A QUALITATIVE STUDY OF THE IMPACT OF PRESSURE ULCERS ON PATIENTS’ QUALITY OF LIFE

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I would like to dedicate this thesis to my darling father Jim who I hope would be proud of me.

“All great achievements require time”

Maya Angelou
Declaration

This thesis is the result of my own work. The material contained in the thesis has not been presented, nor is currently being presented, either wholly or in part for any other degree or other qualification.
A QUALITATIVE STUDY OF THE IMPACT OF PRESSURE ULCERS ON PATIENTS' QUALITY OF LIFE.

ABSTRACT

Pressure ulcers are known to be costly for the healthcare system and delay recovery in many patients. As research continues to highlight the cost of pressure ulcers in humanitarian and financial terms, they are increasingly being used as a key quality indicator. Healthcare professionals and patients may make assumptions about what it must be like to experience a pressure ulcer. Understanding the phenomenon of living with a pressure ulcer is crucial to providing and planning care for the pressure ulcer patient and to enhancing the overall quality of life for these individuals. Pressure ulceration continues to be reported and discussed in the nursing literature whilst the methodological quality of some studies has been poor, there is no doubt that patients continue to suffer harm. One commonly implicated effect of pressure ulcers is a reduction in quality of life. This is believed to be due to factors such as increased pain, social exclusion, malodour and growing limitations on activity and mobility. This study aimed to explore how developing a pressure ulcer affected patients' quality of life. A qualitative approach in the style of phenomenology was used to explore and describe the experiences of people who had endured an episode of an open pressure ulcer. A purposeful sample of fifteen participants (10 females and five males) were selected, age range: 45-89 years. All the fifteen patients recruited, had a new episode of either a sacral pressure ulcer, or heel ulceration, which was graded three to four using the European Pressure Ulcer Advisory Panel grading system. Although grade one and two pressure ulcers are more common, they are not usually referred to the Tissue Viability service as grade three and four are treated as clinical incidents which have to be referred to the Tissue Viability Service. Homogeneous sampling reduces variation and permits a more focused inquiry. For complete confidentiality pseudonym names were given to the participants. Pressure ulcers can result in great discomfort and pain for patients. Enabling respondents to talk freely about their experiences of developing a pressure ulcer, rich data were obtained that should be helpful in understanding the impact of developing a pressure ulcer on people's lives. As emerging themes were similar following data collection the researcher took the decision to stop interviewing at fifteen participants. Six major themes were identified in the study; all the participants had a very good understanding of how a pressure ulcer developed. Each patient could remember exactly when the ulcer developed even though in some cases this had been a long time ago. All the participants expressed feelings of anger and frustration at the impact of developing a pressure ulcer had on their lives.
LITERATURE REVIEW

Pressure ulcers are a major cause of morbidity in the population, yet they are largely an unseen problem. It is known that the treatment and prevention of pressure ulcers is costly to health services, yet there is still little information on precise costs, suggests Franks (2007). They can lead to delayed discharge and are sometimes difficult to prevent (Hampton, 2001). The development of pressure ulceration is a problem associated with a number of concomitant conditions and a range of symptoms, and although little research has been completed on the impact on everyday life, there is an assumption that it affects health related quality of life.

Pressure ulcers remain a constant feature in an ever-changing health service. Bliss (1992) documented the descriptions of the condition by Sir James Paget in his patients in the mid 19th century. He recognised that pressure ulcers were an important complication particularly in the sick, the elderly and following surgery.

Langemo et al (2000) Qualitative work showed that the impact of pressure ulcers is wide ranging, with physical, social and financial aspects affected, whilst changes in body image and the loss of independence and control are profound. All eight patients in this study experienced a range of negative effects. Numerous studies suggest that pressure ulcers are present in 3-18.6% of patients in acute settings (O'Dea, 1993; St Clair and Hewitt-Sayer, 1993).

Franks et al (2002) studied the impact pressure ulceration had on pressure ulcer patients cared for in the community setting. Seventy-five patients with pressure ulcers were compared with a hundred controls without ulcers. Patients were interviewed using the Short Form-36 (SF-36) questionnaire in conjunction with tests of physical function (Barthel Scale) they found that while patients with pressure ulceration experience some deficits in their health-related quality of life compared with a normal population, these differences were similar to those experienced by other patients receiving community nursing care. Clark (2002), reporting on a cohort of 2,507 patients highlighted the difficulties of using generic self-report tools with this patient population.
The incidence of pressure ulcers increases with the older, hospitalised patient and there appears to be a correlation between the underlying diseases of old age and the incidence of pressure ulcers (Harding et al, 1993).

As research continues to highlight the cost of pressure ulcers in humanitarian and financial terms, they are increasingly being used as a key quality indicator. Developing a pressure ulcer is a key indicator of the poor quality of care a patient has received. Today, the development of a pressure ulcer may lead to the involvement of the legal profession and the care of the patient being scrutinised. In addition, prevention and treatment of pressure ulcers is expensive and it is estimated that the annual expenditure on pressure ulcers is as much as £321m. That is 0.8% of the entire NHS budget and equals the whole annual budget for mental health care (Bennett et al, 2004). Guidelines issued by the National Institute for Health and Clinical Excellence (NICE, 2005) and NHS Quality Improvement in Scotland (2005) state that, as a minimum, no patient at risk from pressure ulceration should be nursed on anything less than a high-density foam mattress. Without appropriate guidance, there is a danger that pressure-relieving equipment may be chosen according to staff preference, without rationale or financial basis (James, 2004).

The cost of pressure-relieving equipment will be a major deciding factor for the tissue viability nurse or whoever has the responsibility of selecting equipment; everyone working within the NHS is aware of budget control and the necessity of being clinically and cost-effective. Pressure ulcers can be costly, debilitating and painful and basic, effective nursing can be the key to offering good quality care to at risk patients. Although previous studies have identified signs and symptoms, prevalence and incidence through quantitative research, the impact of a pressure ulcer examined through qualitative research is limited.

The development of a pressure ulcer can occur within any specialism and has relevance to all patients. It is well recognised that with advanced age the risk of pressure ulcers is greatly increased (Gethin et al 2005) With an aging population, and advances in technology the costs associated with pressure ulcers will rise. A lack of clarity over which agency is responsible for providing and paying for the continuing care of elderly and chronically disabled people means this vulnerable category is at increasing risk.
The National Institute for Clinical Excellence published clinical guideline 7. 'Pressure Ulcer Prevention' (2003) which acknowledges that pressure ulcers have a profound negative effect on the physical, social and financial realms of people's lives. The guidelines found that there was a lack of formal economic evaluations and quality-of-life data, and that the clinical effectiveness data were of variable quality. It recommends that investigation is needed of the impact of pressure ulcers on the quality of life of individuals and carers, and of the quality of life achieved with different forms of pressure relief.

Search Strategy
A combined search of the electronic databases Medline and Cinahl was undertaken. In addition, key wound care nursing journals and conference proceedings were hand searched to identify published studies not in the database. A combination of search terms 'pressure sore', 'pressure ulcer', 'decubitus ulcer', 'quality', 'quality of life' and 'pain' was used, both as free text and subject headings. Years of search were between (1990 to 2007). While discussion of pressure ulcers and quality were often combined, limited primary data was found.

Exclusion: foreign citations

As a Clinical Nurse Specialist in Tissue Viability a lot of my time is spent educating and advising nurses, patients and carers on pressure management and prevention. Although we know how to manage and treat pressure ulcers effectively I have felt over the past few years that there is a deficit in the understanding and management from a patient's perspective of how developing a pressure ulcer had an impact on their quality of life. Health care professionals and patients may make assumptions about what it must be like to experience a pressure ulcer. Baharestani (1994) studied the “lived experience of wives caring for their frail, elderly husbands with pressure ulcers”.

Understanding the phenomenon of living with a pressure ulcer is crucial to providing and planning care for the pressure ulcer patient and to enhancing the overall quality of life for these individuals.

I decided to investigate quality of life in a particular sub-set of people with pressure ulcers, those who had deep ulcers and who have had pressure ulceration for more than six months in both the acute setting and the community. This sample of interest is different from the previous literature. Langemo et al (2000) revealed that the impact of having a pressure ulcer on people’s lives had an impact on their social, physical, financial status,
changes in body image and loss of independence and control. Fox (2002) explored the perceptions and feelings of five UK community dwelling patients with pressure ulcers, which were deep ulceration. Participants reported pain specifically related to their pressure ulcers and effects on their quality of life caused by problems with wound exudate, loss of independence, emotional factor and worries of healing, relationship, body image and social isolation. Although these studies provide useful insights into the impact of pressure ulcers, they are limited by the fact that they relate to patients with narrowly defined conditions living in the community.

The purpose of using a phenomenological approach in this study is to describe, understand, and to give meaning to the experience of living with a pressure ulcer. A lived experience encompasses meaning derived from being in the world. It is essential to discover this meaning to provide quality individualised care.
What are pressure ulcers?

Figure 1: Grade IV - Pressure Ulcer

(Patient photographed, patient's permission granted)

Pressure ulcers result in great discomfort and pain for patients as well as diverting a substantial amount of resources (Dealey, 1993; Moody, 1997) and are caused by a variety of intrinsic and extrinsic factors (Banks, 1997). Pressure ulcers (also known as pressure sores, bedsores and decubitus ulcers) are areas of localised damage to the skin and underlying tissue caused by pressure, shear or friction forces (Robertson et al., 1990). They usually occur over bony prominences such as the sacrum, heels, hips and elbows, most often in the immobile elderly people, patients with severe, acute illnesses and in people with neurological problems.

They occur in individuals who cannot tolerate the effect of these forces, with older people being the most vulnerable group (Moore & Pitman, 2000). Despite advances in modern technology and the huge array of preventive equipment available, pressure ulcer incidence is not declining (Wilson, 2007). Pressure ulcers have a dramatic effect on quality of life, contribute to increased morbidity and even mortality, and reduce individuals’ comfort and independence (Clark, 2002). They also delay hospital discharge, increase the burden on long-term placement and add to waiting lists, thus reducing the efficiency and efficacy of the health service in general (Clark, 1994).
However, any person of any age can develop a pressure ulcer if their general condition is sufficiently poor and they are inappropriately managed.

The problem of pressure ulcers is an ancient one; they have been reported in Egyptian mummies and probably have always existed in every human society. The treatment of pressure ulcers is described as far back as 1593 and in the 19th century many papers were devoted to the subject (Torrance, 1983).

A pressure ulcer is defined as any lesion caused by unrelieved pressure resulting in damage to underlying tissue. Pressure ulcers are usually located over bony prominences (such as the sacrum, coccyx, hips, and heels) and are staged according to the extent of observable tissue damage. Pressure ulcers vary from superficial tissue damage to deep craters exposing muscle and bone (Cuddigan et al, 2001).

A consideration of pressure ulcer development depends on an awareness of likely demographic changes over the next 30-40 years. Projections of population growth in the UK show that the total population will have limited growth over the next 40 years. However, the number of older people will increase more rapidly, the biggest increase in the number of people over the age of 65. In 1990 people over 65 formed 16% of the total UK population. It is projected that this group will form 20.5% of the population by the year 2031 (OHE 1992).

Anthony (1996) suggests that it is often assumed that pressure ulcers are preventable and that, when one occurs, it is always because of poor nursing care. There is no doubt that poor nursing care increases the risk of pressure ulcer formation, but there are many other factors involved in pathogenesis. Tissue breakdown can occur in a patient receiving the highest possible standard of care.

Pressure ulcers can vary considerably in size and depth of tissue damage, patients with pressure ulcers present the greatest difficulty in terms of cost and effective wound management.

Although the problem of pressure ulcers remains largely in the nursing domain, there is an increasing awareness of the importance of a multidisciplinary approach to tackling the problem.
Pressure ulcers remain a constant feature in an ever-changing health service. Today, pressure ulcers continue to affect a substantial proportion of the patient population. Pressure ulcers form as a result of a combination of key factors, including the effects of pressure, shear and friction on tissue. Intrinsic factors, such as diabetes or poor nutritional status, can increase the risk of pressure ulcer development, as can extrinsic factors associated with the environment, such as the use of an inappropriate support surface.

Existing health problems are exacerbated by the development of pressure ulcers in vulnerable individuals, causing further pain and debility and necessitating hospital admissions or prolonging their stay in hospital. Pressure ulcers seriously affect quality of life (Clark, 1994) and are a significant financial burden in terms of rehabilitation. Touché Ross (1993) argued that prevention is more expensive than treatment nationally, although their report did not consider the human or litigation costs.

Apart from the human cost in terms of pain and suffering to patients and their families, there is a huge financial cost incurred in caring for patients with pressure ulcers. This is cause for concern to health-care providers and purchaser. In 1994 West & Priestley estimated the total cost at £750 million. They suggested that a full thickness sacral ulcer extends hospital stay by over 25 weeks at a cost of £26,000. This includes all the extra staffing, drugs and dressings as well as hospital overheads. An Australian study undertaken to examine the bed days lost to pressure ulceration in 2001-2002, it was estimated that a pressure ulcer led to an extra 4.31 days per patient, resulting in 398,432 bed days lost and an opportunity cost of AU$285 million in a population of 20.3 million (Graves et al, 2005).

The cost of lost opportunity is even greater, for each sacral pressure ulcer, which is prevented; it is possible to undertake 16 total hip replacements. This emphasises the idea that pressure ulcers develop only in long-stay elderly patients is far from the truth. Most pressure ulcers are to be found in acute hospital wards (Bennett et al 2004).

In a recent study by Bennett et al (2004) estimated the total cost of treating pressure ulcers in the UK to be between £1.4 to £2.1 billion or around 4% of the total NHS expenditure. Holistic assessment is recognized as an integral part of prevention and
management of pressure ulcers (National Institute for Health and Clinical Excellence (NICE), 2005) and accurate assessment of the severity of tissue damage of pressure ulcers is essential for the decision on nursing interventions for the proper management of pressure ulcers.

Traditionally, the prevention of pressure ulcers has been considered a nursing responsibility. Nevertheless, on reviewing the literature, Gould (1986) concluded that the topic was failing to attract the imagination of nurses at the forefront of clinical practice or actively involved in the research, despite the enormous costs incurred by the UK National Health Service in treating established pressure ulcers and the resultant distress experienced by patients and their families. However, since the publication of Gould’s (1986) review there has been growing recognition of the problem such that more articles published in the nursing press in recent years appear to have been related to the prevention and management of pressure ulcers than to any other topic states (Morison, 1989), Witkowski & Parish (1982), who suggest, that there is now a wealth, of research aimed at decreasing incidence yet, despite the research interest, the aetiology of pressure ulcers remains poorly understood.

Sutton & Wallace (1990) reported that senior medical staff perceived nurses as having the primary role in the prevention and treatment of pressure ulcers and hence it is to the workload of nurses that pressure ulcers make their contribution.

In a more recent study Spilsburg et al (2007) suggests that healthcare professionals could learn from patients’ experiences in particular about the management of dressings, providing information in particular about the realistic time expectations for healing, providing preventative interventions and understanding the importance of comfort and positioning for patients.

The problem of pressure ulceration has been highlighted in recent practice guidelines (RCN 2000). But, the majority of the literature focuses on the ‘mechanical’ aspects of risk assessment, nursing knowledge of pressure ulcer prevention and the merits or otherwise of equipment and topical treatments. Maylor (2001) suggests it would be almost heretical to imply that nurses and healthcare workers might contribute to the incidence of ulceration. Olshansky (1992) broached the subject by stating that institutions, rather than patients, need assessing for risk.
Pressure ulceration continues to be reported and discussed in the nursing literature and, although the methodological quality of some studies has been poor, there is no doubt that patients continue to suffer harm (Gould et al, 2000). The development of pressure ulcers has been linked to many deleterious effects, ranging from increased costs of care to patient deaths (Clark, 2001). One commonly implicated effect of pressure ulcers is a reduction in quality of life. This is believed to be due to factors such as increased pain, social exclusion, malodour and growing limitations on activity and mobility.

**Quality of life**

I decided to consider what quality of life means, and how the concept can be measured and its relevance to pressure ulcer prevention and treatment.

