The Prevalence and Experience of Emotional Distress in Patients with Chronic Venous Ulceration

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June Edith Jones

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The prevalence and experience of emotional distress in patients with chronic venous ulceration

Although chronic venous ulceration is a disabling condition both physically and emotionally, it is still not viewed as a chronic illness for which cure should not be the main aim of care. Consequently, care delivery continues to be situated within a biomedical culture, with little attention paid to the psychological and emotional consequences for people living with leg ulcers. This study aimed to firstly determine the prevalence of depression and secondly to explore the lived experiences of individuals living daily with chronic venous ulceration.

In phase I, a prevalence study of 190 patients with chronic venous ulceration was undertaken across nine NHS Trusts in the north west of England. Individuals were screened for anxiety and depression using the Hospital Anxiety and Depression Scale (HADS) and demographic and ulcer information was also collected. Over a quarter of people demonstrated symptoms of anxiety and depression according to the HADS, which were strongly associated with pain and odour from their venous ulceration.

In Phase II, hermeneutic phenomenology underpinned the approach to interview and analysis of data from twenty people purposively sampled from phase I. The findings indicate chronic venous ulceration leaves people inhabiting a world of pain and unrelenting suffering that is not necessarily relieved by the experience of the clinical encounter. Lives are changed considerably by the protracted nature of the ordeal, which lasts months, and sometimes years. There appears to be a misattribution of symptoms by health care professionals, who attribute aspects such as fatigue, insomnia, a sense of loss and hopelessness to venous disease rather than to the depression of which they are classic symptoms. These findings add weight to the case for chronic venous ulceration to be categorised as a chronic condition, and one where symptoms remain inadequately managed, compounded by unrecognised and undiagnosed depression which increases sufferers' risk of further ill health.

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Dedication

I should like to dedicate this thesis to my dad who was on a very lonely and difficult journey of his own. Sadly he couldn't wait any longer for me to finish my journey and left us part way through mine.

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.

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Glossary of Terms

ABPI Ankle Brachial Pressure Index.:

This is a ratio whose value is equal to the systolic pressure at the ankle divided by the systolic brachial pressure. In people with no significant arterial disease in the legs, this ratio is approximately 1.0. Values less than 1.0 indicate that there is a lower systolic blood pressure in the legs than the arms. Values lower than 0.8 indicate significant arterial insufficiency.

Allodynia:

Pain felt from what would normally be a simple touch sensation such as stroking the skin.

Debridement:

The removal of necrotic or devitalised tissue from the wound bed by mechanical means, involving the use of a scalpel or scissors.

Doppler Ultrasound:

The use of the Doppler effect and ultrasound waves to record / measure blood flow. The outgoing wave of ultrasound is transmitted towards the red blood cells in the arteries. A reflected wave of ultrasound can be compared with the original wave in order to ascertain how quickly the red blood cells are moving. The Doppler effect describes the change in frequency in waves between an object approaching the receiver and retreating from the receiver. Doppler Ultrasound is used to calculate the ABPI.

Hyperalgesia:

Increased sensitivity to a painful stimulus.

Hypoalgesia:

Diminished sensitivity to a painful stimulus.

Nociception:

The transmission of electrical impulses from the sensory fibres in the injured tissue to the brain, where perception of pain occurs.

Nociceptor:

Special free nerve ending, sometimes referred to as a bare nerve ending at the distal end of a pain sensing neurone.

Chapter 1: Introduction

> *"The ill already fulfil their responsibility of being ill. The question is whether the rest of us can be responsible enough to see and hear what illness is, which ultimately means seeing and hearing what life is. Being alive is a dual responsibility: to our shared frailty on the one hand, and to all we can create on the other."*
>
> Frank (1991, p.128)

1.1: Introduction: the rationale for the study

When studying the experience of people with leg ulcers it is important to grasp the uphill struggle that researchers and individuals, with more than a "passing interest" in this condition, have encountered in their endeavours to raise its profile and ultimately improve care. One of the most notable omissions in the management of ulceration is that venous ulceration is not defined by health professionals, policy makers or the general public as a chronic illness despite sufferers having to encounter periods of healing (or remission) together with periods of re-ulceration and active symptoms, the hallmarks of a chronic illness.

In this thesis I argue that the complexities of managing ulcers in the twenty-first century National Health Service (NHS) can only be fully grasped through an appreciation of facts and figures relating to epidemiology, aetiology and cost; it is only then that the significance of this study is appreciated and understood. This introductory chapter articulates the question guiding this research, together with factors influencing how this question was originally framed and how it developed over the course of the study. Influences emanating from my own professional background are also presented.

Chronic venous leg ulceration is, particularly among the elderly, a serious condition caused by venous insufficiency (Margolis, Allen - Taylor, Hoffstad *et al.*, 2004b). The precise prevalence of leg ulceration is difficult to ascertain, with estimates varying from 0.11% to 4.3% of the adult population. However, Briggs and Closs (2003) in a recent review concluded that the prevalence of open ulceration (known to health professionals), is approximately 0.11 – 0.18% with the number who suffer recurrence in the region of 1 – 2% of the adult population.

1.2: What is a leg ulcer?

A leg ulcer is defined as "loss of skin below the knee on the leg or foot which takes longer than six weeks to heal" (Dale, Callam, Ruckley *et al.*, 1983). Callam, Ruckley *et al.,* (1985), estimated that over 70% of ulcers are venous in origin, 10% arterial and 10 – 15% of mixed arterial and venous origin. They affect 1.5 – 3.0 per 1000 of the adult population in the UK, with the prevalence increasing with age (O'Brien, Grace, Perry *et al.*, 2000), with a peak prevalence between 60 and 80 years. Margolis, Bilker *et al.,* (2002), estimate 1 – 2% in the over 65 age group and higher among women (Callam *et al.*, 1985;Lees & Lambert, 1992). However, leg ulceration is not just a problem of the elderly as identified by Callam (*op. cit*), since 50% of men and 25% of women in their study were below retirement age (65 and 60 years, respectively) when they had their first episode of ulceration. This has been reinforced in a cross-sectional population survey by Evans, Allen *et al.*, (1999), and also in a comparative study by MacKenzie, Brown *et al.,* (2003), in which significant numbers of patients developed their first episode of ulceration before their 50th birthday. This has potential implications in terms of prescription charges as well as possible lost working time for this age group.

1.3: Chronic wounds and ageing

Chronic wounds are found with a frequency of 0.19% in the population aged over 45. This figure is likely to increase to a projected one billion worldwide aged 60 or more by 2020 (World Health Organisation, 1999) as the incidence of ulceration is known to increase with age (Evans *et al.*, 1999). In the UK, in 2005, there were 20 million people aged 50 and over, with the current UK population estimated to be 59.8 million of which 16% are aged 65 and older, within which the proportion of those aged 85 and older is now 12% (DoH, 2004a). By 2031 it is estimated that this will increase by a further 36% to 27.2 million (ONS, 2006). Chronic wounds are wounds which do not heal as expected, with "healing that takes longer than anticipated, given appropriate therapy" (Ballard & Baxter, 2000), or have been stuck in any of the phases of wound healing for six weeks or more. Age has been identified as a major factor associated with non-healing leg ulcers (Taylor, Taylor & Smythe, 2002), since many of the cellular processes involved in the wound healing process are modified by ageing.

The ageing process itself produces many changes in the skin and tissue and is one of the multiple intrinsic factors that may cause delayed healing and chronic wounds. However, defective healing would appear to be related to co-morbidites that affect all ages, rather than to an inherent age-related defect in the healing process alone (Eaglestein, 1989). A full discussion of the wound healing process per se and the factors that affect wound healing, while outside the remit of this study, are the subject of many reviews (Cherry, Hughes, Ferguson *et al.*, 2000). The terms acute and chronic wounds have historically reflected the aetiology of the wound and whether it heals by secondary intent, such as a leg ulcer, and not necessarily the age of the wound. However, a wound is not always "chronic" because of its aetiology (Harding, 2000). There tends to have been a "slurring" of definitions and terminology with "chronic" often taken to mean delayed, or not healing within an acceptable time frame. As will be discussed later in this chapter predictive ulcer healing rates have been published (Margolis *et al.*, 2004b) which provide a benchmark of "normal" healing rates.

Chronic non-healing wounds affect about 1% of the adult population and are more prevalent in the elderly (Margolis, Knauss & Bilker, 2004a). The most common of these wounds is venous leg ulceration with an estimated prevalence of between 0.15% and 0.3% within the UK population (Moffatt, Franks, Doherty *et al.*, 2004;NHS CRD, 1997). Leg ulcers are considered to be chronic wounds because they take weeks or months to heal due to substantial loss of the top layers of the skin (epidermis and dermis). Ulcers often take years to heal (Lorimer, Harrison, Graham *et al.*, 2003), and studies consistently demonstrate the considerable length of time that patients experience episodes of ulceration. Callam, Harper *et al.*, (1987), reported a median duration of nine months with 45% having ulcers for more than ten months. Nelzen, Bergqvist *et al.* (1997), in a study of 382 patients found the median ulcer duration in the venous ulcer population was 13.4 years. He also found that 54% of patients had lived with ulceration for longer than one year, and 13% for longer than five years. Other studies report a mean ulcer duration of between two and five years (Charles, 2001; Noonan & Burge, 1998). Despite improvements in care, including compression therapy, Nicolaides (2000) states that, after two years, 20% of all chronic venous ulcers remain unhealed. Leg ulceration is known to significantly impact on an individual's quality of life causing an appraisal of day-to-day activities (Hareendran, Bradbury, Budd *et al.*, 2005).

1.4: Chronic condition

Venous ulceration should be viewed not only as an aesthetic problem, namely an unsightly wound, but also as a chronic disease whose impact on lifestyle and quality of life is similar to that of other chronic diseases such as diabetes, rheumatoid disease etc. Healing an ulcer results in a large improvement in quality of life. Unfortunately, approximately 20% of chronic leg ulcers never heal despite being treated by evidence-based care (Barwell, Deacon, Taylor *et al.*, 2001). Although high compression is recognised as the mainstay of treatment for venous ulceration, much of the published clinical data indicates that only approximately 65% of ulcers are likely to be healed within 24 weeks, with over 20% remaining unhealed after more than 50 weeks of compression therapy (Barwell, Davies, Deacon *et al.*, 2004).

1.5: Cost

Leg ulceration is costly to the health service, estimated at £400 - £600 million with costings based on crude estimates from only a handful of studies, of which nursing time is a major element (Bosanquet, 1992;Laing, 1992;Ruckley, 1997). Chronic venous leg ulceration alone has been calculated to account for about 1%

of the total health costs of developed countries (Nelzen, 2000). However, the direct healthcare costs are dwarfed by the indirect costs to the patient in terms of prescription charges (dressings, drugs and bandages), increased laundry bills due to discharge from the ulcer, time off work attending nurse / doctor consultations (Charles, 1995a;Task Force on Chronic Venous Disorders of the Leg, 1999) as well as pain, disability, distress and isolation.

In 1992, Bosanquet reported that community nurses spent 30 – 50% of their time dressing leg ulcers. A survey of nursing activity in the community found that managing leg ulcers (assessment and dressings) was the most prevalent "purpose of visit" in the four grades of staff studied (Audit Commission, 1999). The Audit Commission stated that 2.7 million people with ulceration receive care from district nurses, with 36 million contacts made. Estimates of the cost of care for an episode of ulceration vary between £850 and £1400 and depend on the treatment used and the effectiveness of care (Carr, Philips & Posnett, 1999). Netten and Curtis (2003) calculated costs of community treatments based on one hour treatment to be £56 for a home visit by a district nurse and £40 for a clinic visit.

1.6: Aetiology of ulcers

Although a minor traumatic incident (knocking the edge of a coffee table, or the shopping trolley syndrome) is often the immediate cause of the ulcer, the underlying pathology is usually vascular. A leg ulcer is by no means a diagnosis, just a symptom of an underlying chronic disease. Whilst the author recognises that many differential diagnoses for ulceration of the lower limb exist, as outlined in Table 1.1, this study will concentrate on those ulcers most commonly dealt with in the community by district nurses: venous ulcers.

Venous disease is the major cause of leg ulcers, accounting for 70 – 75% of the total (Cameron, Wilson & Powell, 1991;Morison & Moffat, 1997), arterial insufficiency accounts for 10%, whilst 15% have mixed aetiology ulcers, i.e. venous and arterial disease (Gernstein, Phillips, Rogers *et al.*, 1993), which will be explained in the next section. A further 5% have unusual aetiologies including neoplasm, connective tissue disorders, trauma etc. It is recommended that ulcers of non venous aetiology be automatically referred to the vascular consultant for further investigation.

Table 1.1: Common differential diagnoses

Differential diagnosis of ulceration
Venous ulcer
Arterial ulcer
Mixed venous / arterial ulcer
Pyoderma gangrenosum (Bull, 1997)
Necrobiosis lipoidica
Rheumatoid ulcer (Firth, 2006)
Malignant ulcer (Enoch, Miller, Price *et al.*, 2004)

1.6.1: Venous ulcers

Venous ulceration is a consequence of increased pressure in the venous system referred to as venous hypertension. Venous hypertension is caused by insufficiency of venous valves, deep venous outflow obstructions or dysfunction of the muscle pump. Failure of the calf muscle pump to propel blood from the lower limbs, against the force of gravity, results in the pooling of blood and, hence, venous hypertension (Browse & Burnand, 1988). Failure of the muscle pump may be due to incompetence in the deep, perforating or superficial veins aggravated by paralysis or reduced mobility (Blair, Wright, Backhouse *et al.*, 1988). Damage to valves with resultant venous reflux contributes to venous hypertension leading to venous stasis and oedema.

A history of a deep vein thrombosis (DVT), resulting in post-thrombotic syndrome is widely regarded as a predisposing factor to venous insufficiency and hence venous ulceration (Nicolaides, 2000). Kahn *et al.* (2004), suggest that the post-thrombotic syndrome (PTS) is the single most common complication of venous thromboembolism. PTS is a chronic condition that develops in 20 – 50% of patients after DVT. Kahn *et al.* (2004), also found that quality of life is poorer in patients with chronic venous insufficiency caused by PTS compared with patients whose venous insufficiency is due to other causes. Approximately 40% of patients with a venous ulcer will have had a deep vein thrombosis prior to ulceration (Stacey, Burnand, Lea Thomas *et al.*, 1991). Moher, Silverstein *et al.*, (2000) concluded that 245 / 1527 of people (16%) who had a deep vein thrombosis (DVT) or pulmonary embolus went on to develop venous disease, and 3.7% had developed leg ulcers after 20 years.

Valve insufficiency may also be caused by congenital weakness of the valves or vessels (Mekkes, Loots, Van Der Wal *et al.*, 2003). Other cited factors indicative of venous insufficiency are phlebitis, surgery or fractures in the affected leg (Table 1.2). As a direct result of the increased venous pressure, the capillaries become distorted and more permeable permitting the passage of large molecules into the extra vascular space.

Table 1.2: Factors which may be indicative of ulcer pathology

History indicative of venous disease	**History indicative of arterial involvement**
Family history	Family history
Varicose veins	Heart disease, stroke, transient ischaemic attack
Proven deep vein thrombosis in affected leg	Peripheral vascular disease / intermittent claudication
Phlebitis in the affected leg	Cigarette smoking
Suspected deep vein thrombosis (e.g. swollen leg during pregnancy, post surgery)	Rheumatoid arthritis
Surgery / fractures of the lower limb	Ischaemic rest pain
Episodes of chest pain, haemoptysis or pulmonary embolism	Diabetes

Nonetheless, the patho-physiology of venous ulceration remains contentious, although a detailed consideration of the microcirculatory changes leading to tissue necrosis is beyond the scope of this study. Currently several hypotheses have been proposed to explain the sequence of pathogenic steps from venous hypertension to ulcer formation. These include the development of fibrin cuffs (Burnand & Browse, 1982), white cell trapping (Coleridge-Smith & Thomas, 1988), and growth factor scavenging (Falanga & Eaglestein, 1993), but it has to be emphasised that their role as causative agents only partially explain the pathomechanisms leading from hypertension to venous ulceration.

Chronic venous insufficiency has been characterised by three different stages:

> Stage I: oedema and ankle flare (also referred to as corona phlebectatica).
> Stage II: stasis dermatitis, hyperpigmentation and lipodermatosclerosis characterise this stage.
> Stage III: ulcer formation is evident.
> (Valencia, Falabella, Kirsner *et al.*, 2001)

Management of venous ulceration must be based on an understanding of the causes of the venous hypertension ultimately responsible for venous ulceration. Raised venous pressure is likely to be the initiating event in ulcer formation, with damage to the microcirculation as the initiator of cell damage. Oedema within the dependent lower limb, i.e. when an individual is seated, knees bent, feet on the floor, is a direct result of the sustained venous hypertension. Metabolites then have a greater distance over which to diffuse from the microcirculation to tissue cells. When the leg is dependent, the tissues around the ankle become ischaemic. On walking, or elevation, reperfusion takes place (Herrick, Sloan, McGurk *et al.*, 1992), resulting in an inflammatory process with further oedema, tissue fibrosis and formation of extra-cellular matrix proteins around capillaries. The gaiter area, especially above the medial malleolus is where there is pronounced skin damage, resulting in staining (haemosidirin), atrophie blanche (cutaneous fibrosis with strangulation of the microcirculation), lipodermatosclerosis, ankle flare, eczema and ulceration explained in Table 1.3. The patient also complains of aching, heaviness in the legs and, possibly, itching.

