevent complications and carry out on-going monitoring activities such

as foot care and making sure they attended regular eye screening than the control group (Moriyama et al., 2009).

Overall, the study showed that self-management education programmes can and do work and although a twelve month programme might seem like a long time commitment and costly for already overstretched health services, who need to think of long term health and the cost saving benefits that can be achieved from planning such education (Moriyama et al., 2009). Atak et al. (2008, reflected Moriyama et al's. (2009) findings in their study to assess the effect of patient education on diabetes management and patient knowledge, finding there was some improvement in knowledge in the intervention group. Moriyama et al's. (2009) also suggested that future programmes for diabetic education might need to be developed to include telephone or internet-accessible education. As people's lives are becoming increasingly busy, it can be difficult to make time to attend education sessions. Atak et al. (2008) also state that patients' needs should be taken into account when developing education programmes.

Hibbard (2003) conducted a literature review on the effectiveness of patients' contribution to their care. The findings suggest that although joint decision making between patients and professionals is important, it needs to go further, to revolve around the patient and ensure that the patient and the health care providers have shared goals. In practice it may be that patients have a goal to be free from pain, but the nurse visiting for wound care might be more focused on the task of healing the wound. If nurse and patient communicate effectively with each other and work together, their joint goals may enable them to achieve better outcomes (Hibbard, 2003).

People's belief in their own ability to improve their health is important. If they do not believe they can make a difference they are less likely to participate in activities. Spikmans et al.'s (2003) study looked at diabetic patients' non-attendance at dietician appointments and concluded that patient education needs to focus on reinforcing the fact that people can contribute to their own health. New (2010) took this a step further by including the patients in the development of education strategies. New (2010) conducted a mixed methods quasi-experimental study with focus groups (qualitative) and used a diabetes knowledge test (quantitative). The focus groups helped to develop an education programme for diabetics and the knowledge tests were conducted pre and post the education programme. Interestingly, no significant change in knowledge was noted however, there was a noted improvement in self-care activities.

Although New's (2010), study used focus groups to create an education programme that is co-created by the researcher and patients, it might be difficult for the programme to achieve success with larger groups. People have such different learning styles, which mean it may be impossible to create one ideal education programme. It may be more appropriate to survey the diabetic population, asking about learning styles and preferences for education and create a variety of education programmes based on this, such as classes, interactive websites, or booklets. Further education for nurses would help them to act as a well-informed resource for their patients.

Johnston et al. (2006) conducted a study amongst the Veteran community in the United States of America, looking at the development and use of a questionnaire on diabetic foot care education. The study identified that the links between care and education received, its impact on diabetes self-management practices and the outcomes of diabetes-associated wounds needs more in-depth investigation. This confirms the findings of an older study by Norris, Engelgau and Narayan (2001) whose review noted that although interventions may be successful at improving the outcomes in the short term, the effect on long-term condition management needs further research. Norris et al. (2001) concluded that although didactic education led to patient knowledge being increased, clinical indicators (weight; HbA1c), showed little positive change and the study suggested that collaborative strategies led to better outcomes.

Based on the findings above, the research conducted for this thesis included interview questions aimed at finding what style of education delivery people preferred. The current study asked participants what information they had received from the health professionals involved in their care and followed on with questions such as what participants found useful and what could have been done better. This may serve to identify gaps in the knowledge of health professionals and identify areas that need improvement in the care and education delivered.

## **2.6 Ethnicity, culture and barriers to care**

Culture is how a group of people demonstrate shared beliefs, values and practices whereas ethnicity is associated with where people come from, their race and language, as well as their cultural beliefs (O'Toole, 2003). Cultural needs of patients should be accounted for when developing diabetes education. If a person's culture involves eating certain foods that may be thought of as unhealthy, incorporating suggestions for adaptations to make them healthier would be beneficial (Lawton et al., 2008). Oftedal et al. (2010b) state that patients should be

assisted in setting goals that are in keeping with their own belief system, should they be they cultural or religious.

Although the current study does not focus on ethnicity or culture, New Zealand is a country with a diverse population, predominantly of European origin, (67.6%). Maori represent 14.6% of the national population (Statistics New Zealand, 2006). With diabetes there is a clear increased risk to people of Maori and Pacific Island ethnicity (Ministry of Health [MOH], 2002). The diabetes risk over a person's lifetime is significantly higher in the Maori and Pacific Island population, at 25%, whereas Europeans have only a 10% risk. A later government report stated that in the 2006-2007 period, 10% of the Pacific Island population living in New Zealand were diagnosed with diabetes and of that group, 90% were Type 2 diabetics (MOH, 2008).

Bean, Cundy and Petrie (2007) conducted a study to assess the differences in perceptions, in terms of illness, in self-efficacy, self-care and metabolic control and retinopathy, between Europeans, South Asians and Pacific Islanders. This quantitative study of 86 Europeans, 86 South Asians and 87 Pacific Islanders used data from patient records and a questionnaire to gather data including a summary of diabetes self-care activities. Although this study was not about wounds, it discussed complications of diabetes and found that Pacific peoples in New Zealand, with diabetes, suffered more serious complications than the other ethnic groups.

Robinson et al. (2006) conducted a study looking at the primary diabetes care received by people of different ethnicities, with T2DM, living in Auckland, New Zealand. Maori and Pacific people were more likely to be at greater risk of complications of diabetes. The researchers concluded that whilst different ethnic groups were receiving similar levels of care, not all groups were achieving the same outcomes; different environment, culture and community may all have an impact of the outcomes experienced. Another New Zealand study found that by participating in annual reviews some ethnicity-related disparities were reduced. The researchers also found that by patients attending a diabetes programme, self-management and ethnic disparities may be improved (Agban, Elley, Kenealy, & Robinson, 2008).

Taloyan, Wajngot, Johansson, Tovi and Sundquist (2010) looked at the relationship between ethnicity (Assyrian/Syrian and Swedish) and poor self-related health in people with T2DM in Sweden. They also investigated whether this was still a problem when other factors such as age, gender, employment status, education level, and marital status were taken into account. This quantitative cross-sectional study included participants selected from a diabetes register, 354 in total, 173 Assyrian/Syrian born and 181 Swedish born. Data were collected with questionnaires and face-to-face interviews. The study found that the immigrant group had

lower levels of education and employment as well as higher levels of poor self-reported health than the native (Swedish) group. Although this study was conducted in Sweden, there are immigrant groups in New Zealand that it could relate to.

Jansà, Diaz, Franch, Vidal, and Gomis (2010) conducted a study to identify the profile of Moroccan immigrants (with T2DM) to Spain. The study aimed to use the profile to help in the provision of diabetes education programmes. This cross-sectional study had 40 participants and data were gathered in structured interviews that had closed questions. The researchers identified that language barriers and illiteracy were affecting the management of Moroccan immigrants to Spain with T2DM and suggested a need for tailored education for these populations. Oftedal et al. (2010a) stated that patients should be assisted in setting goals that are in keeping with their own beliefs system. This would suit the idea of tailored education suggested by Jansà et al. (2010). The cultural needs of patients' needs to be addressed more effectively in the planning and delivery of education and care.

Many of the diabetic patients receiving wound care from the community nurses in the area where participants were recruited from were also under the care of the podiatrists at the local diabetes clinic. Bergin, Brand, Colman and Campbell (2009) conducted a survey of community podiatry clinics in Australia to assess the capacity of, and access to, diabetic foot care services in the community. They found that only 39% of the podiatrists surveyed (total n=69) thought that resources for diabetic foot care were sufficient. Barriers to care included inadequate staffing and resources and, although services were available, these were not enough to provide effective care.

## **2.7 Summary of the literature**

This summary will use the literature to help identify and justify the intentions of the current study. The literature reviewed tends to be in agreement regarding the need for better care for people with diabetes to help improve outcomes (Babwah, 2011; Wang & Hazuda, 2011; Moriyama et al., 2009; Atak et al., 2008). Some research has been found investigating people with diabetes and a wound but there is little evidence of research on patients' understanding of their wound in relation to their diabetes. Jindasa and Jeewantha (2011) investigated participants' knowledge of diabetic foot care, and Abu-Qamar and Wilson's (2011) research focused on patients' experience of diabetic foot care in Jordan. Abu-Qamar and Wilson's (2011), study interviewed participants with T2DM and a foot burn injury. Overall, it identified a lack of knowledge on the part of the patient and the health professionals involved in their care.

The available literature covers many aspects of the care, education and experiences of the diabetic patient and although much of the available information can be applied to patients with T2DM who have a chronic wound, there is a lack of specific research focusing on being a diabetic person with a chronic wound.

It is known that quality of life can be affected by both diabetes and suffering a wound (Goodridge et al., 2005). This raises the question of how people verbalise this experience. The current study found that some people did not feel it makes a difference to them, while others had a lot to say on the issue.

Wellard et al. (2008) and Kielmann et al. (2010) both discuss how patients feel their knowledge is not taken into account by their health care providers. It may be that health professionals have insufficient time or are unaware of the need to enter dialogues that would enable them to discover this. At the opposite end of this spectrum, Matthews et al. (2009) identified that participants in their qualitative study felt health professionals were making assumptions about the knowledge they held, assuming they knew things they did not. Therefore it is important to identify pre-existing knowledge, as it may be the case that patients are misinformed or have not been given the information in the first place. Knowing what they know will enable nurses to plan appropriate care and education strategies. Asking what people understand about important aspects of their care will help achieve this. Related to this are patients' self-set goals regarding their health; health care professionals need to identify their patients' goals as this is an important part of working towards successful outcomes (Hornsten et al., 2005). It may be the case that the patient and health care provider have quite different priorities. The current study identified that the participants have goals different to those of the researcher as their pre-existing knowledge impacts on their thoughts on this issue.

Hallet et al.'s. (2000) study identified how important patients' knowledge and understanding is. While it is important to respect this knowledge, it is important to try and identify whether the knowledge held is correct, as misinformation may cause problems, especially if the health professional thinks the patient is aware of the facts and they are not. In contrast, Livingstone et al.'s (2011) study of diabetic amputees' experiences identified that health professionals with poor knowledge were of concern to the participants.

The level of general education people have received may affect the ability to process and use health-related information to their advantage (Tang et al., 2008). Health literacy needs to be taken into account when planning and delivering care and education as some patients may need more support than others. If patients have greater knowledge it will help them to

improve their health. However, lack of knowledge or experience of complications may be detrimental to people with diabetes. This links back to the discussion on misinformation.

Oftedal et al. (2010b) describe the need for individualised care. This is in keeping with the need for a holistic approach to nursing care. However, it is difficult to consistently deliver education that is individually created for each patient. It may be possible to identify multiple methods of education delivery that are preferred by the target population and design multiple formats for delivery of the same/similar information, such as booklets, websites and classes. On a one-to-one, basis education could be individualised to suit the needs of the patient. However, this can be limited by the knowledge level of the person delivering the education and may lack formal planning and evidence base.

Communication is important for successful outcomes but more time is needed to allow for more in-depth interaction (Babwah, 2011). Flood (2009) states that, in the community setting, nurses could have the time to have quality interactions with patients, although the lack of sufficient time may actually prevent such interactions. However, as previously discussed, district nurses may have more focus on the task they are completing (e.g. wound care) and not take a holistic approach. If this is the case it will prevent such in-depth interactions occurring (Haycock-Stuart et al., 2008).

It can be difficult to articulate how severe diabetes and its complications can be. It takes skill and knowledge to discuss this with patients (Roberts & Newton, 2011). If patients are not aware of the risks they face and the complications they experience worsen, it does not reflect good care. They should be made aware of the consequences of poor diabetes management; whilst this may be difficult it must be done (Roberts and Newton, 2011). It may be the case that nurses need more education to enable them to inform their patients of these risks in the most sensitive way possible.

Education is very important in enabling patients to successfully self-manage diabetes and work towards good outcomes in wound healing. It is clear that education can help improve management in diabetes care (Moriyama et al., 2009; Atak, Gurkan & Kose, 2008; New, 2010; Johnston et al., 2006; Norris et al., 2001). However, it has been identified that long term impact needs further investigation. The current study asked participants about education and information they had received from health professionals regarding their diabetes and wound healing.

There is much literature on various aspects of diabetes knowledge and care but studies on patient understanding of how their diabetes control may affect the progress of the

complications they are suffering, are not so evident. Therefore the basis of the following study was to identify participants' understanding of the link between their diabetes management and wound healing. It was anticipated that this would fill a gap in knowledge on this issue and lead to further discussion and research. To further enhance this study, issues that might affect patient knowledge of the perceived link between diabetes and wound, such as quality of life, education received and knowledge of preventative foot care practices, were all covered in the interview process as these are issues that have been raised from the literature review process.

This research intended to find out what people with T2DM and a chronic lower extremity wound know about their conditions, both their diabetes and their wound, and how one can affect the other. The study aimed to improve the understanding of patient experiences and help to inform future care and education strategies. The literature review has helped to refine the research question and the questions used in the interviews that gathered data for this study.

## Chapter Three

### Methodology and Methods

#### 3.1 Methodology and Methods

This study examines the experiences, pre-existing knowledge and understanding of people with T2DM and a chronic wound in relation to their conditions. It was also an intention of the study to establish what participants' self-care practices were as well as their understanding of why such practices might be beneficial to them.

This chapter will explain how the appropriate methodology was selected for this study and will discuss the methods used for data collection for this project. How participants were selected and recruited will be discussed in this chapter as will; the trustworthiness of the information gathered; the ethical considerations; confidentiality and security; and cultural considerations. The use of open-ended questions was chosen to allow people to say as much as they wanted to rather than being limited by closed questions with minimal options available for their response.

The study used a qualitative interpretive descriptive design. This methodology has been selected as the most appropriate as the aim was to gather information on peoples' thoughts and opinions and to explore patient perceptions and experiences of being a diabetic person with a chronic wound (Giacomini, 2010). The background to this choice will now be discussed.

#### 3.2 Qualitative methodology

A qualitative methodology was selected as the most appropriate. This decision was based on the understanding that rather than searching for objective truths (quantitative), the intention was to find meaning from participants as the outcome of the study (qualitative) (Whitehead, 2007). In terms of the current study, the ontological perspective looks into the nature of being a person with T2DM and a chronic lower extremity wound and how this affects the reality and existence of the participants. Ontology looks at the "nature of reality and existence" (Holloway & Wheeler, 2010, p21.). Saldaña (2011) states that epistemology is based on the world view or knowledge of the researcher. In this case, the researcher is aware of the growing number of people with T2DM and the complications these people encounter, and seeks to make improvements in this area. This study investigates what participants understand about their health in relation to specific conditions and interprets meaning from the findings. This is an interpretive approach to research (Whitehead, 2007).

### 3.2.1 Interpretive descriptive methodology

As previously discussed, an interpretive descriptive methodology has been chosen for this study. Qualitative approaches to research do not always meet all of the needs of health related nursing research (Thorne, Reimer Kirkham and MacDonald-Emes, 1997). The authors argue for:

“...interpretive description as one approach that can be applied to qualitative inquiry into human health and illness experience for the purpose of developing nursing knowledge” (Thorne et al.,1997, pp172-173.).

By interviewing participants about their experiences of having T2DM with a chronic wound the researcher intended to improve her own knowledge as a registered nurse as well as contribute to the practice of nursing as a whole. Further, Holloway and Wheeler (2010) state that the interpretive descriptive approach to qualitative research is based upon the way people make sense of their world and develop meaning from it. In terms of the current study, this would be seen as how the participants viewed their experiences of being people with diabetes and a chronic lower extremity wound, and to develop meaning would be to identify how wound healing can be affected by diabetes control or how both T2DM and the wound impact on quality of life.

Thorne, Reimer Kirkham, and O’Flynn-Magee (2004) state that with interpretive descriptive studies it is not expected that the researcher will set aside preconceptions. Rather, it assumes the researcher will have pre-existing knowledge of the phenomena being studied. This varies from the bracketing required in phenomenological research (Thorne et al., 2004; Polit & Beck, 2010). For the current study, the author declared her prior knowledge and thoughts on the research subject and identified a clear interest in the topic of the interaction between diabetes and wound healing (1.2, p11.). Giacomini (2010) states that interpretive descriptive research aims to inform practice within nursing; it is based upon a problem and looks at ways to improve knowledge and care delivery to reduce or eliminate the impact of the problem. Thorne et al. (2004, p13.) state “... interpretive description cannot yield “facts” but rather “constructed truths”. It is intended that this study will enable learning from the patient experience of being a Type 2 diabetic with a chronic wound and help develop nursing knowledge and practice to improve patient outcomes and care delivery, rather than generating hard facts.

### 3.3 Methods

The method is the way in which this study was conducted, how participants were selected and recruited and how data was gathered and analysed. As people who are living with T2DM and a wound have lived with the phenomenon and have a first-hand understanding of it they could be considered sources of expert knowledge on the subject, and as such those people are valuable resources for research such as this study (Morse, 1989b, cited in Thorne et al., 1997, p174.). This study aimed at gaining insight into whether or how the participants link their diabetes control to their wound and also how they feel both their diabetes and wound affect them, as well as what they understand of this experience which was most suited to a qualitative method of enquiry, (Carr, 1994). Foot care knowledge and practices of the participants were also recorded as part of this study to help identify what participants knew and show gaps in knowledge. It could be possible to gather such data with surveys with scales and tools to assess diabetes knowledge, but as more in-depth information is required, this study used semi-structured interviews to gather data (Polit & Beck, 2010). Semi-structured interviews were chosen to prevent too much irrelevant information being gathered, it was designed to keep the participants on track and talking about the issues relevant to the study.

Information gathered from the literature review was used to develop the questions that were used in the interviews (Appendix 1 p.131-132. shows an example of interview questions). Follow-on questions were constructed to gather more information if insufficient response was provided to the initial question. Follow-on questions were required in all the interviews to get more in-depth information from participants. A pilot interview was conducted with a nursing colleague experienced in working with diabetic patients with wounds and as a result of this some questions were rephrased to make them easier to understand. Following the pilot the structure of some questions was altered as they had resulted in confusion over what response to make as the wording was ambiguous. Restructuring these questions would hopefully make them easier for participants to understand and respond to appropriately.

Appointments were made with the participants for the interviews and the researcher went to the participants' homes to conduct the interviews. The researcher did not have easy access to suitable facilities to conduct interviews and it was felt it would be more convenient for the researcher to interview participants in their own homes. This option was accepted by all participants, who were happy for the researcher to visit them at home to discuss the research and conduct the interviews. The participants were given a Participant Information Sheet which also contained the consent form to read through before informed consent was sought (Appendix 2, p.133-138.). They then had the opportunity to ask any questions or decline to

participate. If they were satisfied with the information and wished to proceed, written consent was then gained prior to commencing the interview. The interviews were recorded with a digital recording device and notes were taken by the researcher conducting the interview. Ethical considerations will be addressed later in this chapter.

### 3.4 Participants

Purposive convenience sampling was used for the recruitment of participants for this study. Purposive sampling refers to seeking participants for their relation, suitability or fittingness with the purpose of the study therefore as the study looked at experiences of being a diabetic person with a wound, it was necessary to recruit appropriate people. (Whitehead & Annells, 2007). As the participants had to meet a set criterion (discussed in the next paragraph) and were all conveniently available through the district nursing service where the researcher worked, despite not being in the group of patients usually cared for by the researcher, they were both purposive and convenient (Polit & Beck, 2010; Burns & Grove, 2011).

The following table (Table 1.) outlines the details of the participants recruited for this study all names have been changed to help maintain confidentiality.

**Table 1. Participant information**

Pseudonym	Age	Gender	Ethnicity	Duration of diabetes	Duration of wound	Type of wound	Highest level of education
Albert	81	Male	English	+/-5 years	+/-6 months	Pressure area to heel	High school
Brian	63	Male	NZ/Euro	22 years	15 years	Charcot foot and leg ulcer	4 years high school
Carl	69	Male	NZ/Euro	+/-25 years	2 years	Non healing surgical wound to foot	Undergrad degree
Duncan	74	Male	NZ/Euro	+6 years	21 months	Pressure ulcer heel and toe	Trade certificate
Edward	82	Male	European	25 years	2 years 6	Skin tear	High School

					months	lower leg	
Fran	86	Female	NZ/Euro	+/-20 years	7 months	Diabetic foot ulcer/toe amputation	School certificate
Grace	69	Female	NZ/Euro	+10 years	5 years	Diabetic foot ulcer	Primary school
Henry	72	Male	NZ/Euro	+10 years	55 years (on and off)	Chronic leg ulcers and foot wound	High School
Isabel	64	Female	NZ/Euro	24 years.	3 months	Diabetic foot ulcer/forefoot amputation	School certificate

In New Zealand T2DM most commonly occurs in people over thirty years of age (DNZ, 2008) therefore this study recruited participants aged thirty years of age and over. In actuality all participants were much older than this, and were elderly, with ages ranging from 64 to 86 years old (see Table 1 above). As people with newly diagnosed diabetes are still adjusting to the changes to their health and lifestyle and will likely be receiving education on how to manage their condition, it was decided to include only participants who had been diagnosed with diabetes for a year or more (Clarke, 2009). Amongst the participants recruited, diabetes duration ranged from six years to about 25 years, although it is noted there is not necessarily a correlation between diabetes duration and wound duration (see Table 1 above).