Quality of life first appeared in the USA in the 1950's as a slogan to represent 'the good life'. More recently however, it has become part of a holistic view of the individual within health-care systems and is sued as a global term to cover a variety of measures. Quality of life is a complex concept that relies on many factors, including contact with friends and family, enjoyable work or leisure pursuits, comfortable home and lifestyle and satisfying emotional and sexual relationships.

Clark (2002) says the idea of quality of life is by its nature heterogeneous, with different individuals ranking dissimilar elements as more or less central to their quality of life. He goes on to say given disparate definitions of quality of life, how can it be quantified and the effects of a single event, such as the development of a pressure ulcer, be assessed? He suggests, that one simplification might be to consider the different dimensions of quality individually and attempt to quantify each.

Tooher, Middleton & Babidge (2003) agree with Clark (2002) who say lack of high quality evidence on pressure ulcer care, such as randomised controlled trials, and the variety of methods used to measure incidence and prevalence have resulted in wide variations in practice. Guidelines clearly indicate the instrumental responsibilities of healthcare professionals to prevent and manage pressure ulcers (NICE 2003, 2005).
By accepting that good health is likely to be component of quality of life, we can begin to identify changes in health-related quality of life, seeking to explore how health, or ill health, impacts on our enjoyment of, or anticipation in, life.

It is commonly believed that pressure ulcers reduce an individual's quality of life. A combined search of the electronic databases Medline and Cinahl was undertaken. In addition, key wound care nursing journals and conference proceedings were hand searched to identify published studies not in the database. A combination of search terms 'pressure sore', 'pressure ulcer', 'decubitus ulcer', 'quality', 'quality of life' and 'pain' was used. While discussion of pressure ulcers and quality of life were often combined, limited primary data was found.

Krause (1998) reported a series of correlations between the presence and severity of pressure ulcers and responses to the Life Situation Questionnaire-revised, an instrument developed to explore the impact of spinal cord injury on the aspect of quality of life. The respondents, 1017 adult patients with spinal cord injuries who had experienced traumatic injury more than two years before the survey was conducted, associated development of a pressure ulcer at any time post injury 'with lower levels of subjective wellbeing and activity, and greater health problems'.

Krause also noted that where subjects were less able to sit for prolonged periods following pressure ulcer development, they were likely to exhibit poorer adjustment to life following their injury.

Langemo et al (2000) in a series of interviews investigated how pressure ulcers affected many aspects of each person's life. All eight participants had personal experience of full-thickness pressure ulcers. Negative physical effects reported by the participants included prolonged bed rest, interruption of sleep patterns and the effects of support surfaces on their mobility.

Langemo et al (2000) also highlighted the impact of pressure ulcers on the social activities of the participants, in particular increased isolation from friends and family. Other negative effects of pressure ulcers included financial problems, pain, lack of privacy, changes in body image and loss of control and independence.
It would appear from the limited data that pressure ulcers, at least full-thickness wounds, affect health-related quality of life.

Clark (2002) suggests that perhaps from the paucity of primary data on quality of life stems from assumptions that developing pressure ulcers always reduces health-related quality of life, while successful treatment automatically improves health-related quality of life. These assumptions were discussed during a satellite meeting of the European Pressure Ulcer Advisory Panel (EPUAP 2001), raising awareness that automatic decreases and increases in health-related quality of life cannot be taken for granted as pressure ulcers develop and heal.

Clark et al (2002) as stated earlier reported on a study that focused on the outcomes achieved in pressure ulcer prevention and treatment in four UK hospitals. Over a three-year period from 1996 to 1998 cohorts of 2,507 adult patients were examined and the condition of their pressure areas was recorded. All patients were hospitalised for a minimum of 48 hours. One hundred were admitted with established pressure ulcers, while a further 117 developed pressure ulcers during their stay. In the project at one stage all the patients were invited to complete the SF-36 questionnaire.

The SF-36 poses a series of 36 questions related to current activities and any limitations the individual might experience. It was found that not all patients were able to complete the questionnaire; the subjects who were unable to complete the questionnaire were older than respondents. Typically, those who did not respond stayed in hospital longer, were less mobile, exhibited reduced functional independence, had a lower weight and body mass index, were more incontinent of urine, showed a poorer appetite for food and had a greater degree of vulnerability to developing pressure ulcers. It would appear that even when attempts are made, directly to capture information related to health-related quality of life among patients, with or vulnerable to pressure ulcers, the patients of greatest interest those with pressure ulcers or at greater risk of developing these wounds, might be unable to complete self-report questionnaires, even with the assistance of trained data collectors.

Fleurence (2005) reports that there is a dearth of primary research on quality of life in patients with pressure ulcers. Few studies provide measures of quality of life in these
patients and those that are available do not immediately enable the calculation of QALYs. She suggests that there are a number of difficulties encountered when conducting such studies such as co-morbidity, most patients with pressure ulcers present with another condition. A high non-response rate is also an issue which could be improved suggests Fleurence (2005) by obtaining scores from sources such as relatives, health professionals or other experts, or the general population, although she states it is unclear who is best suited to do this.

Franks (2007) suggests that in the area of pressure ulceration there has been some interest in the evaluation of outcomes of treatment, but very little attention to the overall cost of care, or impact on the patients’ quality of life and that surprisingly, health services do not appear to be aware of the financial burden that pressure ulceration causes. He recommends that there is a clear need for governments to understand that pressure ulceration causes a major financial burden on them, and a burden on patients’ lives. Until the magnitude is appreciated it is hard to push for cost-effective treatment and prevention strategies on a national basis to rationalise the care of patients who suffer from this distressing condition.

A financial burden has a profound effect on the ability to quantify the human costs of pressure ulcers, and might effectively prevent quality of life measures being used in an assessment of the impact of specific interventions on clinical, social and economic outcomes. A combination of tools and measures might be required to assess fully, the impact of a clinical condition such as pressure ulcers on patient’s quality of life.
METHODOLOGY

I decided to interview fifteen participants about their experience of having a pressure ulcer and how it affected their quality of life. From the interviews, it was hoped to capture 'the lived experience' that, once transcribed would give rich data that could be used to improve the quality of care patients received in the future. The participants were selected from across the NHS Acute Sector and the NHS Primary Care Trust.

A qualitative approach utilising phenomenology was used to explore the experiences of people with existing or recurrent pressure ulcers. Phenomenology was chosen, as it is an approach that allows the exploration of individuals' relationships with the world, to understand the meaning of the phenomena as completely as possible. It is the study of the world as it is experienced, investigated through description of these experiences, as removed from everyday life (Van Manen, 1997). Jones&Borbasi (2004) reported that phenomenology has become a dominant means in the pursuit of knowledge development in nursing, and presents' credible displays of living knowledge for nursing'. Phenomenology claims to be scientific in a broad sense, since it is a systematic, explicit, self-critical and intersubjective study of its subject matter, our lived experience (Van Manen 1990).

Heidegger (1968) talked about phenomenological reflection as following certain paths, 'woodpaths' towards a 'clearing' where something could be shown, revealed, or clarified in its essential nature. However Van Manen (1990) suggests that the paths (methods) cannot be determined by fixed signposts. They need to be discovered or invented as a response to the question at hand. It was hoped that by using this approach it would enable me to both tease apart and bring together the elements of living with a pressure ulcer, leading to an understanding of the meaning of the experience. Phenomenological research, unlike any other kind of research, makes a distinction between appearance and essence, between the things of our experience and that, which grounds the things of our experience. It reflectively brings into nearness that which tends to be obscure, that which tends to evade the intelligibility of our natural attitude of everyday life.
The aim of qualitative research is to explore and understand people's experiences, feelings and beliefs and to make statements about how they interpret and structure their lives (Holloway and Wheeler, 1996). The findings from qualitative studies can increase our understanding of a phenomenon in a particular situation and are not generalised in the same way as quantitative studies (Polgar and Thomas, 2000). However, understanding the meanings of a phenomenon in a particular situation can be applied more broadly and is useful in understanding human experiences of living with a chronic condition.

The phenomenological movement began around the first decade of the 20th century. Phenomenology developed by Husserl and Heidegger, is an approach to thinking about what the life experiences of people are like. According to Husserl (1931, 1965) he believed that philosophy should become a rigorous science that would restore contact with deeper human concerns, and that phenomenology should become the foundation for all philosophy and science. There are two 'schools' of phenomenology, descriptive phenomenology and interpretive phenomenology (hermeneutics).

Descriptive phenomenology was developed first by Husserl (1962) who was primarily interested in the question: what do we know as persons? His philosophy emphasized descriptions of the meaning of human experience.

Heidegger, a student of Husserl, moved away from his professor's philosophy into interpretive phenomenology. To Heidegger (1962), the critical question is: What is being? He stressed interpretation and understanding, not just describing, human experience. The focus of phenomenological inquiry, then, is the meaning of people's experience in regard to a phenomenon (descriptive phenomenology), and how those experiences are interpreted (hermeneutics).

The phenomenology of Heidegger and Merleau-Ponty differed from that of Husserl as they considered that the phenomenological reduction or bracketing was impossible, as we are too much 'beings-in-the-world' to achieve such a state (Cooper, 1999). Spiegelberg (1984) chronicles this philosophical development of phenomenology. This notoriety abounds through much of the nursing literature. Jasper (1994) acknowledges Kant as the first philosopher to describe phenomenology.
Ornery (1983) states that ‘the phenomenology method is an inductive, descriptive research method’. The task of the method is to investigate and describe all phenomenona, including human experience; in the way these phenomena appear. The individualistic approach inherent in this methodology, focusing on a person’s unique experience with what is prevalent in both nursing theory and practice today.

Dilthey (1976) says ‘We explain nature, but human life we must understand’.

Essences refer to elements related to the ideal or true meaning of something. Essences are concepts that give common understanding to the phenomenon under investigation. The phenomenological researcher asks the question: What is the essence of this phenomenon as experienced by these people? The phenomenologist investigates subjective phenomena in the belief that essential truths about reality are grounded in people’s lived experiences. The focus of the phenomenological inquiry is about what people experience in regard to some phenomenon and how they interpret those experiences.

Every individual experience has an essential structure, or structures, which make it what it is, and to identify this structure is to identify what that experience means to the person concerned. It is a one-to-one correspondence between particular experiences and particular structures.

On this view, the essence of one person’s experience of developing a pressure ulcer is not identical with the essence of another person’s experience of a pressure ulcer, since there are two numerically different experiences here and each is ‘patterned uniquely’ by a ‘distinctive structure’.

Cohen & Omery (1994) on the other hand say

*The goal of eidetic phenomenology is description of the meaning of an experience from the perspective of those who have had that experience. This eidetic description is not, however, just an individual, subjective perspective of the experience or opinion of a meaning. It is a description of a meaning that is eidetic, that is fundamental and essential to the experience no matter which specific individual has that experience.*

The goal of phenomenological inquiry is to describe fully lived experience that is of interest to phenomenologists.
Van Manen (1990) suggests that these aspects are *lived space* or *spatiality*, *lived body* or *corporeality*, *lived time* or *temporality*, and *lived human relation* or *relationality*.

In a phenomenological inquiry, the main source of data typically is in depth conversations in which the researcher and the informant are full coparticipants. The researcher helps the informant to describe lived experiences without leading the discussion.

There have been a number of methodological interpretations of phenomenology; hence different authors suggest different steps in the conduct of a phenomenological inquiry. However, a phenomenological study often involves the following of steps:

**Bracketing** refers to the process of identifying and holding in abeyance any preconceived beliefs and opinions one might have about the phenomenon under investigation. The researcher brackets out the world and any presuppositions in an effort to confront the data in pure form.

Bracketing is sometimes considered a central component of what is referred to, as phenomenologic reduction, the isolation of the pure phenomenon, versus what is already known of the phenomenon, is the goal of the reductive process.

Crotty (1996) argues that nurse researchers view bracketing, instead of the philosophical underpinnings of phenomenology, as the feature of the phenomenological tradition. However, the use of the term ‘bracketing’ is not without critics.

Dahlberg & Dahlberg (2004) prefer to use the term ‘bridling’ instead of bracketing. They argue that this term is preferred to bracketing as bracketing carries with it an ‘exactness and finitude of mathematics’ and ‘bridling’ also invokes the thought of being respectful, or humble, to that which it bridled in order not to dominate, violate it, or swallow it, as ‘bracketing’ seems to do. Confusion regarding bracketing still abounds. Donalek (2004) advises that research is not truly phenomenological unless the researcher’s beliefs are incorporated into the data analysis.

Olier (1982) suggests that bias comes from the retrospective interpretation of experience built on inaccurate memories. Cohen (1987) adds prejudices and personal commitments as forms of bias. Phenomenological reduction is critical if pure description is to be achieved.
Phenomenological reduction is critical if pure description is to be achieved. The reductive process is also the basis for postponing any review of the literature until the data has been analysed. What the researcher knows or believes about the phenomenon under investigation must always be kept separate from the participant’s descriptions. Therefore, postponing the literature review until data analysis is complete facilitates the phenomenological reduction. 'Reduction' is concentration on the phenomenon, becoming absorbed in it, and through bracketing, seeing it as if for the first time (Olier, 1982).

It is known as a reduction because it leads back to the source of meaning of the experience (Ray, 1985). The purpose of this reduction is to prepare for the analysis suggests (Cohen, 1987).

Bracketing therefore involves deliberately seeing the other side of arguments, allowing thoughts to wander, to be confused and incertain, and seeking the option of others. Beech (1999) claims bracketing to be a process by which "the researcher resolves to hold all preconceptions in abeyance in order to reach experiences before they are made sense of".

**Intuiting occurs** when the researcher remains open to the meanings attributed to the phenomenon by those who have experienced it. Intuiting requires that the researcher creatively vary the data until such understanding emerges. The researcher must wonder and be imaginative about the phenomenon in relationship to other descriptions that have been generated. Intuiting requires that the researcher become totally immersed in the phenomenon under investigation.

The researcher transforms what is understood, about the phenomenon under investigation, into conceptual categories that are the essence of the original experience (Reinharz, 1983). Dwelling with the data is essentially total immersion for as long as needed to ensure pure and thorough description. The goal in intuiting is the expression of the situation from the viewpoint of the subject (Knaak 1984).
The Descriptive phase is the final stage when the researcher comes to understand and define the phenomenon. The researcher transforms the written document into an understanding that can function to clarify all preceding steps (Reinharz, 1983). This written document is often referred to as the exhaustive description, the intent of which is to synthesize and capture the meaning of the experience into written form without distortion or loss of richness in data. The exhaustive description of quality of life would reveal the richness of the experience identified from the very beginning of the investigation as perceived by the individuals with pressure ulcers.

Description, also known as 'transforming', is the analytical process in phenomenology. Involving exploring the meaning as it unfolds for the participants (Omery 1983). The transmission to writing may include full description of thematic analysis (Bartjes 1991) and will express the feeling of the experience in order to generalize it to others.

Benner and Wrubel (1989) said ‘illness as a human experience of loss or dysfunction has a reality all of its own.’ Benner’s theory of novice to expert (Benner, 1984 is another example of phenomenology being used as a research approach to develop nursing theory. But Lawler (1998) suggests that such theory developments through the utilisation of phenomenology are very appropriate for a practice discipline such as nursing. Nursing theory developed through a phenomenological approach reflects the reality of nursing practice, which is complex and situational. Such knowledge generated from practice has therefore more revalence for nurses. Nevertheless, it must be acknowledged that adapting the fundamentally philosophical process of phenomenology as a practical and robust attempt to understand nursing practice is problematic.

The change in nursing philosophy, away from a mechanistic approach to patients towards a more holistic perspective on care, leads to more emphasis being put upon the wants, needs and fears of patients. This change in emphasis inevitably entails the adoption of research methodologies that allow for the elucidation of those wants, needs and fears. Phenomenology aims at gaining a deeper understanding of the nature or meaning of our everyday experiences. Phenomenology asks, ‘what is this or that kind of experience like’ (Van Manen, 1990). Van Manen suggests that phenomenology differs from almost every other science in that it attempts to gain insightful descriptions of the way we experience the world pre-reflectively, without taxonomizing, classifying, or abstracting it.
Phenomenology does not offer us the possibility of effective theory with which we can now explain and/or control the world, but rather it offers us the possibility of plausible insights that bring us in more direct contact with the world.