Table 1.3: Clinical signs associated with venous ulceration

Haemosidirin (brown staining)	The haem (iron content) of the red blood cells deposited in the interstitial spaces causing discolouration
Ankle flare	Dilation of the vessels on the medial aspect of the foot, frequently related to perforator incompetence
Atrophie blanche	Avascular areas of white tissue within the gaiter area
Lipodermatosclerosis	The adipose layer is replaced by fibrosed woody scar tissue
Eczema	Caused by the extravasation of irritating proteolytic enzymes
Oedema	As a result of the increased venous pressure

It would be expected that patients presenting with a history of venous disease, coupled with some, if not all, of the signs outlined in Table 1.3 have an ulcer that fails to heal due to impaired venous return and that the problem is in the veins rather than the arteries. This is confirmed by the use of Doppler Ultrasound, a tool to measure a patient's Ankle Brachial Pressure Index (ABPI), which would be expected to be in the range of 0.8 – 1.3, thus confirming that there is no arterial impairment (RCN Institute, 2006;Vowden, Goulding & Vowden, 1996).

Recurrence rates for venous ulceration have been found to be high, reported to be between 26 – 33% (Dinn & Henry, 1992;Mayberry, Moneta, Taylor *et al.*, 1991;Moffatt & Franks, 1995) if patients stay in compression hosiery, rising to 56% in patients who are either unable, or unwilling, to wear hosiery. Leg ulceration is typically a chronic condition with periods of ulceration followed by healing and then recurrence (Callam, 1987). It is the chronic nature of ulceration, which is significant for the individual concerned as well as for the health professionals involved in their management (Bland, 1999). Callam *et al.* (1987), found that 28% of the 600 patients they assessed had been subjected to more than ten episodes of ulceration, whilst Nelzen, Bergqvist & Lindhagen (1994), found that in a population of 382 patients 33% had had more than four episodes, with 40% of the population experiencing their first episode of ulceration.

1.6.2: Arterial ulcers

Arterial ulcers are the result of an insufficient blood supply to the lower limb causing ischaemia and necrosis. If the onset of ischaemia is sudden, the blockage may be due to an embolism, whereas peripheral arterial disease with the deposition of atheromatous plaques is a more gradual process. Chronic arterial insufficiency of the lower extremity causes two classic symptoms. The first symptom is intermittent claudication of one or both calves when the superficial femoral artery is involved. Pain occurs on walking up slopes or stairs and subsides after a short period of rest. Popliteal and pedal pulses are usually absent. When there is aorta-iliac disease, pain in the thigh or buttocks, or even impotence (Leriche syndrome), occurs. The second classic symptom is when severe pain occurs even at rest (Rutherford, Baker, Ernst *et al.*, 1997); normally apparent when the patient goes to bed. The critically ischaemic leg is painful all the time. Hanging the foot out of bed usually relieves it and the patient often resorts to sleeping in a chair, which results in oedema. Pallor, especially on elevation, venous guttering, and prolonged capillary return can indicate arterial disease.

Thickening, or the slow growth, of the nails is characteristic of chronic arterial insufficiency, as is thin, shiny and scaly skin. There may also be thickening of the skin with fissuring, particularly over the heel (Vowden *et al.*, 1996). A history of heart disease, stroke, diabetes and cigarette smoking are indicative of an ulcer, which fails to heal due to underlying arterial disease (Table 1.2). When the patient's ABPI is checked using Doppler Ultrasound, one would expect a reading indicative of impaired arterial supply and therefore the reading would normally be below 0.6, or above 1.3 in patients with hardening of the arteries (atherosclerosis), commonly found in diabetes.

1.6.3: Mixed ulcers

An ulcer is referred to as being of mixed aetiology if the patient has a history of both arterial and venous problems together with a combination of signs and symptoms. The ABPI would be in the range of 0.6 – 0.8 (RCN, 2006). These ulcers are a particular challenge as they are difficult to manage due to the combination of arterial and venous problems.

1.7: Epidemiology

The prevalence data on leg ulceration dates back to the 1980s with estimates from Scotland, Ireland, England, Sweden and Australia resulting in a range from 0.11% – 4.3% of the population with active ulceration. However, as few studies were population-based, for years the epidemiology of venous disease was poorly understood. Many of these studies have used similar methodology and have similar demographics, although the populations selected are different. Whilst these studies have provided us with important information, the differences between the studies have made it difficult to draw firm conclusions. Chronic leg ulceration has been reported in the literature as either point or overall prevalence:

> a) Point prevalence (the number of patients with open, active ulcers at one time point).
>
> b) Overall prevalence (number of patients who suffer from leg ulceration which includes active (open) and inactive (healed) ulcers.
>
> (Adhikari, Criqui, Wooll *et al.*, 2001)

One issue, which confounds the results of prevalence studies, is the type of ulcer included in the estimates of prevalence data: the decision to include or exclude foot ulcers will affect the estimates. Likewise, duration of ulceration selected will affect the estimate, as some "ulcers" may in fact be traumatic wounds such as blisters or cuts, which will heal uneventfully within a six-week period. A further difference in the studies is the age range of the population. There does appear to be a link between age and chronic leg ulceration with the prevalence of ulceration increasing with age. These factors may help to explain some of the variation in the estimates reported.

Point prevalence estimates, which include only those people with active ulcers, ranging from 0.11 – 0.2%, were utilised in studies by Andersson *et al.* (1984); Callam *et al.* (1985); Cornwall *et al.* (1986); Nelzen *et al.* (1991); Baker and Stacey (1994); Ebbeskog *et al.* (1996) and O'Brien *et al.* (2000). A variety of approaches have been used in these studies to identify patients, including approaching the general population as to the presence or absence of ulceration. Community nurses, general practitioners and nursing homes have also provided data on the number of patients seen. Higher figures, ranging from 0.63 – 1.9% are reported when overall prevalence estimates are quoted as in the studies by Dale *et al.* (1983); Nelzen (1996) and Margolis *et al.* (2002).

The real prevalence is likely to be higher, as under-reporting is a potential problem with surveys and case-ascertainment studies. Some patients are reluctant to see their nurse or general practitioner with an ulcer, preferring to self-care, and are therefore missed from prevalence studies, which health professionals use to provide data on the number of cases seen. It is unclear whether the prevalence of ulceration will increase or decrease in the future. This depends on the incidence of ulceration, the rate with which ulcers heal and the death rate of patients with ulcers. The fact that ulceration is largely a disease of the elderly and the proportion of the over 60s is increasing, as identified earlier, means that the prevalence might be expected to increase. However, improvements in the treatment and prevention of recurrence may reduce the prevalence.

1.8: Management of ulceration

In the UK, leg ulcer management is predominantly nurse-led, with research having had a direct impact on nursing practice. Most leg ulcers are cared for in the community by the community (Nelzen, Berqvist & Lindhagen, 1991b;Ruckley, 2001), with District Nurses spending approximately 50% of their time treating leg ulcers (Taylor, Taylor & Said, 1998) at an estimated cost of £100 - £180 million per annum (Audit Commission, 1999).

1.8.1: Nursing assessment of ulceration

The recognised starting point in any management regimen should be a holistic assessment to determine risk factors such as age, sex, cardiovascular disease, body mass index, mobility, arthritis, diabetes and a history of leg injury or deep vein thrombosis (RCN, 2006). This can only be determined through a full clinical history together with a physical examination, as well as appropriate laboratory tests and haemodynamic assessment (RCN Institute, 2006;SIGN, 1998). This helps to determine underlying aetiology, i.e. why the patient has a wound that fails to heal. However, there are examples in the literature where "best practice" does not happen as reported by Elliot, Russell *et al.,* (1996) who found that 50% of district nurses used visual assessment alone to diagnose a leg ulcer, whilst an audit by Stevens, Franks *et al.,* (1997) found that over 80% of patients known to the district nursing services had not been assessed using Doppler Ultrasound to determine ulcer aetiology prior to treatment. If the cause of an ulcer remains unknown, it would seem only logical that it then becomes very difficult to treat (Jones, 2000). Patients could then be subjected to long periods of ineffective and inappropriate treatment (Roe, Cullum & Hamer, 1995;Stevens *et al.*, 1997); resulting in poor outcomes and an adverse effect on quality of life, as well as being a waste of resources.

Ulcers that are suspected of being malignant, arterial or diabetic in origin require referral for specialist assessment, as excision, surgery or orthotics may be necessary. It is well documented that the inappropriate use of compression bandaging, the mainstay of treatment for venous ulceration, can result in skin damage (Vowden *et al.*, 1996).

Nursing assessments of wounds tend to focus on physical aspects of wound management (Hopkins, 2001). Other associated factors such as pain, mobility and the activities of daily living are also treated as physical dimensions. This has meant that important patient-centred outcomes, such as pain and other quality of life issues, have been marginalised.

1.9: Leg ulcer research

Much of the research in leg ulcers over the past decade has been disease-specific and focused on aspects of treatment. Research is mainly related to clinical aspects of leg ulcers, with particular emphasis on improving understanding of ulcer aetiology and developing effective treatment strategies such as compression therapy, a very biomedical lens.

The mainstay of treatment for venous ulceration is compression therapy, either bandages or hosiery (Stacey, Falanga, Marston *et al.*, 2002), with some areas reporting healing rates approaching 70% at 12 weeks (Moffatt, Franks, Oldroyd *et al.*, 1992;Vowden, Barker & Vowden, 1997). However, overall healing rates remain poor, with healing rates reported for 12 weeks of around 50% and lower (Lambourne, Moffatt, Jones *et al.*, 1996). In a systematic review by Cullum, Nelson *et al.* (2001), high compression was found to be more effective than low compression (relative risk of healing 1.5, 95% confidence interval (CI): 1.2 – 2.0). People thought to be suitable for high compression are those with clinical signs of venous disease (ulcer in the gaiter area, from the upper margin of the malleolus to the bulge of the gastrocnemius: staining of the skin around an ulcer; or eczema), no concurrent diabetes mellitus or rheumatoid arthritis and adequate arterial supply to the foot as determined by the ankle / brachial pressure index.

In recent years, Margolis, Allen -Taylor *et al.* (2004b), have demonstrated that initial measures of wound size and duration can accurately predict which venous leg ulcers (VLU) are more likely to heal by the 24th week of care. Small (<5cm^2 area) and new (<6 months duration) ulcers treated with high compression had a 71% chance of healing at 24 weeks, whereas large longstanding ulcers had only a 22% chance of healing. A prognostic study by Margolis, Berlin *et al.*,(2000), found that 15% of venous ulcers that are both small (<5cm^2) and new (<6 months duration) if treated with high compression (e.g. The Unna's boot method used in the USA) can be expected to heal within six months (95% CI: 75 – 99%). Philips, Machado *et al.*,(2000) showed that 65% of ulcers present for less than a year healed within 12 weeks, versus 29% of ulcers present for two years. Similarly, ulcer size reduction during the initial treatment phase can be used to predict the likelihood of healing within an acceptable time frame (Margolis, Gelfand, Hoffstad *et al.*, 2003;Phillips *et al.*, 2000).

This approach has undoubtedly led to improvements in practice, which has reduced the overall prevalence of leg ulceration. In the main we have moved from ritualistic practice to an emphasis on evidence based practice, and a concomitant stress on clinical and cost effectiveness (Sackett & Rosenberg, 1996). Even the original RCN guidelines (RCN Institute, 1998) were developed using a medical model with the emphasis on correct assessment and treatment, with healing as the only outcome and indicator of quality.

What is apparent from the literature is the fact that the psychosocial impact of leg ulceration remains understudied and, as stated earlier, is a reflection of the assessment process where patient-centred outcomes have largely been ignored. It is important that nurses avoid focusing on the wound alone, but rather concentrate on the patient as a whole, which should also take into consideration psychosocial factors. Wound healing is dependent on a range of factors and not just those localised to the wound site. It is self evident that wound healing must be optimised in terms of the whole patient (emotional, physical and social) and in relation to wound management.

Holistic care approaches therefore incorporate the notion that management plans, however elegant, are of little use if the mental well-being of the patient is ignored. The focus of care needs to be redirected for many of these patients for whom cure is not an option, despite best practice, but who are left to live their daily lives with a chronic wound (Krasner, 1998). It is important to remember that leg ulcers are a chronic problem, with individuals suffering from a cycle of ulceration, healing and re-ulceration (Nelzen *et al.,* 1997), and it is equally important to remember that, despite improvements in care, 20% of all chronic ulcers remain unhealed after two years (Nicolaides, 2000).

1.10: Personal motivation for the study

My role as a clinician, developing and leading an evidence-based service in leg ulcer management for over a decade, had a considerable influence over the conceptualisation and, ultimately, design of this research. Although patients received evidence-based care in the management of their leg ulceration, there remained a group of people whose ulcers did not appear to respond to treatment. In effect, evidence-based treatment had failed these individuals. This led me to question my own practice and the management of ulceration and to explore further to see if there was an important element missing.

Venous ulceration can heal, but you are never cured: a difficult concept for health professionals, and individuals, to grasp. The ulcer is an outward sign of an underlying problem, namely venous disease. The outward sign "may" heal with treatment which addresses the underlying problem. However, the underlying problem, namely venous disease, remains as the chronic disorder which has to be managed as it cannot be cured. The healing of the ulcer signifies remission, but not a cure of the condition, as it can recur at any time.

During attendances at clinics for treatment, some people verbalised feeling fed-up and low, having no energy, not wanting to do things – all symptoms of depression (Dowrick, 2004). It became clearer, from routine discussions with people, that no-one had taken the time to explain that they were suffering from a chronic disorder which may or may not go into remission – in wound care terms "heal" – and that venous disease was a lifetime problem. The people I encountered day-to-day in my practice appeared to be struggling to get on with their lives, believing that one day soon their ulcers would heal. These people needed help and support to come to terms with necessary life adjustments rather than being "left in limbo", waiting and believing they would be cured. I felt as if I watched some individuals in my care change from *having* a body, to *being* a body. Their bodies seemed to have lost "the silence" of a body in health, since their bodies were now disrupted by illness (Sparkes, 1996).

> *"Leg ulceration is an important and extensive class of diseases, the treatment of which is looked upon as an inferior branch of practice, where much labour is bestowed and little honour gained."*
>
> Charles Brown, 1805

The above quote, appearing in the *Edinburgh Medical and Social Journal* of 1805, epitomised the consensus view regarding the management of leg ulceration: a view that was to persist into the late twentieth century. This perhaps helps to explain the marginalisation of people with leg ulceration, which has persisted over the years.

When I initially established a community leg ulcer service in 1994, the managing bodies believed this could be done in two days per week whilst still retaining full responsibility for a district nursing caseload, which in itself is a full-time post. After 18 months an extra day was added, extending the post to three days. It was only in 1997, after a great deal of communication and lobbying on my part, that I was able to appoint a staff nurse to assist in the service. As the manager of the service I am still only employed for three and a half days per week; an interesting comparison with other services within the Primary Care Trust (PCT), which manage chronic diseases such as diabetes where the manager has a full-time post.

There are available research data for many conditions that chronicle the illness trajectory and the impact, not only physically but also psychologically, of living with a chronic disease. Many, such as diabetes, became designated as a government target. This means that services dedicated to the management of diabetes, for example, receive additional resources including staff, to help to manage and develop services within NHS Trusts. Arguably, leg ulceration has remained the "poor relation" of chronic diseases, thus resulting in marginalisation of this group of people in terms of care and resources, since it has never truly been accepted as a chronic disease per se.

Depression is stated to be frequently undetected and poorly treated in general practice (Anderson, Nutt & Deakin, 2000;Peveler, Carson & Rodin, 2002). It is recognised in the literature that depression is commonly encountered in patients with medical conditions (Martin, 2001). However, even in conditions such as coronary heart disease (which is a government target), it is frequently unrecognised. If a condition remains unrecognised, this means it is under-diagnosed and under-treated. In my attempt to discover whether patients with leg ulceration were experiencing symptoms of depression, I was frustrated by the lack of studies linking the two. Recognition of co-morbid depression is difficult, not only because of lack of training, but also because screening tools are not employed by health care professionals caring for patients with chronic ulceration. Also, symptoms are not clear-cut and some of the physical symptoms of chronic ulceration may mimic the core symptoms of depression, e.g. disturbed sleeping pattern and loss of enjoyment. The leg ulcer literature refers to patients with ulceration experiencing "emotional reaction" or feeling anxious and depressed. However, locating any studies, which may provide an answer as to the scale of the problem and the burden of care it represents, has, to date, yielded no results.

Even though depression is identified as a key area in the National Service Framework (NSF) for Older People, Standard Seven (DoH, 2001a), community nurses receive no formal training sessions on the recognition and management of it, and thus depression is likely to be missed in encounters with patients with venous ulceration.