All participants needed to have a chronic wound to meet the selection criterion. However, finding a specific definition of a chronic wound, and the duration of such, proved difficult. Stacey and Lazarus (2010) state there is no official definition of a chronic wound or the time frame that would lead to a wound being defined as chronic. The US Department of Health and Human Services website (n.d.) suggests that a wound of thirty or more days' duration could be classified as chronic, so for the purposes of this study all participants had to have had a wound for more than thirty days and in some cases they may have had wounds for many years (see Table 1 p.42-43).

The study included only participants who had a wound to the lower extremity; i.e., below the knee. This decision was made based on the information available surrounding non-traumatic

lower limb amputation in the diabetic population. Lower limb amputation is 15 times more likely to occur in people with diabetes than non-diabetics (DUK, 2010). Another reason for this choice is that people with diabetes are predisposed to getting lower limb wounds due to peripheral vascular and micro-vascular disease causing poor circulation and loss of sensation due to nerve damage, so people may not feel pressure on an area until it is too late and a wound has developed (Simms & Ennen, 2011).

Only English-speaking participants were recruited to this study as the researcher speaks only English and had insufficient funds to pay for translation services. If people who did not speak English were recruited it would have lengthened the research process as extra time would have been required to interpret the responses. The researcher was not aware of any potential participants meeting all the other criteria who did not speak English and it is not evident that the study was limited by not including non-English speaking participants. Therefore non English speaking people were not included in this study.

Only participants who were competent and able to make decisions for themselves were included in the study as this enabled them to give informed consent to participate (Polit & Beck, 2010).

### **3.5 Recruitment**

Participants were recruited by disseminating information about the research and sample requirements to the nurses working in the community. It was expected the nurses would then refer participants back to the researcher who would then make contact with the potential participants to discuss the research and arrange an appointment for consent and interview to occur. Initially, the coordinators for each District Nursing team were contacted and advised of the research and the requirements regarding participants. They were each given a copy of the flyer (Appendix 3 p.139) and copies of the Participant Information Sheet (Appendix 2, p.133-138). It was requested that coordinators discuss the research with their teams and refer any of their patients deemed suitable. Posters were also put up on the notice boards in the District Nursing office with a plastic wallet attached, containing the information sheet (Appendices 3 and 2 respectively). There was no response to this from the coordinators despite a reminder text message sent out by the researcher therefore flyers (Appendix 3) were distributed throughout the District Nursing offices and in each nurse's mail tray. Text messages were also sent to all nurses working in the community, advising them of the research and what to do if they had a potential participant. This second effort led to the recruitment of just three participants.

Relocation of staff, and the Christmas holidays, appeared to impact on recruitment as did problems with how nurses interpreted the selection criteria for participants. For reasons unclear to the researcher, some nurses believed that only people on insulin were required and one nurse stated she thought participants had to be thirty years of age. The initial flyer stated that participants needed to be 30+, so to remove this confusion a new flyer was created to make all points clearer (Appendix 4 p.140). This flyer was also put in the mail tray of all District Nurses and a follow up text message was sent to all to notify them of this and remind them about the research.

After a further month, only two more participants were recruited from this effort so a final text message was sent out to all District Nurses, reminding them that participants were still required. The researcher also spoke to as many nurses as possible about the research, to raise awareness of the requirements for participants. Interestingly, nurses who had initially said they did not know of any potential participants came forward with participants this time. As all participants had been experiencing their wounds for at least three months it would suggest they were all known to the District Nursing service for the duration of the recruitment effort. Four possible reasons for failure to refer these participants earlier in the recruitment phase were identified. Continuity of care was an issue. The District Nursing service changed about three years ago to prevent the development of unhealthy relationships/dependence on one nurse, so patients are often seen by a variety of nurses, which may have resulted in nurses forgetting which wound care patients were diabetics or not seeing patients until the latest recruitment effort. Another possible reason for failure was a lack of holistic care, where nurses were not looking at the patient as a whole. It may have been that nurses were focused on the task at hand (wound care) and did not realise that the patients they were visiting for wound care were also people with diabetes (Ghanbari et al., 2005). Other possible causes for failure to refer may have been that the nurses lacked the time to discuss the research with their patients or a lack of knowledge about research prevented them from helping with recruitment (Rizzuto, Bostrom, Suter, & Chenitz, 1994; Roxburgh, 2005).

Nine participants were recruited with the assistance of a small group of nurses. It was noted that no participants had been given the information sheet with attached consent form (Appendix 2, p.133-138) prior to being interviewed, despite the researcher making these available to all nurses. This may have been due to the nurses lacking knowledge of research process or lacking time to obtain and give potential participants the information sheet (Rizzuto et al., 1994; Roxburgh, 2005). The research Participant Information Sheet was thoroughly explained and each participant was given sufficient time to read the form. When the

researcher arrived at participants' homes, participants were given the opportunity to delay the interview to another day if they wanted to have a support person available. No participants opted to do this.

### **3.6 Trustworthiness and transferability.**

The nature of qualitative research means that there is a variability associated with being human; therefore research of this type cannot be seen as suitable for generalisation to other settings (Holloway & Wheeler, 2010). However, it is not an intention that this study be generalised.

It is necessary to take measures to ensure there is transparency in the process of how the research was formulated and conducted to ensure it is clearly documented. The nature of an interpretive descriptive methodology assumes that the researcher will have pre-existing knowledge of the issue being studied (Thorne et al., 2004). This has been disclosed in Chapter One (1.2, p11).

The initial research proposal was presented to a group of peers and academics and verbal feedback was received which helped with the development of the formal research proposal which was then submitted to an academic panel. The proposal included discussion of the chosen methodology, methods of recruitment, data collection and analysis. The proposal was reviewed and a letter was received by the researcher, stating the study met the requirements and could proceed (Appendix 9 p.145). Burns and Grove (2011) state the researcher must include adequate information in the report to enable a critical review of the study. It is intended that the analysis and discussion of the information gathered will provide the information required to allow the reader to achieve this. Krefting (1991) suggests that the researcher needs to give sufficient information on the basis of the research and details/demographics of the participants to enable the reader to transfer information to other settings. However, transferability is not an aim of qualitative interpretive descriptive research, rather it is intended it will improve nursing practice and generate constructed truths relevant only to the specific group being studied (Giacomini, 2010; Thorne et al., 2004). In the case of this study, the findings are relevant/applicable to people who have had T2DM for a year or more, a chronic wound to the lower limb for a month or more, are older adults (Table 1 p.42-43), and have access to health services comparable to the usual quality available in New Zealand.

Respondent validation was offered to all participants with them all having the option to have their interview transcript sent to them within the week, post-interview, for them to review.

This was to allow them to read it to ensure the information gathered had been recorded as they had intended (Mays & Pope, 2000). Three participants opted to review their transcripts. All were contacted by telephone after they had had a week to read through the transcript, to give them time to digest the information. All three participants who opted to check their transcripts gave verbal consent over the phone for their transcripts to be used in the analysis process. This process also acted as a way of establishing the trustworthiness, as it ensured the credibility and fittingness of the information gathered by confirming the information was true to the participants' experience (Annells & Whitehead, 2007).

The data trail or audit trail has been maintained as the researcher has retained the transcripts and note books containing the analysis process. Mind maps and tables were also created using quotes from the interviews. These were clustered into groups related to particular themes and illustrate how the themes arose from the data (Figure 3. p.55; Figure 4. p.57; Figure 5 p.60; Figure 6 p.64; Table 2 p.73; Table 3 p.74; Table 4, p.78). Rather than just saying what has been found, the findings have been illustrated with the data throughout the analysis process shown in chapter four.

### **3.7 Ethical considerations**

All research has ethical implications and because of this all efforts must be taken to minimise the potential for unintended harm(s) (Orb, Eisenhauer & Wynaden, 2001). There are many principles that have to be observed in order for research to be conducted in an ethical manner. These include honesty, objectivity, integrity, carefulness, openness, confidentiality, social responsibility and not to discriminate (Holzemer, 2010). The researcher has ensured that all these principles were followed in the planning and conducting of this research.

Honesty, objectivity and openness have been addressed by disclosing the pre-existing knowledge of the researcher (1.2, p11), and clearly laying out what is expected from people participating in the study (Appendix 2, p133-138). These principles also apply to the gaining of informed consent which protects the participants' rights to self-determination; all participants were given the Participant Information Sheet to read through and the opportunity to ask any questions prior to consenting to their interview (Polit & Beck, 2010). The integrity of the researcher has been ensured by avoiding conflicts of interest by not recruiting patients from their regular area of work; this is discussed further in 3.7.1. Carefulness and social responsibility have been addressed by identifying that in conducting a study such as this, there is a particular potential for upset to occur due to participants responses to questions provoking thoughts that may lead to upset. Russell (1999) suggested that if issues are unresolved in the

interview process, the participants may solicit further contact. To deal with this it was decided to refer the participant to contact their GP, District Nurse, their usual care provider or the supervisor of the research project, for further advice, information and/or support if needed.

It is important not to discriminate against people because of their religion, ethnicity or disability. This study was open to participants of any religion, and ethnicity or having a disability did not prohibit people from participating, however they did have to be capable and able to make decisions for themselves. As this study has been conducted in New Zealand and there are health disparities evident for the Maori population, this has been discussed in more detail in 3.7.4. The principles of the Treaty of Waitangi will also be included in this discussion (MOH, 2002).

Ethics applications were submitted to the District Nursing service and The Eastern Institute of Technology research ethics committees for approval, which was gained from both without problem (Appendices 5 p.141 and 6 p.142). The Health and Disability Ethics Committee (HDEC) had a new online form which was completed and through this process it was identified that this study did not need HDEC approval. To confirm no HDEC approval was required, enquiries were made with the HDEC and a letter (Appendix 7, p.143) was received advising no approval was required. A telephone conversation with the HDEC office identified that this was due to the study not involving an intervention and the perceived risk to people participating being low.

### **3.7.1 Conflicts of interest**

The researcher is employed by the District Nursing service where the participants were recruited from the patient roll. To reduce the risk of a conflict of interest no participants were recruited from the researcher's regular area of work. This was intended to prevent patients feeling pressured to participate and also to reduce the risk of the data gathered being affected by participants receiving care from a person knowledgeable of the link between diabetes and chronic wounds. This demonstrates openness, carefulness and social responsibility on the part of the researcher (Holzemer, 2010; Orb et al., 2001).

### **3.7.2 Confidentiality**

To maintain confidentiality of the information gathered, participants' information (Consent form, interview transcript and notes) were assigned a code. This information is accessible only to the researcher and all transcripts and notes will be de-identified (Burns & Grove, 2011). The books containing analysis notes relating to the data and the digital recordings of the interviews

do not contain any identifying details and the participants' real names are not mentioned in the recordings. The consent forms will be stored separately from the rest of the data. They, along with the interview transcripts/notes and recordings, will be stored in locked security boxes for ten years when they will then be securely destroyed.

### **3.7.3 Security**

To maintain the safety of the researcher, a mobile phone was taken into each interview and a nursing colleague notified of each planned visit. The District Nursing service completes a risk assessment on admission of all home-based clients to the service and only clients with no identified risks were visited.

### **3.7.4 Maori considerations and consultation**

The Maori population has an increased risk of ill health compared with the non-Maori population. In 2002, the Ministry of Health found that the Maori and Pacific Island populations had a 25% risk of developing diabetes over their lifetime, compared to just 10% risk in the European population (MOH, 2002).

This research worked within the principles of the Treaty of Waitangi, Partnership, Protection and Participation (Kingi, 2007). The researcher worked in partnership with the participants to ensure they were fully informed prior to participating in the research and to ensure they were comfortable during the interview process. The participants in this study had their rights protected by being given all the information available to help them make an informed decision to participate. The study was open to participants of any ethnicity.

The statistics from the district nursing service for the year April 2011 to April 2012 (see figure.1 p.50) showed that Maori represented less than 4% (2.74% to 3.67%) of the total patient roll with Europeans representing 76.04% to 81.48% (A. Finlay, personal communication, June 19, 2012). Looking at the Canterbury and national population diversity statistics, Canterbury had 77.4% European population compared to the national average of 67.6%, (Statistics New Zealand, 2006). In contrast, the Maori population for Canterbury was 7.2% with the national average being 14.6% which is more than double the Canterbury average (Statistics New Zealand, 2006). Due to the population statistics it was not surprising that only European participants were recruited to the study.

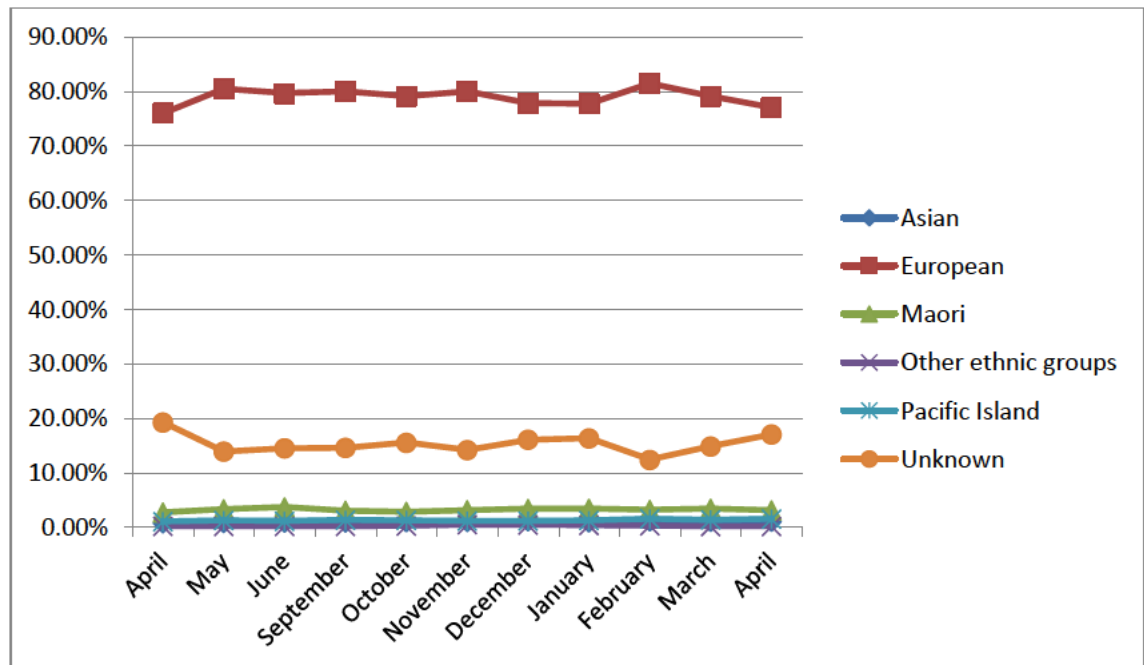


Figure 1. Ethnicity data from Nurse Maude Association April 2011 to April 2012. (Information by courtesy of A.Finlay, personal communication, June 19, 2012.

The researcher liaised with the Maori cultural advisor at the District Nursing service to discuss the research, who offered to provide support and assistance as required with any cultural issues that may have arisen in the process of this research, which they did not (Appendix 8 p.144).

### 3.8 Analysis

Interpretive descriptive studies should identify themes, consistencies and inconsistencies occurring within the data gathered and through analysis see what themes develop from the information, (Thorne et al., 2004). Thematic analysis was used to analyse the information gathered from the interview process. Analysis started immediately the researcher began gathering the data. The audio recording was listened to as soon as the researcher got home from conducting the interview. Saldaña, (2011) suggests this enables anything missed during the interview to be captured while it is still fresh in the mind of the researcher. The interview transcripts were typed up by the researcher, allowing the researcher to become more familiar with the content and meaning of the information gathered. As the researcher was new to this process, typing was done verbatim to prevent changes resulting in information being lost.

The process of thematic analysis requires the development of codes or themes from within the interview transcripts (Boyatzis, 1998). Thorne et al. (2004) state that intellectual inquiry is key to interpretation of the data gathered in descriptive interpretive studies. This involves asking questions on the day; e.g., why is this phenomenon occurring? To achieve this, interview

transcripts and notes were read many times to develop a sense of meaning from the information contained within them (Annells & Whitehead, 2007; Burnard, Gill, Stewart, Treasure, & Chadwick, 2008).

Chapter Four will present the analysis of the information gathered for this study.

## Chapter Four

### Analysis and interpretation of the interview data

This chapter presents the information gathered from the nine participants who consented to be interviewed about living with T2DM and a chronic wound. The participants were all interviewed by the writer in their own home, using the interview question guide. The information has been analysed using thematic analysis and five themes have been identified: *'Letting someone else deal with it'*; *'Ownership'*; *'Not making the link'*; *'Coping with it'*; and *'Self-care practices'*. Each theme is presented in a figure to illustrate how the theme was developed from the participants' responses.

*'Letting someone else deal with it'*, was identified as a key theme of this study. Many participants' responses suggested they were leaving tasks relating to their health (diabetic foot care; diabetes management; wound care), to other people, namely the health professionals involved in their care. A sub-theme of *'Ownership'* also became apparent as some participants were trying to take ownership or responsibility for their own health in some ways, such as practising aspects of diabetic foot care. *'Not making the link'* was identified as a theme and this is vital to answering the research question as many participants did not have an understanding of how their diabetes could impact on their wound healing. *'Coping with it'* was identified as a theme emerging from the questioning relating to quality of life. Participants' responses to questions about QOL and impact of being a diabetic person with a chronic wound suggested that this was something they had to deal with or cope with. Further data regarding foot care practices and educational needs of people with diabetes and a chronic wound was gathered during the interview process and was combined into a theme of *'Self-care practices'* which illustrated how the participants exemplified their knowledge.

All participants are referred to by their pseudonym to maintain confidentiality and anonymity. Direct quotes from the interviews are in italics to help differentiate them from the rest of the text. In some cases quotes were altered to protect anonymity such as when participants mentioned an individual's name or an organisation. Where information was removed, an ellipsis represent this, and changes to names or information are shown within parentheses [ ]. In some cases, additional information was required to enable full understanding of the statement and is presented within brackets ( ). Direct quotes from the interview will be accompanied by numbers such as 7.24 this is to identify what interview and what line of the interview this would be interview 7 line 24, this is to aid the researcher with locating information.

#### **4.1 The participants and demographic data**

Recruitment was dependent on referral from the nursing team. After four months, nine participants had been recruited and an additional potential participant was referred. However, when the researcher arrived to gain consent it was found the participant did not meet the criteria as she had a wound on her head and not to a lower limb. All participants gave informed consent and were interviewed during the same visit. Three participants chose to read through their transcript to check that it had been recorded as they had intended. All three were sent a copy of their transcript to read and telephone contact was made within one week to verify that they consented for their information to be used in the research; all three consented to proceed.

Wound duration varied from three months to 55 years (see Table 1, p.42-43). Some participants were unsure of specific time frames since their wound developed and diabetes was diagnosed. In those cases, +/- or + have been used in the table to show the approximate duration based on what the participants said in the interviews (see Table 1, p.42-43). It may be the case for these participants that the problem had become such a part of their daily life they could no longer recall how long it had been affecting them. All of the participants were of European origin, with seven stating they were New Zealand European. One was English and another described himself as European. This was the expected ethnicity due to the demographics of patients of the District Nursing service (see Figure 1. p.50). Also, regional ethnicity statistics suggest the same thing with about 1,100 Maori, 700 Pacific Island, 300 Indian and 17,400 Europeans with diabetes living in the Canterbury DHB area. Therefore, as expected, Europeans were overrepresented in this study (DNZ, n.d.b.)

#### **4.2 The analysis process**

Figure 2 below has been developed as part of this study to show the process undertaken to analyse the data gathered for themes and meaning. It is based upon thematic analysis literature from a variety of sources (Annells & Whitehead, 2007; Boyatzis, 1998; Burnard et al., 2008; Saldaña, 2011).