Several scholars have developed methodological processes (Giorgi 1970, Colaizzi 1978, Van Manen 1984), which incorporate these features. Omery (1983) however suggests that the phenomenological method is the approach itself for many researchers. She argues that, rather than use the steps identified as the phenomenological method, the method is data-driven and emerges as the research progresses. She suggests that

_The phenomenological method is approaching the phenomenon with no preconceived expectations or categories, performing some form of bracketing to define the limits of the experience, and then exploring the meaning of that experience as it unfolds for the participant._

Husserlian phenomenology was the method of choice for this study. The shift towards qualitative research has been accelerated by the increasing influence upon nursing academics of feminist research concerns, which also place personal experience at the centre of the research agendum.

Hagell (1989) makes this point very clear:

_'Nursing, as a discipline has a distinct knowledge base which is not grounded in empirico-analytical science and its methodology but which stems from the lived experience of nurses as women and as nurses involved in caring relationships with their clients.'_

I decided to attempt Husserl’s pure approach to phenomenology, which, in relation to bracketing, required me to empty my mind of all data, relating to a phenomenon’s context and situation. Thus I began this study by choosing to carry out the literature review of the topic area only once all the interviews had been completed, therefore prohibiting previous studied influencing the questions and assumptions of the findings during this study.

Notably, many authors question the ability to bracket personal experiences and preconceptions. Benner (1994) argues when interpreting data researchers cannot avoid
their own experiences and social backgrounds influencing their judgement, and Mitchell (1993) believes there is no understanding without the pre-understanding that comes from our own experiences.

**Design**

A phenomenological research design that included semi-structured interviews with key participants (e.g. patients with the condition) was the primary method of data collection. As I wanted to capture the participant's rich in-depth feelings vignettes method was excluded, as I did not want brief descriptions of an event. Although some authors would disagree suggesting that the use of vignettes can validate certain phenomena's (Hallett 1996). The aim was to explore the phenomenon in question by focusing on the individuals experiencing it (Vishnevsky & Beanlands 2004). As expert patients the respondents were able to provide an insight into perceptions and experiences in relation to the study.

A semi-structured interview approach was adopted this provided a greater breadth than other types of interviews (e.g. structured) because it enabled free probing beyond the answers, seeking further clarification and elaboration (May, 1997). Ethnographic interviewing is aimed at describing the cultural knowledge of the informant, such as cultural knowledge. In contrast, phenomenological interviewing is concerned with uncovering knowledge related to specific phenomena. Both of these research approaches share certain commonalities related to use of the interviewer as the data collection instrument.

In qualitative studies, the researcher serves as the 'instrument' through which data is collected (Boyd, 1993). The skilled interviewer, as the research instrument, uses responses of the participant to guide data collection, probing for further information as needed for depth and clarity. Although interviews should be guided by a tentative interview schedule, the interviewer must identify a proper balance of structure and flexibility (Swanson-Kauffman, 1986). The format, timing and sequence of questions may change as the data collection process continues. The researcher maintains control of the interview, but there must be sufficient flexibility to respond to important content responses and general non-verbal cues from the participant.
The initial interview schedule (Appendix 4) contained a range of open-ended questions, which were continually amended during the process of interviewing the key participants in response to the identification of new categories or themes produced during the concurrent transcribing of the interviews. Participants were encouraged to talk about factors, which they consider to have influenced their quality of life. The questions addressed the nature of their participation in personal and social activities. These include, has your pressure ulcer affected your daily activities? The questions provided respondents with opportunities to describe (a) their interpretation of quality of life, (b) what their experience of living with a pressure ulcer is like, (c) their perceptions of treatment/management of their pressure ulcer.

Open-ended interviewing allows the researcher to follow the participant’s lead. To ask clarifying questions, and to facilitate the expression of the lived experience by the participant. Silverman (1993) argues for the importance of open-ended interviews, as this enables respondents to demonstrate their unique way of looking at the world their definition of the situation. It recognizes that what is a suitable sequence of questions for one respondent might be less suitable for another, and open-ended questions enable important but unanticipated issues to be raised.

In order to be truly phenomenological in a nursing sense, we must show absolute respect for the people interviewed. In so doing we must inform them of what it is we intend to do in our research. It could be argued that giving people prior warning then they may reflect on their experiences and develop their particular self-presentations concerning the phenomenon under investigation. Hallett (1996) considers self-presentation and lying to be less of a problem than loss of meaning while informing people before hand of the nature of the interview may result in their failure to bracket, this is not as important as the need to ensure their willing compliance and the need to allow meaning to show through indeed in our quest for people’s meaning of experiences.

It is essential to pre-inform the interviewees of the nature of the study it is an ethical requirement. This was completed well in advance of the interviews. A patient information leaflet was given to each patient explaining the study (appendix 2) this was left with the patient to read at their leisure.

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The interview situation carries with it a unique intimacy that is shared between interviewer and respondent. Respondents often reveal information during an interview that they would not discuss in a questionnaire. Since the respondents may be unprepared to find their words mixed with tears, it is important for the interviewer to appreciate the intimacy of the situation, and to plan time during the interview to establish and maintain rapport.

Varying lengths of time may be needed for a ‘warm-up’ period to establish trust between interviewer and respondent, and researchers focusing on very personal and private subjects need to plan substantial time for building rapport (Kondora, 1993).

A semi-structured interview with key respondents (e.g. patients with the condition) was the prime method of data collection. As the respondents were knowledgeable about this subject area, and were able to provide me with an insight into perceptions and experiences in relation to the focus of the study. A semi-structured interview approach was adopted as it provided a greater breadth than other types of interviews (e.g. structured) I was free to probe beyond the answers, seeking further clarification and elaboration (May, 1993). Interviews are a particularly useful way of finding out about people’s perceptions or opinions on specific matters.

I hoped that by using a qualitative approach unforeseen avenues of enquiry would open up during the encounter with the interviewee. Further question were asked, testing out what other interviewees have said about things to see if this corresponds with the experience of the person at hand. By doing this the researcher is ensuring that the experiences that interviewees talk about are meaningful to the interviewees and are not those of the interviewer (Hammersley & Atkinson, 1995).

The interviewer needs skills in listening for and interpreting meaning so as to respond appropriately. The interviewer may use specific techniques in order to stimulate the inarticulate respondent, such as sharing a personal story from the interviewers own experience. Respondents should believe that their participation in the interview is important to the research. Interview strategies such as remaining attentive, providing non-verbal nods, moving closer to the respondent and maintaining eye contact communicate interest in the participant’s response.
Respondents were encouraged to talk about factors, which they consider have had an influence on their quality of life. The interview allows entrance into another person’s world and is an excellent source of data. Non-verbal behaviour such as shrugging or hand gestures was not ignored as it is as important to communication as the words themselves, (Burns & Grove, 1993). For this study the researcher maintained field notes, which included ideas, feelings, and responses that emerged during the data collection.

Using an audio recorder ensured that all the data generated from the interview are captured. This allowed me to turn transient data into permanent data that could be analysed carefully over a longer period of time away from the interview site. Tape recordings are thought to be useful for capturing the mood or strength of feelings of issues raised by participants (Marrow, 1996). The recordings included what was said (as well as what was not said), and the way the interviewee spoke about the topic being investigated (i.e. pauses and tone of speech). Field notes supplemented this data.

The interviews were conducted in a private setting of the participant’s choice. For interviewees to be able to answer questions appropriately, they have to be in a place, which allows them to comprehend the questions. This means that the place should be free of distractions. Interviewees have to be in a place where they feel safe enough to provide answers to what may be difficult, awkward or compromising questions without fear of being overheard.

Moser& Kalton (1971) argue that it is important to consider the ability and willingness of individuals to answer questions. It is therefore essential to assess whether those studied will have the knowledge to answer the questions, whether the questions are relevant to them and whether they wish to reveal the information.

In order fully to comprehend the meaning of what is said during the interview it is important not to lose sight of these circumstances, this is what is meant by placing the data in context’ (Silverman, 1993). Quotes from the transcripts of the audiotapes were used to allow the ‘voice’ of the interviewees to come through the text and speak to me. A text, which allows the reader to ‘hear’ the interviewee’s voice and uses full, illustrative quotes is said to be a ‘thick’ text. A text, which only relies on the researchers’ interpretations and does not include the ‘voice’ of the interviewee is said to be ‘thin’.
Obviously there are degrees of ‘thickness’ and ‘thinness’ (Hammersley & Atkinson, 1995).

The main issues of credibility and validity when using structured interviews relate to language and its effect on the motivation of people to answer the questions appropriately. If the language that is used by interviewers is over-complicated or conversely, too simplistic it will not encourage interviewees to give full and appropriate answers to the questions put to them. Good technique enables the interviewer to gain immediate response from interviewees which allows further questioning or probing on a particular aspect of their replies. It is this particular aspect of the technique that makes interviewing so useful.

Smith (1975) argued that question wording is a significant problem in research and suggests there must be shared vocabulary between the researcher and respondent. The wording should not appear to simplistic, seeming to insult their intelligence, on the otherhand, it must not be too sophisticated for others.

When the opening question is in the ‘right region’, it elicits a narrative directly related to an important experience of the respondent, who then becomes engrossed in the unfolding narrative, as the vividness of the original experience returns. It is often unnecessary in this situation for the interviewer to use much prompting during the interview. Verbal or non-verbal probes may be useful, to enhance the respondent’s description of a lived experience when the response does not seem clear, complete or relevant (Patton, 1980).

Gadow (1980) describes how certain so called professional behaviours serve to distance patients and nurses from each other. She states, regarding the patient, as a ‘whole’ would seem to require nothing less than the nurse acting as a ‘whole’ person. Therefore, the nurse who withholds parts of the self is unlikely to allow the patient to emerge as a whole, or to comprehend that wholeness if it does emerge.

Thoughtful probes by the interviewer can help the respondent to bring forth contextual details important to meanings embedded in the narrative. Gordon (1980) suggests two types of probes may be useful in the interview stage, the recapitulation probe and the silent probe. Recapitulation is used to take the respondent back to the beginning of the
experience described during the interview. When respondents are asked to retell parts of
stories by returning to the beginning they often add new details the second time through.
Periods of silence can be used to establish a comfortable pace during the interview,
encouraging respondents to follow their own path of associations by telling the story their
own way.

Van Manen (1990) describes an 'epistemological silence', which he defines as 'the
silence we are confronted with when we face the unspeakable'. Some ideas or feelings of
the respondent cannot be captured in words, it is important for the interviewer to be
comfortable with silence in order to listen to the powerful silence that may speak more
than words.

For qualitative research, the disadvantage of allowing interviewees to tell their stories and
not wishing to restrict them too rigidly in any one direction, is that they may not tell you
anything that is of relevance to your agreed interview topic (Cormack, 2002).

Qualitative research aims to uncover new meanings, or to describe new, unexplored,
patterns of action or perception. The emphasis being on discovery and illumination,
which indicates a need for open, flexible approach to research (Mays and Pope, 1995a).
Inductive processes generate theory from facts obtained within a natural setting or
contextual setting of the phenomenon. In this context, non-probability or 'purposive'
sampling offers an appropriate method and will be used for the selection of respondents
by which to explore the processes surrounding quality of life of people with pressure
ulcers. The logic and power of purposeful sampling lies in selecting information-rich
cases for study in depth. Information-rich cases are those from which one can learn a
great deal about issues of central importance to the purpose of the research. (Patton 1990).

The emerging nature of the themes and concepts from the data influenced my decision of
which data to collect next, which people to interview, in order to develop and gain an
understanding of the quality of life issues surrounding patients with chronic pressure
ulcers.
Sample

15 key participants were identified to provide oral accounts of their experiences of having pressure ulcers; those individuals who have a chronic ulceration (Grade III to IV) were considered appropriate. The European pressure ulcer grading system was used to grade each pressure ulcer (EPUAP 2001).

They had first-hand knowledge of the issues and experiences associated with the condition; the pressure ulcers had in all cases been present for over six months. Five of the fifteen participants had multiple pressure ulcers. One patient had a spinal cord injury. None of the participants had undergone flap reconstruction. The age range of the patients was between 45-89 years of age. In all the participants the underlying pathology was thought to be caused by pressure to vulnerable areas following a period of confinement to bed.

The sample size I used was small; this was due to the proportion of grade III and IV pressure ulcers referred to the service throughout the study time constraints. Whilst these patients were referred into the tissue viability service they were unknown to the service until referred; this reduced conflict from interviewing patients already known to me.

Bailey (1978) reports experienced researchers start with the total population and work down to the sample, in contrast the less experienced researcher often work from the bottom up, that is, they determine the minimum number of respondents needed to conduct the research.

Researchers must take sampling decisions early in the overall planning of a piece of research. Factors such as expenses, time and accessibility frequently prevent researchers from gaining information from the whole population. Therefore they often need to obtain data from a smaller group or subset of the total population in such a way that the knowledge gained is representative of the total population (however defined) under study (Cohen et al. 2003).

Patton (1990) argues that theoretical samples should be judged on the purpose and rationale of each study and the sampling strategy used to achieve the study’s purpose.
Polit & Hungler (1999) suggest that in qualitative research, sample size should be determined on the basis of informational needs. Hence, a guiding principle in sampling is data saturation; sampling to the point at which no new information is obtained and redundancy is achieved. Redundancy can typically be achieved with a fairly small number of cases, if the information from each is of sufficient depth.

Multiple data sources were used to explore quality of life issues, each providing 'a slice of data' (Glaser and Strauss, 1967). These slices came from key participants who when interviewed; enabled emerging themes from one data source to direct the study in terms of identifying further participants. Fifteen key participant interviews were undertaken. The face-to-face interviews took place in private, in the patient’s home/hospital setting at a convenient time for the participant. The data from these methods were transcribed initially by hand and then by a word-processor. Interview tapes were transcribed and analysed thematically (Miles & Huberman 1994).

The data was organised thematically so as to present a picture in relation to the issues identified. These themes reflected:

- The patient's interpretation of quality of life
- Factors which affect their activities of daily living etc

According to Strauss and Corbin, analysis is the interplay between the researcher and data (Strauss and Corbin, 1998). In this study, the interplay involved me reading and interpreting the many pages of transcripts and identifying themes. This process involved constant comparing of data, which highlighted differing, and related perspectives of the data sources. Whilst this process is similar to the grounded theory approach advocated by Strauss and Corbin (1998) that is, theory is derived from the data, systematically gathered and analysed through the research process.

Existing theory was synthesised with the emerging theory this allowed theoretical ideas in the most fruitful manner possible. Benner (1994), unlike the Strauss and Glaser approach,
suggests that the intent was not to come up with theoretical terms but rather to identify meaning and content.

The interviews were transcribed, the transcripts worked through and analysed using an open coding method, which involves labelling concepts and categories. I used a computer to assist me with this task. Each category or theme was referenced. Having identified the categories, each transcript was analysed in blocks of text (e.g. lines or paragraphs).

Each transcript (including interviews and observations) was worked through in this way, building up references on each node. Following open coding, related categories were grouped together and these subcategories defined. This process is referred to as axial coding (Strauss and Corbin, 1998) and provided the basis for selective coding. Together these processes enabled me to develop a descriptive narrative (a storyline) about the category.

In reality, my analysis began following the first interview. For example, following each interview, I made notes about the relevance and meaning of what was said. This process continued throughout my transcribing of the interviews. I continually asked myself "what is the patient saying?" and "what are the respondents saying about their experience of living with a pressure ulcer?" The comments arising from these notes developed into codes, which subsequently were grouped together under concept headings.

Most qualitative researchers now use computers during some stage of their work, and their use has been strongly advocated for data analysis because they easily offer assistance in the management of complex data (Richards and Richards 1991; Tesch, 1990). However, some caution in their use is advisable (Pope et al. 2000).

Although computers may be perceived to save time, in terms of analysing qualitative data there is no magical wand available to code categories and mark the data ready for the computer, this will still needs to be done with one’s brain (Chapple, 1997). With the understanding that no amount of computer technology can substitute for critical thinking, I used a computer during the data analysis stage of the study for the coding and retrieval of data. This allowed me to store data from several sources, (e.g. observational data,
transcripts from interviews), in one location. I did not have university access to a data package therefore the data was analysed by hand.

Once the data sources had been imported into the database, I was able to create and manipulate concepts and explore emerging ideas.

This section outlines the techniques, which was employed in this study to attempt to address the issues relating to the adequacy of the data from the data collection methods used in this study.