1.11: Study Aims

This study has two broad aims:

1. To determine the prevalence of depression in people being treated for chronic leg ulceration across nine NHS Trusts in the North West of England
2. To explore the experience of depression in people living with chronic leg ulceration

1.11.1: Objectives:

- To provide an account of the factors associated with depression for a purposive sample of people suffering from chronic ulceration at the time of completion of a screening tool for depression.
- To elucidate what are the important features for these people of living day-to-day with chronic ulceration.
- To gain an understanding from first hand accounts, of what it is like to live with a leg ulcer.
- To determine if ulceration changes individuals in any way, and how individuals make sense of living with ulceration.

1.11.2: Overview of design of the study

The study aims and objectives are answered by means of two phases of data collection and analysis:

Phase I: A survey of leg ulcer patients to provide the prevalence of depression and to provide the sampling frame from which to select potential participants for Phase II.

Phase II: To explore the experiences of depression in people living with chronic leg ulceration.

1.12: Thesis structure

The thesis is divided into eight chapters. This introductory chapter has provided background and context, and given the reader an outline of the rationale for the development of the study. In order to help the reader gain an understanding of leg ulcers, this chapter also addressed their aetiology and epidemiology, plus the cost and burden of care they represent to the community where they are predominantly managed. The second, two-part, chapter provides a review of the existing literature on chronic illness, depression and quality of life including Health Related Quality of Life (HRQoL). Screening tools for depression are also discussed. The second part of the chapter looks at the management of ulceration in the UK and the focus of research to date. Attention is paid to the substantive literature relating to venous ulceration, with a particular focus on psychosocial factors and quality of life pertaining to leg ulceration. The review was carried out at the start of the study and refined throughout as new literature appeared. It is presented at the beginning to give the reader an overview of what is known about this topic, the work that remained to be done and, ultimately, how the literature has influenced the shape of the research. The review includes literature from both empirical and theoretical sources.

Chapter three reports on the design, data collection and analysis of Phase I: the prevalence of anxiety and depression in individuals with chronic leg ulcers. The chapter outlines how National Health Service (NHS) Trusts were accessed and individuals recruited to the study and how I utilised my own role as a clinical nurse specialist and circle of contacts to locate the gatekeepers within the NHS Trusts. Clinical governance and ethical considerations are also addressed, as well as the training offered within the areas as an incentive to participate.

The fourth chapter describes the design, methods and analysis of Phase II. Given the nature of the research question, a qualitative methodology was adopted drawing largely from phenomenology and hermeneutics. A research methodology informed by interpretive phenomenology seeks to reveal and convey deep insight and understanding of the concealed meanings of everyday life experiences (Cohen & Omery, 1994;Ray, 1994). The rationale for the adoption of this approach is also detailed. The nature of qualitative studies and the ethical considerations pertinent to this study are also discussed. An outline of the working methods is provided together with how I embraced the philosophical and theoretical underpinnings outlined earlier in the chapter. I include the way in which reflexivity has been included at every step throughout the research process. Chapter four is written in the first person.

The following three chapters illuminate the major themes emerging from the interviews, which provide an understanding of the world of ulceration and depression. Chapter five introduces the individuals providing some background information regarding their ulcer history. This chapter highlights the impact of pain, and how individuals interpret and live with the physical grip of pain on a daily basis, forced to put their lives on hold whilst they grappled with the impact of pain. In chapter six other symptoms of discharge and concomitant odour are explored, together with treatment regimens that appear to collude with an individual's symptoms to limit their quality of life. Ulceration is an apparent "life-time sentence" from which there appears to be very little reprieve. Chapter seven explores what happens when individuals enter the world of the health professional and their experiences of the clinical encounter.

Issues arising from the findings are explored in the discussion chapter, and it brings together the findings from both phases of the research and reflects on the use of the guiding philosophy underpinning the thesis. The important and pertinent aspects of the study are discussed, as is their relevance to day-to-day practice. Limitations of the study and areas for future research bring the thesis to a close. Writing about another's experience in a way that reflects the experience accurately may be an impossible task. In fact, I experienced the limitations of language many times throughout the research process, not only for myself but for participants as well. What these people experienced was not easily captured in our conversations, let alone easily transcribed into this text.

1.13: Summary

This chapter has provided background information as to the definition, cost, aetiology and epidemiology of leg ulceration to enable the reader to understand the huge financial cost of management of ulceration, not only to the NHS but also to the individual. This study, however, is mainly interested in the emotional cost to the individual of living with chronic ulceration.

As stated earlier, venous leg ulcers are generally defined as chronic wounds and as such should be redefined as a chronic illness. With this in mind, chronic ulceration needs to be situated with the chronic illness literature as individuals encounter similar issues to those identified in other chronic illnesses, as discussed in chapter two. It was deemed appropriate, therefore, to access and report on not only literature pertaining to ulceration per se, but also the wider medical sociology literature.

Chapter 2: Literature Review

"Illness is the night-side of life, a more onerous citizenship. Everyone is born holding dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place."

(Sontag, 1978, p.3)

2.1: Introduction

The conceptual phase of the study focused on a review of the literature which includes not only the literature on leg ulcers, but also the wider medical sociology literature on chronic illness, in order to situate the findings from the current study as discussed in chapter one.

This chapter is in two parts, and documents the approach used to search and review the literature, which has also influenced the shape of the research. Part One looks at the chronic illness literature, depression and quality of life including Health Related Quality of Life (HRQoL); whilst Part Two provides a review of the literature on leg ulceration, focusing on the management of leg ulcers by district nurses, before looking at the literature on the psychosocial aspects of ulceration.

2.2: Search strategy

The literature search strategy was iterative and literature was also sought during the study period and at write-up. The relevant literature was accessed using both manual searches and major electronic databases, including:

- Cumulative Index to Nursing and Allied Health Literature (CINAHL) (1985 – 2006),
- Medical Literature On-Line (Medline) (1985 – 2006),
- Psychology Literature (PsychINFO) (1985 – 2006),
- British Nursing Index (BNI) (1985 – 2006),
- Proquest,

- Index to Theses,
- Applied Social Sciences Index and Abstracts (ASSIA) (1985 – 2006),
- Several online journals, including *Health and quality of life outcomes* and *Health Services Research.*

The search terms used included a combination of the following

Leg Ulcer$ / Varicose Ulcer$ / Venous Ulcer$,
Wound Care,
Depression and Anxiety,
Quality of Life,
Lived Experience,
Chronic Illness,
Illness experience.

Searches were conducted using each word-stem, e.g. depress*, ulcer*, to ensure all variants of each word were captured in the search. The review was also an inductive process and occasionally articles were uncovered "by chance", or through the help of colleagues, as well as following-up lines of enquiry that the literature uncovered.

In addition to electronic searches, manual searches were performed of conference findings from wound conferences in the UK and Europe from 1994 – 2005. Specialist journals such as *Phlebology,* which are not included in Index Medicus, were also searched for relevant articles. References were also tracked from published literature. Textbooks were included in the literature review as a means of providing more extensive coverage of particular topics, depression and theory development, relevant to the subject under investigation. The literature review did not include publications in a foreign language, but did include relevant conference abstracts or position documents. The grey literature accessed through the FADE database (FADE, 2001), provided an overview of conference proceedings plus Masters and PhD theses in university libraries.

2.3: Chronic illness

Statistics show a demographic shift in the UK population resulting in an increase in the number of elderly people. By 2025, the number of people over 80 is predicted to have increased by half since 1995, whilst the number over 90 will double. Although many of these people will be fit and well, people over the age of 80 are the biggest users of the NHS (DoH, 2004a). As stated in chapter one, this is particularly relevant to ulceration since the prevalence of ulceration increases with age (Callam *et al.,* 1985). There were 19.8 million people aged 50 and over in the UK in 2002. This number is projected to increase by a further 37% by 2031 when there will be close to 27 million people aged 50 and over (Office for National Statistics, 2002). There are also a dramatically increasing number of people with chronic illness. Increased longevity has brought about a concomitant increase in age-associated pathologies and medical conditions including leg ulceration. For this reason, we can no longer afford to ignore the mismatch of our population's healthcare needs with the way health care is delivered in the UK. Services utilise an acute disease model where the medical paradigm provides the "key reference point" (Finkelstein & Stuart, 1996). Even the quote by Sontag at the beginning of the chapter alludes to an acute illness situation.

Chronic illnesses are those that are present for a long time and may be used interchangeably with "long term illness". Curtin and Lubkin defined chronic illness as:

> *"[A] state of unwellness produced by disability or disease requiring medico social intervention over an extended interval and affecting many aspects of an individual's life."*
>
> (1990, p.18)

Chronic illness involves a permanent alteration in the individual's way of life and a reappraisal of future function and health (Price, 1996a). In today's society chronic diseases are becoming increasingly prevalent, and the objective of treatment is more often a reduction in morbidity than either a cure of disease or prolongation of life. Treatments may not improve the chances of survival but have the potential to improve the quality of life remaining, e.g. joint replacements, cataract removal, which reduce pain and improve quality, although not length, of life. Certainly chronic venous ulceration results in "unwellness" requiring extended medico-social intervention and impacting on individuals' lives.

Chronic disease is now the principal cause of disability and use of health services and consumes 78% of health expenditures (Holman, 2004). It is also the dominant cause of death in the UK (DoH, 2004a). Holman (2004) summarizes the differences in the approach to chronic diseases compared to acute episodic care, which is time-limited. Chronic illness management tends to be continuous, as, unlike an acute illness, there tends to be "no cure" and thus a return to one's highest level of functioning may not be possible. Living with a chronic illness means disruptions and alterations in one's life. There is a growing awareness of how important it is to understand the person's perspective on chronic illness experiences, and that our evaluations of interventions are informed by patient's view (DoH, 2004b). As Aldous Huxley said:

> *"Experience is not what happens to a man; it is what a man does with what happens to him."*
>
> (Huxley, 1932)

Giving patients time and space to talk about what happens to them might help to improve their experience of illness. It is not enough to transpose our management of acute illness into the chronic illness sector and hope that is enough, as identified by Potts:

> *"This means on the one hand, that the symptoms of the illness are treated instead of the person, and on the other, that the treatment aims only at*

> *curing instead of focusing on how to help the patient live with a long lasting illness."*
>
> (Pott, 1992)

The literature on chronic illness is now extensive, having been examined by a variety of disciplines such as sociology, psychology, medicine and nursing. However, much of this literature, like leg ulcer literature, is disease-focused and grounded in an empirical paradigm. The focus tends to be on the disease or the medical condition which has been the cause of the impaired body (Gadacz, 1994). Health care professionals rarely consider the range and impact of chronic illness upon patients' and their relatives' lives (Price, 1996a), and yet, having a chronic illness involves a permanent alteration to an individual's way of life. Interventions to improve disease management by patients can reduce symptoms and enhance physical and psychological functioning, thus empowering patients in their control of their illness (Clark, 2003). The course of a chronic illness is difficult to predict, and acute phases often alternate with resting phases. Once again, this pattern is mirrored in venous ulceration with periods of ulceration alternating with periods of healing or remission, which disrupts peoples' lives.

2.3.1: Illness theory

It helps our understanding of the management of chronic illness to trace the parallel development of the chronic illness literature alongside the medical approach to care. Although 1980's literature marked a movement away from the "outsider perspective" epitomised in the Parsonian concept of the "sick role" (Parsons, 1951), nonetheless, the influence of the traditional biomedical and psychosocial theories was still in evidence in the orientation of the themes towards suffering, loss, disruption and burden (See Table 2.1). Chronic illness was perceived in a totally negative light with an almost "retrospective lens" of what an individual had lost to their chronic illness.

Table 2.1: 1980 – 1985 Loss and burden

Concepts of suffering; loss of self	Charmaz, (1983)
Loss	Duval, (1984)
Biographic disruption	Bury, (1982)
Sick Role	Stewart and Sullivan, (1982)

Allen and Hall (1988), assert that in the traditional medical model disease is treated as a thing in itself, something apart from the individual and reduced to medical functioning of small fragments of the body (Parker, 1991). It was not uncommon, I would suggest, hearing people referred to according to the "malfunctioning" part of the body, for example "The gall bladder in bed six". This divisiveness continues in a much more subtle way today as consultants continue to specialise in "areas" of the body such as gynaecology, haematology, endocrinology etc., with individuals often under the care of several specialists at one time, rather that one consultant dealing with several problems together. In this Cartesian model there is no place for the patient as a human being, which is inclusive of broader environmental and socio-political contexts (Parker, 1991).

By the 1990s there was a more optimistic orientation in the literature with a shift in focus from loss and suffering to illness experiences being transformative and positive. People are supposed to find meaning from their illness experience and ways of regaining control rather than "giving in" to the disease. There is also evidence of the "insider perspective" concerned with patients' subjective influences and experiences in evidence (See Table 2.2).

Table 2.2: 1990 – 1995 More optimistic perspective

Being courageous	Baker and Stern, (1994); Fingfeld, (1995); Rawnsley, (1994)
Maintaining hope	Hall, (1994); Paul, (1994); Nekolaichuk, (1999)
Restructuring	Anderson, Blue and Lau, (1991);Lewis, (1998)
Reframing	Paul, (1994)
Reshaping or Reconstituting self	Kagawa-Singer, (1993); Yoshida, (1993)
Regaining control	Johnson,(1989); Johnson and Morse,(1990); White *et al.*, (1992)
Finding meaning	Baker and Stern, (1994); Bowman, (1991)
Self discovery	Lindsey, (1996); Price, (1996a)

This perspective included a patient's life both in and outside of the medical context (Conrad, 1990). The 1990s heralded a continuing move from the sick-role image, which characterised illness theory in previous decades, to the idea of chronically ill individuals as expert decision makers, informed consumers and active agents in their illness management.

In contrast to earlier interpretations in which non-compliance with medical orders was interpreted as irrational or ignorant, insider research revealed that modifying or defying such orders could be consistent with skilled self-care management (Roberson, 1992;Thorne, 1990). However, Thorne and Paterson (1998), warn against over-generalisation in the opposite direction. As with all human beings living their experiences, people with chronic illnesses differ in their abilities to spend time, energy and emphasis on their illness at varying points in their lives. Likewise they may experience variations in their desire and ability to assume an active role in disease management as the disease progresses. Watson, writing in 1988, proposed that nursing had lost its philosophical way by following the biomedical model and foregoing its original commitment to care. There would appear to be a number of recurring themes in the chronic illness literature as identified in Table 2.3.

Table 2.3: Recurring themes in the chronic illness literature

Dealing with uncertainty	Bury, (1982)
Reconstructing self	Corbin and Strauss, (1987)
Managing regimens	Peyrot *et al.*, (1987)
Managing relationships	Strauss *et al.*, (1984)
Body as uncomfortable; vulnerable body; violated body; the enduring / resigned body	Morse *et al.*, (1994)
Body as disobedient	Bergsma and Tomasma, (1982)

Work on the illness experience (Conrad, 1990) takes a holistic approach to understanding the meaning of illness, moving away from the strict biomedical definition of illness. It recognises that illness is mainly lived outside the medical context. This is certainly true of leg ulceration where the true scale of the problem is "hidden" as many people are known to self-care with "treatments" being purchased over the counter at pharmacies. It is thus important that people are not described as patients. Conrad (1990), recommends that participants are re-conceptualised as "sufferers" or "people with".

Strauss, Corbin *et al.*, (1984) looked at chronic illness generally and introduced the notion of the "illness trajectory" to describe the total amount of work undertaken by the sufferer over time to manage their illness. Themes such as uncertainty, intrusion and social isolation were considered by Strauss to be important in defining the individual's particular trajectory. The research literature on self and identity and the reconstruction of identity began with an interest in

> *"[...] role structure and deviance moved on to patient career and negotiation, then to managing illness and stigma, followed by increased emphasis on self and identity. With each shift, the literature came closer to the experiencing subject."*
>
> (Charmaz, 2000, p.278)

A major key to understanding the human predicament and ambiguity in chronic care is attention to the personal response to the disease. Nurse scholars were beginning, by the 1990s, to acquire insights into the chronic illness experience (Miller, 1997;Mohr, Dick, Russo *et al.*, 1999;Morse & Johnson, 1991;Soderberg, Lundman & Norberg, 1999). Living with a chronic illness seems to absorb most people's physical and mental health; the "illness" exerts a constant influence on family members and significant others. Bleeker and Mulderij (1992), when talking about discomfort, point out that in illness the body "loses its silence", calling attention to itself, our bodies are a way of being-in-the-world. Everyday habits of ignoring the body, with an almost tacit assumption that it just functions, are no longer possible with individuals forced to attend to physical functions in a manner that would seem strange to healthy individuals: people are forced to focus on the "defective" part.

Changes from a predictable body to an uncertain one are likely to raise existential questions around individual freedom, independence, control, invulnerability or mobility. Chronic illness involves a permanent alteration in the individual's way of life and a reappraisal of that which may be hoped for in terms of function and health (Jerrett, 1994). In chronic illness there commonly occurs loss of independence, control, status, social roles and loss of one's identity as a healthy person (Lindgren, 1996;Teel, 1991).