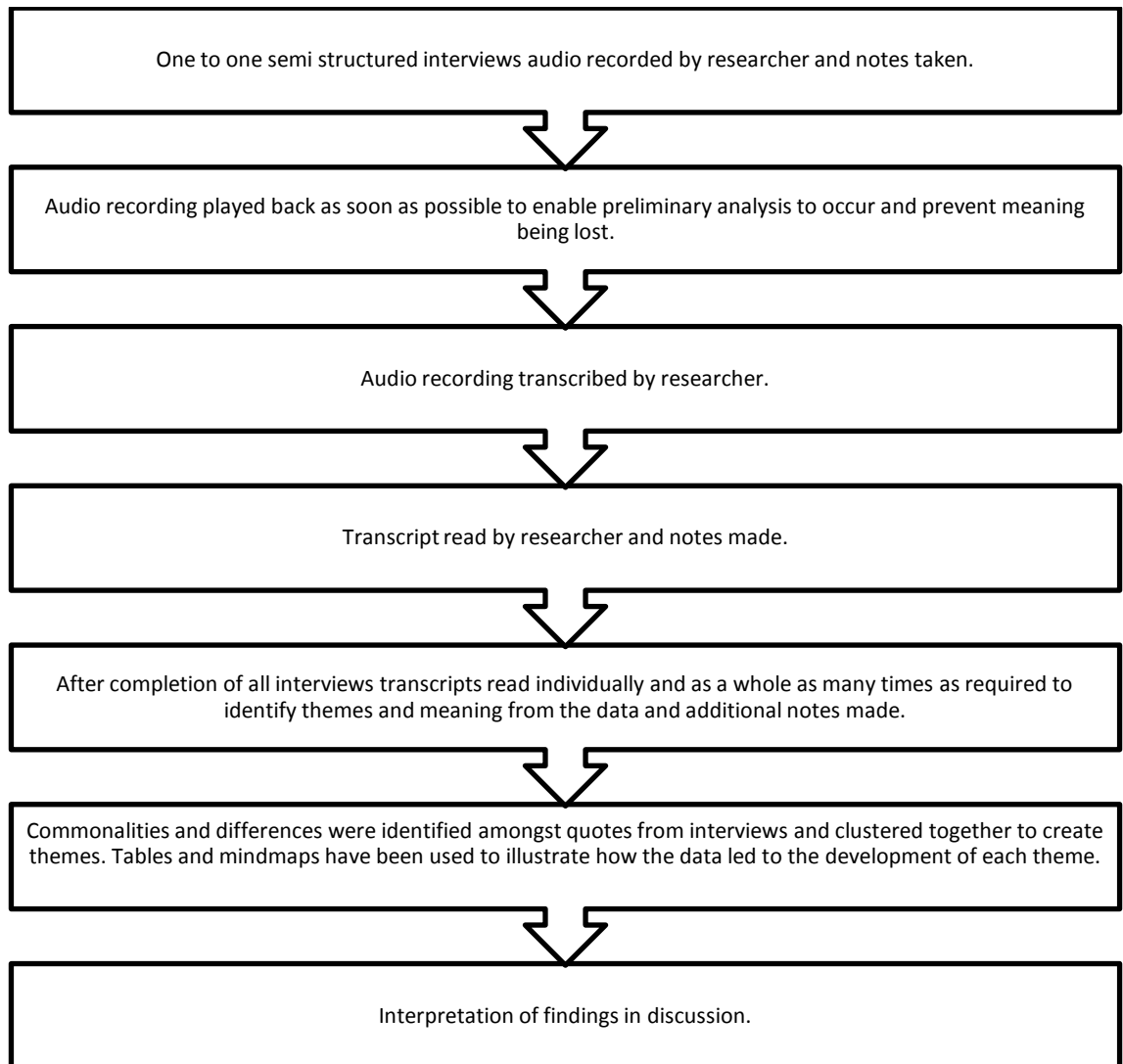


Figure 2. Thematic analysis flow chart

### 4.3 Letting someone else deal with it and ownership

These two themes have been placed together within the analysis as they are direct opposites. However, further reading of the participants' interview responses suggested that although some people may be trying to take ownership for their own health, they may still be letting someone else deal with their health problems. It appears that in some cases the participants' responses intertwined the themes of *'Letting someone else deal with it'* and *'Ownership'* and it wasn't as simple as some participants doing one and some doing the other. The DHB providing health services for the region where this study was conducted has been working towards a strategic goal of enabling people to take an increased responsibility for their own health (CDHB, 2011). However, the information gathered from interviewing the participants suggests that although some participants are taking initiative or understand what their responsibilities are, in many cases people are not taking responsibility for their own health. Figure 3 (p.55) and Figure 4 (p.57) illustrate the two themes of *'Ownership'* and *'Letting someone else deal with it'*.

Duncan made a clear statement taking responsibility for his own health, when foot care was being discussed in his interview:

*Oh well, I have to take responsibility for that and I have booked myself into a podiatrist who I see about once a month.* (Duncan, 4.65-4.66).

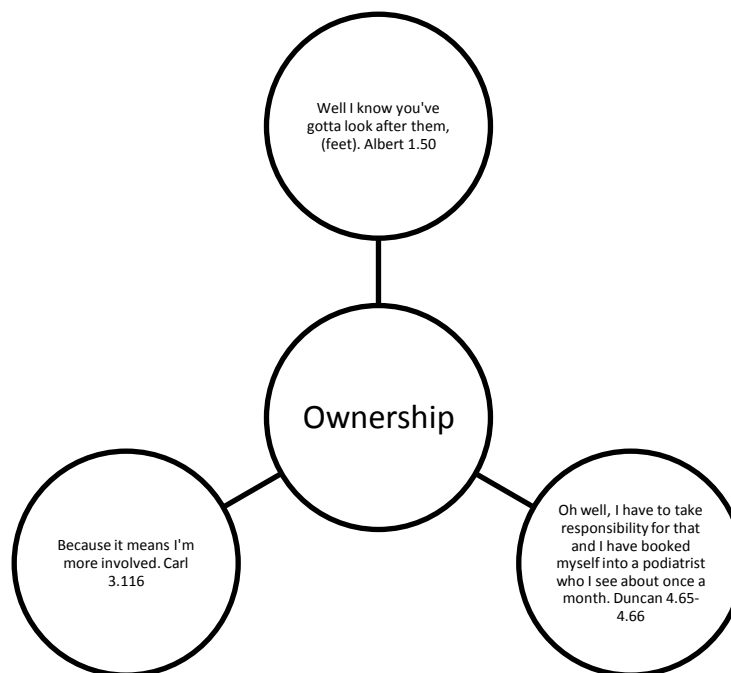


Figure 3. Ownership

However, although he was making the appointment and attending, he was not physically doing anything to care for his feet himself and was actually leaving the task of his diabetic foot care to someone else. Therefore, although he was trying to take ownership or responsibility for his own health by taking these actions, he may have misinterpreted the meaning of this, as the only responsibility he was taking was to make an appointment and he wasn't taking any responsibility for foot care between podiatrist visits.

When discussing education preferences Carl suggested he preferred websites and one-to-one sessions as this allowed him the involvement in discussions and the ability to find information for himself. However, with websites it is often the case that we find the information we want rather than what may actually be beneficial or correct, or we find information without anyone to ask about its meaning if we are unsure, (Sillence, Briggs, Harris & Fishwick, 2007). Although Carl appeared to want to be more involved in his own health, when asked about foot care he stated:

*I regularly go to the diabetes clinic. (Carl, 3.37.3.38).*

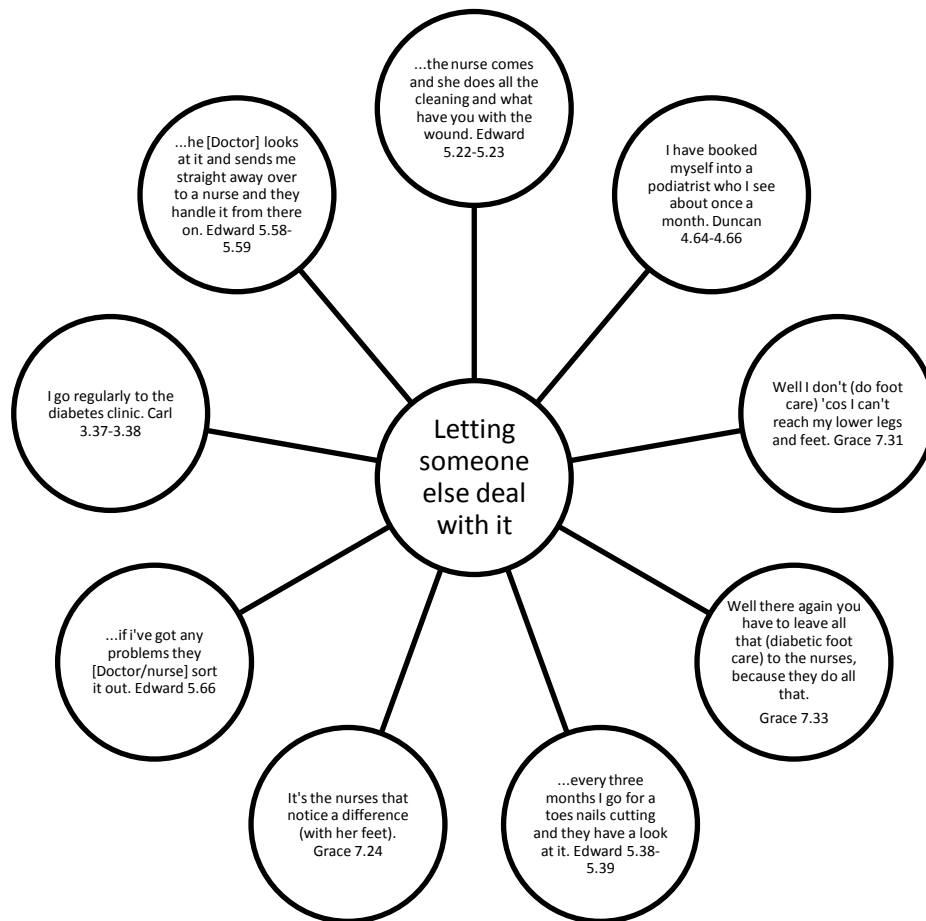
This again, like Duncan, suggested that diabetic foot care is the responsibility of someone other than the participant, although Carl did later go on to discuss other foot care activities he did, so he was taking ownership of the care of his feet. Interestingly, Albert realised that he should have been doing something regarding diabetic foot care, stating:

*Well I know you've gotta look after them, that's about it. (Albert, 1.50).*

However, when asked what he did to care for his lower legs and feet he stated:

*Nothing special, no. (Albert, 1.48).*

This suggests that although people may want to take responsibility for their own health, they are not actually doing the activities that will help them in achieving this. Furthermore, many participants are placing responsibility on others involved in their care. In many cases there was an expectation placed on the nurse providing care to the patient to look after participants' feet and wounds.



**Figure 4. Letting someone else deal with it.**

When asked about things he did that might make his wound better, Edward responded with:

*...the nurse comes and she does all the cleaning and what have you with the wound.*  
(Edward, 5.22-5.23).

Like Carl and Duncan, Edward visits the podiatrist and when asked about what he did to care for his feet and lower legs he stated:

*Yeah, I get it, every three months I go for a toes nails cutting and they have a look at it.*  
(Edward, 5.38-5.39).

This implied that he was not doing any foot care activities between these visits to the podiatrist and didn't see it as his role to do any activity to protect the health of his feet. When asked about the education and information he had received from the doctors and nurses involved in his care, Edward discussed how sometimes he went to the doctor with a problem such as a new wound and made the following statement, suggesting he allowed others to take control over his health:

*...he (doctor) looks at it and sends me straight away over to a nurse, and they handle it from there on. (Edward, 5.58-5.59).*

Edward added to this sentiment. When he was asked what he would like to know about his diabetes management and wound healing, he stated:

*No, not really (he does not think he needs to know more) because I think I'm in good hands with the [district nursing service] when they come and the doctor he knows and the diabetes (nurse) she knows so if I've got any problems they sort it out. (Edward, 5.64-5.66).*

This suggested that Edward was quite happy to leave his diabetes management to others as he trusted them to do what is best for him. Edward was one of the older participants at the age of 82, so perhaps his age and previous experiences of being looked after by health professionals have led to him allowing others to be responsible for his health as that is what he has come to expect. This will be discussed further in Chapter Five.

Grace was not just allowing others to take control of her health; she expected that they would and did not take any responsibility for tasks such as foot care. When asked if there were any actions she did relating to her diabetes, that made a difference to her wound, she stated:

*It's the nurses that notice the difference...(Grace, 7.24)*

Grace continued to discuss the usual care of her feet and lower legs and placed an emphasis on the nurses as being responsible for her care.

*Well I don't (do any usual care) the nurses do, 'cos I can't reach my lower legs and feet. (Grace, 7.31).*

Grace did not seem to feel she needed to have an understanding of diabetic foot care and again placed this responsibility on the nurses providing her care.

*Well there again you have to leave all that to the nurses, because they do all that. (Grace, 7.33).*

This may suggest that there was no expectation placed upon Grace that she should be taking responsibility for her diabetes management and foot care by the health professionals providing care to her.

The analysis in this section suggests that although some people do take responsibility for themselves, within the theme of 'ownership' in many cases the participants are letting other

people deal with their problems which lead to the development of the theme of *'letting someone else deal with it'*. However, as discussed within the analysis, it may be the case that they are *'letting someone else deal with it'* because that is the way it has always been and they are not aware that it should or could be different to this.

#### **4.4 Not making the link**

During the interview the participants were asked how they felt their diabetes control affected their wound, with additional prompts of *'is there anything you do that makes it better?'* and *'is there anything you do that makes it worse?'* Analysing this information has led to the development of the theme *'not making the link'* this has been illustrated in Figure 5 below.

Albert did not feel there was a link between his diabetes control and wound, stating:

*No, I don't think so. (Albert, 1.33).*

This was a common response with other participants stating:

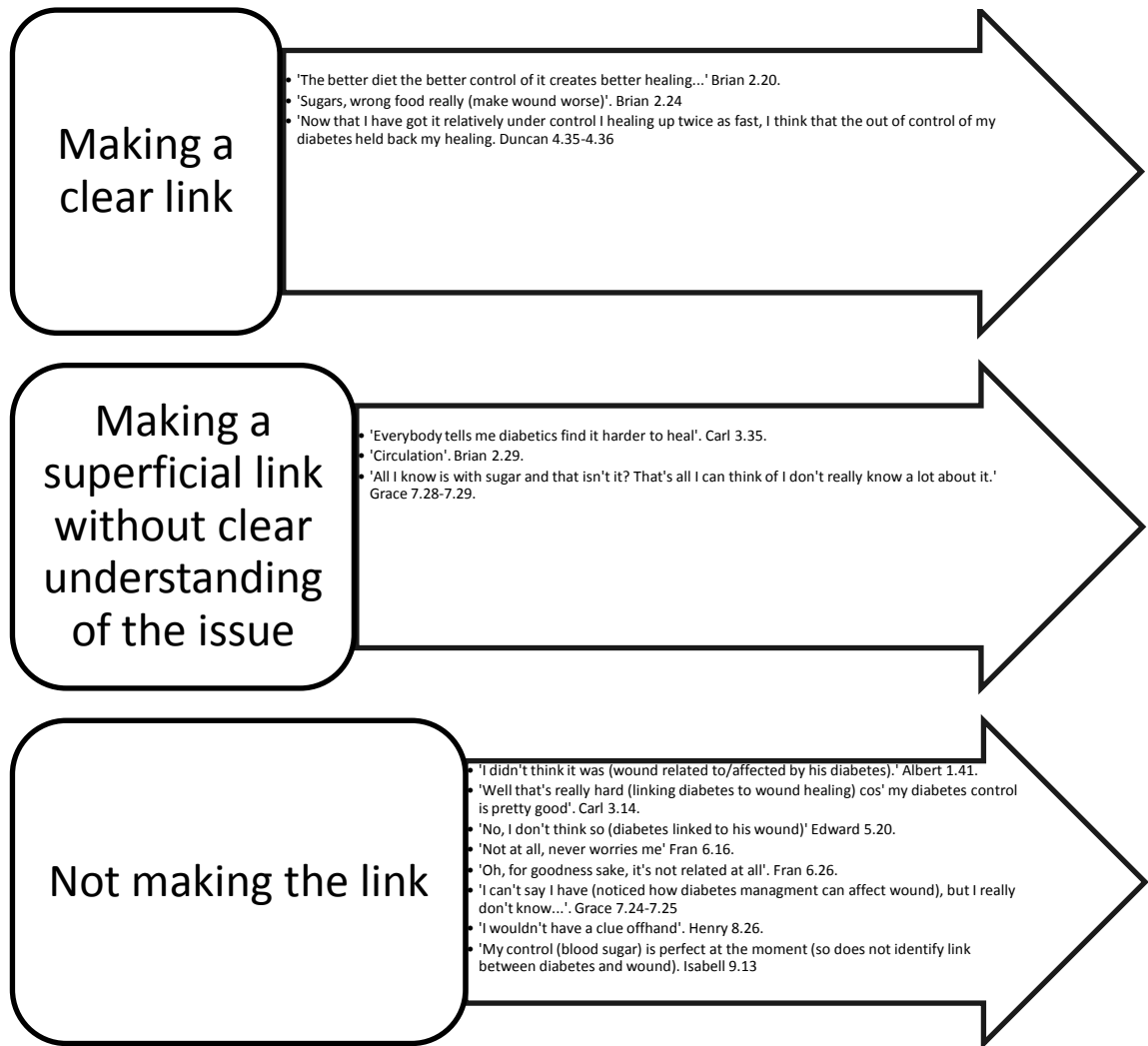
*No I don't think so. (Edward, 5.20).*

*Not at all never worries me. (Fran, 6.16).*

*No not anymore. (Grace, 7.17).*

*I wouldn't have a clue off hand. (Henry, 8.26).*

All these participants either could not see how their diabetes could impact on the healing of their wound or they did not realise that this could be a problem. Interestingly, of all these participants only Grace wanted to know more about diabetes and wound healing with other participants either not interested in knowing more, not feeling they needed to know anything more or because they felt too old for education. Figure 5 shows the statements participants made regarding their understanding of how their T2DM and wound may be linked, showing two participants (Brian and Duncan) were making a clear link, it shows how some participants were making a superficial link without clear understanding of the issue and how others were not making a link at all.



**Figure 5. Not making the link**

Fran did not feel that anything she did would make her wound better or worse and advised that she didn't allow it to bother her.

*I don't let it get to me. (Fran, 6.18).*

Fran identified that her wound originated from a 'corn' which could also be termed calloused skin. This is a known contributing factor in the development of diabetic foot ulcers but Fran appeared unaware of this connection (Sumpio, 2012).

Carl, Edward, Fran, Grace, Henry and Isabel all indicated that they did not know of anything they did with their diabetes management that made their wounds better or worse. This may be because they did not understand how one could affect the other and therefore did not realise that increased wound pain, infection or other wound complications were occurring in response to elevated blood glucose levels and may have dismissed such problems as normal body responses not related to their diabetes. They had all been experiencing their wounds for

at least three months, so they were all experiencing delayed healing which could be considered a wound complication.

Carl found it hard to relate his diabetes control to his wound as he felt that he had good control of his condition.

*Well that's really hard 'cos my diabetes control is pretty good, (So can't see how his diabetes control may affect his wound). (Carl, 3.14).*

Due to this he was unable to see how his diabetes management may have made his wound better or worse.

*Not that I am aware of, 'cos I wouldn't be doing it if I knew. (Carl, 3.32).*

Carl had been in hospital a few times in the months preceding his interview and increased interventions and clinical contact with health professionals may have promoted the good glycaemic control he talked about. However, it might have been the case that before this his control may not have been optimal, contributing to his wound complications and delayed healing.

Isabel also felt her diabetes control was good and couldn't identify how it could be related to her wound healing. It was difficult to get in-depth information from this participant and whilst she gave informed consent to participate and be interviewed, she appeared keen for the interview to be over as soon as possible. It was noted that Isabel's wound was the result of a forefoot amputation and it still had not healed three months post-surgery.

Two participants did show a clear understanding of how their diabetes control could affect the healing of their wounds. Both Brian and Duncan identified that good glycaemic control could help to improve wound healing.

*The better diet, the better control of it..., creates better healing..., balanced diet. (Brian, 2.20).*

Brian also identified that exercise helped to improve his diabetes control as well as a good diet; he continued to discuss this and stated:

*Sugars, wrong food really, (make things worse). (Brian, 2.24).*

Duncan had the best understanding of all the participants; he made a clear link between his diabetes management and wound, healing stating:

*Now that I have got it (diabetes) relatively under control, um, I'm healing up twice as fast, I think that the out of control of my diabetes held back my healing and I've um, I've been on better diabetic control since..., they put my Glargine (insulin) up..., and they have given me this (opens up sheet with diabetes regime information on it).*  
(Duncan, 4.36-4.39).

An additional question was used in the interview to help identify whether the participants understood how their diabetes and wound healing may be related. On reflection, the question could have been phrased better. The question was: What is your understanding of how your wound may be related to your diabetes? Following analysis of the data gathered from the interviews, it may have been appropriate to ask: What is your understanding of how your wound healing may be related to your diabetes?

Most of the participants did not have any understanding of how their diabetes may have affected or even contributed to the development of their wound. Brian just stated one word when asked this question: circulation. Whereas this is a factor that can impede the healing of wounds in people with diabetes, Brian's response showed a limited understanding. Grace discussed sugar but didn't really show any understanding of how her diabetes and wound were related.

*All I know is with sugar and that, isn't it? That's all I can think of, I don't really know a lot about it.* (Grace, 7.28-7.29).

This is common knowledge and showed that Grace's knowledge was poor. However, she also identified that her knowledge was limited when it came to diabetes.

Isabel mentioned circulation; however she did not elaborate on this and the interviewer was unable to get any more information from her.

*My understanding is good because it is to do with your blood flow to the foot.* (Isabel, 9.26).

As it was not possible to get more information from Isabel on this subject it was difficult to identify her level of understanding, and although she stated her understanding was good, this may not have been the case.

From the analysis of the data from this section, the theme '*Not making the link*' was identified as many of the participants did not make the connection between their diabetes (glycaemic control) and its relationship to their wound in terms of how it developed and its potential to

heal. It may be the case that health professionals such as the District Nurses involved in their care are also not making the link between diabetes and the wound. However, as this was not discussed in the interviews there is no data to analyse on this subject. Only two participants showed a clearly developed understanding of the link. Duncan discussed how his healing improved once his diabetes was well controlled and Brian identified that diet made a difference to his healing. Some participants showed a superficial understanding of circulation being a factor linking diabetes and wounds but their inability to elaborate on this suggested they may have not clearly understood the connection.

#### **4.5 Coping with it**

Participants were asked two questions to help identify how being a diabetic person with a wound impacted on their life. Both questions were designed to get an insight into their experience, one asking:

How do you feel your wound and diabetes affect your quality of life?