It is acknowledged that the use of interviewing as a method of data collection carries certain flaws. In defence of using this research method, the key respondents will satisfy the three critical methodological criteria of adequacy suggested by (Plimmer, 1983):

Cooperativeness – in each case the key respondents will be cooperative and willing to take part in the study. Of those interviewed, there will be no observable reluctance on their part to engage in full and meaningful dialogue.

High Consciousness – the respondents will be all of high consciousness in that they had significant experience of a pressure ulcer.

Accessibility – each of the key respondents will be accessible to some degree or other. They will all be amenable to, and willing to, engage in face-to-face interviews and have the interviews tape-recorded.

Equipment and Facilities Used

Fieldwork and interviews were carried out across the Primary Care Trust and Acute Trust following ethical approval. A small Sony Walkman was used for recording the interviews, since this was considered less obtrusive and distracting for patients than the usual large, cumbersome recorders with microphones. This promoted the creation of a relaxed, conversational style of interview. The data were then transcribed and analysed in a private office that only the researcher had access to.
Ethical Issues

The study was approved by the Local Research Ethics Committee and the research governance and management department of the Primary care Trust and the Acute Trust. Participants were informed of the study aims (to understand their experience of developing a pressure ulcer and how it affected their quality of life) what would be involved if they agreed to take part and how their narratives would be used and disseminated. They were informed that they could choose to stop the interview at any point, without giving a reason, and reassured that their decision to take part (or not) would not affect any aspect of their treatment.

Ethical issues arise for all researchers in the social sciences; in essence, most of those revolve around issues of harm, consent, deception, privacy and confidentiality of data (Punch, 1986). The personal nature of phenomenological research results in several ethical considerations for the researcher. Informed consent differs in a qualitative study as opposed to a quantitative investigation. There is no way to know exactly what might transpire during an interview.

Munhall (1988) noted that qualitative research is a moral as well as knowledge-generating activity. Consent should be viewed as an ongoing transactional process.

Consent

In terms of gaining consent and ensuring privacy, I sent a letter to all the key respondents inviting them to take part in the study. The participants were given at least 24 hours to consider the information relating to the research study (appendix 2). This is particularly important as qualitative research often requires participants to ‘grant access’ to their experiences, lives, minds and emotions. I stated in the letter that I would observe strict anonymity with the information and would not include any names or any other means of identifying key people in the writing up of the study. In terms of confidentiality of data, only I knew the origins of the quotes used in the thesis and tapes and transcripts were kept in a locked cabinet accessible only to myself. Written consent was gained from all participants.
Franfort-Nachmias & Nachmias (1992) suggest that the obligation to protect the anonymity of research participants and to keep the research data confidential is all-inclusive. It should be fulfilled at all costs unless arrangements to the contrary are made with the participants in advance.

The law of consent is based on the competence of the patient, so the researcher must ensure research participants are competent to understand the implications and process of the research they are consenting to take part.

Facilitating patients to make an informed choice regarding taking part in the study was an important aspect of the process. According to Johnson (1992) “Patients ought to be able to decide whether to participate, based on reasonable information as to risks, potential benefits and discomforts or inconveniences”.

As such an information sheet was given to each patient selected to participate in the study several days prior to the interviews taking place (see Appendix 2) Thus, enabling subjects to discuss issues concerning them about the study with their relatives, nursing staff and the lead researcher. Consent was then gained (appendix 1).

**Validity**

Qualitative research is often criticised for not making explicit rules for, or achieving, the criteria for rigour in scientific research, reliability, validity and objectivity. However, some would argue that qualitative research does not attempt to control extraneous variables or subjectivity, so is more meaningful to the social world (Hammnersley, 1992). According to Denzin & Lincoln, (1995), qualitative research is many things at the same time and is defined more by uncertainty, fluidity and emerging methods than by consistency of approach.
Brink (1989) however, believes the issues are the same in all research but that the routes to achieving reliability and validity are modified in qualitative research. Alternative terms for qualitative aspects of scientific rigour are given in table 1.

Table 1. Comparison of quantitative and qualitative terms in establishing rigour in research.

<table>
<thead>
<tr>
<th>Aspect of rigour</th>
<th>Scientific term</th>
<th>Naturalistic term</th>
</tr>
</thead>
<tbody>
<tr>
<td>Truth value</td>
<td>Internal validity</td>
<td>Credibility</td>
</tr>
<tr>
<td>Applicability</td>
<td>External validity/generalisability</td>
<td>Fittingness (transferability)</td>
</tr>
<tr>
<td>Consistency</td>
<td>Reliability</td>
<td>Auditability (dependability)</td>
</tr>
<tr>
<td>Neutrality</td>
<td>Objectivity</td>
<td>Conformability</td>
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</tbody>
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Sandelowski (1986) suggested that a qualitative study is valid (credible) when there is confidence that its findings are characteristic of the variables being studied and not of the investigative procedure itself and where it presents such faithful descriptions and/or interpretations of the experience that people having that experience would recognise it.

All interviews were prior arranged at each patient’s convenience, most were held in the patient’s own home or in the wards day rooms where it was felt there would be privacy and minimal disturbance in a comfortable and semi-familiar setting.

I informed my colleagues of my prior engagements and the location I would be visiting throughout all the interviews to ensure safety. Pontin & Webb (1995) argue that interviewers have less control over the "home" environment and there is no guarantee that the interviewee will be able to maintain a "safe" place free from intrusion, interruption and being overheard.
Using a semi-structured interview method, patients were asked to describe their experiences of living with a pressure ulcer (see Appendix 4). This method of obtaining data allows complex issues to be explored in more depth, with respondents telling their own story in their own way (Bowling 2002). Loffland & Loffland (1995) describe this approach as a guided conversation: hence I was able to encourage the participants to express their experiences, feelings and attitudes concerning the phenomena freely.

The luxury of sitting down in a quiet environment, where attention was focused on the patients and their descriptions of their experiences gave a certain degree of depth and richness to the interview.

All interviews were audio taped, with the verbal permission of the respondents, to allow accurate recording of the information.

Data Analysis

The purpose of qualitative is to describe, explore and explain phenomena being studied. Qualitative research answers a wide variety of questions related to actual or potential health problems. The aim of a phenomenological approach to qualitative research is to describe accurately the lived experiences of people, and not to generate theories or models of the phenomenon being studied.

What is ‘lived experience?’ This is an important question because phenomenological human science begins in lived experience and eventually turns back to it. Dilthey (1985) has suggested that in its most basic form lived experience involves our immediate, pre-reflective consciousness of life, a reflexive or self-given awareness that is, as awareness, unaware of itself.

Various thinkers have noted that lived experience first of all has a temporal structure; it can never be grasped in its immediate manifestation but only reflectively as past presence. Lived experience is the starting point and end point of phenomenological research. The aim of the phenomenology is to transform lived experience into a textual expression of its
Phenomenology was used to answer the research question *what is the impact of pressure ulcers on patient's quality of life.*

Because the primary source of data is the life world of the individual being studied, in depth interviews were used for data collection. Furthermore, emerging themes are frequently validated with participants because their meanings of that lived experience are central in this phenomenological study.

**DEVELOPMENT OF THE QUESTIONS**

Qualitative studies have indicated that pressure ulcers are associated with a poorer quality of life. However, few empirical studies have been conducted on the quality of life of these patients (Clark 2002).

There are several ways of measuring health outcomes when undertaking economic evaluations of health-care interventions. These are generally classified as measures of effectiveness or measures of utility.

Health outcomes are measured in natural units such as wound length, depth and width, or the number of wounds that healed. Measures of effectiveness may also capture patients' quality of life using health-related quality-of-life (HRQoL) instruments. One of the most widely used instruments is the short form 36 (SF-36), which provides scores in eight domains.

The SF-36 is frequently used to generate data on health related quality of life. Each respondent is asked to complete 36 questions, which should only take five to ten minutes. The SF-36 instrument provides an overall impression of the health-related quality of life of individuals and populations. It provides an overview rather than a detailed picture of the impact of a particular medical condition. (Clark et al 2002) recently reported the methodology of a study that focused on the outcomes achieved in pressure ulcer prevention and treatment, all patients were invited to complete the SF-36 following
admission. Not all subjects could fill in the questionnaire and there was also lost data. Little information could be obtained on the effects of full-thickness pressure ulcers on health-related quality of life.

Clark et al (2002) recommends that there is a challenge for those involved in tissue viability to work towards the development and validation of a reliable instrument aimed specifically at measuring the effect of pressure ulcers on an individual's enjoyment and participation in life. If such a tool was available may be we would be able to gain a fuller understanding of the impact of pressure ulcers and of the common interventions used on quality of life.

The response to the SF-36 questionnaire is grouped to provide quantitative data on eight domains likely to influence health-related quality of life. These domains include:

- Limitations on physical activity
- Limitations on day to day life caused by health or emotional problems
- Current energy and fatigue
- Emotional well being
- Social functioning
- Pain
- General health perceptions

The SF-12 and the SF-8 are shorter versions of the SF-36 and seek similar domain information using only 12 and eight questions respectively. Kause (1998) reported a series of correlations between the presence and severity of pressure ulcers and responses to the Life Situation Questionnaire-revised, an instrument developed to explore the impact of spinal cord injuries on aspects of quality of life. The results showed that, associated development of a pressure ulcer at any time post-injury with lower levels of subjective well-being and activity, and greater health problems.
Quality of life is a complex concept that relies on many factors, including friends and family, enjoyable work or leisure pursuits, comfortable home and lifestyle, and satisfying emotional and sexual relationships. The idea of quality is by its nature heterogeneous, with different individuals ranking dissimilar elements as more or less central to their quality of life.

An editorial in the Lancet (1995) called for more research into the best way to define and measure quality of life: 'The what (are we measuring) and why (are we measuring it) questions, together with evidence about validity with respect to the patient's viewpoint, must become the central measures of efficacy for a quality-of-life instrument.

The Lancet (1995) also suggested that there is a need to raise awareness of these issues to avoid the 'uncritical acceptance of "expert" driven questionnaires' although raised awareness is vital, the majority of questionnaires used to assess quality of life originate with the patients' perspective rather than of the experts.

Bernheim et al (1995) proposed an 'ambitious back to basics' approach to halt the recent shift from evaluating quality of life to merely describing it. These references add weight to the argument that we must consider very carefully what we are measuring and how we are measuring it so that there are no false assumptions underpinning quality of life.

Gould & Fox (2000) approached a Patients and carers Association to audit the consumers' views of pressure sores. They found that deciding what questions to include in the survey was difficult due to the complexity of pressure ulcer development and the lack of consensus among experts concerning those factors which do not contribute to risk, and continuing arguments about risk assessment (NHSCRD 1995). They also suggest that the general public, however well informed, do not know as much about the theories of tissue viability as clinical experts, although they might be very well informed about the practicalities of caring for individuals with potential problems of tissue viability. They used fixed questions in the survey to encourage completion.

Of the 150 questionnaires posted, only 70 (46.6 per cent) were returned.

While the majority of academics working in this area would agree that quality of life is certainly a complex and multidimensional construct. In an attempt to narrow down the
term' quality of life’ to reflect its use in health care, the term ‘health-related quality of life’ was first used in 1988. Health-related quality of life has been defined as the impact of disease and treatment on disability and daily living, or as a patient-based focus on the impact of a perceived health state on the ability to lead a fulfilling life. This definition allows researchers flexibility to include different key elements.

Fallowfield (1990) has argued that quality of life should be seen as a complex amalgam made up of four core domains. In comparison, Sullivan (1992) listed six core dimensions. In many ways these reflected those of Fallow field, although some factors were classified under different headings. Sullivan also included a wide ranging general dimensions on quality-of-life perceptions that tackled directly the question of patient subjectivity with a global rating. She argued that the patient is often the only expert on the impact of a disease or disorder and should therefore be regarded as ultimate judge of the treatment received.

I developed the open ended questions for the interviews using a mixture of the experience of being a Tissue Viability Specialist for over fifteen years and using themes from validated health questionnaires, the SF12, SF8 and the shorter version of the SF36 gave me an insight and ideas on how to structure my own questions also studies such as Langemo et al (2000) helped me to develop questions around general health perceptions and the limitations on day to day life having developed a pressure ulcer.

Each question has to mean the same thing to each person to whom it is put if there is to be a standardization of data. Therefore, the wording of the questions and the order in which the questions are asked has to allow the best access possible to the variables that are being investigated. I piloted the questions on two subjects the aim of this was to evaluate how well the design research tools performed.

The pilot helped me enormously in many practical issues, such as using the tape recorder. Very naively, I had not considered that some participants would have such variable tones of voice when interviewed which when transcribing were hardly audible taking hours to transcribe with the volume turned up fully. It is essential that the interviewer is confident about the equipment. I had also some concerns regarding the questions as to whether they would be open to misinterpretation this was not found to be so, the participants were very willing to chat, spanning more than one question, frequently digressing but nevertheless providing plenty of data.
Interviewing then, is not seen as a mechanism but as a dynamic interaction between two people, which takes place in a particular set of circumstances for a particular purpose. Although the interaction does not have a rigid, predetermined structure, this is not to say that there is no logic or rationale to the proceedings. Interviewers have a repertoire of strategies and tactics at their disposal, which they may use in conversation to gain access to the meanings people attach to their experiences (Morse 1991).

However, interviewers using a qualitative approach will be open to unforeseen avenues of enquiry opening up during the encounter with the interviewee (Hammersley & Atkinson 1995). Advantages of interviews face to face are that the interviewers can probe fully for responses and clarify ambiguities; more complicated and detailed questions can be asked, more information, of greater depth, can be obtained, inconsistencies and misinterpretations can be checked.

Disadvantages of interviews are they can be expensive and time consuming, there is the potential for interviewer bias, and additional bias if interpreters are used for some participants under reporting of health problems in comparison with postal approaches. If questions are carefully designed for the topic, it can yield highly accurate data.
Interview Schedule

Interviews were planned to take approximately ¾ of an hour at an agreed time convenient for the interviewee.

1. Tell me about your experience of having a pressure ulcer?

2. What areas of your life have been most affected by having developed a pressure ulcer?

3. What was that like for you?

4. What did you understand when you were told you had a pressure ulcer?

5. How did that make you feel?

6. How do you feel regarding the treatment/care you received for the pressure ulcer?

7. Would you have liked anything else?

8. Have you been given any advice regarding your pressure ulcer?

9. Do you feel it is sufficient?

10. What advice would you give others with this condition?
DATA ANALYSIS AND DISCUSSION

Aim of the study

The aim of the study was to look at the effect of having a pressure ulcer and how that affects patients' quality of life.

Data Analysis

Data was analyzed by applying Van Manen (1984).

Van Manen (1984) identified four procedural activities:

- Finding a phenomenon that one is committed to study
- Differentiating between the experience conceptualized and the experience Lived
- Reflecting on the themes that characterize and speak the phenomenon
- Describing what has been learned about the phenomenon through writing

Hence, following each interview I transcribed and analyzed the descriptions by reading through the entire interview to form a general picture, then extracting the thematic statements that were essential to describing the phenomenon, reflecting on the themes. To clarify the meaning of the themes generated and to add depth to the study by generating more discussion around the themes, the participants were visited again at their convenience, validation was sought from them to compare the descriptive results with their experience as lived, within this study the participants themselves became the recognized experts.
PATIENTS EXPERIENCES

Patients’ experience of having a pressure ulcer is a complex evolving process. Six major themes developed characterizing this process:

- Pressure ulcer development
- Areas most affected
- Pressure ulcer understanding
- Feelings regarding treatment
- Advice given
- Recommendations.

All themes were influenced by many variables, each one capable of affecting the patient experience.

The findings presented in the following chapters are based on informants’ descriptions of the specific themes and variables, their general feelings of each theme being experienced either positively or negatively, and the implications of that experience on their quality of life. The final chapter will discuss the main findings in relation to the research aim and the broader literature, followed by concluding remarks.
THE EXPERIENCE OF HAVING A PRESSURE ULCER AND HOW IT AFFECTED THEIR LIFE

Introduction

All the respondents verbalised an understanding of how they developed a pressure ulcer. All could say exactly how the ulcer had developed and what had caused it. They were all amazed at how quickly the pressure ulcer developed.