2.3.2: Chronic illness and stigmatisation

Chronic illness is recognised to have many hallmarks including stigmatisation, with stigma defined by Goffman as:

> *"The situation of the individual who is disqualified from full social acceptance"*
>
> (Goffman, 1963a, p.9)

A person's whole life-situation changes because disease and treatment often require a marked change in a person's lifestyle (Curtin & Lubkin, 1990). People often feel they are alone with their ailments, or at least they may feel disqualified from social acceptance due to stigmatisation as a result of the chronic illness, because their social identity is ruined and they are left feeling inadequate (Goffman, 1963b). People are ashamed of being different and are embarrassed when someone appears to be staring at them. A stigmatised person may start to isolate themselves from the social milieu, not only to avoid embarrassment to themselves but also to avoid embarrassing friends (*cf.* Goffman, 1963). Lives are more seriously disrupted by the consequences of a "felt stigma," which usually precedes an "enacted stigma," rather than ensuing from it. It might be learned in the family (Scambler & Hopkins, 1986) and give rise to strategies of "selective concealment" in the workplace or in relations with others.

This prevailing view of stigma may refer to

- Enacted stigma: actual experience of discrimination.
- Perceived stigma: fear of being discriminated against.
- Self (or internalized) stigma: the devaluation, shame, secrecy and withdrawal triggered by applying negative stereotypes to oneself.

(Van Brakel WH, 2006, p.334)

The way people see themselves is an important part of their everyday lives (Salter, 1997). If there is an alteration in this picture it can have psychological implications in the way people behave (Price, 1990). Stigma affects people psychologically, often lowering self-esteem, and can aggravate psychiatric morbidity. This so-called "self" or "internalized" stigma may lead to withdrawal (Arole, Premkumar, Arole *et al.*, 2002), or, at the very least, participation restrictions (World Health Organisation, 2001).

2.4: Chronic illness and quality of life

Quality of Life (QoL) and Health Related Quality of Life (HRQoL) were concepts emerging in the 1980s in an attempt to understand (from the individual's perspective), the impact of health and illness on physical, and mental well-being as well as social functioning (Fallowfield, 1990). Quality of life is a term over which there is little agreement as to what it actually describes (Hendry & McVittie, 2004). Some of the studies of leg ulceration in the 1990s used QoL tools to determine the impact of ulceration on aspects of daily living, and have informed later work as well as being commonly used in research projects. It was therefore believed to be important to include this concept in the literature review; or risk excluding important studies. However, as I was specifically interested in anxiety and depression, it was not appropriate to select a quality of life tool for this research, but it is important to remember that anxiety and depression are inextricably linked to a person's quality of life, as will be discussed later in the chapter.

Quality of life measurement has become increasingly important as the population ages and, correspondingly, levels of chronic disease increase. Good quality of life encompasses more than just good health and is considered to represent the sum of a person's physical, emotional, social, occupational and spiritual well-being, as well as referring to their ability to function in the ordinary tasks of living. The emphasis is therefore on the individual's perspective of their health and situation and how illness impacts on all aspects of daily living and life satisfaction (Stewart, Greenfield, Hays *et al.*, 1989). Increasing self-reported satisfaction in the domain of life is associated with higher levels of quality of life. Improving HRQoL has become an important objective of medical care (Ferrell, Wisdom & Wenzi, 1989;Stewart *et al.*, 1989).

Prutkin and Feinstein (2002), suggest that a person's quality of life is a state of mind, not a state of health, as uniquely perceived by each individual – this would be an interesting concept to suggest to a person with a visible and painful leg ulcer. What complicates matters is that there is no consensus as to what constitutes QoL, although there is general agreement that quality of life is a multidimensional concept, including both subjective and objective perspectives. The World Health Organisation has described QoL as:

> *"[An] individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns."*
> (WHOQOL, 1995)

This broad, generic conceptualisation of QoL can be distinguished from the more specific concept of "health-related quality of life" (HRQoL), which refers to those aspects of an individual's life that impact directly upon their health (Patrick & Erikson, 1993). Since QoL is highly subjective, and potentially fluid, this further complicates this area of research as it becomes a major challenge to measure QoL reliably and accurately.

There is no single and definitive way to measure HRQoL, and different techniques may be employed according to the different requirements of individual studies. Some quality of life measures are "generic", e.g. SF-36, Nottingham Health Profile, and they may be used to assess the impact of any treatment or disease process. Others are "disease-specific", e.g. Arthritis Impact Measurement Scale, designed to assess treatments and the disease process of a particular condition (see Table 2.4).

Generic measures can help to compare the impact of a wide variety of treatments and diseases on people's lives. They may lack precision, however, in measuring outcomes that are relevant to a particular disease process for which disease-specific measures are better suited. HRQoL tools in trials gives us information on the impact of treatment on quality of life, so that if two therapies have similar levels of effectiveness and cost, but have different effects on quality of life, then this important finding can inform the choice of acceptable interventions. Quality of life research enables the evaluation of health outcomes from the perspective of patients (Garratt, Schmidt, Mackintosh *et al.*, 2002).

The SF-36 is currently the most widely used generic measure of HRQoL (Garratt *et al.,* 2002). This self-report questionnaire comprises eight multi-item sub-scales each containing between two and ten items: physical functioning, physical role, bodily pain, general health, vitality, social functioning role, emotional and mental health. Subscales are scored separately, weighted, summed and transformed onto a 0 (poor health) to 100, (excellent health) scale.

Table 2.4: Quality of Life Tools

Name of Tool (Acronym)	**Author**	**Items of Tool**	**Application**
Nottingham Health Profile (NHP)	Hunt *et al.*, (1985)	38 items covering: physical (8), pain (8), social isolation (5), energy (3), sleep (5), emotional reactions (9)	Reported use in asthma Well validated and widely used in research
Short-form Health Survey (SF-36)	Ware Sherbourne, (1992). Originated USA Brazier *et al.*, (1992)Anglicised for use in the UK	36 items covering: physical functioning (10), bodily pain (2), energy or vitality (4), emotional problems(3),mental health (5), general health (5), Physical role (5) social functioning (2)	Used in the elderly suffering from various diseases
Short-form McGill Pain Questionnaire (SF MPQ)	Melzack, (1975). Melzack, (1987).	Short version 15 questions or pain descriptors rated on an intensity scale: 11 sensory 4 affective	Quantitative measure of pain
Hyland Ulcer Specific Tool	Hyland, Ley *et al.*, (1994)	Functional limitations and emotional reactions: 34 questions in 3 sections	Designed for patients with chronic wounds
EuroQol (EQ)	EuroQol Groups, (1990)	5 questions Mobility Personal care Usual activities Pain / discomfort Anxiety / depression	Self completion, often used as an additional instrument to the above

2.4.1: Testing the tools in leg ulcer studies

In order to assess the usefulness of the SF-36, (Price & Harding, 1996), presented the results of 55 questionnaires completed by patients with chronic leg wounds (aetiology of ulceration not provided), compared with an age-matched cohort. Persons with leg ulcers experienced more pain, less vitality, more restrictions in physical and social functioning and poorer general health and emotional roles. The authors concluded that leg ulceration has a tremendous impact on quality of life.

Using a cross-sectional study with the Nottingham Health Profile (NHP) and age / sex-matched normal scores, (Franks, 1998), examined health-related quality of life (HRQoL) in patients with leg ulceration and determined which patient groups are most affected by this condition. Patients produced significantly higher scores than age / sex-matched normal values for all domains of the NHP. Increasing age led to greater deficits in energy and mobility, thus resulting in greater social isolation.

Guyatt, Feeney *et al.* (1993), reinforce the importance of an instrument having the capacity to differentiate between patients with, or without, the disease, e.g. ulceration, at a point in time, (discriminative properties) as well as being able to measure any change in HRQoL within a patient over time, (evaluative properties) in response to treatment. Items in the NHP require dichotomous, yes / no, responses, meaning that even participants with quite mild effects will score zero on an item. The SF-36 uses a Likert type response choice, increasing the number of possible different scores (health levels), in which to classify the respondents. Consequently, the NHP produces more skewed results than the SF-36, suggesting a greater sensitivity to floor (worst score), and ceiling (best possible score), effects, as was found to be the case in a comparison by Prieto, Alonso *et al.* (1997), with chronic obstructive pulmonary disease (COPD).

2.5: Chronic illness and depression

Physical illness can be debilitating and often means that people are no longer able to care for themselves properly. This loss of physical health and functioning has an impact on mental health. Penninx (2007), describes the link between depression and physical disability as a process whereby depressive symptoms and physical dysfunctions interact to cause a progressive downward spiral in health status.

This research is taking the physical illness, namely ulceration, as the starting point and then actively looking at depression. Therefore the logical starting point may well be the symptoms of the disease. However, it was deemed easier for the reader to follow if depression was dealt with first and then the symptoms which have the potential, given the right set of circumstances, to give rise to depression in some individuals.

Many individuals are not even aware that they have depression. Therefore the importance of the ability of family and health care professionals to identify depressive symptoms is crucial. It is recognised in the literature that depressive disorders occur more frequently alongside physical illness, with severe forms of depression experienced by some people who are physically ill (Katon & Sullivan, 1990).

2.5.1: What is depression?

Depression is often described as the "common cold" of mental health disorders, and has an estimated point prevalence of between 15 – 30% of the population in the UK (Hotopf, Lewis & Normand, 1996). The word "depression" is linked historically with melancholia and semantically with words such as dejection, despair and discouragement, which carry a sense of a lowered, darkened mood and the experience of loss: loss of interest, loss of hope, loss of energy, loss of courage (Dowrick, 2004). In the NHS, the cost of treating depression, £887 million, exceeds the cost of treating hypertension, £439 million, and diabetes, £300 million (DoH, 1996). The World Health Organisation (WHO) stated in 2000 that depression is the leading cause of disability, as measured in years lived with a disability, and the fourth leading contributor to the global burden of disease, as indicated in terms of disability-adjusted life years (DALYs). By 2020, depression is projected, behind cardiovascular disease, to become the second most common cause of loss of disability-adjusted life years in the world, calculated for all ages and both sexes (Murray & Lopez, 1996;World Health Organisation, 2001).

Depression is an illness of the brain in which there is an imbalance of neurotransmitters, e.g. serotonin, norepinephrine and dopamine, affecting a person's mood. The cause of the imbalance is unknown and thus the pathological basis of depression remains uncertain, although studies have found that there are some connections to biologic inheritance. Current theories of depression are complex and beyond the scope of this thesis and covered in other texts (Dowrick, 2004). Diagnosis continues to focus on definitions developed from clinical observation.

The Diagnostic and Statistical Manual of Mental Disorders (DSM-IV, 1994) defines minor depression as a mood disturbance of at least two weeks' duration with between two and four symptoms of depression from a cluster of symptoms (see Table 2.5), plus a depressed mood for most of the day, nearly every day and a loss of interest or pleasure (anhedonia), in almost all the activities of the day, nearly every day, are at the core.

Table 2.5: Depressive symptoms

1. Significant weight gain or loss when not dieting and decreased appetite.
2. Insomnia or hypersomnia.
3. Abnormal restlessness or a drop in physical activity.
4. Fatigue or loss of energy.
5. Feelings of worthlessness or excessive or inappropriate guilt.
6. Diminished ability to think, concentrate or make decisions.
7. Recurrent thoughts of death, or suicidal thoughts.

Adapted from Beech, (2003).

In DSM-IV, major depression and minor depression differ on two points: the number of diagnostic criteria and the exclusion of a depression history. Major depressive disorder requires five, out of a possible nine, symptoms of depression, while minor depressive disorder requires two to four depression symptoms. A number of studies suggest that minor depression may be an early warning sign for major depression if left untreated (Angst & Hochstrasser, 1994;Howarth, Johnson, Klerman *et al.*, 1992). Depression adversely affects the quality of life and well-being of patients, and is the most common psychiatric condition found in older people (Copeland, Beekman & Dewey, 1999). At some time in their lives 60 –

70% of adults will experience depression or worry of sufficient severity to influence their daily activities (Mann, 1992).

2.5.2: Anxiety and depression

Anxiety and depression are major factors impacting on a patient's quality of life, which persists over time, and the associated symptoms (inability to concentrate, loss of motivation, disturbed sleep, fatigue, pessimistic mood) may influence their ability to benefit from treatment programmes (Sherbourne, Wells, Meredith *et al.*, 1996). High levels of anxiety have been associated with poor concentration and difficulty comprehending information provided by clinicians (Scalzi, Burke & Greenland, 1980). Depressed mood may also adversely affect a patient's willingness to comply with prescribed medication and to undertake necessary lifestyle changes, e.g. exercise, diet. The depressed individual often feels overwhelmed by what they perceive as the enormity of everyday living and has difficulty with motivation, concentration and memory (Peveler *et al.*, 2002).

Both anxiety and depression can have a negative impact on patients' quality of life, on their perception and response to pain, their treatment adherence and on their ability to benefit from treatment programmes (Harter, Reuter, Gross-Hardt *et al.*, 2001). DiMatteo, Lepper & Croghan, (2000), in a recent meta-analysis of the effects of anxiety and depression on patient adherence concluded that the odds are three times greater that depressed patients will be noncompliant than those of non depressed patients.

Depression in people aged 65 and over is especially under-diagnosed (Iliffe, 1991), with a prevalence in the elderly of 10 – 16% (Audit Commission, 2000), depending on the instrument and diagnostic criteria used. One of the contributing factors to this could be that the elderly will report their physical symptoms to the doctor, but will seldom discuss feelings of hopelessness or sadness. This may be related to the fact that depression is still associated with substantial social stigma (Priest, Vize, Roberts *et al.*, 1996). There are many life events that can contribute to depression. However, the number one risk factor for depression in later life is poor physical health (Lenze, Rogers & Mortire, 2001).

2.5.3: Depression and physical illness

Depressive symptoms are frequently experienced with physical illness exacerbating symptoms and illness recovery (Katon, 1996;Katon, Von Korff & Lin, 2003) and are associated with higher levels of functional disability and pain. Several prospective studies have found that physical disability is a risk factor for the development of depression (Kennedy, Kelman & Thomas, 1990;Prince, Harwood, Thomas *et al.*, 1998;Roberts, Kaplan, Shema *et al.*, 1997;Zeiss, Lewinsohn, Rohde *et al.*, 1996).

A review by Martin (2001) noted that depression is commonly encountered in patients with medical conditions such as coronary heart disease, but is frequently unrecognised, hence under-diagnosed and therefore under-treated. Coronary heart disease was identified by the UK government as a top priority in the National Service Framework (NSF for CHD, DoH, 2000) with increased investment in the cardiac workforce and in the capital infrastructure and, therefore, high profile with dedicated charities such as the British Heart Foundation (BHF). If depression is frequently under-diagnosed in a disease with such a profile, it follows that in a marginalised condition such as ulceration, depression is more likely to be under-diagnosed and under-treated. The onset of disability is a major stressor that leads to loss of perceived control, restriction of valued social or leisure activities, isolation and reduced quality of social support, all of which are psychosocial risk factors for depression (Penninx, 2007). This is coupled with additional factors resulting from acquired physical disabilities such as loss of function, role and body image and a negative view of themselves, the future and their world.

The figure for depression may be doubled for those older people with physical health problems (Banerjee, Shamash & Macdonald, 1996). House and Hughes (1996) suggest that depression and physical illness may be associated in several ways. They can co-exist by chance or depression can be a reaction to, or be precipitated by, physical illness or by its treatment. Steptoe (2007, p.400) refers to this as a consequence model, but also recognises that in some cases an antecendant or shared determinants model may be in operation. A meta analysis of ten studies by Wulsin and Singal (2003) examining the contribution of depression to the onset of cardiovascular disease revealed that depression is an independent risk factor for the development of cardiovascular disease. Depressed physically-ill patients require more investigations and treatments than those that are non-depressed, have worse function (Wells, Rogers & Burnam, 1993), and are also less likely to concord with treatment (Guiry, Conroy, Hickey *et al.*, 1987). Kennedy *et al.* (1990), found that physical ill health was an important precipitating and perpetuating factor in the onset of depression. Several studies among older people have shown that symptoms of depression are predicted more strongly by the level of physical disability than by the number, or specific type, of chronic conditions (Beekman, Deeg & Geerlings, 2001;Zeiss *et al.*, 1996). This has major implications, therefore, when considering the level of disability endured by some people with chronic illness.

Depression is identified as a key area requiring attention in the National Service Framework for Older People Standard Seven: Mental health in older people (DoH, 2001a) with 10 – 15% of the population aged over 65 thought to have depression at any one time. Physical ill health, especially resulting in functional disability, has consistently been linked to depression especially in older people (Zeiss *et al.*, 1996). Prince *et al.* (1997) demonstrated that increased impairment, disability and handicap resulted in older people experiencing more depressive symptoms. The difficulty of recognising depression in the context of medical illness is a topic that has received a great deal of attention (Acharya, 2004;Martin, 2001;Patten, 2005). The implications of depressive co-morbidity can be a serious consequence. Depression not only impacts on physical, mental and social well-being, but also contributes to poor self care and adherence to treatment, whilst ultimately diminishing a person's quality of life.