The second question focuses more on their feeling towards their wound:

You've had this wound for over a month now, how do you feel about that?

It was quite evident that the impact of the experience varied, with some people not being affected at all and others experiencing distress. In some cases the effect on quality of life and how the participant felt about having a wound for so long did not correlate. The statements made by participants suggesting they were coping with their T2DM and chronic wound have been illustrated in figure 6 (p. 64).

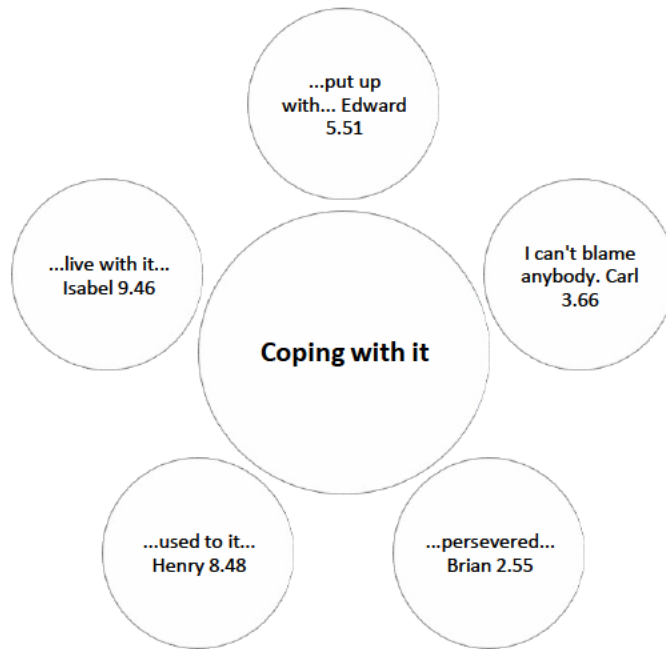


Figure 6. Coping with it.

Grace's responses to the inquiry about her quality of life and her feelings about having a wound for so long did not match. In response to the question about the impact on her quality of life she stated:

*Actually I don't know it's never really bothered me if you know what I mean? (Grace, 7.36).*

But, when asked how she felt about having a wound for so long, she said:

*I hate it. (Grace, 7.40).*

Whilst she doesn't see her diabetes and wound as something affecting her quality of life, for her to state she hates having a wound for so long suggests it is a negative experience for her and perhaps it does affect her more than she says.

Henry appeared to have a similar response stating:

*It's never affected my quality of life really. (Henry, 8.41).*

When asked how he felt about having a wound for so long, he stated:

*I just got used to it. (Henry, 8.48).*

Stating this suggests that perhaps an adjustment was required for him to deal with having wounds. This participant had suffered wounds over many years so he may have adapted and become used to having wounds.

Isabel didn't see that her wounds and diabetes affected her quality of life

*They don't really. (Isabel, 9.40).*

However, then she said:

*Well you've got to live with it. (Isabel, 9.46).*

This suggested that whilst she didn't feel that her diabetes and wound affected her quality of life her second statement suggested that it is something that she also had to cope with, as Henry did.

Edward could not really verbalise how his diabetes and wound affected his quality of life, due to other health problems.

*Well to be honest I don't know (how his diabetes and wound affect his quality of life), because I've got sore everywhere and I don't even know if there is a wound there or not. (Edward, 5.43-5.44).*

Edward clearly did not feel he could do much about having the wound and appeared to be resigned to the fact he had one.

*I just have to put up with it, can't do much about it...(Edward, 5.51).*

Other participants discussed physical effects of their diabetes and wound including pain, mobility problems and sleep disturbance. Albert discussed how his wound prevented him from mobilising, as well as causing so much pain it disturbed his sleep.

*Well, it stopped me walking for a while, it gets so painful, it still wakes me up in the night, I have to get up 'cos I can't go to sleep. It's very painful then. (Albert, 1.59-1.60).*

His comments below on how he felt about having a wound for so long correlate with the experiences stated above:

*I don't like it, I've never had things last this long, crikey, usually well, I cut myself and everything is cleared up in a couple of days. (Albert, 1.82-1.83).*

This statement suggested a feeling of frustration that things had not been progressing as Albert expected and his earlier comment illustrated the impact of having a chronic wound on the individual. It is not just the wound itself that is the problem to be faced; the effects of it can be far reaching and disruptive to quality of life.

Brian suggested his diabetes and wound changed his lifestyle and limited what he could do, but didn't specify how.

*It changes lifestyle...There's things that you can't do now that the normal person that hasn't got it can do. (Brian, 2.50-2.52).*

This statement suggested that Brian didn't feel 'normal' because of his diabetes and wound. Brian showed a resilient spirit and suggested that whilst his condition affected his mood he tried to continue and get on with his life.

*It does (his wound) get you down but, um, some people can bear it, some don't, I've persevered. (Brian, 2.55).*

Carl's response to the question on quality of life suggested his mobility has been reduced due to his wound and the treatments for it.

*Well it would be nice not to have to wear a cast all the time, or a boot (as part of treatment for wound), but apart from that I mean I guess I can't, there's things I can't do anymore, like taking the dog for a walk is really hard work now. (Carl, 3.52-3.54).*

When asked about his feelings towards having his wound for so long, Carl appeared angry, stating:

*Pissed off, but I realise it's nobody's fault and I can't blame anybody. (Carl, 3.66).*

Mentioning blame suggested that Carl had considered who may be at fault for his wound. Feeling that way indicated that he may not have been coping well with his situation. Stating he cannot blame anybody for his predicament suggested he was trying to cope with, or deal with his situation.

Duncan was not happy at how long his wound was taking to heal and it was apparent that his mobility had been affected by his wound.

*Ah, well, I'm really distressed about how long it's taken to heal...I'm only just starting to walk about now (due to pain from wound). (Duncan, 4.77, 4.89).*

Duncan was clear and concise in his response to the question about how he felt about having a wound for so long.

*I'm not very happy. (Duncan, 4.97).*

Only one participant appeared to have experienced no effect from having diabetes and a long term wound. This participant appeared almost angry at the asking of such a question. When asked how her diabetes and wound affected her quality of life she stated:

*Oh for god's sake not at all. (Fran, 6.36).*

When asked how she felt about having a wound for such a long time, she responds in a similar manner:

*God almighty, well it doesn't bother me. (Fran, 6.43).*

These responses made it difficult to get any additional information out of this participant. The participants appeared to focus more on the effects of their wound on their quality of life rather than how their diabetes or diabetes and wound affected them. This was possibly because wounds can be perceived as a temporary problem being experienced, whilst their diabetes is a life-long issue that many of them are simply coping with, not necessarily identifying it as an issue affecting their quality of life at the time. In hindsight it would have been appropriate to have had two separate questions regarding quality of life, one asking about diabetes and the other, the wound. This would have enabled more specific responses to be gathered.

Mobility and pain appeared to be the main concerns for participants relating to quality of life. Some of the participants were not happy about having a wound for so long and, as illustrated in Figure 6, they appeared to be '*coping with it*'. Overall, the experience of being a diabetic person with a chronic wound appeared to be a negative one for the participants, with both physical and emotional effects evident from their responses in the interviews. Despite this, five of the participants made statements suggesting they were coping with their situation.

#### **4.6 Self-care practices.**

Participants were asked about their usual care of their feet and lower legs, their understanding of diabetic foot care, what education they had received as well as what they wanted to know and what, if any goals, they had regarding their health. The enquiry regarding participants' health-related goals was to help identify what participants were working towards in relation to their health and see if this related to what they had stated they wanted to know, as well as knowledge deficits identified throughout the interview process. These have been combined into the theme of '*Self-care practices*'. This section starts with the analysis of participants' understanding of diabetic foot care and what actions they did to care for their feet and lower limbs. Foot care practices of the participants have been described in Table 2 (p.73).

Following this, the information regarding education received by participants, their preferences and goals have been analysed. Table 3 (p.74) outlines what participants know, want to know, prefer (education delivery method) and what goals they have regarding their health. Table 4 (p.78) shows what the participants' education delivery method preferences were. Knowing what they prefer will help with planning for future care and interventions.

On the whole, participants did not have a very clear understanding of diabetic foot care. Most did not do more than one foot care activity and two did not do any at all, leaving that activity for other people to do for them. This may be because participants' health care providers have not placed the responsibility for foot care onto them. However, it is suggested that foot care should be part of education for people with diabetes, which implies that the patient should be taking responsibility for this task (Singh et al., 2005; Walker, 2005). The information on this subject gathered through the interview process has been important to the study as it has helped to clarify the understanding of the need for diabetic foot care education to be improved. Although it has been assumed that people with diabetes are receiving foot care education, they may, in fact, not be; if it has been occurring it appears to have been ineffective within the participant group.

Albert was aware he needed to look after his feet; however he did not actually do anything to care for them. When asked what he did as usual care for his feet, he said:

*Nothing special, no. (Albert, 1.48)*

However, when asked what his understanding of diabetic foot care was, he stated:

*Well I know you have gotta look after them, that's about it. (Albert, 1.50).*

This suggested that despite knowing that he needed to look after his feet, he was not actually doing it and he didn't appear to be aware of the actions to take to care for his feet. It was clear there was a deficit in Albert's knowledge. There is no good in knowing you need to do something without having the skill or knowledge to achieve it.

Brian did have some awareness that he needed to take action to protect the health of his feet and lower legs. However, although identifying two activities that could possibly help to prevent diabetic foot wounds he lacked insight into why such activities were necessary, stating another action rather than explaining what his understanding of diabetic foot care was. When asked what he usually did to care for his lower legs and feet, Brian said:

*Elevation. (Brian, 2.35).*

When asked what his understanding of diabetic foot care was Brian suggested another action:

*Observance. (Brian, 2.42)*

Whilst observing and checking feet is a very important part of diabetic foot care, this response did not show a clear understanding. When Brian was asked if he had anything else to add, he just stated 'no' but then repeats what he had already said.

Carl attended appointments at his local diabetes clinic, applied moisturiser to his feet as part of his usual care of his feet and discussed foot-protecting activities when asked about his usual care of feet and lower legs.

*I go regularly to the diabetics clinic. (Carl, 3.38).*

*I'm using a cream... (Carl, 3.42-3.43).*

*I'm careful to wear shoes most of the time, don't go around barefoot anymore because um the opportunity to make wounds is obviously stupid cos then they won't heal so well. (Carl, 3.47-3.49).*

Carl showed a clear understanding of some of things he needed to do to protect his feet and suggested a clear rationale for why he made sure he wore shoes most of the time to protect himself from injury. However, Carl's comments suggested that he found some tasks a chore, such as moisturising his feet. It may have been the case that this is something he does but perhaps not as frequently as he should.

*On a relatively regular basis (he applies moisturiser to feet), I did find that hard to get used to. (Carl, 3.45).*

Whilst Duncan showed a good understanding of how his diabetes and wound were linked, his understanding of foot care appeared limited. When asked what he usually did to care for his feet and lower legs, he said:

*Oh I walk as often as I can as long as they are not too painful but they are getting better all the time and I keep my feet elevated...(Duncan, 4.62-4.63).*

Although walking can help with circulation, it is not really a foot care activity, more an activity of daily living. When Duncan discussed his understanding of diabetic foot care, although he said it was his responsibility he placed emphasis on the podiatrist (as previously discussed in 4.3., 'Letting someone else deal with it').

*Oh well, I have to take the responsibility for that and I have booked myself in to a podiatrist who I see about once a month. (Duncan, 4.65-4.66).*

So, although Duncan was taking responsibility for himself by booking the podiatrist appointments he was not actually doing any specific activities to care for his feet and didn't appear to have any knowledge of standard foot care activities.

Edward does not complete any foot care activities despite mentioning what he does not realise to be a symptom of diabetic neuropathy, decreased sensation.

*Well I've got no feeling in my toes it is feeling like there is a band around my toes there, no feeling I don't know if they are warm or cold. (Edward, 5.30-5.31).*

He also spoke of a problem nail that he stated was due to his diabetes.

*...and there is one on my big toe on the left hand side there is a funny nail but that's through diabetes, that doesn't get any blood through there. (Edward, 5.33-5.34).*

When asked about his understanding of diabetic foot care, Edward initially started talking about his diet and required the question to be repeated, with emphasis on foot care. After this redirection Edward stated:

*Yeah, I get it, every three months I go for a toes nails cutting and they have a look at it. (Edward, 5.39).*

Edward did not do any activities to care for his feet and left these to the podiatrist who he saw every three months. This suggested he was vulnerable to new wounds developing in the time between appointments. This was quite alarming as a three month interval between foot care episodes is too long, especially when there were signs of decreased sensation. However, Edward also visited his doctor and left it to him to identify problems, rather than identifying them himself.

*But the doctor he keeps an eye on it. And as soon as he picks something up he gets a nurse to look after it. (Edward, 5.46-5.47).*

When asked what she did to care for her feet and lower legs, Fran gave a rather mechanical-sounding response that did not clearly demonstrate her knowledge of diabetic foot care:

*Make sure they are well oiled and greased. (Fran, 6.30).*

Fran was aware of a need to be cautious with her feet but did not elaborate on what activities she actually did. When asked what her understanding of diabetic foot care was, Fran responded with:

*One has to be careful.* (Fran, 6.32).

When asked if there was anything she did to actually care for her feet, she stated:

*Well I make sure they are not in danger.* (Fran, 6.34).

Fran does not offer any specific actions that she does to protect her feet, despite her statements above, both of which have similar meaning. It was interesting to note that Fran does not mention visiting a podiatrist; as her wound was the result of a callous it would perhaps be important for her to be regularly seen by a podiatrist who could help prevent the development of new wounds.

Grace did not see it as her responsibility to care for her feet and lower legs, and although leaving this to the nurses who visited, she made an alarming statement about the quality of the care she receives. This was in response to a question about how her diabetes control affects her wound. Follow-on questions were required, asking if there is anything she did regarding her diabetes management that made the wound better or worse. She said:

*It's the nurses that notice the difference, but then again they can neglect it quite good too.* (Grace, 7.24-7.25).

This statement might suggest that the nurses caring for her did not necessarily identify and attempt to rectify the factors such as elevated blood glucose levels and poor diet that were contributing to her slow wound healing as she had been suffering from her wound for five years. Grace stated she cannot reach her feet and lower legs, the reason for this is not clear but it was noted that she was overweight, which may have prohibited her reaching her feet.

*Well I don't (care for her feet and lower legs), the nurses do 'cos I can't reach my lower legs and feet.* (Grace, 7.31).

Grace also suggested that she did not need to know about diabetic foot care as it was not something that she did. However, it may be that the nurses visiting her were just conducting foot care as a matter of course and may have never suggested to Grace that this was something she could be doing herself.

*Well there again you have to leave all that to the nurses, because they do all that. I used to go to the wound clinic all the time. (Grace, 7.33-7.34).*

The wound clinic Grace referred to provides specialist wound care and would have assessed and dressed her wound accordingly. Although they may have checked her feet for wounds, they are not equipped to provide the same level of foot care received by a podiatrist, such as nail trimming.

Henry did not do any foot care activities and when asked what his understanding of diabetic foot care was, he stated:

*Well never really tried it, I wear diabetic socks now and again, I've got some of them. (Henry, 8.39).*

This implied no understanding of why he should be wearing the socks. Stating now and again as the frequency for wearing the socks suggested it was not a regular part of his daily routine. Henry had been suffering wounds long before he developed diabetes and may not have been able to check his own feet for some time due to the toe-to-knee bandaging applied to both of his legs. As well as this, the wearing of socks designed for diabetics would be impractical over the top of bandages.

When asked what she did to care for her lower legs and feet Isabel said:

*Wear decent shoes. (Isabel, 9.28).*

When asked what her understanding of diabetic foot care was, Isabel stated:

*All I do is wear normal shoes, good shoes. That's about all I do. (Isabel, 9.36).*

Whilst wearing good well-fitting shoes is important in diabetic foot care, Isabel had part of her foot amputated. Post-operatively her wound was slow to heal and was still bandaged after three months. It would be unlikely she would be able to wear normal shoes on the affected foot, so her statement above also suggests poor understanding.

Table 2 (p.73) summarises the foot care activities undertaken by the participants of this study, it has been separated into active and passive foot care activities to reflect what the participants were doing for themselves and what they were leaving to others.

**Table 2. Foot care practices undertaken by participants.**

<b>Active foot care activities</b>	<b>Passive foot care activities</b>
Elevation (Brian, Duncan).	Go to diabetes clinic (Carl).
Observance (Brian).	Go to podiatrist (Duncan, Edward).
Moisturise feet (Carl, Fran).	Go to general practitioner (Edward).
Wear shoes (Carl, Isabel).	Nursing care (Grace).
Walking (Duncan).	
Wearing diabetic socks (Henry).	

Overall, the evidence suggests there is a poor understanding of diabetic foot care and limited participation in activities to monitor and protect feet, amongst the participants. Most participants mention one or two activities and there are three participants who do not participate in any active foot care activities at all. The majority of participants had wounds to their feet, but despite this they are not fully aware of diabetic foot care practices. This lack of knowledge regarding foot care could be interpreted as a possible contributing factor to the development of foot wounds. The participants of this study were not doing enough to protect the health of their feet. There is a lot of information on the issue of foot care; however it is unclear if the participants had access to such information.

Next, education relating to health will be discussed. Participants were asked what education and information they had received from people providing care to them, what they wanted to know and what goals they had in relation to their health, this information is shown in Table 3. (p.74). Participants were also asked what their highest level of education was, to help identify if there was any relationship between education level and knowledge. In some cases it was evident that participants' health goals did not match with what they wanted to know in relation to helping their diabetes and wound healing. In most cases the participants were unable to state what information they had actually received and tended to state what they thought of the information received, instead of the content of the information. Albert said:

*They don't tell you a lot. (Albert, 1.54).*

However, he also showed no desire to know more. When asked what he wanted to know, Albert said:

*Um, no, I think it's very steady. (Albert, 1.65).*

This conflicted with his goal for his health which was:

*To get this sore fixed up.* (Albert, 1.77).

This suggested he wanted to know what could be done to aid healing of his wound but it didn't show if he actually wanted to be an active participant in this process.

Table 3 below shows the information regarding each participants education level, what diabetes information they had received, what they wanted to know, what method of education delivery they preferred and what goals they had in relation to their health.

**Table 3. Education and goals.**

Name and highest level of education	What diabetes related education has been received	What do you want to know?	What is the preferred education method?	Goals
Albert: High School	'They don't tell you a lot'. 1.54	'Um, no, I think it's very steady'. 1.65	Leaflets	'Get this sore fixed up'. 1.77
Brian: 4 years high school	'Very informative, um good advice from all angles'. 2.58	'Getting ulcers healed'. 2.68	One to one, and leaflets.	'...well to keep as fit as uh as long as possible with knowing that it's not going away I'm going to have to grin and bear it.
Carl: Undergraduate degree	'It's varied over the years...'. 3.72. '...stuff that comes online'. 3.88	'I would like to know if there is anything more I could do to help with the wound healing, but as far as I can see there really isn't'. 3.108-3.109.	Websites, one to one.	'I just want to stay as well as I can, yeah, so that the aging process is graceful.'. 3.119.
Duncan: Trade certificate	From doctors and diabetic clinic.	'Well I don't think there is...(anything more he needs to know)'. 4.73.	One to one, and leaflets.	'Ah, well I don't think that's relevant'. 4.205.
Edward: High school	States 'No' 5.61. But states can talk to GP's practice nurse.	'No, Not really because I'm in good hands'. 5.64.	Nothing.	'Well I like to keep healthy...'. 5.71.
Fran: School certificate	Can't remember.	Nothing, 'No, I'm well aware of it all'. 6.48	Doesn't state.	'Oh god, just to keep well.' 6.66
Grace: Primary	Doesn't recall.	Everything, general information.	Leaflets	'No, because I'm getting better...'. 7.63
Henry: High School	Doesn't recall.	'Not really no, just keep going the way I am I suppose now'. 8.62. 'I'm getting too old now'. 8.67	No preference stated.	'I could lose some weight...'. 8.75
Isabel: School certificate	Doesn't state, says, 'It's all been fantastic'. 9.52.	'No, nothing'. 9.59.	'One to one'. 9.70	'Well everyone wants to have good health don't they?' 9.74

One participant made a rather contradictory statement after stating that she could not recall what information she had received from health professionals about diabetes and wound healing. When asked what she wanted to know, she stated:

*No, I'm well aware of it all. (Fran, 6.48).*

She went as far as to state:

*I know it all I'm sorry. (Fran, 6.50).*

This raised a question in the researcher's mind. If the participant cannot recall what she has been told, how can she be aware of it all? With such people it may have been beneficial to conduct a diabetes knowledge test. This would have identified whether their perceived knowledge correlated with their actual knowledge. Fran also spoke of her knowledge of diabetes from before she was diagnosed.

*My husband was a diabetic, class two and so was my father so there's not very much that I don't know about it. (Fran, 6.58-6.59).*

It was noted that Fran had been a diabetic for about twenty years. Knowledge and treatments have changed a lot in this time so what she was told twenty years ago would not necessarily be relevant today. Longo et al. (2010, p337) suggested a need for "Periodic re-education" to refresh existing knowledge and impart new information, with the goal of improving patient knowledge. It is likely that Fran would have benefited from some degree of re-education regarding diabetic foot care and how diabetic control can affect wound healing. However, as Fran felt she knew it all she may not be willing to receive further education on the subject. Fran identified a goal relating to keeping healthy (Table 3, p.74), but she showed no desire to receive assistance or information to help her achieve this.