Joyce... I got my pressure sore on my ankle when I had been in hospital for only two days.

So quickly they developed, she shakes her head.

Bill... I am a spina bifida so I can’t feel my legs. I did months in hospital no sores then I came here and they developed within a few weeks. I have got them on my heels and bottom.

Sarah spoke of the shock.

Sarah.... I woke up in hospital following a fall. I was unconscious for five days when I woke up they told me I had a sore, it was a shock.

The meaning and or significance of a pressure ulcer vary from person to person. Many of those with pressure ulcers have viewed the ulcer as worst thing that can happen suggests. On the other hand, some family caregivers view pressure ulcer formation as a normal consequence for the bedridden, reports (Baharestani, 1994).

Some of the literature suggests that pressure ulcers are typically described as being caused by pressure but pressure it is argued is not the root cause. It is said that cells can withstand very high pressure, up to 830 millionKg/m or about 17000 atmospheres, so direct pressure caused by a body’s own weight will not cause tissue destruction directly
(Torrance 1983). However, small relative changes in pressure distort the tissues and occlude the microcirculation, and necrosis may follow within a few hours.

It has been implied that divers can withstand pressures of 16 atmospheres without pressure damage, but a relative sustained change of one-sixteenth of an atmosphere will cause tissue necrosis (Hussain 1953). The duration of shear pressure is therefore a pivotal factor in the development of ulcers, as is the patient's physical and psychological condition (Anthony & Dunn 1987).

The majority of the literature agrees that pressure ulcers are not a new problem, the mummy of an elderly Egyptian priestess of Amen of the twenty-first dynasty was found to have large pressure ulcers over the buttocks and shoulders (Thompson 1961). Moody (1987) suggests that tissue viability is of particular interest to nurses because it affects the management of everyday patient care, which is the core of nursing practice. Versluysen (1985) goes on to say that pressure ulcers develop soon after a patient’s admission to hospital, when the injury or illness is most acute and recommends that preventative action should begin as soon as the patient is admitted. Regularly changing the patient’s position in order to relieve pressure must be the main treatment strategy for pressure ulcer prevention.

These suggestions are reiterated by some of the patient’s comments.

Joseph... I am a diabetic and I have had problems before with sores on my feet. Recently I went into hospital for an operation and I got a nasty sore on my heel.

Martha... I was poorly and ended up in hospital with my breathing. I was only in hospital for a few days when they said you have a sore bottom. I was shocked; I could not believe it could happen so quickly.

Mary comments on the pain.
Mary...It developed here at home. I was ill last winter and I was in bed for a few weeks and this sore developed on my heel gosh it has been painful. I can’t believe how sore it has been.

Pain is rarely a simple sensation produced by a specific stimulus. Pain is very individual, subjective experience, ameliorated or enhanced by such things as culture, conditioning, attention and emotional state.

Kathryn... I watch my skin but I have never had a pressure sore before, they say it is caused by pressure. God the pain was indescribable the sore happened so quickly.

Maud... Well it happened in this care home I was ill for a few days, off my food I had flu and I am a diabetic not a bad one. One minute my skin was fine next thing I knew I had a sore Anyway I got a sore bottom oh it has been so bad for eight weeks I have had the district nurses coming and treating me.

Clearly a mobile patient is not likely to develop a sore, as the pressure will be constantly altered on the various parts of the body. Pressure ulcer prevention techniques normally involve either instituting a pressure relief support system or physically moving the patient, or using a combination of both methods should be prescribed for patients who are identified ‘at risk’.

Mark... I am terminally ill and have been for sometime I developed a pressure sore on my elbow and my bottom. I tend to lie on the same side as I am much more comfortable I know I shouldn’t.

A study undertaken within a palliative specialist unit over two years reported that out of 542 patients admitted to the unit, 26.1% were admitted with pressure ulcers while 12.0% developed pressure damage during their stay. The unit found that these patients were older, stayed 12 days longer and more of them died than the average for all patients admitted to the unit (Galvin, 2002).

Comfort is particularly important for patients with terminal illness, where the priority is to maximise quality of life. Equally important is effective pressure care; as such patients are
at high risk of developing pressure ulcers because of their general condition (Bale & Regnard 1995).

Experience has repeatedly shown that if a person is given the opportunity to learn the facts of his/her case, little by little, at his/her own pace, and provided he/her is encouraged to share with others the feelings which these facts evoke, and provided that others are not constantly feeding back to them their own fears, he/her will move progressively closer to a full realisation of the situation without suffering over-whelming panic and despair.

Developing infection and soreness was expressed by two of the respondents.

Louise... I have had them (sores) off and on for years let me see about eight years or so. Because I spend a lot of time sitting or in bed due to my arthritis and the stroke I had. It's nice when I don't have any sores at present I have a really sore one on my bottom. I got it when I went in for respite care for two weeks but I ended up being transferred to hospital I got sick through the sore I developed what do you call it? Err septis.

Eunice... They developed in hospital on my heels they became very dry and cracked open and caused an infection they became a terrible mess. Very, very sore.

Alan... They developed in Pakistan. The one I had healed up after one month survived the plane journey. When I got ill it went on and on, in and out of hospital, one to another I deteriorated. Very, very stressful for me with my spinal injury. I am so independent even with my disability I could not believe that a sore could make me so ill (he shakes his head).

Pressure ulcer development in the spinal cord-injured population remains high at 80%, of whom 7-8% will die as a result of the ulcer (Bryne & Salzberg, 1996). Pressure ulcer formation has been found to be more extensive in paraplegics, related to the lower level of self-care responsibility (Anderson & Andberg 1979), although the research failed to determine the reason why.
Olshansky (1992) recognised the significance of the high occurrence of pressure ulcers in paraplegics, theorizing that the true aetiology has a psychological basis, illustrated by an almost 'self-mutilation' attitude. A paralysed individual may develop a fear and hatred of his/her affected body parts (Zeidlik 1992), enhanced by a distorted body image, relative to reduced proprioceptive feedback (Partridge 1994).

Harding-Okimoto (1997) determined that the subjects she interviewed had negative body image perceptions, which interfered with their ability to instigate pressure ulcer preventative measures.

Not all patients found the explanations given by healthcare professionals as acceptable on how the pressure ulcer had developed.

Tom...I asked the nurses to move me but they kept telling me the mattress I was on would help and I did not need to be moved. This went on for a while I said my bottom was sore and my heels were really sore but no one took any notice.

Edna...I kept telling them my bottom was sore but no one seemed to bother they just put cream on my bottom. I couldn’t see my bottom I asked the nurses and they said it was not too bad they had seen much worse.

Gould (2000) found in a small survey that carers thought that pressure ulcers might be avoidable, attributing their development to lack of regular turning or changes of position.

Sheila...After about a week my bottom and heel was sore I asked the nurse to have a look and she said they were the start of pressure sores so she put some cream on the areas. That was it!

Appleton (1992) suggests that instituting the values of the art of nursing creates a context described as an atmosphere of caring’, a place of safety where the physical environment is beautiful and the patients feel welcome and comfortable.’ A ‘home away from home’.
Moore (2004) says that the development of pressure ulcers may be linked to nurse attitudes, education and competence, although all practitioners are responsible for prevention. But Benbow (1992) argued that education alone would be of limited value if it were not reflected in clinical practice.

Hulland (1985) explored nurses' actions and beliefs on pressure-ulcer prevention and treatment. Although the sample was small (n=29), the author was able to identify many variances in the nurses' education, sources of information and opinions regarding ownership of responsibility for prevention.

DISCUSSION

All the respondents expressed how they could not believe how quickly the pressure ulcer developed 'Shocked, amazed' where many of the expressions used to describe how they felt. All the patients could remember exactly when the pressure ulcer developed and the verbal descriptions they gave were still very vivid in their minds even though some had, had the pressure ulcer for more than six months.

The amount of suffering shocked all the respondents and how long the pressure ulcer was taking to heal they could not believe. Pain also was an over riding factor, two respondents expressed their amazement at how painful a small pressure ulcer could be. Some patients felt that the explanation they were given when they expressed their concerns was not acceptable.

Nurses have shouldered the responsibility for patients developing pressure ulcers from as far back as 1899. Galloway (1899) stated explicitly that pressure ulcers were caused by poor nursing, although he did allow that, under some circumstances, particularly spinal cord injuries, it is almost impossible to prevent them. A nurse writing in the same text was more dogmatic, stating 'except, perhaps, in some cases of spinal disease, bedsores are always preventable'. Cope (1939) asserted that bed sores were a reflection of bad nursing, while Brownell, in the same year, stated that sores were the result of negligent nursing, an opinion repeated in a later edition of the text (1954).
In more recent textbooks, nurses continue to be blamed for patients developing pressure sores. According to Agate (1973) 'bedsores were a failure of the nursing staff'. Ferguson (1982) suggested that well run wards had fewer sores. Mobily (1991) stated that while immobility caused sores, astute and vigilant nursing could, to a significant extent, remove the possibility of the complications of immobility.

Some authors have promoted an alternative view; Love (1937) stated that sores develop even with good nursing care. Much later, Chalmers (1980) similarly claimed that sores could occur even in the presence of good nursing. Redfern (1986) stated that pressure sore prevention needed a multidisciplinary approach.

Anthony (1987) identified that nurses appeared to have good knowledge about prevention, yet continued to use inappropriate equipment. So why is education not reflected in clinical practice? Is it because of the source or quality of education? Or are there other barriers to integrating knowledge in the clinical setting.

Bostrom and Kenneth’s (1992) findings support those of Hulland (1985) and Anthony (1987). Pressure ulcers were not considered a high priority, suggesting that education alone may not improve practice. Conversely, others have identified that nurses need a wide range of knowledge to manage prevention effectively. Therefore one must question the connection between education and prevalence.

I suggest that ‘blaming’ nursing care is counterproductive in the battle to reduce pressure ulcer incidence and prevalence. Spilsbury et al (2007) stated that all the participants attributed blame for pressure ulcer development. Some participants directed blame at their chronic condition, poor health, or loss of weight and appetite. Others blamed healthcare professionals for failing to attach priority to their reports of an ulcer or delays in skin inspection. Similar findings emerged from the participants I interviewed.
AREA OF THE PATIENTS LIFE MOST AFFECTED

All the respondents stated that their lives had been greatly affected. They all also expressed how it made them feel.

Tom... I walked into this hospital and now I can’t walk at all, it does not seem right. Well I am very angry that I have ended up like this. I asked to be moved but no one listened. I feel upset and angry that I cannot do for myself. I have to rely on the nurses for everything; I feel like a baby, it should not have happened. If only they had listened to me I might not be in the state I am now. I know I was ill but you don’t expect to end up like this (He shakes his head and his eyes fill up with tears).

Pearce (1953) states that a patient ‘likes to feel that the nurse will not miss any feature of his case, which should be observed and that the nurse knows how to interpret his needs and how to relieve them’.

Patient repositioning should be part of a planned pressure ulcer prevention strategy. Repositioning, though labour-intensive, should be undertaken as often as is tolerable for the patient, particularly if not on a pressure-relieving support system (Russell 2004).

The Nursing and Midwifery Council (NMC 2002) states ‘that we have a responsibility to deliver care based on current evidence, best practice and, where applicable, validated research, when it is available’. The need to practice evidence-based care is fundamental aspect of clinical governance and is a concept that can be seen to permeate through the NHS Plan (Department of Health 2000).

Alan... Life as it should be isn’t, it grinds to a halt day in day out; you are stuck in bed. I know it is for your own good but it’s not what I would recommend. I mean you have no social life, nothing left at all when you are in this condition. It has totally affected my life especially with the children. They say ‘why can’t you come shopping with us?’. That sort of question I am stuck for an answer at times it is hard on everyone, (at this point the children come home from school and come running
up the stairs to see their daddy, they become very shy when they see a strange person in the room we stop the interview whilst Alan talks to them about their day).

Suffering was expressed by some of the respondents although it was described in different ways.

Eunice...I don’t think I should have suffered so much. But you put up with it, it just happens. I could not walk properly and I live on my own so I could not come home. I had to stay in the rehab ward. It upset me I wanted to come home.

Joyce expressed the sores as painful.

Joyce... Well it really hurts (the pressure sore) in bed, I can’t get comfy; I can’t sleep as well as before. I have to get up when it is so bad and have a warm drink. I didn’t realise that these sores could be so painful. It has really affected me I can’t get my shoe on and I have to stay in. Well I have got really depressed, you see I used to like going out and now it is coming up to Christmas and I am going to miss all the celebrations. I just wish it would heal and I could get back to how I was. Joyce shows all the tablets she now takes for pain and depression.

This is also mentioned in Langemo et al (2000) study as all eight subjects verbalized experiencing the impact of pain from a pressure ulcer.

Pain is an individual phenomenon that is both physiologically and psychologically complex (Cassey 1998). Therefore, pain may be significantly shaped by age, gender, and emotional, social and cultural factors. Most wounds cause a certain degree of pain as a result of inflammation and hyperalgesia. There is a certain misconception that wounds are not painful.

King (2003) suggests wound pain could be divided into chronic present when the dressing is in place and acute, present during dressing removal. Therefore, it is recommended that practitioners should understand pain development and assessment, which should be performed at every treatment.
However, pain in wound care is either dismissed by those who inflict it or is not assessed appropriately and is therefore subsequently badly managed (Hollinworth & Collier 2000). Ketovuori (1987) claims nurses have preconceived ideas about the degree of wound pain that a patient is likely to experience.

Edna... I have never had a pressure sore before, I was very upset my husband has looked after me for thirty years and I have never had a sore. They (nurses) should have realised that anyone like me who cannot move, requires help more often. I use to wait hours to get a bedpan, they always said 'in a minute' well you can’t wait can you? It was horrible. I felt so humiliated I am only an old woman to them with no feelings (she shakes her head). Edna’s husband comes into the room at this point he says he is angry at the treatment she got, shakes his head and goes out of the room.

Humiliation that Edna felt has also been expressed in other studies. Langemo et al (2000) quoted a quadriplegia patient who had a pressure ulcer which had required surgical intervention, the patient said he felt humiliated when doctors looked at his sores and sometimes five or six people would want to look.

Sarah... Lots of runny liquid I was ashamed it messed the bed linen and they smelt, it put me off my food. I was conscious for the other ladies in my bay. I kept saying the smell was not I.

Langemo et al (2000) conducted a study to describe, understand and give meaning to the experience of living with a pressure ulcer, using descriptive phenomenology. The major findings were that pressure ulcers had a profound impact on the lives of the participant’s physical, emotional and social life. Additionally they found that those with a stage 4 pressure ulcer and a flap repair and those with a spinal cord injury inevitably experienced the grieving process in some form.

Two respondents became quite distressed over the odour; Bill isolated himself because he was so conscious of it.
Bill... I can’t go into the lounge due to the smell they don’t hurt because I can’t feel them luckily. I love going to the football but I am really conscious of the smell so I have missed a few matches, which hurts. I have all my meals in my own room now. I am lonelier now I spend a lot of time on my own. I only have the TV for company.

Louise describes her feelings of embarrassment and being ashamed that she smelt.

Louise... Well I had to stay in bed, which I don’t like to do but it was so sore to sit on. I could not sleep, it was really bad at first. The dressings kept falling off and my bed was always wet with the leaking, it was embarrassing for me and it smelt. I could not believe it at first, I did not think that the smell in the room was me. They put me in a room on my own as the other patients complained of the smell. I felt terrible I couldn’t look at anyone I was so ashamed. I like company. I was so lonely in my own room, just waiting for visitors.

Bush (2002) says that in the area of pressure ulcers, much emphasis has been placed on the physical manifestations and treatment available, but suggests it is imperative that more is learnt about how chronic illness affects people on an individual level. Sullivan (1992) argues that patients are often the only experts on the various impacts of their disease or disorders and should therefore be regarded as the ultimate judges of the treatment they receive.

Body malodour can cause withdrawal and intense misery (Van Toller 1994). Smell carries a social stigma and the effect can make the patient feel guilty and ashamed, as well as inhibiting sexuality and physical intimacy (Price 1994). Finley et al (1996) reported that, when assessing a malodorous wound, practitioners sometimes assume patients become used to and unaware of the smell. However their study demonstrated that patients remain aware of malodour but may not spontaneously report it due to a sense of shame and hopelessness. In this study patients were relieved and surprised when the malodour was controlled.