2.5.4: Psychological factors and wound healing

A link has been established between psychological factors and the endocrine and immune systems in the area of psycho-immunology (Ader, Cohen & Felton, 1995). It is postulated that psychological factors have a role in the pathogenesis and recurrence of some chronic wounds (Anderson, Marcia & Andberg, 1979;Olshansky, 1992). Stotts and Wipke-Trevis (1996) refer to research showing how psycho- physiological stress has been identified as a cause of delayed healing. Psychological factors can disrupt the activity of macrophages and lymphocytes, both important immune system cells of the inflammatory phase in the healing process. This was demonstrated by Kiecolt-Glaser *et al.* (1995), in acute wounds, when carers supporting a relative with Alzheimer's disease took up to nine days longer to heal a 3.5mm punch biopsy than a similarly matched carer group. They attributed the healing time to the increased stresses incurred by caring for a relative with dementia.

Palmer, (1995) discusses how psychological and psychosocial problems can affect wound healing, suggesting that the psychosocial aspect of community nursing is often the most vital part of dealing with wounds that will not heal. Indirect factors that might lead to delayed healing in a depressed individual include self-neglect, disturbed sleep and poor appetite (Cole-King & Harding, 2001). Anxious patients were found to report more severe pain and have higher cortisol and blood pressure values, suffer greater limitations of activity and mobility, increased worries about their health and significantly lower self-esteem (Augustin & Maier, 2003).

Polignano and Rowan (1999), in a group of 36 patients with venous leg ulcers, found that those people not experiencing pain at the beginning of treatment with compression therapy had higher wound-healing rates than those experiencing pain. Cole-King and Harding (*op cit*), found a statistically significant relationship between psychological factors and the rate of wound healing in 53 patients with chronic wounds, using the Hospital Anxiety and Depression Scale (HADS). They believed that delayed healing is the result of psychological factors rather than the reverse, a theory that is supported, as discussed earlier, by other research into acute wounds (Kiecolt-Glaser, 1995).

Franks, Moffatt *et al.*, (1994), investigated changes in the quality of life, interference in daily activities and pain of patients with leg ulcers who were treated in community leg ulcer clinics in the UK, using the Symptom Rating Test (Kellner, 1986). They found a statistically significant mean reduction in depression in patients whose leg ulcers had healed, although the mean reduction in anxiety was not significant. However, these results must be interpreted with caution because this was an uncontrolled study and thus the results cannot be attributed to any particular aspect of the treatment.

2.6: Living with a leg ulcer

Research on the experience of living with a venous leg ulcer is somewhat limited for, I would suggest, two reasons. The first is that for almost ten years, research into leg ulcers has tended to focus on aetiology and treatment. This has been compounded by the retention in assessment approaches of the biomedical model with a firm focus on physical aspects. In a study by Hollinworth and Hawkins, (2002), 50 qualified nurses were asked how they provided holistic care to patients with wounds. They identified patients' feelings of isolation and misery; but actively recognised they actually did nothing about it as they felt they were too busy treating the clinical manifestation and symptoms of the wound. Likewise, in a study by Kammerlander and Eberlein (2002) of 3,300 questionnaires from three countries (response rate: 15.1%), only 16% of respondents used a standardised scale to assess patients' pain. However, findings do provide some indication of the limitations and difficulties associated with this chronic illness.

Chronic leg ulceration as a major cause of morbidity is identified in all the studies discussed below (with a summary table in Appendix 1). These studies utilised a variety of methodologies, including qualitative approaches which are inductive and in-depth such as phenomenology and grounded theory to inquire about life with a leg ulcer from a patient's perspective; and cross-sectional measurements using generic and / or leg ulcer-specific health-related quality of life (HRQoL) instruments, for example Short Form with 36 items (SF-36), Nottingham Health Profile (NHP).

The major findings of the studies, discussed in the following sections, have provided us with rich data identifying pain, mobility, sleep, problems with activities of daily living, restrictions of treatment and impact on social life as some of the major factors associated with having a leg ulcer. Pain is by far the dominant feature in the studies and it was thus felt to be appropriate to provide background information on pain so that the reader has an understanding of some of the factors associated with it and how our understanding of pain has been shaped.

2.7: Ulceration and pain

2.7.1: What is pain?

Pain has been described as one of the most significant and universal features of living with a chronic wound such as leg ulceration (Smith, Guest, Greenhalgh *et al.*, 2000). The International Association for the Study of Pain defines pain as:

> *"An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage."*
>
> (ISAP, 1994)

Pain is a protective mechanism occurring when tissues are damaged; pain receptors in the skin are all free nerve endings that are stimulated by chemicals released at injury. Bradykinin and proteolytic enzymes are the primary chemical mediators for the skin, plus prostaglandins, which enhance the sensitivity of the nerve endings. Bacterial infection can be a precipitant to pain because of the toxic products of bacterial metabolism. The greatest amount of pain is caused by the release of bradykinin with cellular damage. Tissue ischaemia caused by decreased blood flow also causes pain in chronic ulcers. However, as reported by Eccleston (2001), some people report pain even when it is difficult to identify the source, whilst people with overt tissue damage may not report pain.

In the UK, elderly people are the most rapidly increasing population of pain sufferers (Closs, 1994). Pain appears to often be under-treated in elderly patients due to several factors: patient fears, lack of education for health care professionals and misconceptions that either pain is a normal part of ageing (Becker, 1999;McElhaney, 2001;Turk, Okiko & Schraff, 1995), and / or older people have a higher pain tolerance (Davies & McVicar, 2000). McElhaney, (2001) claims that pain should not be regarded by people as a normal and inevitable consequence of ageing; pathology either physical of psychological is always involved. Shahady (1990), suggested that 50% of older patients have beliefs that inhibit diagnosis and effective management of pain, such as beliefs about the ageing process itself and about the potential consequences of treatment, such as addiction.

It is estimated that 64 – 83% of older people suffer from chronic pain (Ferrell & Ferrell, 1990;Ferrell, Ferrell & Osterweil, 1990), with chronic pain generally defined as lasting more than three months (Portenoy, 1995;Turk, 1997). Laboratory studies of pain perception in older people suggest that the pain threshold to noxious stimuli increases with age, but once pain is felt, older people report pain of the same severity and quality as younger people (Harkins & Price, 1992). Hofman *et al.,* (1997), found that between 17% and 65% of patients experience severe or continuous pain associated with a leg ulcer. However, the precise prevalence of pain in venous ulceration is difficult to determine due, to both the methodological differences between studies, as well as the use of predominantly hospital populations. Evidence about pain prevalence, drug utilisation and treatment effectiveness is scanty, most deriving from placebo trials with very few comparative studies in large and well-characterised cohorts of leg ulcer patients. Unresolved pain negatively affects wound healing and can adversely affect a patient's quality of life (Michelson, Bolund & Brandberg, 2001).

However Queen, Woo *et al.* (2005), observed that pain control often appears to be more important to patients than it is to healthcare professionals.

2.7.2: Types of pain

In order to appreciate the pain suffered by patients with venous ulceration, it is useful to try to elucidate the different aspects of pain associated with venous ulceration: namely, neuropathic and nociceptive pain. Neuropathic pain arises from damaged nerve tissue, whereas nociceptive pain results from actual tissue damage (Sykes, Johnson & Hanks, 1997); both types are significant factors in the development of chronic pain. Neuropathic pain may be spontaneous or precipitated by various stimuli, some of which are not normally painful (allodynia), such as light touch or cold. This is because the normal pain transduction pathways are altered, resulting in an increase in pain sensation. Nociceptive pain has been defined as "pain that is the result of the stimulation of intact afferent nerve endings" (Salerno & Willens, 1996, p.563) and is an appropriate physiological response to a painful stimulus. It involves the relay of pain signals from the nociceptors (pain-sensing nerves) in the peripheral tissues to the central structures in the brain. Acute or nociceptive pain is an inflammatory response to painful or noxious stimuli (actual tissue damage) and is usually time-limited.

Neuropathic pain arising from damaged nerve tissue has been defined as "pain that is the result of peripheral nerve injury and not stimulation" (Salerno and Willens, 1996, p.563), and is an inappropriate response caused by a primary lesion or dysfunction in the nervous system of which nerve damage is the commonest cause. In contrast to nocioceptive pain, persistent injury or abnormal function of the peripheral or central nervous system (neuropathic pain) is a major factor in the development of chronic pain. Pain that is neuropathic-related is often described as burning, tight or aching in nature, while nociceptive pain may be described as cramping, gnawing and sharp. Ulcer-related pain can result from heightened sensitivity in the wound bed (primary hyperalgesia), or in the surrounding area (secondary hyperalgesia), particularly in chronic wounds where there has been a prolonged inflammatory response (WUWHS, 2004). Persistent pain may result in increased sensitivity to non-painful stimuli. Thus, for a person with an ulcer due to venous insufficiency, even a gentle touch of the skin may cause pain and an uncomfortable sensation (Cooper, 2003).

2.7.3: Living with constant pain

In everyday life, and when people are healthy, the body is taken for granted. Most of us get up and get on with our day without thinking about our bodies. It is only when we are ill that we really notice it and the body "loses its silence" and can no longer be taken for granted (Bleeker & Mulderij, 1992). The body becomes a hindrance, related first and foremost to pain and fatigue, which arouses feelings of suffering. Pain can outlive its warning role and become persistent and debilitating (Julius & Basbaum, 2001). Pain by itself has a negative impact on the financial, legal, familial, physical, social, occupational and behavioural dimensions of life (Ferrell *et al.*, 1989). The ability of pain to interfere with normal functioning and quality of life is well documented in the literature (Elliott, Smith, Penny *et al.*, 1999;Johnson, 1995;Sofaer, Moore, Holloway *et al.*, 2005) Living with chronic pain, is a theme that constantly emerges from qualitative studies, and is one of the most significant negative consequences of living with a leg ulcer. This situation is aggravated by the fact that elderly people often under-report pain (Ferrell and Ferrell, 1990) and regard it as a normal part of growing old (Stein & Ferrell, 1996;Weissman & Matson, 1999). Mitchell (2001) reported that persistent pain in elderly people had a greater impact on their sense of well-being (QoL) than in younger patients, giving rise to symptoms such as insomnia, depression, anorexia, apathy and impaired mobility (Justins, 1993). Alleviation of pain has been shown to improve QoL for several chronic conditions such as diabetes (Backonja, Beydoun, Edwards *et al.*, 1998). The personal experience of chronic pain was explicated by Davis (1992), with poor pain management resulting in the negative effects of anxiety, depression and helplessness. These emotions often result in avoidance behaviours such as decreased physical activity and negative self-image, which in turn compound the social isolation cited in some of the studies.

2.7.4: The complexities of pain

Our modern understanding of pain has moved forward from viewing pain as a one-dimensional anatomical, physiological body process, towards the recognition of pain as a complex biological, psychological, social and existential phenomenon (Gardea & Gatchel, 2000;Petrie & Azariah, 1990). Walding (1991), suggests that an individual's experience of pain can have its' basis in a multitude of psychosocial and environmental factors such as gender, education and history of previous pain. Turk and Okifuji (2002), provide evidence that patients' beliefs, their ability to control pain, and concerns for the future impact not only on the perception of pain but also the response to treatment.

From a healthcare professional's perspective, wound pain can be categorised as persistent (chronic) or temporary (acute cyclic or non-cyclic) pain (Krasner, 1995). Chronic wound pain is unrelated to physical movement and may be constant. Non-cyclic acute pain and cyclic acute pain may occur with the removal of dressings and aggressive debridement. Later Bendelow (2000), added socio-political and spiritual aspects to this, which should be considered since pain lies at the intersection of biology and culture. Early pain control may improve the individual's psychological state and is thought to have an impact on wound healing (Moffatt, Doherty & Franks, 2001). Pain, particularly if severe, persistent or multiple, is known to be a risk factor for depression (Dworkin, von Korff & LeResche, 1990), with feelings of depression frequently accompanying pain (Fishbain, Cutler, Rosomoff *et al.*, 1997). Depression and pain, although clearly distinct conditions, have a shared aetiology with the proposed mechanisms including neuro-transmitters such as serotonin, noradrenaline, substance P and corticotrophin-releasing factor (Campbell, Clauw & Keefe, 2003).

Other researchers propose that chronic inescapable stress might be a link between chronic pain and depression (Blackburn-Munro & Blackburn-Munro, 2001). Pain and depression in elderly people appear to be strongly associated and may even intensify each other (Casten, Parmelee, Kleban *et al.*, 1995;Romano & Turner, 1985). High levels of anxiety and distress not only affect the experience of pain, but also affect processing and recall of symptoms. Depression is recognised as a major outcome of chronic pain, and a meta analysis by Dworkin & Gitlin (1991), confirmed that depression was more common in chronic pain patients than in healthy controls, and indicated that depression was a "consequence" of the presence of chronic pain and not a predisposing factor; it is thought that more than half of chronic pain patients suffer from depression. Depression has been reported to be associated with higher levels of self-reported pain and pain behaviour, lower levels of physical and psychosocial functioning and poor response to treatment (Adams et al 2006).

2.8: The case for depression in people with chronic leg ulceration

2.8.1: Pain

A large number of studies began to appear in the mid to late 1990s, reporting on pain in venous ulceration, and reinforcing that it is not just arterial ulcers that are painful, but venous ulceration is also known to cause severe pain. Indeed, McCaffery and Pasero (1999), state that "clinicians should assume that all wounds are painful". As noted in a review by Snyder (2006), pain appears to represent the most profound symptom of venous ulceration. A view that resonated with studies by Hamer *et al.* (1994); Walshe (1995); Bland (1995); Hofman *et al.* (1997); Chase (1997); Krasner, (1998); Hyde *et al.* (1999) and Husband (2001a), where pain was reported to be the worst thing about having an ulcer, with between 17% and 65% of patients experiencing severe or continuous pain associated with their leg ulcer. Participants in the Hofman study rated pain as "horrible" or "excruciating". Both Walshe (1995), and Husband (2001b), comment on the poor management of pain by health professionals. In her grounded theory study of 39 patients, Husband (2001a) reports that, in some cases, the nurses noted that the patients had some pain but, rather than dealing with it as a symptom in its own right, they viewed it as a diagnostic factor that helped to differentiate between ulcer types – it was rarely approached as a biographical / quality of life issue. Chase (1997) found that pain was a recurring and difficult aspect of living with a leg ulcer.

Studies by Hamer *et al.* (1994); Flett *et al.* (1994) and Wissing and Unosson (2002), used control groups to emphasise the fact that people with ulceration report significantly more pain than those without. Whilst in Walshe's study pain intensity was found to be stable over time, other studies report day-to-day variation, increased pain intensity during the night, or effects caused by weather and seasonal influences (Hyland *et al.,* 1994; Hyde *et al.,* 1999). Pain was reported in studies by Phillips *et al.* (1994), and Krasner (1998), to be so severe that it interfered with the ability of some individuals to remain in employment. Krasner felt that people in her study identified pain as a normal and expected part of the experience of living with a leg ulcer, with oedema and long periods of standing contributing to increased pain. Although studies have suggested that people may feel low or depressed, no studies to date have actively screened patients for anxiety and depression because of chronic pain of ulceration.

2.8.2: Sleep

Sleep is considered a universal basic need for health and survival.

> *"That we are not much sicker and much madder than we are is due exclusively to that most blessed and blessing of all natural graces – sleep."*
>
> Aldous Huxley

Disrupted and lost sleep has complex systemic effects. Short term, 24 – 48 hour, sleep loss impairs mental performance, lowers pain thresholds, and heightens emotional reactivity (Landis & Whitnew, 1997). It is generally accepted that sleep and pain are interrelated phenomena, having a bi-directional relationship with pain often disturbing sleep, but changes in sleep could also influence pain perception (Onen, Alloui, Gross *et al.*, 2001), with tiredness increasing the awareness of pain. This was evidenced in many of the studies where pain was cited as a major factor.

Friedman and King (1995), in their study of heart failure, found that fatigue was significantly correlated with long term sleep difficulties (r=0.37) and pain (r=0.36). Similarly Wolfe *et al.* (1996), in a study of older people with rheumatic disease, pain and constant sleep disturbance were strong predictors of fatigue. Fatigue and chronic pain are known to be closely related to each other, and both result in low quality of life, particularly among older people (Jakobsson, 2006). Disordered, and loss of, sleep are thought to adversely affect resistance to infectious disease, increase cancer risk and alter inflammatory disease progression (Irwin, 2007).

In most studies, pain appeared to be inextricably linked to sleep or at least disturbed sleep. Sleep disturbance caused by pain was reported by 64% of people in the Hofman *et al.* (1997), study. Likewise night pain interrupting sleep was cited by Flett *et al.* (1994). Douglas (2001), spoke to eight people who cited pain as the main factor causing disturbed sleep, a feature mentioned by Charles (1995); Walshe (1995); (Hyde *et al.*, 1999), and Brown (2005).