Health literacy has been identified from the literature as a possible factor affecting peoples' condition management. This ability to have sufficient numeracy and literacy skills to cope with a chronic medical condition such as T2DM is important for successful outcomes to be achieved (AMA, 1999, cited in Tang et al. 2008, p75). Most participants in the current study had been educated to high school level, one had an undergraduate degree, one a trade certificate and one had not advanced their education beyond primary school level (Table 3 p.74). The participant with the lowest level of education was most dependent on health care professionals for foot care. This may be related to her ability to comprehend the information received regarding her health. Grace did not recall what education she had received from health professionals regarding her diabetes management and wound healing but was open to

learning more. The participant with the highest level of education mentioned technical terms related to diabetes management, including neuropathy and HbA1c levels and identified an awareness of recent changes to the reference ranges.

*'I average seven (HbA1c), and that's sort of over the year...That's in the old reading, I should call it something else now but I still see it as a seven (referring to changes with the way HbA1c is recorded)...Which I thought was pretty good control but evidently, obviously over twenty something years I've got a bit of neuropathy, that's the correct term isn't it? (Carl, 3.14-3.20).*

Carl was the only participant to mention the internet as a source of information on diabetes management. At the age of 69 Carl wasn't the youngest or oldest participant but he was the participant with the highest level of education, having attended university (see Table 3, p74).

*Stuff that comes online and the magazine from [local regional] diabetes association seems to me to be a very active one. (Carl, 3.88-3.89).*

This suggested Carl was an active seeker of health information although his comment about not being able to identify what he could do differently to help improve his healing suggested that he may have felt he knew all he needed to on the subject. Some of the participants did not identify that they needed to know more or else did not want to know more. Carl felt that although he was open to learning more about what he could do to help the healing of his wound, he could not see that there was actually more to know.

*I would like to know if there is anything more I could do to help with the wound healing, but as far as I can see there really isn't. (Carl, 3.108-3.109).*

Six other participants did not want to learn anything new; Edward felt he was in good hands, which meant he did not need to know more as it would be managed for him. However he was quite elderly at the age of 82 and it may be that his health had deteriorated to the point where he is becoming increasingly dependent on others (Waterworth & Jorgensen, 2010).

*No, not really because I'm in good hands. (Edward, 5.64).*

This suggests that it is important to ensure health professionals are well educated on diabetic foot care and other aspects of diabetes management, to ensure people like Edward receive the best care possible and that trust in those providing care to such people is not misguided (Bell & Duffy, 2009).

Duncan's and Fran's responses to the question about what they wanted to know suggested they felt they knew enough.

*Well, I don't think there is...(anything more he needs to know). (Duncan, 4.73).*

*No, I'm well aware of it all. (Fran, 6.48).*

However, both of these participants had little knowledge of diabetic foot care and would likely have benefited from more education on such issues.

Henry, who had been suffering wounds on and off for 55 years, responded to the same question with:

*Not really no; just keep going the way I am I suppose now. (Henry, 8.62).*

As previously discussed in the analysis of quality of life (4.5), Henry may have adapted and be 'dealing with it'. He also stated his age was a factor affecting his desire to learn more:

*I'm getting too old now. (Henry, 8.67).*

In hindsight it may have been appropriate to try and get more information from Henry on this subject. He certainly was not the oldest participant and improving his knowledge would be beneficial to both his general health and his quality of life.

Isabel showed no desire to know anything more as she felt she must have learnt enough over the time since she was first diagnosed.

*Well I feel I've been after twenty four years I must have learnt something. (Isabel, 9.61).*

It was interesting to note that Isabel could not specify what information she had actually received over the years despite saying she must know something due to the duration of living with the condition.

Participants were asked what their preferred method of education and information delivery was. Participants' choices have been recorded in Table 4 (p. 78).

Table 4. Diabetes education preferences.

Leaflets	One to one sessions	Websites
Albert	Brian	Carl
Brian	Carl	
Duncan	Duncan	
Grace	Isabel	

Edward, Fran and Henry do not voice a preference, with Henry stating:

*Doesn't worry me. (Henry, 8.73).*

Fran did not feel she was in a position to need further education on the matter.

*Ah, if I was desperate yes, (she's be open to receiving education), but I'm not. (Fran, 6.64).*

Leaflets and one-to-one sessions appear to be the preferred option for education and information delivery. Albert felt that leaflets were 'good enough' for him and when asked if he normally read them, he said:

*Yeah, I don't have to be lectured. (Albert, 1.75).*

Brian's lack of access to a computer meant he appeared to feel his options for education are limited.

*Well one to one and leaflets 'cos I haven't got the computer. (Brian, 2.76).*

This is in contrast to Carl's response as he did have access to a computer.

*Websites and a chance to one to one on a, it doesn't matter if it's infrequent but then knowing there are certain websites and places that I can go to and there are people at the end of the phone I can get help from. (Carl, 3.112-3.114).*

When asked why he preferred these methods of education delivery, Carl said:

*It means I'm more involved basically. (Carl, 3.116).*

Isabel also preferred one to one sessions for similar reasons.

*You can ask questions and get a response then and there. (Isabel, 9.72).*

Duncan thought leaflets were 'OK' but he had more frequently experienced one-on-one education. He preferred the latter, stating:

*Yeah, that works good for me. (Duncan, 4.202).*

Everybody is different and what works for one person will not necessarily work for another, suggesting one size definitely does not fit all and more tailored options need to be available (Kreuter, Strecher, and Glassman, 1999).

For Grace, transportation issues affected her preference.

*Leaflets will do me, I don't like going to classes thank you....Well, I'm just not keen on doing anything that's out 'cos I have to have somebody take me everywhere. (Grace, 7.56-7.59).*

The findings from this analysis of the data gathered through the interviews will be discussed in depth in Chapter Five.

## Chapter Five

### Discussion

Chapter Four was a straightforward analysis of the raw data to define themes, supported by verbatim quotes to exemplify the participants' understanding of the link between their diabetes management and chronic wound. This chapter will build upon the findings from the analysis. During the analysis, significant themes emerged and have been identified as "*Letting someone else deal with it*"; "*Ownership*"; "*Not making the link*"; "*Coping with it*", and; "*Self-care practices*". Health literacy is discussed as the literature review identified that it can impact on a patient's ability to receive and process information related to their health. Health literacy's relationship with this study will be discussed in more depth. The analysis suggests there may be a lack of holistic care, which is care that looks at the whole person, including the mental, social and spiritual well-being of patients and does not just focus on one symptom or physical ailment (O'Toole, 2003). It appears that opportunities for nurse-patient interactions are being missed in the community nursing setting. This will be an area of discussion. All of the findings from the analysis will be discussed in relation to the available literature. In some instances it will be a revisit of what has been discussed in the original literature review (Chapter 2) and will include new literature found, following the information gained from the interviews.

#### 5.1 Letting someone else deal with it and Ownership

Many of the participants were leaving parts of their care to health professionals, be it their district nurse, podiatrist, family doctor, or practice nurse. This was mostly in regards to their foot care. In some cases, participants such as Grace were placing full responsibility on their nurse. Grace suggested this was the role of the nurse, not herself. Rather worryingly, Auduly, Asplund, and Norbergh (2010) identified that people who leave it to external forces such as nurses or doctors to be responsible for their healthcare are vulnerable when they do not have the required support available to them. With foot care, if participants are seeing health professionals only intermittently as they remain in their home environment, they have the potential to be exposed to foot damaging hazards much of the time if they are not taking responsibility for this aspect of their care. This perceived risk would be applicable to many participants in the current study.

It was clear to the researcher that many participants were not autonomous in their self-care activities. However, Hornsten et al. (2005) suggested that autonomy and equality are required to empower patients to better manage their health. Are we respecting our patients and

treating them as equals? This has not been uncovered during the course of this enquiry. If we, as health professionals, are to work towards enabling our patients to successfully self-manage their diabetes care, we must respect and work with our patients to achieve this. Hornsten et al. (2005) discussed this further, identifying that for satisfying interactions to occur patients should be shown respect for their decisions around goal setting and not forced to make changes against their wishes. Spikmans et al. (2003) suggested that education for patients needs to reinforce that they can contribute to their own health. If people do not see they can make a difference then they will not be empowered to try. This relates to self-efficacy (see 5.4.1).

From the information gathered it was apparent the participants of the current study did not have adequate knowledge or practice of diabetic foot care and it was difficult to assess what education had been received as many could not recall this. It may be the case that the participants had not been given sufficient information on what actions they could take to prevent foot complications associated with diabetes. Without this knowledge, perhaps they cannot see the benefits of participating in foot care activities. This links with Hallet et al. (2000) who suggested that patients' knowledge can affect compliance, and if they did not know why something would be of benefit to them, they would be less likely to do it. The current study found that many participants did not link their diabetes to their wound healing and this gap in knowledge may have contributed to the lack of empowerment shown in relation to foot care practices. Delamater (2006) suggested a respect of patient autonomy can help to improve self-management. The current study did not ask participants about their thoughts on autonomy and empowerment. However, as it was identified that self-management activities in relation to foot care were poor, it may be the case that autonomy is not being supported by the health professionals working with this group.

A multi-national study conducted within seven countries found that differing health care systems did not impact on patient adherence to care, but patient knowledge, beliefs and attitudes about their diabetes did, as did their relationships with the health professionals providing care to them (Vermeire et al., 2007). Problems with communication between patients and health care providers were also identified. Although participants in the current study were mostly identified as leaving tasks relating to foot care to others, they were also not doing activities that were in their best interest, such as checking their feet every day. As most participants could not recall what information and education they had received, it was impossible to assess what information had been received and whether they were adhering to it. This may have been an indicator of ineffective communication between health care

providers and their patients. It could also be a sign of a bigger failure within the health sector. It is optimal from a funding/cost aspect for patients to be successfully self-managing their condition, but in reality it may be that time and knowledge are insufficient to allow this to occur, which would indicate a need for further research on this subject. It is also evident that although facilitating patient empowerment can improve outcomes for patients, the nature of these improvements through interventions to assist condition management is unclear (Spence Lashinger, Gilbert, Smith, & Leslie, 2010; Magnezi, Kaufman, Ziz, Kalter-Leibovici, & Reuveni, 2013).

Anderson and Funnell (2005) stated that patients can feel they are judged by health care professionals if they don't follow advice. However, the participants in the current study did not indicate they felt judged but this may have been due to their not being fully informed of what they could or should be doing to help protect their own health. All of the participants are older people, (See Table 1, p42-43) and perhaps they do not want to take responsibility for their diabetes. Gorter et al. (2011) found that amongst their participants who were, on average (mean), 65 years old, some did not want to take responsibility for their diabetes management, especially those who were experiencing complications. This was reflected in the current study during the interview with Henry. He felt he was too old to learn more about his diabetes and wound healing and had also been suffering wounds for a very long time. It may be that Henry had been suffering his wounds for so long that he had become used to others taking care of them and he did not see a need to do anything to help improve his wound healing. Although this was not discussed in the interview it may be an indicator of a need for further research into factors affecting the desire to learn more in people with diabetes and associated complications.

Lack of knowledge can be seen as a barrier to effective diabetes self-management. Nagelkerk, Reick, and Meengs (2006) suggested that it is vital to identify such barriers and methods in order to overcome them. However, it may be that the barrier is the patients themselves. If they do not want to participate in self-care, this needs to be identified by health professionals working with the individual and care needs to be planned to help ensure the best health outcomes (Gorter et al., 2011). Participants such as Grace made it quite clear that she did not see it as her responsibility to care for her feet; therefore nurses need to be aware of this, when they are planning her care, to ensure she does receive foot care.

The current study suggests the participants are not taking responsibility for their own health. This could be due to a lack of knowledge and may identify a need for appropriate education and support to enable this group to overcome what could be seen as a barrier to successful

health outcomes. However, it could also be suggestive of care delivery that is not proactive in enabling patients to become responsible for their own health or perhaps the participants do not want to participate in self-care. However, no participants actually stated they did not want to conduct foot care, it was just apparent that they were not doing it. In hindsight it would have been appropriate to ask participants why they were not doing foot care. In future studies it would be worthwhile asking people who are not conducting effective foot care why this is the case. It might be that they don't know what it entails, or they just choose not to. It cannot just be assumed that they have poor knowledge; the reason for this needs to be investigated.

Anderson and Funnell (2010) identified that there is a need to enable patients to become empowered by giving them all the information required for them to make informed decisions about how they manage their diabetes. An interesting notion recorded by Asimakopoulou, Newton, and Scambler (2010) suggested that in some cases patient empowerment may conflict with the ethical notion of not causing harm, as some patients may make conscious decisions to do actions that may not necessarily be in their best interest. It may be that empowerment can be detrimental to the health of others, such as Fran whose actual knowledge differed greatly from the knowledge she believed she held. In relation to being lectured, didactic education has been proven to be effective only in the short term, without evidence to suggest its long term benefits, so lecturing patients is not really the best way to deliver health information (Clement, 1995, cited in Norris et al., 2001, p 582). Depending on a patient's ability, it may be that they need more guidance and support. This will be discussed in more detail in section 5.4 Self-care practices.

Oftedal et al.'s (2010b) study suggested a need for individualised empathetic care and education for people with diabetes, to help improve their motivation with self-management. The findings of the current study indicate that the level of care suggested by Oftedal et al. (2010b) is not being delivered and participants appear to be unmotivated to learn more about how they can help themselves. The reason for this lack of motivation may be due to the aging group of participants recruited to the current study and they may not feel the need/desire to self-manage their condition as they shift from being independent to dependent people as they age (Waterworth & Jorgensen, 2010). It could also be that the health professionals working with people such as those in the participant group are not engaging with their clients to promote motivation. This is an area that needs further exploration in future research. It is important for health professionals to discuss the issue of responsibility with their patients so they can understand how patients feel about this and deal with this issue appropriately (Gorter et al., 2011). Although this was not discussed in the interviews for the current study, the

findings do suggest that some participants are not aware of their responsibilities in relation to their health, which may indicate that health professionals may have assumed participants are aware of what they should be doing, without discussing it with them.

Three participants of the current study made statements that suggest they are trying to take ownership for their own health. Most notable is Duncan who, when talking about diabetic foot care, states:

*Oh well, I have to take the responsibility for that and I have booked myself in to a podiatrist who I see about once a month. (Duncan, 4.65-4.66).*

He identified it was his responsibility to look after his feet but his knowledge on foot care was poor and he didn't actually do many activities to care for his feet, as going to the podiatrist could be seen as '*letting someone else deal with it*'. Therefore, although some participants were trying to take responsibility for their own health, they may not have been fully empowered to achieve this, perhaps due to lack of knowledge, lack of support or lack of motivation to do so. This develops a concern that if patients are taking control and responsibility for their own health and are suggesting they are confident with this, as Fran does, but are not equipped with the life skills or tools to achieve this, it will lead to poor health outcomes. This relates to the discussion of Asimakopoulou et al. (2010) that suggests empowerment of patients may contribute to harm or undesired outcomes.

Audulv et al. (2010) stated that when people took responsibility for their own health it led to a belief that they could make a difference to their own health in a positive way as well as improving their quality of life. However, for this to be successful, people need to be fully informed of all the facts regarding diabetes management, be it from the health professionals they see, or self-enquiry. There is a lot of information available regarding diabetes management, especially on the internet. Longo et al. (2010) suggested there needs to be further research into the implications of patients searching for information on diabetes management, especially online because levels of health literacy can affect an individuals' ability to interpret the information, they also identified that it would be beneficial to know what types of information can lead to improved behaviours. Only one participant Carl, spoke of looking online for information and the others gave no information of health information-seeking behaviours.

The current study indicates that many of the participants are not well informed and need more education and support to enable them to take full ownership of their health, although this needs to be relevant to the individual situation. To successfully support patients in taking

ownership of their own health, they need to be fully equipped with the skills and knowledge necessary before they have this responsibility placed upon them (Redman, 2007). Health professionals need to ensure they are fully informed of the most up-to date research and recommended practice in their management of chronic illnesses such as diabetes and work in a way that supports the autonomy of their patients if patients want to manage their diabetes this way (Redman, 2007).

Wellard et al. (2008) and Kielmann et al. (2010) identify that health professionals did not acknowledge their patients' knowledge, which could have a negative impact on people trying to take ownership. In the current study, no participants vocalised that they felt this had happened to them. Although it may be the case that the opposite was occurring and perhaps health professionals were assuming the participants were holders of knowledge regarding diabetes management and foot care, when they were not (Matthews et al., 2009).

It may be necessary to identify what health professionals' expectations are of patient knowledge. Identifying what nurses think their patients should, or do know, might identify gaps and areas for improvement. In the community setting where the current study was conducted, patients are not always seen by the same nurse. It may be that assumptions are made that someone else has talked with the patients about self-management and foot care and the nurse may not delve into what patients know in order to identify whether there is more they can offer them in regards to education and knowledge.

Perhaps it would be beneficial to complete some form of assessment to identify the extent of knowledge of diabetes and its complications, in new patients admitted to the District Nursing service. Although the Community Nursing service from which the participants were recruited does conduct thorough assessments when patients are admitted to the service, there is no tool to assess pre-existing diabetes knowledge. Also, if deficits in knowledge were identified, there is no current easy access to resources that may assist patients. It would require skill and knowledge on the part of the nurses delivering care to ensure the assessment is completed properly. There are formal diabetes knowledge test tools available, such as that used by Fitzgerald et al. (1998), which was a 23-question test that would take about 15 minutes to complete. However, this tool is also very Americanised in the terminology used, so would need to be adapted to suit a New Zealand population. Another factor that may prohibit the use of such a test is time. An extra 15 minutes in an already busy day may deter nurses from using even a brief diabetes knowledge test. Such a tool may gather more information that is required for the purpose of assessing what a Community Nurse may need to educate a patient on. Rather than gather unnecessary information, alternatives need to be considered to allow

for consistency in assessment and care delivery. A prompt sheet with a few quick questions to identify what patients do know about diabetes management and its associated complications might be simpler to use, as it takes less time. The information gathered through this study may enable the development of such a tool.

## **5.2 Not making the link**

The theme of *'Not making the link'* was derived from the lack of understanding of the link between their T2DM and chronic wound, as demonstrated by some of the participants in this study. This theme is fundamental in answering the research question upon which this study is based.

In many cases the participants of the current study were not making a link between their diabetes control and the way in which this impacted on their wound. Only three of the nine participants had some understanding of how their wound and diabetes may be linked. Brian and Duncan made the strongest links, identifying how better diabetic control improved healing. Brian had been suffering his wound for about 15 years and been a diabetic for 22 years, whereas Duncan had his wound for 21 months and had been diabetic for over six years. Other participants' who did not make any link, or only superficial links, had had their wounds and been diabetic for less or more time. Therefore, there is no clear correlation between wound and diabetes duration and the understanding of the link between the two. Only one other participant made a superficial link based on what he had been told by other people. Carl states:

*...everybody tells me that diabetics find it harder to heal. (Carl, 3.35).*

So, while this tells us that Carl knows that, as a diabetic he will find it harder to heal, it doesn't show that he understands why that is the case. The remaining six participants did not have any clear understanding of the link.

Only two participants clearly identified that their glycaemic control could impact on their wound healing, with the remainder of the participants not making this link. This concurs with the findings of Gale, Vedhara, Searle, Kemple, and Campbell's (2008) study which found that the relationship between a person's glycaemic control and occurrence of foot complications was not identified by its participants. Although the participants of the current study were already experiencing the complication of a wound, it was interesting to note that Gale et al.'s (2008) study identified that their participants did not see that they, as people with diabetes,

would experience any problems with healing should they develop a wound. This would also be suggestive of no link being made between diabetes and wound healing.

It was noted by the researcher during her practice as a nurse that some patients with diabetes and a wound talk of not wanting to lose a limb, suggesting they may be making a link between their being a diabetic and the perceived risk of amputation being necessary due to the complication of a chronic wound. Two participants in the current study had experienced an amputation; one lost a toe and another, a forefoot. However, none of the participants of the current study discussed possible limb amputation as a concern. This is a real risk as diabetics are over-represented in the numbers of people having non-traumatic limb amputation and 85% of all diabetes-related amputations are on patients who have a foot ulcer (IDF, 2005; NZGG, 2003).

Spikmans et al. (2003) asked participants in their research about their understanding of the severity of their diabetes. Although participants in the current study were not asked how severe they thought their diabetes was, when asked about goals none said they had a goal of making sure they didn't lose a limb because of their wound, even though that occurring is a very real possibility. This may indicate a lack of knowledge of the consequences of diabetic complications, on the part of the participants. Spikmans et al. (2003) and Searle et al. (2008) both suggest that if people have little or no experiences of the complications of their condition, they may not feel certain aspects of the care are relevant to them. The findings from the current study suggest that despite experiencing the complication of a chronic wound, some of the participants still don't identify that some aspects of care and education are relevant to them. This was evident with a few of the participants. One felt he was too old (Henry), and some felt they knew all they needed to know (Carl, Duncan, and Fran).