Joseph describes how disgusting he felt.
Joseph... I am not allowed to put any weight on it, (heels) which is really hard. I don’t have much pain as I have no feeling in my feet, high risk they say I am. But it’s the stuff that leaks out of the bandage it is disgusting. It put me off my food have to stay in hospital till it is much better they say. I wish it had not happened, I don’t blame anyone, maybe I should have taken more care but I did not realise that this could happen, you don’t do you? But I have to stay in hospital I could have been at home now, I miss my dog, my son has to look after him. I feel a burden, (he cries quietly looking at a picture she is holding of her dog).

Poor nutritional status and poor dietary intake have been associated with pressure ulceration and impaired healing. Prospective studies comparing the dietary intake of patients with and without pressure ulcers in both hospital and community settings have found a decreased intake of energy, protein, vitamin C, zinc and iron (Grey & Harding 1998). However, patients with pressure ulcers who had an adequate or increased nutritional intake, particularly of protein, arginine, vitamin C and zinc, had faster healing rates than patients whose nutritional intake was adequate (Gorse & Messner 1987).

Kathryn expressed feelings of depression and not being in control.

Kathryn... It has wrecked my life having a pressure sore, I don’t have a life it has been in describable. I would never have thought it would be like this. Just one sore can affect you so much I have been really depressed. It is so boring, there is only so much TV and reading you can do. I have been in bed for three months, now that is a long time. I used to love going shopping with my daughter but all that has stopped. It’s like your life is put on hold all because of a sore, I can’t believe it. It is not only me that is affected the whole family if we want to talk, discuss things it is all done in my bedroom. I don’t feel in control any more: I used to feel very much in control but I feel things are slipping away. It has been really hard on us all. It is what I call a nightmare that at present I do not see any light at the end of the tunnel. I am so fed up (She looks at me with tears in her eyes).

Sometimes it is difficult to relinquish duties to others in the family whilst still trying to manage the household from the environment of a bed. The loss of control of the body’s physical boundaries (Lawton 2000).
Pressure ulcers have a dramatic effect on quality of life; they contribute to increased morbidity and even mortality, and reduce individuals’ comfort and independence (Moore 2004).

Mark remarked on reduction of activities.

Mark… It’s the discomfort it has caused that affects me as the side I like to lay on I cannot now, and I have to have a special mattress which is not that comfortable. I wanted to go on holiday, I like swimming but I am frightened that they will get infected and the nurses have advised me not to at present, but I don’t know how long I have got left. I want quality time not to be stuck at home. So at present it is affecting me more than the illness. At present it is hard for me and my family to come to terms with having these sores as well as the illness. I have just been really unlucky. I must say they are not as painful as they were a few weeks ago.

It did appear that all the respondents had been very traumatised in one way or another following the development of a pressure ulcer. As the researcher I encouraged the participants to describe their experiences as fully and deeply as possible without suggesting to them what to say. I tried to be an interested and a sensitive listener, and attempted to set aside my own judgements and preconceptions about caring in order to focus on the participant’s experience.

The fear of dying from a pressure ulcer was expressed by a few of the patients.

Bill… It was only when the specialist came did I realise that I could have lost my leg. My God, you would not think that pressure sores could end up like this could you? The specialist said it was a risky operation as my chest was not good it was then I realised I could die. I tried to put a brave face on for my family but I was frightened.
Maud...I was worried at first Ooh, I trusted the nurses but when they said ‘pressure sore’, I thought of the people here who have died with them so I did cry a lot at first but I am okay now.

Alan... I just wanted to get back (to the UK) I thought I was going to die and not see my children grow up, that frightened me.

DISCUSSION

It was alarming as the researcher to hear such vivid accounts of how having a pressure ulcer had such a detrimental effect on their quality of life. The saddening and shocking aspect was some of the interviewee’s accounts of expressing fears of dying.

Symptom control can encompass a wide range of bodily ailments and their side effects. With symptoms successfully treated or controlled, the boundedness of their bodies is reinstated encompassing good wound management with odour control dressings. Having had their bodies successfully ‘rebounded’ it is then possible for the patient to return to their own normality.

Lawton (2000) says that a hospice setting is seen as a mediator between the unbounded and the bounded body, with patients being moved into the hospice when surfaces of their bodies rupture and break down, and are moved out again when their bodily boundedness and integrity were subsequently restored.

Health-related quality of life has been defined as the impact of disease and treatment on disability and daily living, or as a patient-based focus on the impact of a perceived health state on the ability to lead a fulfilling life (Price 1996). Fallowfield (1990) has argued that quality of life should be seen as a complex amalgam made up of four core or primary areas.
In comparison, Sullivan (1992) listed six core dimensions. In many ways these areas reflect those of Fallowfield, although some factors are classified under different headings. Sullivan also includes a wide-ranging general dimension on quality-of-life perceptions that tackles directly the question of patient subjectivity with a global rating. She argues that the patient is often the only expert on the impact of a disease or disorder and should therefore be regarded as ultimate judge of the treatment received.

Having dealt with the areas of a patients life most affected we are now going to discuss what understanding patients had of 'what a pressure ulcers is' and how they are caused.
UNDERSTANDING OF A PRESSURE ULCER

The majority of respondents had an understanding of what a pressure ulcer was and how they were caused. All the patients knew that they are caused by pressure and the need to change one’s position regularly was vital in the prevention.

Tom... I had heard of pressure sores I knew that people got them if they are in bed for a long time. But I didn’t think that I would get them, I can’t believe I have ended up with them and be in this state now. I only came in with my breathing (patient shakes his head).

Interviewer... How does that make you feel?

Tom... Well I feel very angry that I have ended up like this I knew I should be moved, I asked to be moved but no one listened to me only the specialist nurse. Why don’t they listen to me? (He shakes his head).

Moore (2004) states that nurses have traditionally led pressure ulcer prevention and management and, while not having sole responsibility, they have a unique opportunity to make an impact.

Bill... I knew about them, I have heard stories about sores but I was shocked when they said how bad they were. After all I have looked after myself for seventy years and no sores now I am in a mess. Daily visits from the nurses, my life is not my own anymore I am a very proud and private man.

Interviewer... How did that make you feel?

Bill... Well I have accepted it now but I was really upset at first and angry, yes angry it should not have happened if I had been moved more regularly through the night.
Research suggests that 95% of pressure ulcers are preventable (Alexandra et al 1992, Hibbs 1990, Waterlow 1998). Diseases associated with older people correlate with the development of pressure ulcers in hospitalised patients. Up to 52% of elderly patients being nursed in hospital have pressure ulcers (O’Dea 1993). The incidence being greater in those admitted with femoral neck fractures (Hawthorne & Nyquist 1988; Versluysen 1986; Hibbs 1982). This situation could persist as the number of older patients with femoral neck fractures continues to increase (Royal College of Physicians 1989).

Edna explains how her husband is her main carer.

Edna... I know all about the problems pressure sores can do my husband is very careful in how he positions me in the chair and when I am in bed he gets up twice in the night to change my position.

Interviewer… So your sleep is disturbed at night due to changing position?

Edna… Yes both of us have a disturbed night with sleep but it was worth it or at least it was till I went into hospital.

Interviewer… Do you feel anyone is to blame for the sores developing?

Edna… I can’t forgive them (ward) they have caused me so much suffering I dread it if I have to go back into hospital. I got multiple pressure sores and yet none of the nurses or doctors seemed to be bothered or concerned.

Sarah… I was shocked I had known about sores but I never thought I would get one.

Interviewer… How did that make you feel?

Sarah… I was really upset and I could not understand why it had happened then one of the nurses had a chat with me and how they develop. I did not realise that be falling and being in one position for so long can cause this amount of damage.
Louise explains her concerns of developing a pressure ulcer.

Louise... Well I have had them before (sores) so I knew what they were like. But I got worried when they said it was really bad, it did frighten me then, as I have never had one so bad. It came so quickly.

Interviewer... Would you have liked anything else?

Louise... It would have been nice not to get one. I have had good treatment so I am not complaining its just one of those things.

Joseph... I had heard of them (sores) but you don’t think you will end up with them do you? After all I only came in hospital for a simple operation on my knee so you don’t expect this.

Interviewer... How did that make you feel?

Joseph... I could not believe it and when it got bad and I had to go to theatre and have it cleaned out, I was worried I was told that I could have lost my leg if it did not improve. God I was frightened (he shakes his head).

Vulnerability to pressure damage because of immobilisation begins with the initial fracture (Versluysen 1986). The individual may have fallen and been lying on a hard surface for several hours before admission. He or she may then spend several hours in the accident and emergency unit (RCN 1996), lying on hard support surfaces on narrow trolleys, which are not conductive to positioning for pressure relief.

Cullum (2001) and NICE (2005) recognise the need for the risk assessment to be completed within six hours of hospital admission, and at regular intervals post-initial assessment.
Kathryn... Because of my injury years ago I was told about pressure sores but you never think it can happen to you do you? But it has and I don’t really know what I did wrong. The nurses say the sore is due to pressure. But I have not done anything different.

DISCUSSION

Pressure ulcers are wounds that afflict thousands and cost millions, but are not caused by anyone. ‘No other wound in the body has been subjected to such a variety of unusual treatments, ranging from vegetable poultices to sugar, charcoal or baked in hot lights, soaked in brine or pressed upon by an array of mechanical contrivances (Shea, 1975).

Moore (2004) explored nurses’ ‘attitudes and behaviours in relation to pressure ulcer prevention and management and their perceptions of barriers to see whether or not pressure ulcers could be realistically prevented. In reviewing the literature Moore found that there was no consensus on the precise definition of a pressure ulcer and so suggested that therein lies the primary problem. If practitioners are not clear what a pressure ulcer is or what indicates the start of damage, how can they know what the prevalence is or how effective prevention strategies are.

In the UK, the Department of Health suggested that pressure ulcer prevalence is an excellent indicator of the quality of care delivered in a health-care setting, and recommended an annual 5% reduction. However, agreement with these recommendations is not widespread, with the National Health Centre for Reviews and Dissemination suggesting that prevalence rates cannot be used alone as a determinant of quality of care (Gould, James & Tarpey et al 2000). It has been argued that, to infer quality of care, prevalence needs to be combined with knowledge of the population’s risk status and case mix.
FEELINGS REGARDING TREATMENT RECEIVED

The overall feelings that emerged were that the treatment the patients initially received was unacceptable, of a poor quality which left the respondents feeling angry, confused and upset that they were not listened too.

Tom... At first when my heels and bottom were sore no-one listened to me I think they thought I was exaggerating (He Laughs) I think they thought I was confused I was not, I know when I am sore and in pain, it was only when my relatives complained and asked questions that they took me seriously. It does not seem right that no one listens to you. I have had good treatment now in this ward. I know the sores are getting better, but it is not right that I have got them it’s because of poor care. I think nurses should listen to us patients, not treat us like an idiot (he shakes his head and looks sad).

Alan reiterates this.

Alan... Sometimes I think it helps if the nurse asks the patient about the dressing. When you have been in a chair as long as I have and you get a young nurse comes in, no reflection on their ability but you do feel sort of left out. You would rather know what’s going on sometimes you could help. Sometimes you can actually help with the dressing, you can advise. You can show them a better way of doing the dressing rather than Mefix stuck on me.

Three of the respondents commented on the variation of dressings.

Bill... I don't think at first they knew how to treat them (sores). Each nurse had a different idea. It was only when the specialist got involved that things have improved. Thank God I did think I might die at one stage, all through sores. I managed to pull through pretty well after my stroke to end up with sores. Can you believe it? Why oh why did this happen?
O’Flynn (2000) suggests the ‘individual’ is initially ‘eclipsed’ by the wound, and adapts by assuming the sick role, becoming a patient during the ‘healing and coping’ phase of the process. As the patient recovers he or she begins to ‘re-merge’ and regain normality as aspects of health and quality of life return. The individual is then able to resume his or her normal roles.

This is verified by some of the patients.

**Edna...** They should have (nurses) but they did not it was as though they could not be bothered or not that interested. They all had their own ideas how to treat my pressure sores, each putting a different thing on. I cried a lot I could not cope with their attitude to me. They could not bandage I am glad the district nurses know what they are doing it is only now they are improving. I feel a bit better now and can manage a bit more around the house.

**Joyce...** At first the treatment in hospital was not good. I told them about my ankle they did not notice that is wrong, isn’t it. All the nurses had different ideas on what to put on it I did not know who was right and who was wrong. When I got home the nurses now seem to know what they are doing thank goodness.

Many dressings are still not being used properly despite the advances in wound care research and the development of new dressings, patient assessment and wound assessment are still at the heart of effective clinical decision-making and cost-effective care. Although there are numerous study days, courses, conferences and journals on wound care, Benbow (2004) argues that information on dressing application and removal is not being delivered and that practitioners’ general knowledge of them is poor. Given the abundant information from NICE, the Health Technology Assessment report and books, Benbow concludes there is no excuse for ignorance.

**Sheila...** Well I don’t think that the cream they applied helped it just messed up my nightdress and then when the sheets where blood stained they started to put dressings on, but I think that was a bit late, something should have been done sooner. But the treatment is okay now these nurses know what they are doing so I am okay now.
Professional accountability is regarded as an integral part of nursing today (Symon 2000). Walsh (2000) defines accountability as ‘being able to give an account of your actions, to explain and justify what you did’. This produces potential difficulties for nurses treating wounds. Wound care is a complex speciality and new methods of treatment appear frequently. Information about best practice can be difficult to access because conflicting opinions and the wide variety of information sources imprint and online.

A working knowledge of available wound care products is essential to accountable wound care. The treating nurse needs to consider the patient’s lifestyle, the wound’s location and many other variables.

Joseph...Well once they said what it was I had a lot of people come to see me, specialists so they have taken over the treatment, which is good as I was becoming quite concerned before. Everyone should be aware of these sores especially in people who have diabetes because they are at risk. I think there was a lack of awareness amongst the ward staff. Now everything is okay.

Not all respondents had totally negative thoughts on the treatment they had received.

Sarah... The treatment I have had is excellent I could not have asked for more it has been good. The only thing that I have dreaded is when the dressings have needed changing that sticky stuff hurts when it is coming off and at first the smell and stuff coming from it was horrible. But it is much better now.

Kathryn... The treatment I have had has been good, the nurses have explained everything to me and have been good with visiting.

Mary praises the treatment.

Mary... As soon as it was recognised I had one by the nurse, that the doctor had asked to visit I have had really good treatment. Some are more caring than others.

Mark... The treatment has been good, the advice has been excellent and I have followed it all and they are improving, hopefully they will have healed soon.
DISCUSSION

Most of respondent's were quite critical of nurse not including them in the treatment process and not listening to them. Although they sought informative support from the health professionals they were not satisfied with the outcome.

Within the UK, nursing and medicine is demanding increased evidence-based care and randomised controlled trials have become the gold standard for research. Indeed, the NHS Executive recommends RCTs as the most reliable evidence for the efficacy of interventions (NHS Centre for Reviews and Dissemination 1997). However one patient cannot be compared with another without noting potentially the high number of variables in their health status and these differences will alter healing outcomes for each subject. This means that to eliminate the confounding or intervening variables, an inordinately large number of patients would need to pass through the study. The results of practical experience may often be discounted. An example of this is Preston’s work on the 30-degree tilt (Preston 1988). Gebhardt (2000) criticized the general use of the system as being unresearched, being based on Preston’s one paper. Nevertheless practical experience has demonstrated that the method has positive benefits. There is a potential for nursing and medicine to become so focused on research that valuable practical experience is ridiculed and disregarded by academics (Hampton 2001).

Use of research-based evidence within the Western world may be viewed as a luxury that cannot be afforded in poorer countries. In poorer countries the 30-degree tilt and changing the patients’ position regularly according to need is widely used effectively. This is reminiscent of the ritualized, non-research-based practice of the ‘back round’ when nurses went from bed to bed, washing, creaming or rubbing patients’ buttocks to prevent pressure ulcers (Walsh & Ford 1989). Evidence-based care is vital and supported must be by further studies and application in practice. Nevertheless, there is also a place for care based on practical experience.
ADVICE ON PRESSURE ULCERS

All the patients said that advice was given too late. The specialist equipment in the majority of cases was prescribed after the development of the pressure ulcer. All respondents were angry at the fact the advice came too late. Many of the patients wanted explanations as to why advice on pressure ulcers was not widely available to them at the start of developing the ulcer.