Sleep is also recognised as important in the healing process, since it is widely accepted that cell division and protein synthesis reach their maximum values during the hours of sleep (Oswald & Adam, 1984). Closs (1992), in a study of pain at night, suggested that sleep deprivation can impair tissue restoration and create a negative state of well-being. Therefore, long-term sleep deprivation can have a major impact on people with chronic ulceration, particularly as disturbed sleep and fatigue are symptoms associated with depression (Harter *et al.*, 2001). Solnek and Seiter (2002), went further to suggest that disturbed sleep patterns, particularly early morning awakening, can be used as a reliable indicator of depression in older adults.

2.8.3: Mobility

Mobility, the physical activity of being mobile, has its origins in the Latin, ***mobilis:*** to move. In the concept analysis by Rush and Ouellet (1993), mobility is described as encompassing the attributes of movement, flexibility, versatility and changeability. Mobility has been conceptualized as a critical component of a person's functional health and self-esteem (Rush and Ouellet, 1993). As discussed earlier, the level of physical disability is a strong predictor of symptoms of depression.

Impaired mobility is mentioned in all but one qualitative study and it would appear to be pain-related. Walking, and even just standing seems to aggravate the pain, and is thus avoided by some patients (Walshe, 1995; Krasner, 1998). The study by Chase *et al.,* (2000), used a measure of functional status (SF-36) with participants reporting moderate to severe limitations in physical function. Mobility was found to be a factor in the healing of ulcers (Franks, Moffatt, Connolly *et al.*, 1995), with differences in healing rates between those who could walk freely, walk with aids and chair / bed-bound patients. Limits to mobility and activity were, at times, profound. In a New Zealand case-control study, (Flett *et al.*, 1994), assessed how often participants had trouble performing routine household tasks, e.g. climbing stairs, with individuals with leg ulcers experiencing significantly greater pain and mobility problems. Studies by Phillips *et al.* (1994), and Johnson (1995), found that for some, mobility was so adversely affected by their ulceration, that it not only had an impact on social activities, but also on their ability to work.

2.8.4: Ulcer discharge and odour

While moisture is a necessary and normal part of healing, an overly wet wound may damage the wound bed, as well as the surrounding skin (Cutting & White, 2002), causing maceration or excoriation of the surrounding skin which may lead to infection, increased odour and hypersensitivity. Bishop and Warr (2003), described wound exudate as a “corrosive” biological fluid with the potential to cause considerable discomfort, as well as tissue damage.

In chronic wounds or where the process of healing is disrupted, such as when a wound becomes infected, the exudate level may increase. Not only is there a lack of consensus as to what constitutes a normal amount of exudate for a particular wound type, there is also a lack of standardized terminology with practitioners relying on subjective descriptors. Falanga (2000) proposed the terms: none / minimal, moderate amounts and very exudative, while Sibbald (2000), used “scant”, “moderate” and “copious” as descriptors. Chronic wound exudate contains high concentrations of proteolytic enzymes which can cause tissue and cellular damage to the delicate tissue around a wound (Moore, 2003). Increased production of exudate may be associated with high bacterial growth in the wound, inadequate compression in the management of venous ulcers, inappropriate dressings or wear time, oedema and lymphoedema (Cutting and White, 2002). Exudate production will also be exacerbated if the patient sits with their legs in a dependent position all day.

Odour, or rather malodour from a heavily exuding wound, often resulting from multiplication of, and colonization by, bacteria (Van Toller, 1993), can have an adverse effect on a person’s psychological state and social life, since smell would appear to influence the ability to be socially accepted. It can be particularly distressing for patients and can lead to isolation due to embarrassment, since odour often carries a social stigma (Douglas, 2001;Rich & McLachlan, 2003). Cameron, Hofman *et al.*, (2005), similarly noted, that skin maceration causing soreness and pain are also factors associated with uncontrolled exudate levels. Walshe (1995), and Bland (1995), both used phenomenology to explore the experiences of patients with leg ulcers. Whilst pain emerged as the most profound experience of chronic leg ulceration, leakage and smell also caused a great deal of distress, especially as this was often associated with repeated infections. Leakage and smell were also common occurrences that had to be managed for the 12 women interviewed in the

Hyde *et al.* (1999), study. Once again the researchers would seem to have highlighted some distressing symptoms, but appear most concerned with ensuring that the symptoms of ulceration are given a profile as opposed to the impact of the symptoms on the individuals' lives.

2.8.5: Time to heal

Bland's (1995) study explored the fact patients desperately want their ulcer to heal, challenging what she believes to be a myth: that patients with ulceration deliberately delay healing to ensure continued nurse contact. This myth gained popularity after Wise commented about a patient:

> *"Her ulcer has healed twice in the past two years but recurred within two months of healing...so probably it is a factitious ulcer which she uses to ensure regular contact."*
>
> (Wise, 1986, p.39)

Whilst in reality there is no evidence to substantiate this viewpoint it is, in my personal experience, a statement often made inappropriately by some community nurses, particularly if the patient is perceived as non-concordant; that patients tamper with their dressings and / or wound. Indeed, there may be a few patients who use their ulcer as a ticket to social and health care (Muir-Gray & Wilcock, 1981). Moody (1984), interviewed ten patients who said there were good things about having an ulcer, such as accessing the meals on wheels service. However, this cannot be interpreted to mean that patients do not want their ulcers to heal specifically to maintain nurse contact. There is currently no literature to support this belief.

Chase (1997), in a phenomenological study in the USA of the lived experience of having a venous ulcer, articulated a "forever healing" experience which refers to the lengthy period of treatment over which healing occurs. She also identified three other themes: limits and accommodations, powerlessness, and a sense of who cares. Patients felt resigned to the slow wound healing and the inevitability of wound recurrence, expressing a feeling of powerlessness over the situation. She found that persons with a venous ulcer experience different dimensions of healing than persons with a surgical wound. The current venous ulcer might heal, but the underlying condition remains present: this healing never ends.

2.8.6: Impact of treatment

For individuals whose leg ulceration is due to venous insufficiency, evidence suggests that the most effective method of achieving healing is through the application of graduated, multi-layer compression bandaging (Cullum *et al.*, 2001). The system most commonly in use in the UK is the four layer system which consists of four layers of bandage applied from the base of the toes to just behind the knee, designed to be left in place for a week. Short stretch bandages, consisting of two layers, are also used, although more in Europe and Australia than in the UK. A recent randomised controlled trial (Iglesias, Nelson, Cullum *et al.*, 2004), compared the effectiveness and cost-effectiveness of both systems and concluded that four-layer bandaging did seem to be slightly more effective and cost effective. However, they did suggest that the slight benefit clinically was probably due to proficiency linked to familiarity with the four-layer system in the UK.

The treatment itself may be problematic, as compression therapy is recognised as being bulky, making it difficult for people to wear their normal footwear. This was reinforced in the Ebbeskog & Ekman, (2001), study conducted in Sweden, when 15 elderly patients (mean age: 79.4), with active chronic venous leg ulcers were interviewed. Ebbeskog and Ekman elucidate on the fact that the body becomes the focus of attention, with the ulcer constituting a defective body part. The treatment caused patients to feel as if they were imprisoned, not only in their body, but also in the bandage "like armour around the body" (p.238), and ultimately in the home. The bandages meant that they were forced to lead restricted lives as they had problems finding shoes that fitted the bandaged foot. Old worn-out shoes were cut to make them fit. One of the key features of this study is that, despite the slow healing coupled with pain etc., hope of healing was still there and freedom from a burdensome body.

In a grounded theory study in the UK, (Husband, 2001b), found that painful, slow to heal wounds were compounded by the treatment, namely bandaging, which prevented self-care and normalisation in individuals' lives. Likewise Bland (1995), elucidates on the unsightly appearance of the dressings which impacted on personal hygiene.

2.8.7: Social isolation

According to Hodges, Keeley *et al.* (2001), social isolation occurs when individuals are unable to participate fully or meaningfully in social relationships, despite wanting to. This can be because of either physical or emotional reasons, which prevent individuals from making the contacts necessary for interpersonal involvement (Carpenito, 2000). Regardless of who initiates the withdrawal from social networks, either the individual or others, Hodges *et al.* (2001), noted that isolation often becomes reciprocal.

Social isolation has been recognised as a potential problem for some individuals with ulceration. Social isolation and negative self-image were expressed when Phillips *et al.* (1994), interviewed 73 patients about quality of life factors. These sentiments were echoed in studies by Charles (1995), and Krasner (1998), who identified that fear of additional trauma and the stigmatizing effect of an offensive wound were some reasons for withdrawal from social activities. These problems were further compounded by pain and reduced mobility (Krasner, 1998;Lindholm & Erikkson, 1993;Price & Harding, 1996). Wissing and Unosson (2002), reported that individuals with leg ulcers performed more poorly in assessment of not only their physical health but also social interactions and psychological well being, than a matched control group.

In a recent report by Moffatt, Franks *et al.* (2006), of a matched case-control study of 113 patients matched to controls, they identified that patients with ulceration have deficits in their perceived social support compared with the general population, with smaller social networks. This social isolation can lead to loneliness and depression, particularly in the elderly. However, it is worth noting that just because someone lives alone, and / or is socially isolated, loneliness is not a natural consequence. Bowling (2001), reminds us that these are different constructs, with different psychometric properties. Loneliness needs to be distinguished from related, but not coterminous concepts of being alone (time spent alone), living alone and social isolation. Although there are common features which they all share, Victor, Scambler, Bond *et al.,* (2000) warn against using them interchangeably. Those at greatest risk of emotional isolation are people without a spouse, in poor health or unable to engage independently in daily activities (Blixen & Kippes, 1999).

2.8.8: Emotional impact

Emotions of fear, anger, depression and negative self-image weave throughout many of the studies with people spending an average of 1.5 hours per day just thinking about their ulcer (Hyland *et al.,* 1994). Lindholm, Bjellerup *et al.,* (1993), used the Nottingham Health Profile (NHP) to investigate self- perceived quality of life for 125 older persons with chronic leg ulcers in Sweden. Energy, pain, emotions, sleep and social and physical well-being were analysed with sex and age, matched with normative scores. Men tended to have less energy, more pain, and a greater emotional reaction to ulceration than women; as well as experiencing adverse effects on social life and physical mobility. However, in this study quality of life did not appear to be correlated with ulcer duration, perhaps suggesting that patients use adaptive or coping mechanisms to deal with long term ulceration.

Charles (1995a) used a phenomenological approach to explore the impact of leg ulcers on patients' quality of life, with feelings of hopelessness the most significant theme to emerge. The Philadelphia Geriatric Center Multilevel

Assessment Instrument (PGC MAI) was used by (Wissing & Unosson, 2002), to assess and compare the life situation in 144 elderly people with (70) and without (74) leg ulceration, with respect to function, psychological well-being and perceived environmental quality. The PGC MAI (Lawton, Moss, Fulcomer *et al.*, 1982) is an assessment approach based on the conception of "good life" of older people and contains four sectors: behavioural competence, psychological well-being, perceived quality of life and objective environment. They reported that patients with ulcers reported more emotions such as feeling lonely, sad and being less useful, as well as more psychiatric symptoms than those without ulcers.

2.9: Screening tools for depression

One of the issues facing clinicians wishing to screen for high levels of anxiety and depression among their patients is the choice of a screening tool. Screening tools do not guarantee a diagnosis of depression, but they can provide enough information to decide whether further assessment of the patient's mental status is required.

In a clinic or home setting when the clinician can give treatment for a wound such as a leg ulcer, the tool needs to be quickly administered and have good psychometric properties. In the selection of assessment tools for screening and evaluation there are a number of issues to be considered. Guyatt *et al.* (1993), in their guidelines on the selection of health-related quality of life measures, highlight a number of factors that are relevant here. Measures need to be reliable (internally consistent, and stable over time), valid (measuring the intended characteristic) and responsive (able to detect change). Reliability, accuracy and reproducibility are important qualities for a discriminative instrument (for use as a screening tool in distinguishing those with a high versus low level of a characteristic). For an evaluative instrument, responsiveness (as indicated by sensitivity to detect changes in patients who have improved or deteriorated) is also essential.

Many of the available measures, e.g. Beck Depression Inventory (BDI), (Beck, Steer & Brown, 1996), are quite long and detailed, and are restricted for use by psychologists, psychiatrists or other suitably trained personnel. This makes them unsuitable for routine administration as part of a normal assessment procedure. Measures such as the BDI also contain a number of questions relating to physical (bodily) symptoms of depression such as fatigue, weight loss, pain and anorexia. Since these physical symptoms may be a direct result of physical illnesses, it is inappropriate to include them as contributors to a diagnosis of depression. Also, while a number of tools have been designed to assess depression in populations, few have been specifically designed for use in non-psychiatric settings, or in patients who do not have a primary diagnosis of depression (Beck, Ward, Mendelson *et al.*, 1961;Montgomery & Asberg, 1979;Zung, 1986).

2.9.1: Hospital Anxiety and Depression Scale (HADS)

One of the tools considered for use as a discriminative measure in the leg ulcer context was the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983). HADS has been designed to detect the presence and severity of relatively mild degrees of mood disorder in general populations. It was designed to exclude symptoms that may have both an emotional and physical aetiology, for example dizziness or sleep disturbance. The depression scale is based on anhedonia – the complete loss of pleasure or interest in life – which Snaith described as the "exclusion from the pleasure dome". This was also considered by Klein (1974) to be the best guide to the type of depressive mood disorder. Other symptoms of anhedonia include: a lack of enthusiasm, sluggishness, apathy, social withdrawal and disinterest.

HADS is a 14 item, self-report scale assessing current levels of anxiety (HADS-A) and depression (HADS-D) independent of somatic symptoms. It comprises seven questions relating to depression alternating with seven anxiety items: six are coded on a four point response scale from zero, representing absence of symptoms, to three representing maximum symptomatology. Eight items are coded from three to zero, i.e. reversed. Individuals are required to make a response to each item which is ordered in terms of frequency or severity. The anxiety items of HADS can be allocated into three clusters (Keedwell & Snaith, 1996). The first cluster is labelled *Mood:* "the experience of a groundless sense of fear not attached to any particular situation or circumstance". The second cluster is *Cognition*: "the preoccupation with the possibility of some adverse event occurring to oneself or others". The last cluster is *Behaviours:* "restlessness: the inability to remain still and relaxed for more than a few minutes at a time".

The completion of a depression questionnaire is known as case-finding. Zigmond and Snaith (1994), recommend that raw scores of between eight and ten identify mild cases, 11 – 15 moderate cases, and 16 or above severe cases, for each dimension. Herrmann, in his review of HADS literature, noted there is "no single, generally accepted, cut off for HADS" (Herrmann, 1997, p.21). In a literature review, Bjelland *et al.* (2002), report that the optimal balance between sensitivity and specificity for "caseness" is achieved with a cut off of 8+ on each subscale.

The scale has been used in numerous studies of patients in non-psychiatric settings, such as general practice and outpatients. A number of studies have used patients with chronic conditions including rheumatoid arthritis, cancer, myocardial infarction, respiratory disease and early dementia (Wilkin, Hallam & Doggett, 1993). Further validation studies of the English and foreign language translations of HADS were undertaken in a variety of settings and centres. The first review of these, by Herrmann, was published in 1997. A more recent review by Bjelland *et al.* (2002), of 747 identified studies concluded:

> *"HADS was found to perform well in assessing severity and caseness of anxiety disorders and depression in both somatic, and psychiatric cases and – not only in hospital practice for which it was first designed – in primary care patients and the general population."*

(Bjelland, *et al.*, 2002, p.75)

It has demonstrated good internal consistency with Cronbach alpha values ranging from 0.67 to 0.90 for HADS-D (Bjelland *et al.,* 2002). HADS was originally designed to assess two separate dimensions of anxiety and depression. The case for the bi-dimensionality of HADS was supported in the review by Bjelland (*Op cit*). A strong argument for the use of the two factors is also made at clinical level where it is clinically relevant to separately determine levels of anxiety and depression.

2.10: Summary

What has been indicated by these studies is that leg ulceration has a far-reaching impact on various aspects of an individual's life. It also emphasises the need for more than just lip service to psychosocial factors in assessment and an ongoing review of patients with leg ulceration.

Psychological aspects of wound management are poorly addressed in the literature (Hopkins, 2001), which is likely to be a reflection of what happens in practice. When studies use ulcers of different aetiologies it is difficult to explore the factors, as for example, one would expect a person with arterial disease to have disturbed sleep, whereas this would not normally be a factor associated with venous disease. As stated by (Husband, 2001a), patients' greatest problems occur because nurses fail to hear what patients are saying in the context of their lives.

Living with a chronic illness means disruptions and alterations in one's life. There is a growing awareness of how important it is to understand the person's perspective on chronic illness experiences, and that our evaluations of interventions are informed by patients' views. Chronic leg ulceration must be viewed as a chronic illness as it is a major cause of morbidity; the impact of living daily with a wound can be seen in different ways, but only the individual genuinely understands the meaning of that experience. A person's whole life situation changes because the disease and treatment often require a marked change in their lifestyle.