In some cases people have the necessary knowledge, yet choose not to do what they know is best for them (Jinadasa & Jeewantha, 2011; Lawton et al., 2008; Oftedal et al., 2010a). However, the findings of the current study suggested that participants responses indicated that a lack of knowledge is a reason for poor foot care practices. No participants mentioned a need to check their feet regularly, with only one participant (Brian) stating that observance was part of foot care, suggesting participants were not fully informed on the need for them, as diabetics, to regularly check their feet for injury or potential problems developing. This confirms the findings of Abu-Qamar and Wilson's (2011) study looking at foot care practices and knowledge in Jordan.

### 5.3 Coping with it

As discussed in the literature review, being a diabetic person with a wound can have an impact on quality of life (Goodridge et al., 2005). According to Lloyd, Sawyer, and Hopkinson (2001) quality of life can be negatively affected by even minor diabetic complications. The current study made only a superficial inquiry into quality of life; the use of a more in-depth quality of life tool may have led to more in-depth information being gathered on this subject. However, this was not the main aim of this study, so two open-ended questions were asked to gather information. These asked participants to identify how being a diabetic with a wound affected their life, and the responses were quite varied. The most affected participants talked of symptoms they experienced that were mostly associated with their wound. Some participants were not affected at all, or at least their initial responses suggested this. However, as discussed in analysis, the follow-on question, asking how participants felt about having a wound for so long, elicited more of a response with indications suggesting many participants were not happy about having a wound for so long.

One participant talks of many factors affecting his quality of life, mobility, pain and reduced sleep:

*Well, it stopped me walking for a while, it gets so painful, it still wakes me up in the night, I have to get up 'cos I can't go to sleep, it's very painful then. (Albert, 1.59-1.60).*

Whereas some participants did not see their diabetes or wound as something that affected them in that way, such as Fran who, when asked how her diabetes and wound affect her quality of life, states:

*Oh, for god's sake not at all! (Fran, 6.36).*

When asked the follow on question of 'How do you feel about having a wound for so long?' Fran states:

*God almighty well it doesn't bother me. (Fran, 6.43).*

Fran's response was surprising but it suggests that the effects of diabetes and wound on quality of life are quite varied for the people experiencing them. Gurková et al. (2009) and Koopmanschap (2002) stated that quality of life was impacted on by severity of complications, treatment regime, age and how long the participants in their study had been diabetic. The severity of participants' wounds was not assessed as part of the current study, although type of wound was noted; Albert had a pressure ulcer and Fran a diabetic foot ulcer and she had a

toe amputated as a result. It is interesting to note that Fran had been a diabetic for about 20 years and Albert only about five years, therefore it could not be said that diabetes duration related to negative effects on quality of life in all cases. Perhaps the perceived severity of the wound (complication) had more of an effect, although that is not confirmed by this study.

Although no participants included in the current study had wounds that had recently healed, Ribu et al. (2008) identified that people with on-going ulcers had lower levels of quality of life than those who had healed. Five participants of the current study had been suffering from their wound for two years or more, and contrary to Ribu et al.'s (2008) findings, suggesting that people with non-healing ulcers were increasingly socially isolated, no participants in the current study indicated they were experiencing this. When asked about quality of life, three participants (Albert, Carl, and Duncan) mentioned decreased mobility as a factor affecting them. Oka and Sanders (2005) suggest that people with diabetes and peripheral arterial disease (PAD) are at greater risk of reduced mobility leading to isolation. Although it was not identified if PAD was a factor contributing to the development of participants' wounds, their wound did affect their mobility but did not appear to leave them feeling socially isolated. Brod's (1998) study, looking at quality of life issues affecting diabetic people with lower extremity ulcers, stated mobility impacted on every domain of quality of life. Brod suggests people experienced anger and frustration due to limitations mobilising. Carl showed signs of frustration at not being able to take his dog for a walk and suggested he missed being able to walk properly most of all and has to rely on orthotic equipment to enable him to mobilise:

*That's probably what I have missed most of all, is not being able to walk...properly. I mean I'm OK when I've just got a brace or something or my own personal moon boot on that's not so bad. (Carl, 3.59-3.3.61).*

Although not related to his mobility, one participant (Brian) made a statement suggesting that he felt different, not "normal", which may have been an indication that in some ways he felt isolated from others; however, without more in-depth information, this is just speculation. Byrne and Kelly (2010) stated that pain was the worst symptom affecting the quality of life of people with wounds. This was followed by mobility, embarrassment due to odour, physical complications, and psychological complications such as depression. Some participants in the current study talked about pain being a factor affecting their quality of life. Albert, Duncan and Edward experienced pain; however the remaining six participants did not talk of experiencing any. Albert and Duncan talked of very specific wound pain, however Edward's pain was much more generalised. Edward's pain may have been due to neuropathy. While it is known that many diabetics have peripheral neuropathy with loss of sensation to their feet contributing to

the development of wounds, some experience pain due to their neuropathy which also has a negative effect on QOL (Davies, Brophy, Williams, & Taylor, 2006).

No participants talked about how the adaptations to life necessary to manage diabetes affected their quality of life. Brod (1998) identified that wounds and diabetes necessitate lifestyle adaptations. Only one participant talks of this in the current study. When asked 'how do you feel your wound and diabetes affect your quality of life?' Brian states:

*It changes lifestyle. (Brian, 2.50).*

Whilst Brian sees it as something that changes his lifestyle, he does not elaborate on this further than saying that there are things he cannot do.

Watkins et al. (2000) found that while adhering to treatment may be seen as beneficial to QOL, they also found that adhering to dietary advice could have a negative impact on QOL due to restrictions. So it could be seen that by trying to do what is in the best interests of their health, they may not actually feel good about it. In relation to wound healing, good glycaemic control can help improve healing but it may be that the dietary changes required may be hard for people to cope with. This relates to Sundaram et al. (2007) who found that HbA1C does not have a strong relationship with quality of life. This suggests that although someone may have what is deemed good control, they may not feel they have desirable QOL due to the adaptations required to achieve it. This was not identified by the current study. Four participants did not see that their diabetes or wound affected their QOL and overall mobility and pain were the main factors seen to be affecting QOL.

Brod's (1998) study suggested that worry about the future was an issue for its participants. However, none of the participants in the current study talked about concerns for their future, although many of them talked about wanting to stay healthy. This may have been due to them trying to cope with the present problems they were facing, or they were not thinking about the negative possibilities. As previously discussed in 5.2, amputation is a possibility facing diabetic people with chronic wounds that has not been identified as a factor by any of the participants.

Ghanbari et al (2005) found that assessing quality of life helped to quantify the success of patient care and education. Furthermore, Pibernik-Okanovic, Prasek, Poljicanin-Filipovic, Pavlic-Renar, and Metelko (2004) found that quality of life and control of disease improved following patients participating in empowerment-based interventions. The findings of the current study suggest participants had not been exposed to much, if any, health-related

education that has had an impact on them, therefore it was impossible to identify whether increased knowledge from education helped improve their quality of life.

Health professionals need to be knowledgeable about how being a diabetic with a wound can affect a person. For the patient, it is a lifetime commitment to treatment for their diabetes and a wound can complicate this experience further for them. Health professionals need to be understanding and realise that it is not always easy, having to consider your diabetes when making decisions (Price, 2004). Many participants made statements to suggest that they were dealing with the effects of being a diabetic person with a wound and just getting on with their lives. How well they were coping was not identified from the analysis, but another study suggested that developing strategies to promote coping ability may help improve healing in people with diabetic foot ulcers (Vedhara et al., 2010). Therefore, equipping patients with all the necessary information to help them successfully manage their conditions could improve their coping ability and improve healing.

#### **5.4 Self-care practices**

The self-care practices involved in diabetic foot care, the knowledge held by participants as well as that required to conduct such care, health education preferences and health goals will all be discussed in this section. The participants were asked what they did to care for their feet and lower legs, as well as their understanding of diabetic foot care, during their interviews. This information helped to emphasise their level of knowledge on the issue of foot care and the risk of lower limb complications. It has been identified that foot care knowledge and practice was poor amongst the participants of the current study, this concurs with the findings of other studies by Abu-Qamar and Wilson, (2011); and Jinadasa and Jeewantha, (2011). As previously discussed, some participants are leaving this task to others, which could be considered passive participation in diabetic foot care (see Table 2 p.73). Some participants did do activities to care for their feet, such as moisturising their feet and ensuring they wore shoes to prevent injury; such activities could be considered active participation (see Table 2). Carl appeared to be the most proactive participant, ensuring he did not go bare foot in order to avoid the potential for injury. He also moisturised his feet and attended the diabetes clinic. Duncan identified that walking was something he did to care for his feet, however this is just a normal part of daily life and cannot be deemed as a specific foot care activity.

Out of the nine participants, only three did two active foot care practices, three did one, and three did not do any at all. It is suggested that to help prevent the development of diabetic foot ulcers it is necessary to understand why good glycaemic control is necessary; have

adequate medication management; take an appropriate diet; check feet daily; ensure well-fitting (custom made if necessary) foot wear is worn; and arrange regular visits to the podiatrist to prevent nails and calluses becoming problematic (Frykberg et al., 2006). An understanding of the reasons for, and actions required to care for diabetic feet was not evident amongst most of the participants in the current study.

Khamseh, Vatankhah, and Baradaran (2007) conducted a study on knowledge and foot care practices in Iran and found that 60% of their 148 participants did not inspect their feet. A study conducted by De Berardis et al. (2005), had 3,564 participants who completed questionnaires on foot care; 33% of participants did not examine their feet. Only one participant (Brian) of the current study suggested he checked his feet saying 'Observance' was an important part of foot care. Although the current study had only nine participants and such findings cannot be applied to the general population, this suggests that about 89% of participants were not inspecting their feet as part of diabetic foot care. Khamseh et al.'s (2007) study used a tool to assess foot care knowledge which was also found to be poor, with a mean score of 6.6 out of 16, suggesting that poor foot care practices are clearly linked to inadequate knowledge.

Dorresteyjn, Kriogsmann, Assendelft, and Valk (2012) suggested that although patient education can contribute to improved patient behaviour there is limited evidence to suggest education alone will improve outcomes. This was confirmed by Adolfsson, Smide, Rosenblad, and Wikblad (2009) who suggested that education needed to be improved as it did not necessarily lead to improvements in patients reaching their health targets. Some education is better than none, as diabetic patients who never receive education on the issue are four times more likely to suffer a major complication (Mensing et al., 2006). In the late 1970's and early 1980's a randomised control trial found that, about a year after health education interventions, there was only a slight difference between the experimental group (who had received up to seven didactic education modules, including the opportunity to practise skills and set goals, as well as access to follow up care) and the control group who received standard care (Mazzuca et al., 1986). This suggests the failure of health education for people with diabetes is not a new phenomenon and emphasises the need to find a different way to proceed into the future of diabetes care. All participants in the study were asked what education and information they had received in relation to their diabetes and wound healing and what they wanted to know. Of the nine participants, five either could not recall what information they had been given or stated they hadn't been told very much about diabetes and its relation to wound healing.

Norris et al. (2001) stated more research was needed on the effect of education on long term condition management. Although this was not a direct line of inquiry of the current study, it

was noted that the minimum duration of diabetes was five years. Three participants could not recall what education they had received, suggesting that whatever information they were given at the time of diagnosis was ineffective in the long term. On the whole, participants did not actually say what education was received but either said they could not remember what they had been told, or they commented on the quality of it, with two participants (Brian and Isabel) appearing satisfied. The inexperience of the researcher conducting the interview may have limited the information gathered in relation to this; more probing questions may have benefited this study.

Pibernik-Okanovic et al. (2004) stated that further research was needed to identify what people prefer when it comes to educational approaches. The current study identified that most patients prefer leaflets and one-to-one sessions for education delivery. It should be noted that the question posed to participants was *“When it comes to education about health issues what do you prefer?”* All participants required follow-up prompts to this question, which offered them some options: *“Do you like classes/leaflets/websites/one-to-one sessions?”* This may have limited the possible responses as participants may have just picked an offered option rather than considering another response. Although participants were not able to readily respond to this question anyway, perhaps they should have been given an option to state they did not wish to receive education. It is important to ensure that if people wish to receive education that is appropriate for them, it should, according to Mensing et al. (2006), be an on-going process to ensure appropriate content is delivered over time. Kreuter et al. (1999) suggested that tailoring health education to suit the patients’ needs is beneficial to health outcomes. However, it may be costly to provide that level of support to all people with diabetes; therefore it may be more appropriate to develop multiple strategies (discussed further in 6.4, Implications for future practice and research). Interestingly, Grace stated she preferred one-to-one and leaflets as she found it hard to arrange transport to appointments and did not like to rely on others. This suggests that informative patient-focused literature should be developed covering all aspects of diabetes self-management and foot care, as well as ensuring health care staff are fully equipped to provide information and education as it is required.

As time for interactions is often limited, online learning is a practical solution to enable on-going learning in patients who are able to access such resources (Misra et al., 2012). Only one participant identified the internet as a source of education and information (Carl). He found it reassuring to know there were places he could go for information at any time. Glasgow et al. (2012) studied the outcomes of an internet based patient education programme for people

with diabetes. They suggested internet resources are able to offer continuous support; however, whilst there was improvement in behaviours it was minimal. Their study included participants who were 25 to 75 years of age, whereas participants in the current study were all older adults with the youngest being 63 and the oldest 86. With increasing numbers of diabetics being diagnosed at younger ages more people may be using the internet as a health education resource in the future. However, in relation to the current study only one of the nine participants used the internet for diabetes information/resources. It may be that the advancing age of the study group and access to a computer acted as a barrier to accessing online information.

It may be beneficial for each region to have their own website with local support services, contact information and question and answer facilities so patients can ask questions and get responses from a health professional. Carl stated that he liked the idea of someone being at the end of the phone. An online service with a frequently asked question section and the option to send a question to a health professional may enable people to have access to support seven days a week at any time. However, as many people do not have easy access to the internet it is still important to have other avenues of education available for people with diabetes. Brian indicated that he preferred leaflets and one-to-one sessions because he did not have a computer to access the internet.

All participants of this study were patients of a Community Nursing service, receiving care for their chronic wound. Most participants who mentioned the Community Nurses talked about them as providers of wound care; only Grace stated that it was the Community Nurse's role to provide foot care for her. The findings of the current study have resulted in more questions being asked. Are District Nurses aware of the need to provide foot care to diabetic clients who cannot do it for themselves? If they are visiting people to check blood glucose levels and give insulin, then this should be part of the patient's care. The participant Grace was probably quite rightly the most dependent participant, as the researcher was aware that Grace relied on the Community Nurse to administer her insulin and conduct her foot care as she had some short term memory problems, and, whilst she was safe enough to live at home alone and able to make decisions for herself, she could not always remember to take her insulin at the appropriate times therefore she required assistance. The researcher is aware that it is not standard practice for nurses visiting diabetic patients for medication management to provide support with foot care. Although this study has not assessed this, participants such as Grace do identify a need for foot care to become part of the standard care received by diabetic patients requiring assistance with their condition management. Grace's statement about neglect during

her interview suggested a need for up-to-date education for the nurses providing her care. Do the Community Nurses provide education to their patients and is it effective? It is unclear what, if any, foot care or education is provided by District Nurses. This is an area that needs further investigation in the future.

Interestingly, Schmidt, Mayer and Panfil (2008) found that participants in their study needed to attend more than three education programmes to equip them with the skills and knowledge required to care for their own feet. The researchers identified this from participants' responses. Those who had attended three or more education programmes conducted a higher level of foot care than those who had received less. Again, as many of the participants of the current study could not recall what education they had received, it was not surprising that levels of foot self-care were low, indicating a clear need for change.

At the end of their interview, participants were asked to identify their health related goals. Five participants had non-specific goals around staying healthy, one focused on getting the wound healed, one losing weight, and two did not identify any goals regarding their health. Interestingly, when looking at patients' goals in relation to what they wanted to know about their diabetes management and wound healing, their goals and what they want to know are often not connected. It was anticipated that people would want to know things to help them achieve their goals. In reality there were six participants who did not identify anything that they wanted to know, despite having goals related to wound healing and staying healthy. Rather alarmingly, one participant could not recall what information and education she had received. Fran had a non-specific goal of wanting to keep healthy, but did not feel she needed to know anything more, stating:

*I know it all I'm sorry. (Fran, 6.50).*

It was identified earlier in this thesis that it may be the case that some people would not want to know more and it has been proven that some people do not. For a variety of reasons, Fran felt she knew all she needed to know, and Henry didn't feel he needed to know any more as he felt he was too old to learn. Misra et al. (2012) found that females and older people over 65 were less likely to ask questions and were more likely to feel anxious. Anxiety wasn't identified as a problem within the current study, but a lack of desire to know more was. If people are more motivated to learn, wound healing outcomes are improved (Misra et al., 2012). This is most likely due to the fact that people who are motivated to learn may transfer this motivation to their condition management, leading to better outcomes. Conversely, if people are unmotivated to learn what they can do to improve their health, this may contribute to poor

outcomes such as a long term chronic wound. This is reflected amongst the participants of this study.

#### **5.4.1 Health literacy**

It has been noted that Carl, who had the highest level of education (University), did the most foot care activities and used technical terms related to his condition, although his knowledge of the link between his diabetes and his wound was limited. Gorter et al. (2011) suggested that those who have higher education levels are more willing to accept responsibility for their own health. However, although he was the most educated participant, Carl was not necessarily taking full responsibility for his own health. He was the only participant to talk about not appointing blame for his wound occurring, as he talked about how he couldn't see that this was anyone's fault, suggesting this was something that he had considered. He also spoke of going to the diabetes centre as part of his foot care, which was classified as a passive foot care activity in the analysis (Chapter Four).

Khamseh et al. (2007) stated that participants in their study who were the least educated, were the least knowledgeable. In the current study, Grace had the lowest level of education, stating she did not go further than primary school. Grace appeared the most dependent on others for her care and had no knowledge of the link between her diabetes and wound. When asked during her interview, Grace indicated she was keen to learn more; however, it was evident from her lack of knowledge that she had clearly not sought out information for herself in the past. De Berardis et al. (2005) found that lower limb complications were higher in those with low levels of school education. All participants of the current study had a lower limb wound but, as there were only nine participants, a larger study would be necessary to identify a possible link between health literacy and diabetes complications.

As previously discussed in Chapter Two, health literacy needs to be taken into account when planning patient education. Ascertaining what people are able to understand needs to be assessed on an individual basis (Gazmararian et al., 2003; Tang et al., 2008). New's (2010, study on co-created health education programmes involved health professionals collaborating with patient groups to create an appropriate learning environment. If utilised, it would be necessary for health professionals to use this as an opportunity to identify the health literacy of their patients and develop different education strategies that are appropriate for the differing levels of health literacy. It may be that health professionals need more instruction on how to assess health literacy because we cannot treat everyone the same. A holistic approach taking the whole person into account is required with every patient we treat, to ensure they

are getting what they need. This emphasises a need for health professionals to be equipped with a variety of tools to enable them to provide the most appropriate education and information to each patient they see. It is not just patients' ability to understand information that we need to consider, but also their ability to receive it. With an aging population and the complications of diabetes, including failing eyesight (retinopathy, discussed in 1.6.1), perhaps we need to think about how information is delivered. It may be the case that methods usable by younger groups will not be suitable for older people (Speros, 2009). We cannot assume that because one patient in a similar situation understands what we are saying to them, that they all will, and we as health professionals need to cater for this.

It was noted during the analysis that some participants were quite dependent on others for aspects of their care and some were not doing activities that would be to their own advantage, such as foot care. A study on nurses' experiences suggested non-compliance with treatment contributed to poor wound healing (Hallett et al., 2000). Merriam-Webster's online dictionary (2013, noncompliance) defines non-compliance as "failure or refusal to comply". However, if patients such as those interviewed as part of the current study are not fully informed of tasks they can do to protect their health, they cannot be accused of non-compliance with treatment. Their lack of knowledge suggests gaps in care delivery with patients not being given all the information they need from health professionals involved in their care. Further, Bell and Duffy's (2009) study talked about trust between nurses and patients. Nurses may sometimes trust that their patients are doing activities to protect their own health; however, it is evident from the findings of the current study that this trust may be misguided. As participants did not appear to be fully informed of strategies to prevent complications and what they needed to do to conduct standard diabetic foot care, the patients' trust in those providing their care may also be misguided.

Self-efficacy is "An individual's perceptions of his or her ability to overcome the difficulties in a specific task that will predict future attempts to engage in various behavioural challenges related to this task" (Mishali et al., 2011, p 82). Explaining this further, self-efficacy is about how we perceive our own capability rather than the reality of how capable we actually are (Williams, 2010). Self-efficacy impacts on a patient's ability to follow recommended treatment, as does health literacy, therefore it needs to be considered and assessed to enable the provision of appropriate interventions to the patient (Mishali, Ome, & Heymann, 2011). Relating back to health literacy, those with lower levels of this may find it harder to identify shortfalls in the care they receive, possibly putting them at higher risk of complications arising. Therefore to help ensure patients receive care and information that is relevant to them, as

nurses we must assess each patient's self-efficacy (Mishali, et al., 2011). Both Ishikawa, Takeuchi, and Yano (2008); and Sarkar, Fisher, and Schillinger (2006) assessed health literacy, diabetes knowledge and self-efficacy in their studies and found they can all impact on self-management behaviours of people with diabetes. With a condition like diabetes there are many challenges faced by the person experiencing the condition. It is not just as simple as not eating sugar to control the condition. As well as dietary considerations there are other factors to take into account, such as emotional and physical effects. Some people with diabetes may see that they are capable of managing their diabetes by avoiding sugary foods but in reality they are not successfully managing their diabetes as other things such as carbohydrate intake and exercise/activity levels impact on their glycaemic control. By assessing self-efficacy in relation to diabetes management, it may be possible to identify and clarify misunderstandings, although it may be necessary to use a more formal assessment tool such as a questionnaire which would be more suited to a quantitative study.