Martha... If I had been given much more information when I went into hospital to make me aware of the problems when not moving much this might never of happened and I would not be in this condition now would I?

Interviewer... Do you feel the advice you have been given is sufficient?

Martha... I was told to move, move every so often that is what all the nurses tell me every time they come. It seems a shame that I was not warned before this happened. I wish this advice, I had been given before it seems that the advice is given far too late.

It has been argued that the increase in the use of pressure-relieving devices has not led to a corresponding reduction in pressure-ulcer prevalence. Although such equipment is of value, its use alone will not improve outcomes. This is confirmed by two of the participants’ comments.

Joseph... Yes lots now, what not to do but at first nothing. When the blisters appeared I was told to put them on a pillow, does that not put more pressure on the heel? I don’t know I just did what they said they are the professionals. Now I am not allowed to put any weight on them yet.

Interviewer... Do you feel the advice you have been given is sufficient?
Joseph... At first I don't think they knew what to do. Some wanted to pop the blister, some said not to. I did not know who to believe it was only when the specialist came I felt okay. Should the staff not be aware and know what to do or is special training needed.

Tom is critical that no one listened

Tom... I would have liked the nurses to listen to me sooner. I know I should have been moved more often. I would like to have seen that special nurse sooner I did not know they had those sort of special nurses. She helped and now the treatment is good thank god, people can die of these sores you know (patient shakes his head). They have told me to move more, if they had moved me more I wouldn't be in this state now would I? They have put me on this mattress and I have a special cushion for when I sit out.

Interviewer... Do you feel the advice you have been given is sufficient?

Tom... I think they should have a strict regime for moving a patient who can't move him or herself. Like in the army regular times to check each patient. It would stop the suffering that I have had to go through, I would not wish this on anyone I will be in here for weeks maybe months, it does not seem fair, I am sure it could have been prevented. There does not seem to be any leadership on these wards.

Bill queries training issues.

Bill... Just to move more this is difficult with my stroke and spina bifida. I do try though and the carers now come and turn me in the night.

Interviewer... Do you feel the advice you have been given is sufficient?

Bill...Well it is better now than it was at first and now the specialist visits I think that keeps them all on their toes (he laughs). Do nurses have training on sores and on how to prevent them? It would make sense wouldn't it all this suffering which could be prevented.
Skills and knowledge are important influencing internal factors. Without adequate instruction, a tendency to adhere to ritualistic practices may prevail (Hicks 1996). A tendency to cling to ritualistic practice may stem from fear of change due to lack of knowledge, rather than an unwillingness to change.

Joyce... I was told to keep off my ankle but that was hard with the other hip being so sore, they didn’t show me how to keep the pressure off. Now I am at home I have a special cushion the nurse got me to put my feet on its more comfy now.

Interviewer... Do you feel the advice you have been given is sufficient?

Joyce... The advice is good now, but I have been thinking since coming home more could have been done in hospital surely to try and prevent these horrible sores.

Kathryn... Oh yes I have been given good advice now and I have got a new cushion which feels better and the nurses are always nagging me, like my family to move.

Interviewer... Do you feel the advice you have been given is sufficient?

Kathryn... Well I would have liked maybe looking back more advice on prevention before it happened, it is only when you get a sore do you realise that there are people out there that can help. I had no idea they existed. Now I have assessments frequently for pressure relief, as before I did not, maybe I should have had.

Sarah... All the nurse’s keep telling me not to stay in one position for too long but I can’t anyway as it gets sore so I do move around a lot now.

Interviewer... Do you feel the advice you have been given is sufficient?
Sarah... I don’t think I could have asked for more. I had really good care I got a special mattress and cushion to help, which did the trick. I still have the cushion; I don’t need the mattress now thank goodness.

Mary... They (nurses) keep telling me to keep moving but at first it was terrible I could not move, it was the pain it was awful you would not think a heel could cause so much pain but it did.

Interviewer... Do you feel the advice you have been given is sufficient?

Mary... it has been good the advice but I neither did nor realise that by lying in bed you are prone to pressure sores. I know I was ill and I did refuse a lot of help, so I suppose it is my fault I was ignorant and now I am paying for it.

DISCUSSION

The majority of the respondents were quite critical of health professionals’ explanations feeling the advice given was of poor quality. Gould (1986) assessed the amount of education nurses received on pressure ulcer prevention and management at undergraduate level and sought to address why many nurses do not consider prevention as important as other aspects of care. Thirteen schools of nursing outlined which aspects of prevention and treatment were routinely taught and why, and how this related to the current literature. While acknowledging the study limitations, Gould identified that education was inadequate and poorly taught. These findings are disturbing, education alone will not alter practice, but without it, awareness of the need for prevention will not exist (Halfens & Eggink 1995).

Arblaster (1998) suggests that education heightens awareness of the problem and provides the information needed to carry out prevention effectively. However the content and quality is of major importance. Nurses with a sounder knowledge base make better decisions than those with a poorer knowledge base (Collier 2004).
Harding & Jones (1993) argues that wound care will continue to present a challenge for the foreseeable future with increasing numbers of older people developing wound problems. The high cost and often-ineffective care is an aspect of clinical management that requires attention. They go on to suggest that the modern approach to wound care should foster an interdisciplinary approach that relies on the expertise of individual health professionals. Only then will it be possible for the development of appropriate wound management regimes that will both prevent and treat the epidemic of wound problems currently seen in clinical practice.

THE FUTURE MANAGEMENT OF PRESSURE ULCERS

The respondents’ recommendations were based on their bitter experience and so should be taken seriously. Of the respondents who had a hospital admission they all said they would not recommend admission to hospital if at all possible. Education was an over-riding theme. All respondents queried whether nurses received education on the management and prevention of pressure ulcers. They expressed concerns that this was an area of neglect with no structure in place to prevent pressure ulcers developing. A few respondents suggested that a booklet would be helpful on admission to hospital/caseload so that they could read it at their leisure. That more awareness towards pressure ulcers should be widely available was suggested. It was raised that the correct treatment came too late in some cases when the suffering had already taken a hold on their lives.

Mary... Try to avoid getting them (pressure ulcer) in the first place but some of us are ignorant to how they develop, maybe we should be informed, I don’t know but it would help, look at the time my sore has taken to heal.

Edna... They (nurses) could learn to listen to the patient more and in the old days what was it called that trolley thing they use to have. You knew when that came round that it was time to be washed and moved. Are nurses educated in pressure sores? It should be part of their training after all they are supposed to be caring for us patients’ are they not?
Joseph... Be careful and aware that this can happen I would never have thought this could happen to me. I wish I had not come into hospital, as I have been in so long now all because of these sores. Keep out of hospital is my motto.

Martha recommended more information

Martha...I would say listen to the experts but make sure yourself if you are ill you need to move to take the pressure off. There should be a leaflet that you or your family are given when you go into hospital that makes you aware of the problems.

Tom.... Try not to get them as they ruin your life, all you have is pain and suffering. Pain when they are being dressed, the smell and all that stuff leaking on to the bedclothes and on my clothes. I feel embarrassed that my relatives have to take them home and wash them it’s not right. What advice would I give others? Don’t come into hospital stay at home (patient laughs and shakes his head).

Not all respondents were negative

Bill... If you become ill were aware what could happen if you are not moved, I don’t blame anyone, but I wish it had not happened.

Mark... Trust the professionals and don’t give up they will improve if you get the right treatment. I am improving and I feel soon I will be okay, my aim is to heal and that should be every body’s aim.

Louise advises to ask for help.
Louise... Take care you never know and if you are sat a lot of the time, get help to move you. I am very careful now and I always ask my carers what my skin is like. You can’t be too careful can you?

Maud agrees.

Maud... Be careful this can happen to anyone, I was only ill for such a short time and look at me. Get help as soon as you can from the professionals it does really help.

DISCUSSION

Some of the respondents who had been in hospital had very strong negative feelings regarding any further hospital admissions. Not being listened too was also a strong criticism from many of the respondents. For more than 20 years pressure ulcer prevention and the treatment of established pressure ulcers have continued to generate research by nurses and those in allied disciplines. Pressure ulcer aetiology is established and much is known about the healing of chronic wounds, but little impact has been made on clinical nursing practice (Gould 1986). The aetiology of pressure ulcers is understood, but the treatment of established ulcers, in the company with many other nursing procedures, lacks justification.

The nursing profession is renowned for its tradition and its hierarchy. Many of the nurses who presently occupy senior positions and who could be influential in the implementation of research findings, completed their formal nurse education at a time when many of the nursing treatments for pressure ulcers now known to be of little value, had been regarded as beneficial. It is not easy for senior nurses, qualifying at a time when treatments such as massage were advocated as a sound method of pressure ulcer prevention, to accept that these may actually be damaging (Dyson 1978).

Monafo & Ayvazian (1978) contrast the treatment of chronic lesions to that of burns, which are also ischaemic wounds, prone to infection. Unlike pressure ulcers, burns have generated a great deal of medical interest and there is sound, overwhelming research evidence to suggest certain topical agents that are effective.
David (1982) found that topical applications to pressure ulcers were most often prescribed by nursing staff, nurses still depend upon medical prescription to obtain many of these and may be further constrained by the ‘clinical preferences’ of doctors for particular regimes of treatment for which there is no underlying rationale.

**Summary of findings**

In summary, this study sought to explore patient’s experiences of having to live with a pressure ulcer grade III to IV. Following interviews with fifteen respondents the data were transcribed and analysed according to the principles of Husserlian phenomenology. On listening to the respondents’ narratives it has emerged that living with a pressure ulcer is characterised with certain themes emerging. The themes are influenced by many different variables; they’re general feeling of each theme being experienced either positively or negatively, and the implications of that experience on their quality of life. One of the first questions was to identify if the participants had an understanding of how they developed a pressure ulcer. This showed that all the respondents had a good understanding of what a pressure ulcer was and how they developed. Each patient could remember exactly how the ulcer developed even though in some of the cases they developed the ulcers a long time ago, but yet it was still vivid in their minds. All the respondents used the terminology ‘pressure sore’.

Another theme was revealed, as to be the area most affected in their lives again very explicit verbal accounts were given of how it had greatly affected their lives and family life. A few respondents had very negative thoughts regarding dying, emotions were strong in this stage with some expressing fear, tears and fright with having no control of the situation. All the participants had feelings of anger and frustration.

I then looked at what understanding of a pressure ulcer the patients had. The majority had a very good understanding of what pressure ulcers were and how they occurred. Anger came throughout this stage with some participants finding it hard to come to terms with
how they had developed a pressure ulcer. Feelings of not being able to forgive the health professionals were expressed by quite a few of the patients. The majority had negative thoughts regarding pressure ulcers again the majority-expressed anger.

I then asked the participants of their feelings regarding the treatment they had received. The overall feelings that emerged were that the initial treatment that they had received was of very poor quality, which again led to feelings of anger being expressed. Feelings that the health care professionals did not listen or try to understand the patients' experience. Feelings of no confidence in the nurses were also expressed. A few respondents voiced positive thoughts on the treatment they received but they were in the minority.

I asked about the advice the patients were given regarding their pressure ulcer all of the patients said that the advice given came far too late. The specialist equipment in the majority of cases was prescribed following the development of the pressure ulcer. Again the majority questioned why they received poor advice from health care professionals and felt anger. Confusion and that they had had mixed advice was also expressed.

What is clear from this study is that the patients had very negative views on the whole process of having and living with a pressure ulcer. The anger and frustration many of the respondents felt was alarming and concerning. With all the expensive specialist equipment readily available and specialist advice the basic treatment in the majority of cases did not happen.

The themes that emerged from this study were similar to other studies (Spilsbury et al 2007) found that pressure ulcers have a physical, social, emotional and mental impact on patients. Causing much pain, discomfort and distress that is not always recognised or adequately treated by health professionals.
Some Implications

I believe the patients' experiences reported in this thesis and the themes generated have significant implications for present nursing practice.

From this study it emerged that patients' felt that they were not listened to even though it was their pressure ulcer. Barriers of communication emerged. Feelings of desperation and frustration and anger were continually expressed. Therefore, it is recommended that there is a more effective way of communicating with patients and relatives through assessment of individual needs, planning and continuous reassessment. It is the reassessment that is frequently missed. NICE (2005) recognise the need for the risk assessment to be completed within six hours of hospital admission, and at regular intervals post-initial assessment. Pressure ulcer documentation needs to be a universal policy which is made mandatory throughout the two Trusts, this would ensure that all health care professionals communicated in exactly the same way, i.e. pressure grading system, pressure relief systems, treatment and prevention. Ensuring the patient is included in all aspects of their prescribed treatment is important. NICE Pressure Ulcer Prevention (2003) and the patient information leaflet should be given to every patient on admission to hospital or caseload. Patients need to be felt they are listened too and taken seriously this would endeavour to maintain an effective communication pathway.

Consistency of intervention

One of the issues highlighted in the study was variation in treatments for pressure ulcers. Due to the different views of the health care professionals, there needs to be a standardisation in treatments this should be through guidelines in wound care. With the enormous amount of wound care products now available it is no wonder there is confusion and varied ideas regarding products. Limited wound care prescribing may be beneficial to prevent confusion. An individualised treatment plan should be evolved following an in depth discussion with the
patient. Good wound management practices that consider both the patient and the wound can significantly improve quality of life.

**Improved education in pressure ulcer treatment**

The structure of nursing is rooted in the past and is traditionally military in design. Hierarchical relationships, regimented schedules and rules of conduct still form the framework for much of the nursing environment. Woundcare has been an area where the doctor-nurse relationship has had a traditionally paternalistic pattern. However, the past decade has seen a substantial shift in how the relationship is expressed, as well as the ways in which nurses implement their role.

Healthcare professionals must ensure that they have had training in all pressure relieving equipment, risk assessment of the equipment, as it is their responsibility if they have prescribed it and they are nursing the patient on equipment. As new equipment becomes available it should be each healthcare professional's own responsibility to keep up to date.

A general public awareness is required to highlight pressure ulcer prevention and treatments available, road shows, meetings, and leaflets available in public settings could provide this. This would raise the public's 'awareness on' prevention is better than cure.' The voice of patients and their families need to be heard.

**LIMITATIONS OF THE STUDY**

Although this project has achieved what it set out to achieve, that is expressing the feelings and needs of patients’ living with a pressure ulcer in their own words study like this clearly has some limitations. One limitation is that the study was confined to two Trusts. The sample size was small which could influence under representation or over representation although the patients who contributed to this project were rich in experience, generating a wealth of data, which reflected other similar studies. The study may also have benefited from a wider cultural mix. Whilst these issues may be restrictive,
the themes generated in this study are still relevant to all healthcare professionals and exploration of the themes is to be encouraged in a wider range of clinical settings.

A further limitation of the study may have been in the methodological approach chosen to underpin the project. Certainly phenomenology presents a perspective which may illuminate and clarify some of the fundamental and important issues within nursing (Hallett 1995), embracing a holistic approach (Polit & Hungler 1991; Van der Zalm & Bergum 2000) and giving a voice to human experience (Jardine 1990). However, once I had identified phenomenology as the investigative strategy which aligned most with my volition to seek an understanding of patients’ experiences of living with a pressure ulcer, like others before me such as Koch (1995) and Paley (1997), I discovered inconsistencies in its philosophical underpinnings and application. Similarly, Crotty (1996) believes there to be a lack of relationship between the philosophical traditions of pure phenomenology as championed by Husserl, and the ‘new phenomenology’ espoused by nursing researchers such as Giorgi (1985).

This is reaffirmed by Van Manen (2001) who believes qualitative researchers now utilize approaches and methods that have moved far beyond traditional methods and methodologies, which can be seen when comparing the works of traditional phenomenological philosophy with the work of phenomenological research in the multidisciplinary field. For instance, the structure added to the interpretation of phenomenology by social scientists, such as Colaizzi (1978), is disparate from the origins of Husserl’s science of essences’ aimed at revealing true essence by peeling back the phenomenon and facilitating the reader to attempt an understanding of the individuals’ lived experience for themselves (Corben 1999).