What appears to have been inadequately identified in these studies is whether individuals suffer depression as a result of leg ulceration. Some studies have “suggested” that depression is a likely outcome but have not explored which particular aspect of ulceration is associated with feelings of depression. There seems to have been concern to ensure that people are made aware of the symptoms of ulceration, as opposed to a great focus on the impact of these symptoms. This is particularly evident in the work on pain, which ensured that the pain of venous ulceration was heard, as opposed to being simply a diagnostic factor.

House and Hughes (1996), suggest that depression and physical illness may be associated in several ways. They can co-exist by chance or depression can be a reaction to, or precipitated by, physical illness or by its’ treatment. If anxiety and depression cause delayed wound healing then it is vital that, as practitioners managing individuals with this chronic and debilitating condition, we understand not only the extent of the problem but also the emotional impact. The conclusion of previous studies notes that the level of disability and perceived physical health are very important risk factors of depressive symptoms in the elderly (Broe, Jorm, Creasey *et al.*, 1998).

To understand why the individual with chronic ulceration is at risk of depression, physical and mental stresses must be examined. The individual’s physical capabilities can often be limited by pain and decreased mobility, which will affect their capabilities to perform common daily activities. This will require them to depend on others and, in return, create a loss of independence and sometimes low self-esteem, which can lead to depression in many individuals. Other variables that must be considered are stress caused by the inability to fulfil occupational roles and / or financial stress.

The chronic illness literature constantly refers to the emotional and psychological impact of living with a chronic disorder, and the links between physical illness and depression, which can exacerbate symptoms, and impact on illness recovery. It is also noted that depression can frequently remain unrecognised and therefore under-treated, with some symptoms of depression being ascribed to the illness per se.

To date, depression in patients with chronic venous ulceration has been sparsely investigated. We do not have any idea of the prevalence of anxiety and depression in individuals with chronic ulceration, and consequently, the main features of ulceration, which could be linked with depressive symptoms. These aspects are addressed in the following chapter, which aims to determine the prevalence of anxiety and depression in nine NHS Trusts across the North West of England.

Chapter 3

Phase I: Prevalence of anxiety and depression in individuals with chronic venous ulceration

3.1: Methods

Whilst the literature review has identified studies that have recognised anxiety and depression as factors in the lives of individuals with ulceration, to date there is a gap in the literature as to the prevalence of anxiety and depression in people with chronic venous ulceration. This chapter discusses the design and findings of Phase I of the thesis – a prevalence study across nine NHS Trusts in the North West of England – aiming to provide an answer about the scale of the problem and the burden of care it represents.

The aim of Phase I of this study, reported in this chapter is:

- To determine the prevalence of anxiety and depression in people with chronic venous ulceration across nine NHS Trusts in the North West of England.

Objectives:

To ascertain the relationship between anxiety and depression and the following:

a) Mobility,
b) Living alone,
c) Pain,
d) Exudate,
e) Odour,
f) Duration of ulceration.

3.1.1: Recruitment of Trusts

Clinical Nurse Specialists (CNS) in either leg ulcer management or tissue viability in the North West of England were contacted by telephone to establish if they might be interested in assisting with the project. An important issue in negotiating access, both to organisations and to participants, is the development of a relationship with a *gatekeeper*. Burgess (1984) defines gatekeepers as:

> *"[T]hose individuals in an organisation that have the power to grant or withhold access to people or situations for the purposes of research."*
>
> (Burgess, 1984, p.48)

Having worked as a CNS helped the author with the formation of an informal network of colleagues who were able to provide information on the trusted gatekeeper within Trusts. A meeting was consequently arranged with the selected individual to discuss the study in more detail and to set up training for the nurses who would assist with data collection.

Subsequently, Clinical Nurse Specialists, lead clinicians in leg ulcer management or tissue viability working in five Trusts were approached and agreed to take part in the study. This number of areas was based on discussion with the CNS as to the number of patients required, and their ability to recruit. Unfortunately, at the eleventh hour the line manager of the CNS in one Trust decided it would not be possible for that Trust to support the study and they withdrew.

3.1.2: Sample size

Sample size calculation was based on the depression rates reported in the literature for all adults in the general population, as well as for those adults with a physical illness. Depression in people aged 65 and over has a prevalence of 10 – 16% (Audit Commission, 2000). This figure may be doubled for those older people with physical health problems (Banerjee *et al.*, 1996). If 20% of patients with a chronic ulcer are also found to be depressed, then, according to a power calculation using NQuery Advisor 4.0, a total of 246 people were required to give 95% power of detecting depression in patients with chronic ulceration

3.1.3: Access to Trusts

With regard to formal access arrangements, the research and development (R&D) committee at each of the four remaining Trusts (after one withdrew) within the region was contacted by letter to inform them about the proposed study (Appendix 5). At this time, many R&D committees were just acquainting themselves with the new arrangements introduced by the research governance framework in 2001 and revised in 2005 (DoH, 2001, 2001 / 2005). This document sets out the standards and protocols required for any research undertaken within health or social care settings. The response to the letter varied from Trust to Trust, some simply documenting receipt of the letter, some requiring completion of extra local documentation and four (from the nine NHS Trusts involved in the study), requiring application for an honorary contract. Section 3.1.6 details the recruitment of the NHS Trusts and clarifies the shift from four to nine as referred to in this paragraph.

3.1.4: Governance

Research Governance is about improving standards and protecting patients. It includes obtaining informed consent; ensuring proper ethical approval; ensuring clear responsibilities for partners in research collaboration; and identifying clear lines of accountability. The importance of these areas has been magnified in light of audit and research problems at the UK Bristol United Hospitals (Kennedy, 2000), and Alder Hey Children's Hospital Liverpool (House of Commons, 2001), which resulted in recommendations for governance of research in the report *An organisation with a memory* (DoH, 2000). This highlighted the need for risk management strategies and a culture of learning from previous errors, essential to ensure that the public can have confidence in, and benefit from, quality research in health and social care.

3.1.5: Ethical considerations

All research studies conducted within the NHS, which include human subjects, are required to meet certain ethical requirements (Tierney, 1995), and this is reflected in the fact that attention to ethics forms one of the criteria for determining rigour in both quantitative and qualitative studies. Details of the ethical considerations that require attention can be found in many sources, including the national web site for ethics committees: www.corec.org.uk. In summary, these require that:

- Study participants should be protected from harm, and any potential risks to those involved must be outweighed by the likely benefits of the study (non-maleficence and beneficence).
- Potential participants should be given sufficient information, in an appropriate format, to judge whether or not they wish to take part in the study (informed consent). Participation in the study should be voluntary and attempts should not be made to coerce individuals to take part.
- The confidentiality of research participants must be maintained. That is, researchers must not disclose any information that links data to an individual study participant or site.

The core ethical principles of respect for autonomy, prevention of harm, promotion of benefit and justice must be addressed in the design and conduct of all research. In reviewing a proposal, a research ethics committee needs to form a view on the relative risks and benefits of the research, but researchers must also carefully consider this balance at the earlier stage of developing the research protocol, as part of their duty of care to participants.

The data collection tools were, at this stage, being piloted in the researcher's own area following ethical approval, with ten people. This proved to be a useful exercise not only in subsequent modification of these tools, but also in preparation for Multi Centre Ethical Approval, sought via the Central Office for Research Ethics Committees (COREC). One particular aspect, which was raised by the ethics committee, was the use of "depression" on the information sheets. The ethics committee felt that "distress" is more readily accepted and less embarrassing than a psychological or psychiatric term and encompasses a range of emotions along a continuum from sadness and vulnerability to disabling depression. Hence, after attending the local research ethics committee meeting with one of my supervisors, the information sheets were amended to reflect this discussion (Appendix 2).

Information regarding the study was also sent to each of the local research ethics committees (LREC) responsible for the areas taking part in the study. Five of the NHS Trusts appeared to be grappling with the new research governance framework and insisted that the research proposal went to their full ethics committee meetings, despite having MREC approval from North West MREC in January 2003.

Respect for the integrity and autonomy of the individual underpins the requirement for informed consent of research participants. Consent must be properly obtained and documented and requires that:

a) The person is informed of the nature of the research, including likely risks and benefits.
b) The person is competent to make the decision.
c) The decision is made freely and without coercion.

Maintenance of confidentiality and compliance with the relevant Privacy / Data Protection Acts (1998) were to be emphasised to all study participants. Participation in the study was entirely voluntary and written consent was sought. All data were treated with the strictest confidence, with paper copies of patient information kept in a locked cupboard within a locked room at the University of Liverpool, and identifying information kept separate from coded data collection forms. Computerised data is password protected on a computer at the University of Liverpool.

3.1.6: Preparation for data collection

The preparation of the sites for data collection was begun in conjunction with ethical and research governance applications in an attempt to ensure that progress of the study was as unhindered as possible.

Participating nurses attended a training programme, delivered by the researcher, on the rationale for the study, eligibility, recruitment procedure, and data collection (completion of study documentation). This was to ensure that potential participants were given enough information which was presented to them in a clear, accurate and comprehensive manner to enable them to make an informed decision as to whether to take part or not. It was emphasised that people must be given enough time (at least 24 hours) to consider the information and discuss it if they wished with family and friends. It was important that in no way would people feel either coerced or that refusal would jeopardize their care in any way. Research has shown that in some cases, where individuals have been provided with detailed information and been given time to digest it, they have opted not to take part in studies (Weston, Hannah & Downes, 1997). Equally, the training discussed the necessity of capacity on the part of the individual to give consent. The training also included a lecture on a topic chosen by the nurse specialist in each area. This was to act as an incentive to encourage community nurses and / or clinic nurses to attend the training session and become involved in the study.

As data collection commenced, it was soon evident, that the original four Trusts would not achieve their individual target of 50 patients, resulting in a subsequent shortfall. A decision was taken to approach four more CNS in a further four Trusts following the same approach highlighted earlier. This in itself was a protracted process: the initial meeting could take weeks to set up, owing to commitments of the nurse specialist. The time that training could be delivered was also problematic, since this involved booking a suitable venue and giving nurses enough notice to enable them to attend. Despite the lead nurse within each Trust being contacted every two to three weeks, recruitment nonetheless remained problematic, and was still not on time, with a delay of six months from the initial target. A final CNS was approached in a further Trust to see if they could assist. However, within this final Trust the process of ethical approval and research governance approval took almost five months, significantly affecting the amount of time possible for the nurses to recruit as the first phase of data collection was then ending.

Data were collected over a ten-month period (from May 2003 until March 2004). Time constraints on the study, as well as the tail off in recruitment, from the Trusts assisted in this decision. However, as already stated, some Trusts were only recruited six months into the study and it was necessary to allow them a minimum of three to four months in which to collect some data.

3.1.7: Data Collection

3.1.7.1: Inclusion / Exclusion Criteria

Inclusion:

- Individuals aged over 18 years.
- Active ulceration of a minimum of three months duration. Leg ulcers are considered to be chronic wounds because they can take weeks or months to heal due to substantial loss of the top layers of the skin (epidermis and dermis). This study is interested in people with chronic venous ulceration.
- The primary cause of ulceration is chronic venous disease determined by the nurse in charge of the patient's care based on a thorough assessment which includes history, clinical appearance and an ABPI to rule out arterial insufficiency (RCN guidelines, 1998). The individual must have an Ankle Brachial Pressure Index (ABPI) of ≥ 0.8, which indicates that arterial insufficiency is not a feature and the ulcer can be regarded as venous.
- Mixed venous and arterial ulcer where the ulcers are predominantly venous combined with detectable arterial impairment; the ABPI is generally 0.6 – 0.9 (Nelzen *et al.*, 1991b).

Exclusion:

- Individual unwilling / unable to give consent.
- Rheumatoid arthritis (RA).

- Diabetes.
- Ulcer caused by a medical condition other than venous insufficiency, e.g. malignancy.

The medical conditions cited above, may result in people scoring as depressed, as opposed to a consequence of leg ulceration. Major depressive disorder affects between 13 – 17% of patients with RA (Dickens *et al.*, 2002); whilst between 15 – 30% of diabetes patients meet the criteria for depression (Anderson *et al.*, 2000).

3.1.8: Measurement of ankle brachial pressure index (ABPI)

A Doppler-determined ABPI was obtained from clinical records for each individual. This is information routinely obtained for all people receiving care for a leg ulcer in the UK. All nurses use a non-directional Doppler with an 8 MHz probe to record arm (brachial) and ankle pressure measurements according to the method described by Vowden *et al.* (1996). People were considered eligible if they had an ABPI of 0.6 or greater. An ABPI of 1.0 indicates that the limb at the ankle is fully perfused. Including individuals with an ABPI down to 0.6 reflects the fact people with leg ulcers may have some degree of vascular impairment; however these ulcers should still heal with conservative treatment.

No special arrangements were made for subjects for whom English was not their first language. This is because there is limited epidemiological evidence describing the prevalence of venous ulceration by race. Franks, Morton *et al.* (1997), report a lower prevalence of ulceration in an area of west London with a large south Asian population, than would be expected from the overall prevalence described previously (Callam *et al.*, 1985). This may be due to either a lower actual prevalence or to under-reporting. It was anticipated that the overwhelming majority of individuals presenting at the clinical sites would have English as their first language. The clinical sites confirmed this.

The clinic, or community, nurse attending to the patient identified potential individuals and supplied them with a study information sheet. People were given a minimum of 24 hours to read this and consider their participation, before completing a written consent form. Baseline data were obtained at this point via a baseline questionnaire covering clinical and demographic characteristics outlined in section 3.1.9.

3.1.9: Data collection tools

3.1.9.1: Baseline questionnaire

Data were collected on the following aspects of each individual in order to gain an overall picture of this group, and to allow for descriptive analysis of the individuals. This also reflects the information, which would be collected at the initial assessment of an individual with a leg ulcer. Table 3.1 shows the information collected in the first two sections of the questionnaire.

Table 3.1: Demographic and medical history of the individuals

Demographic details	**Medical history (Yes / No)**
Gender	History of DVT
Age and date of birth	Stroke
Marital status	Hypertension
Living status	Heart failure
Occupation / previous occupation	Osteoarthritis
	Depression
	Other (specify)

The next section asked specific details regarding:

1. Mobility.

- Fully mobile (walks unaided),
- Immobile (cannot walk),
- Limited mobility (with aid),
- Housebound (Yes / No).

2. Ulcer history.

- Date of 1st episode,

- Date current episode,
- Number of episodes,
- Number of ulcers.

3. Pain.

- Pain level scored from 0 – 4,
- Continuous pain,
- Intermittent pain,
- Triggers to pain.

Pain was measured on a combination of the numerical rating scale from zero (no pain) to four (overwhelming pain) and the verbal rating scale using “none”, “mild”, “moderate”, “severe” and “overwhelming” (MEP, 2004). These are accepted methods of pain scoring in clinical areas (Closs, Barr, Briggs *et al.*, 2004). The questionnaire asked about triggers to pain, such as a change of dressing or when the legs are in a dependent position. People were also asked for information regarding the chronicity of ulceration in order to determine the duration, not only of the current episode, but also of ulceration per se, the number of episodes of ulceration and the number of ulcers people had endured. For some individuals on their first episode of ulceration we would expect the two dates – date of 1st episode and date of current episode – to be the same.

The final section asked for the size of ulceration as determined by the largest width and the largest length in centimetres. In practice, this is usually determined by counting the number of 1cm squares, covered by an ulcer on a grid.

Ulcer size can help to describe the severity of ulceration since this is a recognised risk factor for ulcer healing (Margolis *et al.*, 2000). With regard to odour, the question asked if there was “none”, “some” or “offensive” odour present. The information ultimately recorded is normally a combination of the subjective opinion of the nurse, together with information supplied by the individual as to degree of odour noted between dressing changes.

Similarly, data collected on levels of exudate is subjective and usually described as "light" (or minimal), "moderate" or "heavy" (Thomas, 1997). Whilst this is a subjective and imprecise measure it remains the accepted way of describing exudate levels. Most clinicians would recognise the very heavily-exuding wound which requires dressing changes daily, if not more frequently; and also the dry wound is not without problems. The difficulty comes in estimating and differentiating heavy and moderate levels of exudate.

3.1.9.2: Hospital Anxiety and Depression Scale (HADS)

People in each Trust who fitted the eligibility criteria and consented to take part were given the Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983. See section 2.9.1 and Appendix 3), to either complete at the time of their leg ulcer treatment (in the clinic or at home) or to take away and complete when convenient. The individual would then return the form, in the sealed envelope provided, to the nurse who would then forward the HADS, together with the completed baseline questionnaire, to the University of Liverpool.

<u>Participants:</u>

- Completed HADS.

<u>Nurses:</u>

- Completed baseline questionnaire.
- Collected HADS from participant.
- Returned baseline questionnaire and HADS to University.

The HADS comprises seven questions relating to depression and seven to anxiety with the questions divided into two subscales. The scale does not include any items that could relate to both physical illness and emotional distress, for example insomnia. The seven items relating to depression are based on the concept of anhedonia – the complete loss of enjoyment. Each question has four possible responses and the score is determined on scales of 0 – 3: the most negative response receiving the highest score.