In the current study, some of the participants demonstrated low levels of self-efficacy. Henry showed no clear desire to overcome the difficulties he was facing and did not indicate he wanted to make any changes, but, rather, continued with the status quo. However, Fran was quite the opposite, showing an inflated level of self-efficacy as she appeared over-confident in her ability, yet she did not appear to have the knowledge to back it up (Williams, 2010) . At both ends of this spectrum these participants could, in fact, be at high risk of complications from their diabetes. Not showing an interest in learning more about the condition and thinking one knows it all can leave one vulnerable to developing problems.

### **5.5 Holistic care: more than the task at hand**

As previously discussed in the introduction to this chapter, holistic care is not necessarily delivered to the participants. Ghanbari et al. (2005) stated that a holistic approach to diabetes care, where the person as a whole is assessed and treated, instead of a task-focused method of care delivery, needed to be employed in order to improve outcomes. The recruitment process of the current study raised an issue. Many nurses did not appear to be identifying that the wound care patients they were visiting were also diabetic and therefore were not referring people to participate. Whilst no patient actually states it, the information or rather lack of it suggests that nurses may be task-focused and not looking at the person as a whole. It is necessary to take a holistic approach when developing health education. Culture, medical history, attitudes to health, and pre-existing diabetes knowledge need to be considered when developing education strategies and delivering interventions (Mensing et al., 2006). Holistic care is also necessary to improve wound healing. Simply putting a dressing on a wound will not

make it heal. Glycaemic control, diet, other health problems, and social problems, all need to be addressed to enable healing to occur (Russell, 2000; Russell, 2001). Conducting a thorough holistic assessment will enable nurses and other health care professionals to identify areas that need addressing and work with patients towards the common goal of wound healing.

### **5.5.1 Opportunities being missed**

Nurses need to use the time they have with patients effectively. When visiting for wound care, nurses should endeavour to encourage patients to ask questions, and provide them with education as required (Misra et al., 2012). Participants in the current study were regularly visited (at least once a week) by Community Nurses for wound care; however, no participants mentioned their Community Nurse as a source of information on diabetes management or how to improve wound healing. It may be the case that the participants did not identify informal education received during wound care visits as actual education or they may have not received any information at all from the nurses visiting them at home. It may have been beneficial to ask patients how they would define health education. Siminerio, Funnell, Peyrot, and Rubin (2007) found that nurses were more effective at providing health education to patients than doctors were. This was due to nurses having more time and being more proactive in promoting effective self-management than doctors. The findings of the current study do not reflect this. Flood's (2009) study, investigating interactions on foot care, suggested nurses working in the community setting have more opportunities to have effective interactions which could be seen as opportunities for education on diabetic foot care with patients to occur. However, the current study's findings suggest that these opportunities are being missed.

As health professionals should know the risks their patients face, they should impart this knowledge to help improve outcomes (Lavery et al., 2008). Although this does not appear to be occurring, the reasons are unclear, but possible reasons will now be further discussed. It may be there is insufficient time to allow nurses to build therapeutic relationships where they feel confident providing information and education to their patients, despite other studies suggesting they are in a good position to be achieving this (Flood, 2009; Robert & Newton, 2011). Time can play an important part in the development of successful therapeutic relationships in health care, as demonstrated in Babwah's (2011) study. Patients seen in a specialist clinic which allowed for longer interactions showed an improvement in diabetes control.

It may be the case that the nurses are not identifying it as their role to deliver such information. To ascertain if this is the case, a study of nurses' perceptions of their role in health education to promote condition management would be required. It is of note that patients of the District Nursing service are often seen by different nurses. This is an intentional strategy on the part of the service to prevent the development of dependent/unhealthy relationships. However, continuity in care can be especially beneficial when trying to establish a patient's knowledge and understanding (Delamater, 2006). It may be the case that different nurses going in to a patient result in assumptions being made about what information has been delivered to the patient previously. When interviewed, Albert suggested he did not like to be lectured by health professionals. If different nurses go in to visit a patient and repeat the same information, it may result in patients feeling like they are being lectured. To prevent this will require nurses skilful in assessing knowledge and the needs of their patients, so repetition can be avoided.

Participants of the current study spoke of their community nurses as sources of wound care and one client said they thought their District Nurses were responsible for foot care. Grace stated it was the nurse's role to do foot care for her as she could not do it for herself. However, no participants talked of the District Nurse as a source of information or education. As previously discussed, interactions may be occurring but may not be identified as education as it may get lost within an interaction about wound care. When talking about sources of support/advice or information, participants spoke of other health providers including general practitioner, practice nurse, podiatrist, dietician and diabetes centre nurses. This suggests that most of the participants did not see their District Nurse as a resource with the potential to provide education and inform them about their diabetes and the associated complications. It may be beneficial for a study to be conducted looking at how District Nurses perceive their role in the provision of education to promote well-being and disease control for diabetic patients, especially those with complications such as wounds.

## **5.6 Summary**

The findings of this study have been discussed in relation to the available literature. Some participants were identified as taking ownership over aspects of their health whereas the majority placed responsibility on others. The latter was under the themes of *'Letting someone else deal with it'* and *'Ownership'*. It was unclear if the act of letting someone else deal with their health problems was because they chose for it to be this way or it was imposed upon them by the services providing their care.

The analysis of the interview transcripts did not reveal whether participants of the current study felt they were having their autonomy and right to equality respected by those delivering care and education; however, this was not directly asked (Hornsten et al., 2005).

Health professionals need to make sure they are aware of patient expectations and plan care delivery appropriately, and need to make patients aware of the potential risks of not conducting tasks such as foot care. Audulv et al. (2010) identified that people who leave care to others are more vulnerable to injury or complication than those who are active participants in the management of their condition. To improve health and quality of life it is necessary to ensure patients are fully informed of what they can do to keep themselves healthy and aware that they can make a difference to their own health (Audulv et al., 2010; Redman, 2007; Spikmans et al., 2003). Taking ownership for your own health can be a positive experience with positive outcomes (Audulv et al., 2010). Health professionals cannot make assumptions about patient knowledge and understanding; it is necessary to identify what patients know and ensure they are fully informed (Matthews et al., 2009; Redman, 2007).

If a person has no experience of a complication, he or she may not feel that certain aspects of education and care are relevant (Searle et al., 2008; Spikmans et al., 2003). It was evident that many participants were not connecting the delayed healing of their wound to their diabetes and therefore may not have thought certain aspects of care were relevant to them. Seven out of the nine participants did not make a clear link between their T2DM and the healing of their wound, which confirms findings from Gale et al.'s (2008) study. This lack of awareness of the link between their diabetes and chronic wound suggests that the participants are at risk of wound complications such as infection, and delayed healing caused by poor circulation (Ekmektzoglou & Zografos, 2006; McCance et al., 2010; Sheetz & King, 2002; Singer & Clark, 1999). The research question was based on identifying what people understood of this link. As the majority of participants were not making a link between their diabetes and wound, this suggests changes to care delivery are required to make people with diabetes aware of the risks they face and give them the skills to identify potential problems, prevent them, and improve outcomes for all people with T2DM.

Whilst some people did express that their conditions affected their quality of life, some did not experience any problems that they felt impacted on their QOL. So, whilst Lloyd et al. (2001) state even minor complications in diabetes can affect QOL, the current study suggests that this is not always the case, as seen with participant Fran who denied any impact on her QOL from her wound or diabetes. However, amongst other participants, mobility and pain were identified as factors affecting QOL. Whereas Byrne and Kelly (2010) said pain was the main

problem experienced by the people with chronic wounds included in their study, the current study found that mobility was just as much of a problem for participants. However, their experiences of reduced mobility did not leave them feeling socially isolated, as has been described in other studies (Brod, 1998; Oka & Sanders, 2005; Ribu et al., 2008). There is no denying that being a diabetic person with a chronic wound can affect quality of life. However, the current study is too small to identify whether variables such as wound duration/severity or diabetes duration impacted on QOL (Goodridge et al., 2005; Gurková et al., 2009; Lloyd et al., 2001; Koopmanschap, 2002). A QOL tool would be beneficial for assessing how chronic conditions and the associated complications affect a person. Just asking how it affects QOL did not gain much information and participants may have not clearly understood what was meant by QOL. A tool that breaks down the aspects of this may have garnered more meaningful information.

A person's quality of life can be affected by a chronic wound as well as by being a diabetic; therefore actions to prevent wounds developing could be seen as beneficial to QOL. However, foot care knowledge and practice amongst participants was poor, which was not surprising, and confirms the findings of other recent studies investigating foot care practices of people with diabetes (Abu-Qamar & Wilson, 2011; Jinadasa & Jeewantha, 2011). As foot care practices were poor amongst the participants it became clear that further education is needed on diabetes self-management to help improve outcomes and each patient's ability to follow recommended treatment (Hallet et al., 2000; Hornsten et al., 2005; Spikmans et al., 2003).

However, patient education alone has been identified as not being enough to improve outcomes, even though some education is better than none (Adolfsson et al., 2009; Dorresteijn et al., 2012). Insufficient knowledge is a barrier to successful diabetes management. By providing education, health professionals can enable their patients to effectively manage their diabetes, although more support is also needed (Anderson & Funnell, 2005; Nagelkerk et al., 2006). As five participants could not recall what education they had received in relation to their diabetes and wound healing, this would suggest the long term effectiveness of any education they had received may have been poor (Norris et al., 2001). Also, it cannot be assumed that people will want to know more regarding their health; however, motivation can help improve outcomes (Misra et al., 2012).

The current study asked participants what styles/methods of education they preferred to receive and offered suggestions if they could not initially think of anything. Only six responded, with some choosing more than one option. Leaflets and one-to-one sessions were equally preferred, with only one participant wanting to use internet resources. Other studies have

suggested a need for individualised education for people with diabetes, however this may be very expensive to achieve with the growing number of people with the condition (Kreuter et al., 1999; Mensing et al., 2006; Pibernik-Okanovik et al., 2004). Taking this further, Kreuter et al. (1999) suggested that one education delivery method is not enough; therefore it is evident that more research is needed to identify education preferences. Perhaps a selection of resources should be prepared, such as leaflets, videos, websites, or learning packages that are available to be used as required. This may reduce time constraints and rather than having one size fits all, or tailored education, the variety of options may cover most patients' needs, which, in turn, will help control costs (Kreuter et al., 1999). Looking to the future, online resources need more research and development to make them usable for all people who can access the internet (Glasgow et al., 2012; Misra et al., 2012).

The level of general education received can influence a person's ability to interpret and utilise health information/education they receive, (De Berardis et al. 2005; Gazmararian et al. 2003; Khamseh et al. 2007; Tang et al. 2008). Health literacy was identified as a factor that needs to be taken into account when providing education and information to patients. Carl and Grace were at opposite ends of the spectrum and their responses reflected the findings of other studies, (De Berardis et al., 2005; Gorter et al., 2011; Khamseh et al., 2007). This finding emphasises the need for differing degrees of health education to ensure it meets the education levels and abilities of patients. Physical factors such as vision need to be considered when developing education. A leaflet in large print or a one-to-one session with a health professional would be of more benefit to a patient with failing eyesight than giving them a general information leaflet in standard print that they cannot use.

Nurses, especially those working in the community, have great opportunities to provide education and impart knowledge to patients during their visits. However, as participants did not identify their District Nurses as sources of information and/or education, it may be the case that this is not occurring. It has been identified that opportunities for interactions are being missed, despite other research suggesting that community nurses are ideally placed to have effective interactions (Flood, 2009; Roberts and Newton, 2011). Nurses need to look at the whole person and ensure both physical and psychological needs are met when providing care and education, ensuring the provision of holistic care (Ghanbari et al., 2005; Mensing et al., 2006).

## Chapter Six

### Conclusions and recommendations

This study has found that participants in most cases did not make sufficient links between their diabetes and their wound nor did they appear to understand how their diabetes and glycaemic control could affect their wound. Despite suffering what could be deemed serious complications (chronic wound/ amputation) of their diabetes, many participants were unaware of what actions they could take to help prevent complications occurring.

In some cases participants were not taking responsibility for their diabetic foot care and were passing this on to others with expectations that someone else would monitor and treat them. It is unclear if this is due to their making a conscious decision to allow others to take responsibility, or other people (health care providers) are taking on the role without detailed consultation with their patients. To successfully move into the future, this needs to be rectified by promoting independence and responsibility for one's own health, where appropriate. This will help not only to improve outcomes but also to reduce the burden on already overstretched health services, both in New Zealand and internationally. It has been identified that it may not always be appropriate for independence to be expected from patients, with participants such as Grace emphasising this point, and with an aging population in New Zealand it may be that more people move from independence to dependence (Waterworth & Jorgensen, 2010). With this expected shift it is vital that people should be able to trust that they will receive good care from the health professionals they see (Waterworth & Jorgensen, 2010).

#### 6.1 Looking back at the aims of the study

In the introduction to this thesis the aims of the study were identified as being:

- Learning how the participants understood the relationship between their T2DM management and chronic wound;
- Identifying preferred methods of health education/information delivery;
- Finding out knowledge of and practice relating to diabetic foot care amongst the participants;
- Finding out the impact of T2DM and chronic wound on quality of life.

In the conclusion to this study it is apparent that improvements are needed to diabetes self-management education strategies and this study has identified that knowledge of links between diabetes and wound healing are poor, as exemplified in the participants' self-care

practices. This study has therefore identified gaps in knowledge that need to be addressed. Participants identified that they prefer leaflets and one-to-one sessions for education delivery, suggesting that informative literature needs to be formulated and health professionals working with this group need to be educated to equip them to act as resources for their patients. However, it was noted that participants were given the suggestions of leaflet, classes, websites and one-to-one sessions by the researcher conducting the interview, as none of them was able to answer the initial question about education preferences without prompting. This may have skewed the results and it may be that some people did not have any preference for education delivery, and/or participants did not actually have any interest in health education, such as Albert, Duncan, Edward, Fran, Henry and Isabel, (See Table 3 p.74).

This study also identified that some participants did not feel that being a diabetic person with a chronic wound affected them. When asked about this as part of their interview, this was not expected as the researcher held a pre-existing belief that the phenomenon of being a diabetic with a chronic wound would affect the quality of life of participants in a major way. However, some participants appeared to be coping with the problems they faced, without perhaps realising that this constituted an impact on their quality of life.

## **6.2 The research question revisited**

What do people with T2DM, who also have a chronic lower extremity wound, understand about the management of their condition and the complication of a wound?

It has been found that the majority of participants in the current study did not understand how their diabetes control could affect the healing of their chronic wound. Only Brian and Duncan showed a clear understanding of how diet can impact on blood sugars and healing, with Duncan making the clearest link:

*Now that I have got it (diabetes) relatively under control, um, I healing up twice as fast, I think that the out of control of my diabetes held back my healing and I've um, I've been on better diabetic control since..., they put my Glargine (insulin) up..., and they have given me this (opens up sheet with diabetes regime information on it). (Duncan, 4.36-4.39).*

Carl understood that diabetics found it harder to heal but the way he stated this made it appear to be hearsay and it did not indicate he truly understood the link. The remaining participants did not make a link between their diabetes and wound. This study shows that all participants would benefit from further education to help improve their knowledge and skill

base to help them successfully manage their diabetes and help create conditions to promote healing of their chronic wound. However, it was evident from the participants' responses in Table 3 (p.74) that not all participants were open to learning anymore and as a result it has been identified that education alone is not enough. More support is needed for patients and education for health care providers would be beneficial for improving outcomes.

### **6.3 The themes**

The analysis of the data gathered during the interview process revealed five themes relating to areas explored within this study. The first theme of *'Letting someone else deal with it'* was identified from participants leaving tasks such as foot care to health professionals involved in their care. Many of the participants were vulnerable to developing further complications because they were not engaging in their own care (Audulv et al., 2010). However, the discussion identifies that it can be appropriate for patients to let health professionals be responsible for diabetes management when they are no longer able to effectively do this for themselves but this needs to be identified and addressed by health professionals to prevent people being left to self-care when they aren't capable (Gorter et al., 2011; Waterman & Jorgensen, 2010).

The second theme of *'Ownership'* came from some participants trying to take responsibility for their own health. This was in keeping with the strategic goal for the region, to enable people to be responsible for their own health (CDHB, 2011). This goal suggests health professionals have a responsibility to provide patients with the knowledge and skills to achieve this.

From the analysis and discussion, the fact that participants were *'Not making the link'* between their diabetes and how it may affect their wound healing suggests they were not fully informed. This concurred with Gale et al.'s 2008 study.

From the analysis of the information relating to quality of life it was evident that many participants were *'Coping with it'* and were getting on with their daily life despite their diabetes and the complication of a chronic wound. It was evident that the severity of complications in the participants' wounds did not necessarily impact on quality of life, and feelings of social isolation were not identified despite other studies indicating diabetic people with wounds may experience this (Brod, 1998; Oka & Sanders, 2005; Ribu et al., 2008).

*'Self-care practices'* were identified through the analysis as being poor in relation to diabetic foot care. The participants showed little knowledge of diabetic foot care, and education alone will not improve outcomes for such people (Adolfsson et al., 2009; Dorresteyn et al., 2012).

Health literacy was included in the discussion on self-care. Two participants at opposite ends of the education spectrum emphasised the impact of health literacy on diabetes management, however it is not a simple thing and even the most educated participant was not fully informed regarding diabetes self-management. It was interesting to note that the person who knew the least about diabetes (Grace), wanted to know the most, whereas other participants who were clearly not fully informed felt they knew enough and didn't want to know more. To enable successful self-care, patients need to receive adequate assessment and information/education dependent on their needs. The study identified that holistic assessment/care isn't necessarily being effectively conducted by people delivering care to the participants of this study. Despite being regularly visited by community nurses participants did not identify their nurses as anything more than providers of wound or foot care. There was no mention of them as sources of education or information, despite the literature suggesting they are ideally placed to deliver such care (Flood, 2009; Robert & Newton, 2011; Siminerio et al., 2007).

#### **6.4 Implications for future practice**

Whilst this study has been a qualitative enquiry and the information gathered cannot be generalised to the rest of the population, the findings are important for all people with T2DM and a chronic wound. With such patients often being seen by multiple health professionals, it is vital that assumptions not be made about patient knowledge. Therefore health professionals need to be equipped with the skills to enable them to assess patient knowledge without causing offence to their patients. It is a nurse's role to deliver health information and education to patients, as required, as part of general nursing care. To achieve this they, along with other health professionals, must make sure they keep up to date with the latest information, to ensure best practice. Nurses need to be aware of their patients' willingness to participate in their own care, when planning interventions and on-going care. They also need to be able to identify patients who are not able to be independent with self-care and ensure they receive comprehensive care that encompasses all aspects of diabetes management. Nurses also need to be reminded that holistic nursing care, taking into account all things affecting the person and not just the specific problem, is important to address issues faced by diabetic patients with chronic wounds. This suggests a need to develop education programmes for health professionals to help them develop such skills.

Appropriate education and support are needed to enable those patients identified as willing to be responsible for their own health to do so effectively. Time and monetary factors limit the ability of health services to provide individualised education on a large scale, therefore the development of a variety of patient education delivery methods such as classes, leaflets,

books, websites, and health professionals skilled in the delivery of diabetes-related education would be beneficial. If health professionals had access to such a range of methods it would enable an 'off the rack' approach to health education where they have the choice to pick what is most appropriate for each patient on a case-by-case basis. This is as opposed to individualised or 'one size fits all' approaches to health education, which can be prohibitively time and money consuming, and lacking in suitability, respectively (Kreuter et al., 1999).

It cannot be assumed that patients who say they know all they need to know actually do; a tool is needed to enable nurses to easily assess this and ensure appropriate care and education is delivered (Mensing et al., 2006). It is also important that health professionals realise that their priorities may vary from those of their patients.

This study has confirmed the findings of other studies regarding diabetic foot care practices. Such practice was poor among participants (Abu-Qamar & Wilson, 2011; Jinadasa & Jeewantha, 2011). This needs to be addressed, nurses need to be champions for change and new strategies need to be developed that have an impact on patients and are memorable.

### **6.5 Recommendations for community nursing practice**

As this study was conducted in the community setting amongst participants recruited from a Community Nursing service, recommendations have been made relating to this setting. In the community nursing setting, it might seem that opportunities are being missed for effective interaction with patients. If such interactions were occurring there would most likely be an improvement in health outcomes, therefore more education is needed to increase the knowledge of nurses providing care to community patients and courses need to be developed to be taken as part of on-going professional development. An assessment tool to identify patients' diabetes knowledge and what their needs are should be developed to help ensure appropriate care is delivered to all patients. Diabetic foot care needs to be provided to all patients who are unable to do this for themselves and perhaps care pathways for diabetic patients with and without wounds should be developed, to ensure they receive the necessary care.

### **6.6 Suggestions for future research**

This study has asked many questions and while many can be dealt with by effecting change in nursing practice, some indicate a need for further research to gain a greater understanding. The suggestions for future research identified by this study will now be listed:

- A study to investigate factors affecting patients' desire to learn more about their chronic condition management.
- A study to identify why people are not conducting diabetic foot care.
- A large scale study to identify knowledge of diabetes, its associated complications and what education people are interested in receiving.
- A study to develop and trial a tool to easily identify what patients know about diabetes management and the complications associated with the condition.
- A study to assess patients' self-efficacy in relation to diabetes self-management.