This lack of relationship became increasingly evident as I studied the expansive literature concerning phenomenology. In addition there appeared to be no clear defining consensus of phenomenology, which made it increasingly difficult to adopt as a specific approach. Wimpenny & Gass (2000) argue this lack of congruence equates to lack of rigor and lower acceptability to the research community. It was precisely these arguments that may have led me to compromise my personal position. In other words, I had initially been determined to use Husserl’s pure approach to phenomenology which, in relation to
bracketing, would have required me to empty my mind of all the data relating to a phenomena’s context and situation (Hallett 1995), which is in contrast to the principles of intentionally bringing these elements into view and using them to control for bias in a study as I did.

In addition, Paley (1997) argues true Husserlian phenomenology is based on intuition and description, not induction nor deduction. Furthermore he suggests pure phenomenology is not an empirical procedure, but an imaginative one found in the researchers own consciousness once eidetic reduction is achieved. This is reiterated by Corben (1999) who also suggests Husserl viewed phenomenology as essentially a descriptive process with conclusions being presented as raw data, giving no reference to analyses beyond bracketing. Controversially, Paley (1997) claims that due to their misinterpretations of Husserlian phenomenology ‘nurses are not entitled to make use of Husserl’s terminology, and should abandon their attempts to ground phenomenological research. As Hallett (1996) observes, it is precisely these issues and judgments that cause many nurse researchers to feel under pressure to conform to a more ‘scientific’ form of phenomenology.

I used the Van Manen (1984) approach to process which identifies four procedural activities, finding the phenomenon, differentiating between the experience conceptualized and the experience lived, reflecting on the themes that characterized and spoke the phenomenon and the describing what had been learnt through writing. Essentially, this allows the reader to map my decision-making processes throughout the study, whilst I systematically attempted to justify those decisions in order to ensure the study is acceptable to the research community. However, ultimately I feel I was able successfully to utilize many positive aspects of valuable philosophy to enlighten my understanding of patients’ living with a pressure ulcer.

Van Manen (2002) suggests that you have to find space that is comfortable for the body, but not too comfortable. Once the physical space is conductive to reading, you are ready so to speak, to enter the other space, the space of the words that transports you away from the everyday reality to the reality of the text. When you have entered this world of the text, then you are somewhere else. So there is a doubling of space experience there. The physical space of reading or writing allows you to pass through it into the world opened
up by the words, the space of the text. Van Manen (2002) queries if this is not a misleading way of speaking? After all, the space opened up by the text is not a ‘real’ physical dimensional space. He suggests that the idea of textual space is just a metaphor and therefore a gloss for how we actually experience the process of reading and writing. The term ‘space’ itself possesses rich semantic meanings etymologically, the word does not just refer to physical extension and perspective. Space possesses the meaning of temporal and physical expanse as well as the time spent in an experience. When we enter this space of the text we indeed seem to enjoy a temporal experience in a world evoked by the words of the text. We step out of one world, the ordinary world, and enter another, the textorium, the world of text.

Relations in the field are such that the researcher is provided with trusted information of the sort necessary to both understand and empathize with the observed, but the researchers’ presence itself creates little change or disturbance concretely, however, such relations wax and wane over the course of a study, approach or exceed the upper and lower limits with different individuals on the scene, and vary according to the practical situation (Van Manen, 1984).

As Van Manen asserts there are no definite answers or solutions when using this approach. ‘The point is that no conceptual formulation or single statement can possibly capture the full mystery of this experience’ (1997), the approach of descriptive studies, questionnaires and rating scales lack the opportunity to express the wholeness of meaning within patient care. Rather, it is a way of unlocking hidden perspectives, and providing the opportunity for expressions of thoughts and feelings.

Qualitative research does not provide ‘answers’ or conclusions in the same way as quantitative research. It can rigorously challenge one’s assumptions and biases. It is a robust methodology that forces engagement and implicates the reader in the process in a way that can be unsettling to one accustomed to the more predictable format of qualitative research. However, it is my belief that both of these approaches serve to assist in the quest for truth and understanding in the complex world of human health.
Concluding Comments

In conclusion, this enquiry has revealed many issues in the management and treatment of patients living with a pressure ulcer. It is far more complex than was first anticipated. Nurse’s play a central role in the management of pressure ulcers, but that role seems to be loosing its way some how, identifying quickly the patients requirement and implementing the most appropriate treatment seems to be low on the agenda. Pressure ulcers are one of the top four expensive diseases, along with cancer, cardiovascular diseases and aids. It is vital that we understand the importance of understanding how patients feel about having a pressure ulcer and identifying their individual requirements. This knowledge could only improve nursing care since it would allow nurses to recognize and identify what each patient requires early rather than later this would improve all aspects of nursing care. In this way the nursing profession has much to learn from listening to the voice of the patient with a pressure ulcer if they are to give quality care.

A worrying and concerning finding from O’Flynn’s study (2000) was that 43% of patients with a wound were discharged from hospital with pain present ‘all the time’, and a further seven 20% with pain ‘most of the time’. One patient commented: ‘I suffered in silence, (the pain) restricted my movement and I took a stiff drink at night to help with sleeping’. 57% of the patients had difficulty sleeping at some point because of pain from the wound. Pain is one of the most common symptoms that cause patients to consult healthcare professionals. However, it is often inadequately treated leading to unnecessary suffering, poor quality of life and poor outcome of treatment Haddox et al (1997).

For the person in pain, so incontestably and unnegotiably present is it that ‘having pain’ may come to be thought of as the most vibrant example of what it is to ‘have certainty’ while for the other person it is so elusive that ‘hearing about pain’ may exist as the primary model of what it is ‘to have doubt.’ Thus pain comes insharably into our midst as at once that which cannot be denied and which cannot be confirmed (Scarry 1985). Health professionals need to start believing in what the patient says People with wounds do have pain which has been confirmed by the patients interviewed in this study.
Hoffman et al (1997) suggests that chronic pain in particular, is poorly controlled in patients with chronic wounds. The psychological elements of pain sensation means there are often discrepancies between the nurse's assessment and the patient's experience of pain.

Pain control is not simply a quality-of-life issue, it may improve the patient's psychological state, and is thought to have an impact on wound healing (Glyn 2002). Wound pain assessment has been generally regarded as inadequate, since pain sensation is a composite of neurochemical and psychological elements, measurement methods cannot be quantitative and objective instead, subjective tools have to be used to assess the level, cause and nature of pain (Sussman 2003).

Patients generally experience most pain at dressing removal (King 2003) but the true extent of any patient's pain experience is often subsumed by the focus on the wound (Hallett et al, 2000).

Two publications of recent years reflect the growing interest in the problem of pain associated with chronic wounds: the European Wound management Association's position document (EWMA, 2002) and the World Union of Wound Healing Societies' principles of best practice document (WUWHS, 2004). Both stress the importance of recognizing and dealing with wound-related pain. However both concentrate on pain at dressing change, which important as it is to recognize and deal with, it is only part of the problem for many patients with chronic painful wounds.

Practitioners often give pain management a low priority when dealing with patients with chronic wounds. This maybe due to preoccupation with treating the wound, lack of time and/or ignorance. Ignorance may encompass many mistaken beliefs, that pain is harmless and an unavoidable consequence of having a wound, that the patient is exaggerating the pain or that if the patient does not complain that he or she is not in pain. In addition, health-care professionals without sufficient knowledge of the physiology of pain are less likely to address the problem.
In 1993, a prevalence study on patients with leg ulcers stated that the overwhelming feature of the experience of leg ulceration was of it being painful and the pain had a profound effect on patients' lives (Lindholm, 1993). Other studies have confirmed this (Walshe, 1995; Franks and Moffatt, 1998).

Pain affects not only the individual's capacity to enjoy life but also has an impact on interpersonal relationships so that a whole family network can be put under pressure. Biggs (2007) found when interviewing one patient that the patient's non-concordance was the result of two conflicting actions, while the healthcare professionals were giving treatment based on their expert knowledge according to what they interpreted as the aetiology of the leg ulcers, the patient was instigating actions that she felt necessary to alleviate her pain and discomfort. She found there was an obvious gap in communication between patient and healthcare professionals. The failure of satisfactory pain relief appeared to have been the main motivation for the patient's non-concordance. Without concordance with the treatment it was not possible to achieve therapeutic goals, resulting in poorer patient outcomes.

Wound malodour is increasingly becoming a critical issue, as it can affect patients in numerous social and psychological ways (Benbow, 1999). Healthcare professionals need to become aware and more vigilant to patients with malodorous wounds. Odour can become such a problem that it can create a boundary around a patient repelling others away. It can cause problems for carers and relatives.

Lawton (2001) found that when she discussed with carers their reason for wanting a patient to be admitted to a hospice, their comments revealed one particularly notable theme. Carers, as a general rule, did not seem to be explicitly concerned about the fact that a patient was dying: on the contrary, the main reason they gave for wanting a patient to be admitted was they felt repelled by the patient being incontinent, vomiting and/or emitting other bodily fluids within their own homes. Patients themselves often shared these perceptions. Patients often felt home did not afford an appropriate space for their bodily disintegration, since the experience of being incontinent in front of family and friends could be extremely distressing and humiliating to them.
Medical diagnosis is a very peculiar kind of knowledge. With diagnosis, the body is drawn into a certain sphere of instrumentality. Instead of being able to take the body for granted, it is now a constant reminder of something (Van Manen, 2002). As long as we are healthy, there is little reason to think about our body. ‘Sometimes only a reassuring explanation is required to appease us and to help us to resume or rebuild an unbroken relation with the body and thus with the world. Explaining can heal, in the sense that it prompts us to a less anxious, more liveable relation with our body’ (Van Manen, 1998).

There is increasing pressure to maintain an attractive and healthy image, therefore patients are concerned about how others will react to them when changes take place (Price, 2000). This change of body image leads to loss of confidence, affecting the patients’ social status leading to social isolation Young, 2005). To be socially acceptable, one must smell nice (Price, 1990). It is very common for patients with fungating wounds to become isolated; Lisle (2001) reported that patients stated that their symptoms, such as exudate leakage and malodour, affected their body presentation more than the look of the wound itself.

As nurses, we have been taught to hide any feelings of disgust regarding the appearance or smell of a wound so as not to upset the patient and increase their anxiety with regard to altered body image. This silence is questioned by Wilkes et al (2003) and Arunda (2001), stating it may be detrimental for both nurse and patient. In a study by Arunda (2001), nurses discussed comments by a dying patient who smelt very badly: The medical staff’s reactions were causing her to feel confused and isolated as they behaved as if the smell did not exist and when she asked them directly and they refused to acknowledge this, she felt she was not able to ask them for ideas on how she could improve the smell of her room. This is an example of not allowing the patient to be able to discuss openly and share the problems of malodour. The patient needs to feel in control and should be able to participate in decisions about their care.

The respondents in this study confirmed experiencing feelings of boundedness on page 50 and 69.

Smell creates a boundary around a patient, repelling others away. Sometimes, staffs attempt to manage the problem of smell by transferring a patient to a side room, thereby
enabling the odours emitted from his or her body to be contained within a more bounded space this is enforced strongly by respondent on page 50.

The study by Lange et al (2000) found similar issues, they found that patients who had an ulcer for longer than six months experienced pessimism a poorer adherence to treatment. Coping with the pressure ulcer was difficult, and patients felt isolated, particularly when they were often left in a side room on their own. Patients felt humiliated that healthcare professionals were seeing parts of their body, which were normally private. The odour from the pressure ulcer made them feel dirty.

This study has found similar themes as the study by Lagemo et al (2000) several themes emerged from that study, perceived aetiology of the pressure ulcer, life impact and changes, psychospiritual impact, extreme painfulness associated with the pressure ulcer, need for knowledge and understanding of pressure ulcers, need for and effect of numerous stressful treatments and the grieving process. The major findings in both studies enforced that pressure ulcers have a profound impact on the lives of the participant’s physical, emotional and social life. Quality of life is influenced by sickness, treatment and the underlying disease. Any attempts to measure quality of life must involve the patient. Wound management therapies are invariably assessed in terms of cost-effectiveness and healing, rather than quality of life.

From a patients’ perspective the phenomenon of living with a pressure ulcer is a multifaceted process, and for too long this process has been ignored. Incalculable resources have been spent on specialist equipment, education; specialist nurses yet with all these things we cannot prevent pressure ulcers from developing.
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Appendices
CONSENT FORM

Title of project: To explore the experiences of patients with a pressure ulcer and identify the factors that impact on their quality of life.

Name of researcher: Jacqui Ashton

Please initial box

1. I confirm that I have read and understand the information sheet dated ......................... (Version 01) for the above study and have had the opportunity to ask questions.

2. I understand that my participant is voluntary and that I am free to withdraw at any time, without giving any reason, and my medical care or legal rights will not be affected.

3. I understand that sections of any of my nursing notes may be looked at by the researcher I give permission for this individual to have access to my records.

4. I consent to the researcher's informing my GP of my participation in the study.

5. I agree to take part in the above study.

Name of Patient                      Date                      Signature
To explore the experiences of patients with a pressure ulcer and identify the factors which impact on their quality of life.

Please ask if you do not understand anything in this information sheet, or if you would like further information.

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Take time to decide whether or not you wish to take part.

What is the purpose of the study?
Pressure ulcers are areas of localized damage to the skin and underlying tissue caused by a combination of pressure, shear and friction. Having a pressure ulcer can take in some cases quite a while to heal. I would like to know how you feel during this time and whether having a pressure ulcer has had an effect on your daily activities and daily living.

How will this benefit me?
You may not benefit personally by participating in the study. However, the information will enable us to understand how a patient feels when they have a
pressure ulcer and whether this has any effect on the healing of their pressure ulcer.

**Why have I been chosen?**

I have contacted you, as I understand that you currently have a pressure ulcer.

**Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

**What will happen to me if I take part?**

I will be using the semi-structured interview to collect my data. The interviews will be tape-recorded and last approximately ¾ of an hour. During these interviews questions will be asked regarding what it is like to have a pressure ulcer.

**Will my taking part in this study be kept confidential?**

All of the information obtained as part of this study will be treated confidentially. All tape recordings, transcripts and field notes will be kept in a secure place accessible to myself only. All study participants will be ascribed a unique identification code. I will be the only researcher who is able to match these codes with individual respondents. These codes will be used in all written reports/publications. The audio tapes will not be shared with medical, nursing or managerial colleagues, but the final report, containing anonymous quotations will be available to all at the end of the study.

The audiotapes will be erased once data has been transcribed from them.
What will happen to the results of the research study?

Study findings will be fed back to respondents following data collection and transcription on request. The researcher will use the results to complete the study and write up a dissertation for submission towards a Phil degree.

Who has reviewed the study?

The study has been reviewed by Bolton Local Research Ethics Committee, which has given independent approval for the study. My supervisor at Salford University has also reviewed the study.

Contact for Further Information

You can contact Jacqui Ashton on (01204) 360005 for further information about this study.

Lever Chambers Centre for Health
Ashburner Street
Bolton
To explore the experiences of patients with a pressure ulcer and identify the factors which impact on their quality of life.

Date
Dear:

Patient's Name:
Patient’s Address

This letter is to inform you that having been seen by the tissue viability service your patient was recruited to the above study. Research has demonstrated the impact of pressure ulcers on quality of life. The cost to patients is high; including experiencing prolonged hospital admissions, pain and discomfort, immobility and a reduction in quality of life. It is therefore, essential that causative factors leading to the development of pressure ulcers be fully understood. More work is required on the experiences of patients with a pressure ulcer. The Local Research Ethics Committee has approved the research on (date approved).

If you have any questions regarding the study, or any concerns regarding your patient’s participation, please do not hesitate to contact me.

Yours sincerely,

Jacqui Ashton Nurse Consultant-Tissue Viability
APPENDIX 4

Interview Schedule

Interviews will take approximately ¾ of an hour at an agreed time convenient for the interviewee.

1. Tell me about your experience of having a pressure ulcer?

2. What areas of your life have been most affected by having developed a pressure ulcer?

3. What was that like for you?

4. What did you understand when you were told you had a pressure ulcer?

5. How did that make you feel?

6. How do you feel regarding the treatment/care you received for the pressure ulcer?

7. Would you have liked anything else?

8. Have you been given any advice regarding your pressure ulcer?

9. Do you feel it is sufficient?

10. What advise would you give others with this condition?