### **6.7 Strengths and Limitations of the study**

As with anything, there are strengths and limitations within this thesis. The researcher decided not to recruit participants from among patients she usually visited, in order to reduce the risk of patients feeling pressured into participating. It was also a concern that the researcher might inadvertently affect the responses of participants if they were also being visited for nursing care. In some ways, this limitation in selection was strength of the study but in terms of recruitment it was a limitation. However, despite the trouble with recruitment it was decided to recruit participants only from outside the researcher's usual area of work. Response to recruitment was slow and made more difficult by the re-location of the District Nursing office in the middle of the recruitment phase.

The lack of response to the various recruitment attempts suggested a lack of interest in the research process by the majority of District Nurses. It may have been that they felt they had insufficient time to discuss the research with their patients during visits or a lack of knowledge about research in general may have prohibited them from becoming involved in the process, (Rizzuto et al., 1994; Roxburgh, 2005).

The researcher was conducting this study whilst also working full time, therefore time constraints limited this study. Recruitment was limited to a certain geographic area to reduce time spent travelling to conduct interviews and the costs involved with travel, so this will have reduced the number of potential participants.

This study was the first piece of research that the author had participated in and she was supported by two supervisors experienced in research, which enabled her to receive feedback and instruction on how to develop this thesis this would be seen as a strength of this study. Interpretive methodologies such as the descriptive exploratory methodology utilised for this study are emerging as worthwhile for use in nursing research, enabling researchers to let the information gathered take them wherever it leads. As the researcher was new to conducting

research interviews, her ability to do this task might have limited this study, especially when follow-on questions were necessary to gather more in-depth information. However, a lot of information was gathered in the course of this study.

### **6.8 Final summary**

This interpretive descriptive study has interpreted and described the information gathered through the course of the enquiry. Thematic analysis was used to analyse the information gathered during the course of interviewing nine participants in semi-structured interviews. Five themes were identified from interpreting the participants' responses; *'Letting someone else deal with it'*, *'Ownership'*, *'Not making the link'*, *'Coping with it'*, and *'Self-care practices'*. These findings suggested that whereas some people do not appear to want to take responsibility for aspects of their condition management, some do try and go some way towards achieving this. More research is needed to investigate factors affecting the motivation of patients to participate in education and self-management and what needs to be done differently to improve care. Making the link between diabetes and the complications experienced is important for patients and health professionals. If neither patient nor health care providers are identifying a link between diabetes management and wound healing it may be impossible to achieve good outcomes. As this study was conducted amongst a group of participants who were patients of a Community Nursing service, a possible need for further education for nurses working within the service has been identified. Such education would give them the skills required to assess patient knowledge and deliver appropriate education strategies. Community Nurses have the opportunity to work with patients to help with wound healing but it has been identified that a focus on caring for the person as a whole is necessary to help ensure all factors affecting wound healing are taken into account, such as elevated blood glucose levels.

If patients are aware of the link between their diabetes control and the healing of their wound and they realise that getting their blood glucose level within safe limits will help their wound heal quicker with less complication, they will ultimately have improved wound healing outcomes. Improvements in glycaemic control to aid wound healing may also reduce the impact of the many other complications of T2DM. Overall, this may improve the quality of life and life expectancy of people with the condition.

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## Appendix one

### Sample interview questions

Questions for the interview:

How old are you?

How would you describe your ethnicity?

What is the highest level of education/qualification you have?

How long have you been a diabetic for?

How long have you had this wound?

How do you feel your diabetes control effects your wound?

Prompts: Is there anything you do that makes it better?

Is there anything you do that makes it worse?

What is your understanding of how your wound may be related to your diabetes?

What do you usually do to care for your lower legs and feet?

What is your understanding of diabetic foot care?

How would you feel your wound and diabetes effect quality of life?

Prompts: Does it stop you doing things you would like to do?

You have had this wound for over a month now,(or) quite some time, how do you feel about that?

Tell me about the information and education you have received from the doctor/nurse you see about your diabetes and wound...

Prompts: What could have been better?

What did you find useful?

What other things do you want to know regarding your diabetes management and wound healing?

If nothing: why do you not want to know anything more?

When it comes to education about health issues what do you prefer?

Prompts: Do you like classes/leaflets/websites/one on one session's?

Why do you prefer this method over others?

Tell me about any goals you have regarding your health...

**Appendix two**

Information for research participants sheet and consent form

**Participant Information Sheet**

Study title:	<b>How adults with T2DM and a chronic lower extremity wound understand the link between their wound and their diabetes management.</b>	
Locality:	<b>Christchurch/Nurse Maude Association.</b>	Ethics committee ref: EIT 32/12; Nurse Maude approval dated 27/8/2012
Lead investigator:	<b>Lucy Beams</b>	Contact phone number: ***** or *****

This document is **four** pages long including consent form.

You are invited to take part in a study on diabetes and its impact on chronic wounds to the lower limbs.

**Why are we doing the study?**

- To learn more about people with diabetes and their experiences of living with a chronic (long standing) wound to the lower leg, foot or toes.
- To identify what people already know about T2DM management and their wound;
- To explore peoples understanding of how their diabetes can affect their wound healing;
- To identify what people would like to know more about to help improve their ability to manage their diabetes and rate of healing.

This Participant Information Sheet will provide you with the necessary information to help you decide if you would like to take part in the study. It sets out why the study is being done, details what your participation will involve, what the benefits and risks to you might be, and what will happen after the study ends. The researcher will go

through this information with you and answer any questions you may have, it is expected this process will take about 30 minutes. You may also want to talk about the study with other people, such as family, whānau, friends, or healthcare providers. Feel free to do this.

Whether or not you take part is your choice. If you do not want to take part, you do not have to give a reason, and it will not affect the care you receive. If you do want to take part now, but change your mind later, you can pull out of the study up until the time you have completed your interview or have verified your interview transcript if you chose to do this.

The person conducting the interviews is a registered nurse working for Nurse Maude Association the study is part of their Masters Degree in Nursing. They will not be the nurse who usually provides your care and will be seeing you in their capacity as a researcher not a nurse.

If you agree to take part in this study, you will be asked to sign a consent Form .You will be given a copy of this form and the Consent Form to keep.

### **What would your participation involve?**

- Reading this information for participants' sheet;
- Asking any questions you have;
- Signing a consent form when you are happy to do so;
- Being interviewed by the researcher in your home or other suitable location, this will take approximately one hour and will be audio recorded with a digital recording device and the researcher may also take handwritten notes
- Talking about your experiences of living with diabetes and a wound;
- If you choose to, the researcher will return the interview transcript to you so you can read it and confirm it has been recorded correctly or make any changes you feel are necessary.
- It is anticipated that it will take about 30 minutes to read this information, ask any questions and sign the consent form, the interview will last approximately 60 minutes. It may take up to 30 minutes to read the interview transcript and make any changes necessary if you choose to do this.

**What are the possible benefits and risks to you of participating?**

**Benefits:** Being able to provide information on your experiences to help develop and improve the care received by all people with T2DM.

**Risks:** The questions asked in the interview may provoke thoughts about your own health and may unintentionally make you upset. Every effort will be made to ensure you are comfortable and free from upset but if this occurs, the researcher will suggest you contact your usual health provider for advice/support.

It will not affect your current care if you participate in the study. If you choose not to participate, it will not affect your future care.

The study has approval from the Nurse Maude Association and the Eastern Institute of Technology, (EIT) ethics committees.

**What are your rights as a participant in the study?**

- Participation in this research is voluntary, you are free to decline to participate and you can withdraw from the research up until the time you have completed your interview or when you verify the interview transcript (if you choose to do this) without experiencing any disadvantage.
- No one will be able to identify you from the interview transcript as your name will be removed and a pseudonym will be used. The transcripts and consent forms will be stored separately. Only the researcher will have access to your contact details.
- You can retain a copy of the interview transcript if you wish to do so. Please let the researcher know and they will provide you with a copy you can keep.
- You can request a summary of the research to be posted to you on completion of the study.

### What will happen after the study ends, or if you pull out?

- If you choose to pull out of the study that is your choice, if the interview has been completed the transcript can be returned to you or destroyed and the audio recording will be deleted.
- Study data will be stored for 10 years in a secure locked box; any electronic data will be password protected and only available to the primary researcher. The data may be used to inform future research but it will be de-identified so no one will know it came from you.
- The data will be destroyed in a secure way with paper documentation (transcripts, consent forms), being disposed of through a secure document disposal company (e.g. Recall), advice will be sought on how to thoroughly delete information from the computer used throughout the research.

### Where can you go for more information about the study, or to raise concerns or complaints?

If you have any questions, concerns or complaints about the study at any stage, you can contact the researcher (details at top of form) or:

Research Supervisor: Lesley \*\*\*\*\*

Telephone number: \*\*\*\*\*

Email: \*\*\*\*\*

Associate supervisor: Judy \*\*\*\*\*

Telephone number: \*\*\*\*\*

Email: \*\*\*\*\*

If you want to talk to someone who is not involved with the study, you can contact an independent health and disability advocate on:

Phone : 0800 555 050

Fax : 0800 2 SUPPORT (0800 2787 7678)

Email : advocacy@hdc.org.nz

# Consent Form



## Declaration by participant:

I have read, or have had read to me, and I understand the Participant Information Sheet. I have had the opportunity to ask questions and I am satisfied with the answers I have received.

(Please tick all that apply).

I consent to participate in this study:

I consent to being interviewed:

I consent to my interview being audio taped and notes being taken:

I understand I will not be identified in the write up of the study:

I wish to read the transcript from my interview to confirm it has been recorded as I intended:

Yes  No

I wish to receive a summary of the research when the study is completed:

Yes  No

**All participants will be given a copy of the participant information sheet and consent form to keep.**

Participant's name:

---

Signature:

---

Date:

---

**Declaration by member of research team:**

I have given a verbal explanation of the research project to the participant, and have answered the participant's questions about it.

I believe that the participant understands the study and has given informed consent to participate.

Researcher's name:

---


Signature:

Date:

---

## Appendix three

## Recruitment poster 1



# Nurses

**Do you have a diabetic patient with a wound who may be interested in being interviewed about their condition?**

**What we are looking for:**  
**Participants who are...**

- Aged 30yrs +
- Have type 2 diabetes diagnosed for one year or more;
- A wound of thirty days duration or more to the lower leg; foot or toes;
- Participants must be English speakers,
- Competent and able to make decisions for themselves.

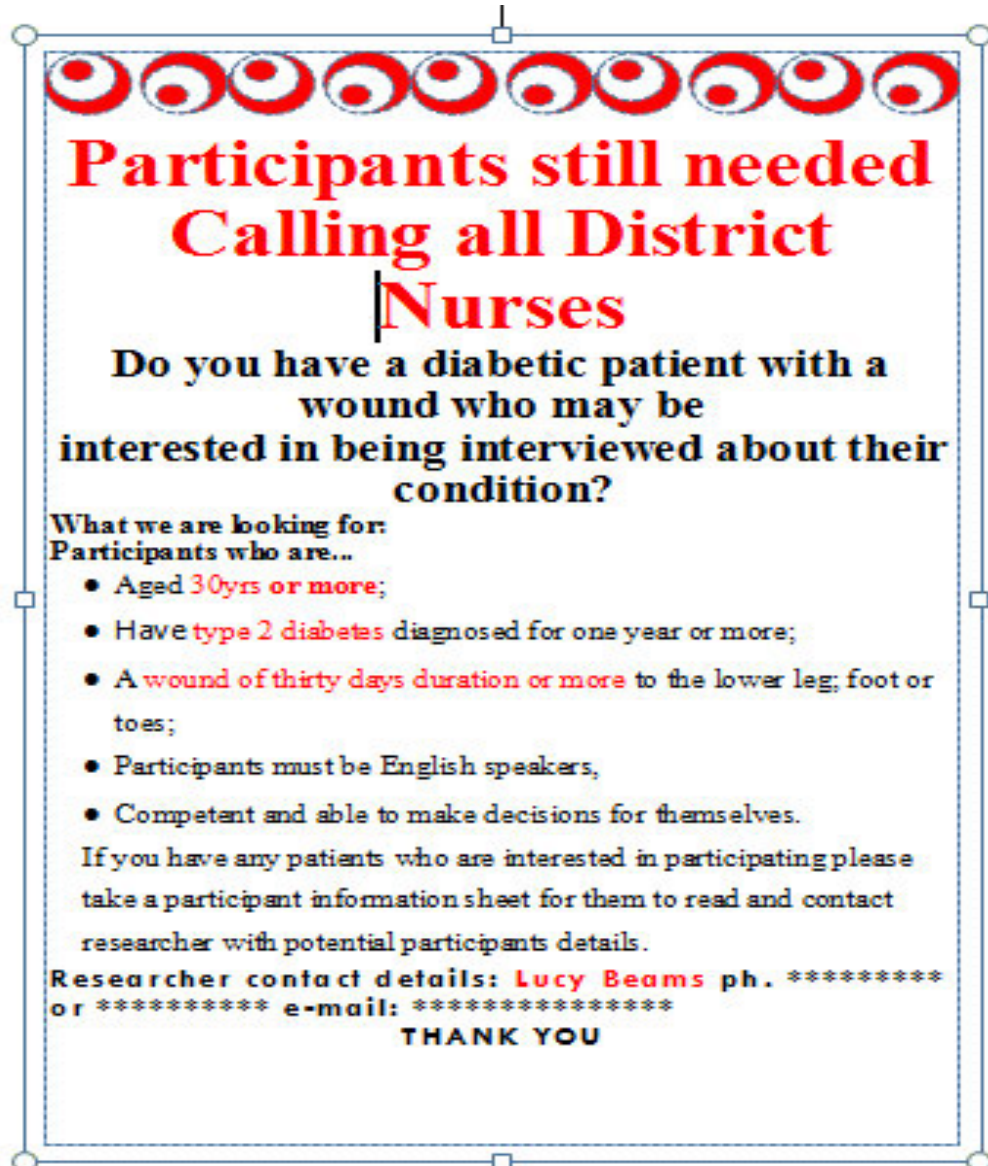
If you have any patients who are interested in participating please take a participant information sheet for them to read and contact researcher with potential participants details.

**Researcher contact details: Lucy Beams ph. \*\*\*\*\*  
or \*\*\*\*\* e-mail: \*\*\*\*\*@student.eit.ac.nz**

**THANK YOU**

## Appendix four

## Recruitment poster 2



The poster features a decorative border at the top with a row of ten stylized red and white circular patterns. The main text is centered and uses a mix of red and black fonts for emphasis.

**Participants still needed  
Calling all District  
Nurses**

**Do you have a diabetic patient with a  
wound who may be  
interested in being interviewed about their  
condition?**

**What we are looking for:  
Participants who are...**

- Aged **30yrs or more**;
- Have **type 2 diabetes** diagnosed for one year or more;
- A **wound of thirty days duration or more** to the lower leg; foot or toes;
- Participants must be English speakers,
- Competent and able to make decisions for themselves.

If you have any patients who are interested in participating please take a participant information sheet for them to read and contact researcher with potential participants details.

**Researcher contact details: Lucy Beams ph. \*\*\*\*\*  
or \*\*\*\*\* e-mail: \*\*\*\*\***

**THANK YOU**

Appendix 5

Nurse Maude Association Ethics letter

**Nurse Maude**  
*Leading the way in community care.*

27 August 2012

COPY

Lucy Beams

Dear Lucy,

This letter is to advise that the Nurse Maude Ethical Advisory Group have approved your application to undertake the study of "How Adults With Type 2 Diabetes and a Chronic Lower Extremity Wound Understand The Link Between Their Wound and Their Diabetes Management" as part of your Masterate Research Paper.

I understand that you have had an initial discussion with Jackie Walker, of the NZ Institute of Community Health Care. As part of the research process can you please keep Jackie informed.

Please provide us a copy of the Regional Ethics Committee approval prior to commencing the Research.

We look forward to receiving a report on your study.

Yours sincerely,

Sheree East  
Chairman  
Nurse Maude Ethical Advisory Group

Copy: Jackie Walker, Nurse Educator Research, New Zealand Institute of Community Health Care

**Appendix six**

## Eastern Institute of Technology Ethics approval



Reference Number 32/12

11 October 2012

Lucy Beams  
Master of Nursing Student  
C/- Faculty of Health Science  
EIT Hawke's Bay

Dear Lucy

Thank you for providing clarification regarding Health and Disability Ethics Committee approval. I am pleased to inform you that your research project "*How adults with type 2 diabetes and a chronic lower extremity wound understand the link between their wound and their diabetes management*" was approved by the Research Ethics & Approvals Committee at their meeting held on 31 August 2012.

You are reminded that should the proposal change in any significant way, then you must inform the Committee.

Please quote the above reference number on all correspondence to the Committee.

Please provide the Committee with a progress report after one year of the project and a brief summary at the conclusion.

The Committee wish you well for the project.

Yours sincerely

**Jeanette Fifield**  
Secretary – Research Ethics & Approvals Committee

**Eastern Institute of Technology**

**Hawke's Bay Campus** 501 Gloucester Street, Taradale, Napier, New Zealand P 06 974 8000 F 06 974 8910 E [info@eit.ac.nz](mailto:info@eit.ac.nz) [www.eit.ac.nz](http://www.eit.ac.nz)

Postal Private Bag 1201, Hawke's Bay Mail Centre, Napier, 4142, New Zealand

**Tairāwhiti Campus** 290 Palmerston Road, Gisborne, 4010, New Zealand P 06 869 0810 F 06 869 0825 E [info@tairawhiti.ac.nz](mailto:info@tairawhiti.ac.nz) [www.tairawhiti.ac.nz](http://www.tairawhiti.ac.nz)

Postal PO Box 640, Gisborne, 4010, New Zealand

**Regional Learning Centres:** Central Hawke's Bay, Flaxmere, Hastings, Maraenui, Napier, Ruatoria, Tokomaru Bay, Wairoa

## Appendix seven

## HDEC Letter



Health and Disability Ethics Committees  
1 the Terrace  
PO Box 5013  
Wellington  
6011  
0800 4 ETHICS  
hdec@moh.govt.nz

06 August 2012

Miss Lucy Beams

Dear Miss Beams

Re: <b>Ethics ref:</b>	<b>12/STH/5</b>
Study title:	How adults with type 2 diabetes and a chronic lower extremity wound understand the link between their wound and their diabetes management

I write to inform you that this application has been withdrawn from HDEC review, as it was validated in error. As per our previous letter to you of 18 July 2012 I can confirm that HDEC review is not required for this study.

I would like to take this opportunity to apologise for the issues that you have experienced in submitting your study for HDEC review, and to thank you for your feedback on how the process could be improved.

Yours sincerely,

Rohan Murphy  
Administrator  
Health and Disability Ethics Committees  
hdec@moh.govt.nz

**Appendix eight**

## Maori consultation

RE: this may assist your study

<https://mobile.nursemaude.co.nz/owa/?ac=Item&t=IPM.Note&id=...>**RE: this may assist your study**

Annette Finlay

**Sent:** Tuesday, June 19, 2012 2:37 PM**To:** Lucy Beams**Attachments:** Ethnicity pamphlet NM.pdf (145 KB) ; Graphs All Services May 2-~1.xlsx (64 KB)

Kia ora Lucy,

Thank you for meeting with me the other week to discuss your research proposal. *An exploration into how people with type 2 diabetes living with a chronic lower extremity wound understand how their diabetes affects their wound, how do their conditions affect them and what do they know about managing their conditions.*

I have read your proposal and it would be good for you to collect ethnicity data using the collection diagram in the above Nurse Maude pamphlet.

I have also provided a statistics NZ Website that may be of use to you and the latest Ethnicity Data Graph of Nurse Maude patients and clients. I am happy to support your study from a Maori perspective at Nurse Maude should you require any assistance during this time please feel free to contact me.

Naku noa

Na Annette Finlay

Maori Advisor

Nurse Maude

**Appendix nine**

**Research approval letter**



21 June 2012

Lucy Beams

Dear Lucy

The Faculty Academic Committee met on 19 June, and approved your research proposal topic *"How do adults with Type two diabetes and a chronic lower extremity wound understand the link between their wound and the management of their diabetes?"*, to progress.

If you have any questions, please do not hesitate to contact me.

Yours sincerely

Ruth Crawford  
MN9.490 Course Coordinator  
For the Faculty Academic Committee  
Faculty of Health Sciences

Cc: Dr Lesley Seaton; Judy Yarwood

**Eastern Institute of Technology**

**Hawke's Bay Campus** 501 Gloucester Street, Taradale, Napier, New Zealand. P 06 974 8000, F 06 974 8910 E [info@eit.ac.nz](mailto:info@eit.ac.nz) [www.eit.ac.nz](http://www.eit.ac.nz)

Postal Private Bag 1201, Hawke's Bay Mail Centre, Napier, 4142, New Zealand

**Tairāwhiti Campus** 290 Palmerston Road, Gisborne, 4010, New Zealand. P 06 869 0810, F 06 869 0825 E [tairawhiti@eit.ac.nz](mailto:tairawhiti@eit.ac.nz)

Postal PO Box 640, Gisborne, 4010, New Zealand

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