When the HADS scale is used in research, the cut-off point for a case may be either the upper or lower end of the borderline range. In this study, as in the study of chronic wounds by Cole-King and Harding (2001), a cut-off of nine was used for both subscales. This cut-off will provide a low proportion of false-negative results: any choice of a cut-off is a compromise between sensitivity and specificity. Sensitivity refers to the number of people scoring at the chosen threshold or above who are actually true cases, whilst the specificity refers to the number of people scoring below the threshold who were true non-cases. Screening tools should be sensitive, so that a high proportion of those who may be depressed are identified for further assessment, while having acceptable specificity in order not to produce too many false positives.

3.2: Data analysis

All data obtained from the questionnaire and HADS were entered onto a database in SPSS^{TM} for Windows version 12, by the researcher. The data were then cleaned and analysed using descriptive statistics to describe demographic and diagnostic data. Cross tabulations were performed using the Chi-Square test to show the degree of association between two or more non-continuous variables (such as sex), or continuous variables, which have been categorised (e.g. age in years to age groups). Using data obtained from the baseline questionnaire completed by the nurse, the chi-square test for independence was used to determine if there were any associations between any of the following variables and anxiety and depression. All tests were two-tailed and statistical probability was set at the customary level of $p=0.05$ (5%).

- Mobility.
- Living alone.
- Pain.
- Exudate.

- Odour.
- Duration of ulceration.

3.3: Results

3.3.1: Populations from which sample derived

Patients were recruited from eight Primary Care Trusts and one Acute Trust in the North West of England within the areas of Greater Manchester (Bolton, Oldham, Rochdale, Stockport, Ashton-under-Lyne, Wigan), Cheshire (Countess of Chester Hospital, Nantwich) and Merseyside (Southport). Table 3.2 presents the population served by each Trust based on data available from each Trust and the 2001 Census.

Table 3.2: Adult population totals within each Trust

Trust	**Total Population**	**Male**	**Female**
Bolton	261,035	127,099	133,936
Cheshire	111, 006	54,372	56,634
Countess of Chester	118,207	56,966	61,241
Oldham	217,393	105,094	112,299
Rochdale	205,233	99,650	105,583
Stockport	284,544	137,099	147,237
Southport	118,565	56,963	61,597
Tameside	213,045	103,366	109,679
Wigan	301,422	147,857	153,565

A total of 190 patients were recruited to the study between May 2003 and March 2004 from nine areas across the North West of England (Table 3.3). This represents 77% of the target.

Table 3.3: Areas involved and number of individuals recruited per area

Trust	**No of people (% of total)**	**Male**	**Female**
Bolton	37 (20%)	20	17
Cheshire	18 (10%)	6	12
Countess of Chester	17 (9%)	6	11
Oldham	19 (10%)	12	7
Rochdale	6 (3%)	4	2
Stockport	44 (23%)	22	22
Southport	10 (5%)	8	2
Tameside	14 (7%)	9	5
Wigan	25 (13%)	14	11
Total	***190***	***101***	***89***

3.3.2: Demographic characteristics

The sample consisted of a total of 101 (53%) males, 89 (47%) females with a median age of 69 years (range 24 – 96). The majority (156; 82%) were aged ≥65 years, with 34 (18%) aged ≤64 years (Table 3.4). These individuals came from nine Trusts in the north west of England that are a mix of rural, town centre and seaside areas (See Figure 3.1). There were a total of 67 (35%) who lived alone, 31 males (16%) and 36 females (19%).

Table 3.4: Demographic characteristics

	Individuals	%	
	N 190	%	**Median**
Age (Years)			69 (IQR: 59 – 79)
15 – 24 Years	1	0.5%	
25 – 34 Years	2	1%	
35 – 44 Years	15	8%	
45 – 54 Years	16	8%	
55 – 64 Years	41	22%	
65 – 74 Years	45	24%	
75 – 84 Years	53	28%	
85 – 94 Years	16	8%	
95 – 104 Years	1	0.5%	
Gender			
Male	101	53%	
Female	89	47%	
Marital Status			
Single (never married)	28	15%	
Married	94	50%	
Widowed	57	30%	
Divorced	11	6%	
Living Status			
Lives alone	67	35%	
Male	31	16%	
Female	36	19%	
With spouse	93	49%	
Relative / Companion	22	12%	
Residential setting	8	4%	

N.B. % may not exactly total 100% due to rounding errors.

Figure 3.1 Map of areas in which Trusts located

KEY:

Place names in red and underlined denote areas in which Trusts involved in the research are located.

The sample consisted of 107 people who were retired and stated their previous occupation (seven retired people did not provide their previous occupation), 63 people who were working (six individuals in this group failed to provide information), of the remaining 13 people, four were on benefits with the remaining nine stating they were housewives.

3.3.3: Medical history

The questionnaire asked seven questions about participant's medical history. As can be seen from Table 3.5 this totals more than 100%, as some of the participants had more than one co-morbid condition. There were 10% of individuals with other medical conditions such as fracture and obesity. The medical history of individuals also tended to reflect their age.

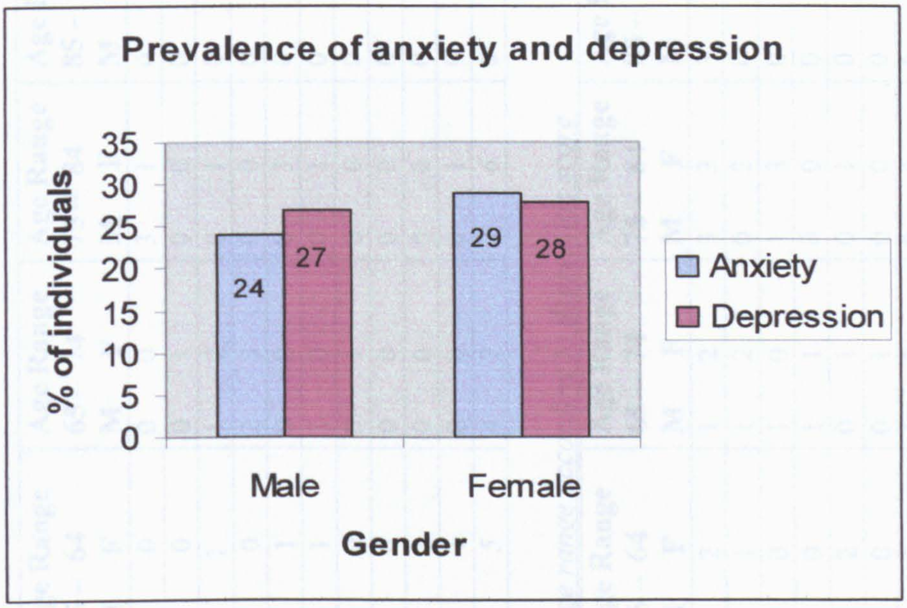
Table 3.5: Medical history

Medical History	**Number**	**Percentage**
Deep vein thrombosis	48	25
Stroke	11	6
Hypertension	66	35
Heart disease	15	8
History of depression	19	10
Osteoarthritis	56	30

3.3.4: Anxiety and depression

For both the anxiety and depression subscales of HADS, a cut-off of nine was used as indicative of "caseness". A total of 52 people (27%) scored as depressed, whilst 50 individuals (26%) scored as anxious; this comprised of 24 of the total males (24%) scoring as anxious and 26 of the total females (29%), whilst 27 males (27%) scored as depressed and 25 females (28%) (Figure 3.2) (Jones, Barr, Robinson *et al.*, 2006). When scores for anxiety and scores for depression were explored together 34 people (18%), who scored as depressed, also scored as anxious. Features of anxiety often coexist with depression and in practice many, but not all, patients have both (Shorter & Tyrer, 2003).

Figure 3.2: Anxiety and depression



The numbers of males and females reaching "caseness" in each age range for anxiety and depression are depicted in Tables 3.6 and 3.7. Zigmond and Snaith (1994), recommended that raw scores of between eight and ten identify mild cases, 11 – 15 moderate cases and 16 or above severe cases, for each dimension. As can be seen from the tables, whilst 44 scored as mild cases of depression, 17 scored as moderate and one as severe. Whereas for anxiety only 12 were in the mild category compared to 32 with a moderate score and six severe.

Table 3.6 Number of males and females reaching "caseness" in each age range according to anxiety score

Anxiety score	**No of Males**	**No of Females**	**Age Range 35 – 44**		**Age Range 45 – 54**		**Age Range 55 – 64**		**Age Range 65 – 74**		**Age Range 75 – 84**		**Age Range 85 – 94**		**Total**
			M	**F**	**M**	**F**	**M**	**F**	**M**	**F**	**M**	**F**	**M**	**F**	
9	7	3	1	1	2	0	1	0	0	0	3	1	0	1	*10*
10	1	1	0	0	0	0	1	0	0	1	0	0	0	0	*2*
11	4	5	1	0	0	0	1	1	1	2	0	1	0	1	*9*
12	6	5	1	0	2	0	1	0	2	3	0	0	0	2	*11*
13	1	4	0	0	0	0	1	1	0	0	0	3	0	0	*5*
14	2	3	0	1	0	0	1	1	1	0	0	1	0	0	*5*
15	1	1	0	0	1	0	0	0	0	1	0	0	0	0	*2*
16	2	0	0	0	0	0	2	0	0	0	0	0	0	0	*2*
17	0	2	0	0	0	1	0	1	0	0	0	0	0	0	*2*
19	0	2	0	0	0	0	0	1	0	0	0	1	0	0	*2*
Total	*24*	*26*	*3*	*2*	*5*	*1*	*8*	*5*	*4*	*7*	*3*	*6*	*0*	*3*	*50*

Table 3.7 Number of males and females reaching "caseness" in each age range according to depression score

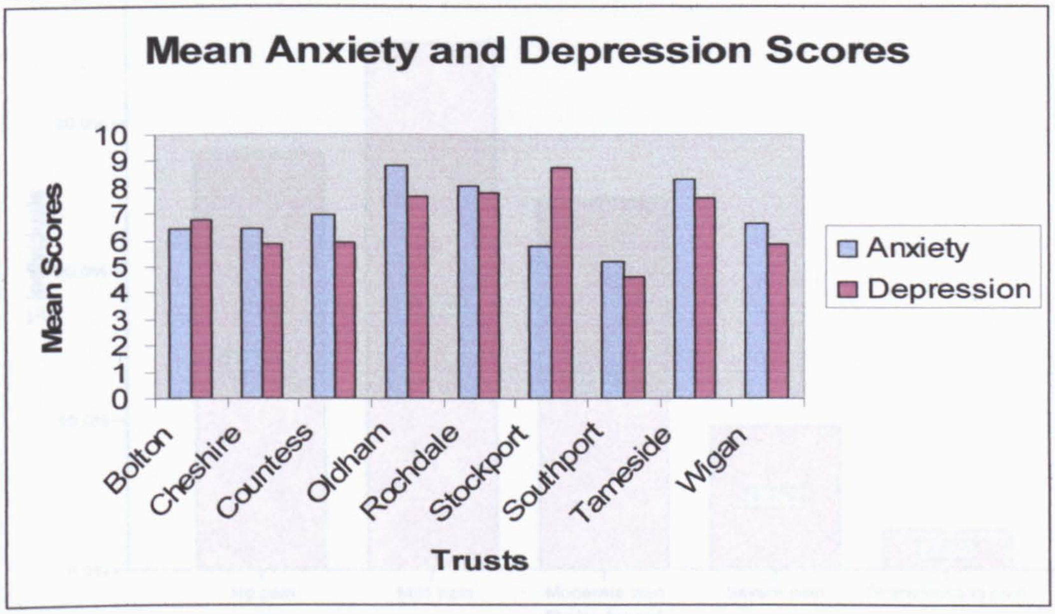
Depression score	**No of Males**	**No of Females**	**Age Range 35 – 44**		**Age Range 45 – 54**		**Age Range 55 – 64**		**Age Range 65 – 74**		**Age Range 75 – 84**		**Age Range 85 – 94**		**Total**
			M	**F**	**M**	**F**	**M**	**F**	**M**	**F**	**M**	**F**	**M**	**F**	
9	11	11	1	1	2	2	1	2	1	2	3	3	3	1	*22*
10	7	5	2	0	2	0	2	1	1	2	0	2	0	0	*12*
11	3	3	0	0	1	0	0	0	1	0	1	3	0	0	*6*
12	3	1	0	0	1	0	1	0	1	1	0	0	0	0	*4*
13	1	4	0	0	0	0	1	2	0	1	0	1	0	0	*5*
14	0	1	0	0	0	0	0	0	0	1	0	0	0	0	*1*
15	1	0	0	0	0	0	0	0	1	0	0	0	0	0	*1*
16	1	0	0	0	0	0	0	0	0	0	0	0	1	0	*1*
Total	*27*	*25*	*3*	*1*	*6*	*2*	*5*	*5*	*5*	*7*	*4*	*9*	*4*	*1*	*52*

The mean scores for each NHS Trust involved in the study are depicted in Table 3.8 and also in Figure 3.3.

Table 3.8: Mean anxiety and depression scores by area

Area	**Number**	**Mean Anxiety Score (SD)**	**Mean Depression Score (SD)**
Bolton	37	6.43 (5.03)	6.78 (5.78)
Cheshire	18	6.44 (3.98)	5.83 (3.77)
Countess	17	6.98 (5.46)	5.94 (3.91)
Oldham	19	8.84 (3.54)	7.64 (2.88)
Rochdale	6	8.04 (4.81)	7.76 (3.42)
Stockport	44	5.75 (3.80)	8.78 (3.79)
Southport	10	5.20 (3.70)	4.60 (2.20)
Tameside	14	8.29 (4.05)	7.59 (4.17)
Wigan	25	6.65 (4.25)	5.87 (3.67)

Figure 3.3: Mean anxiety and depression scores



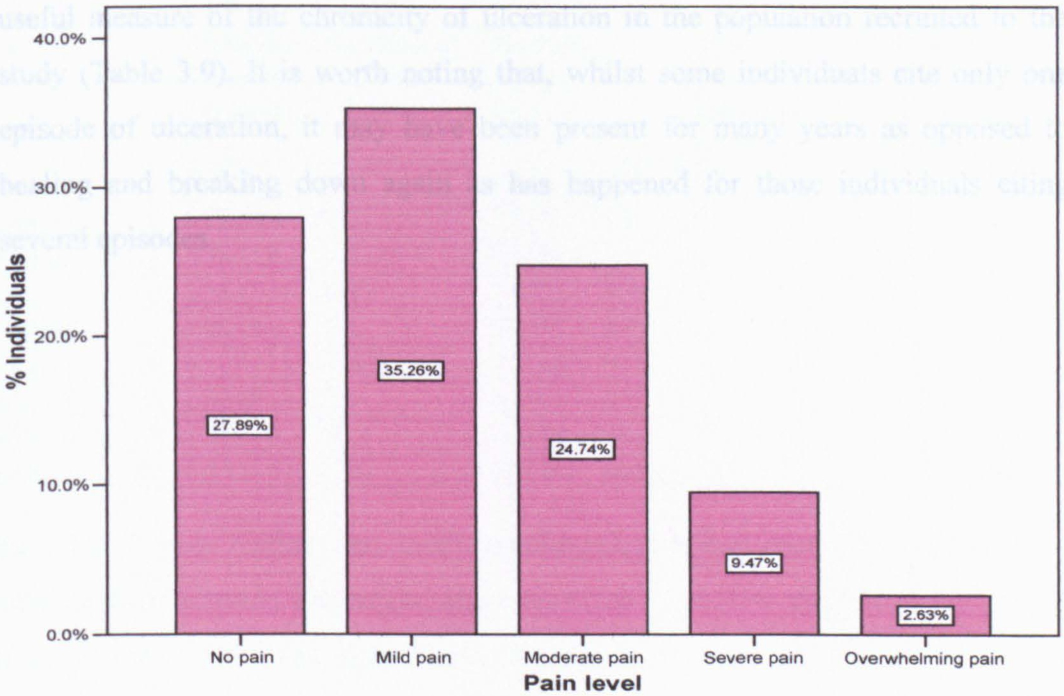
3.3.5: Level of mobility

There were 146 people (77%) who stated that they were fully mobile, whilst a mobility deficit was present in 47 (23%), who stated that they required some form of aid to assist them with walking.

3.3.6: Level of ulcer pain

This section relates to pain associated with leg ulceration; only 53 of sample members (28%) said they had no pain at all, whilst 67 (35%) complained of mild pain. The remaining 70 people (37%) complained of moderate to overwhelming pain (Figure 3.4). Therefore, a total of 73% of individuals suffered some degree of pain at some time of the day, of which 40 (57%) complained of pain during dressing change, with the remainder experiencing pain at night time and / or dependent on the position of the leg. For 46% of people pain was intermittent, however, for 14% it was something they had to live with constantly.

Figure 3.4: Level of pain experienced by individuals



3.3.7: Leg ulceration

This section was dedicated to building a picture of ulceration endured by the individuals, with 119 (63%) having one ulcer and 71 (37%) having more than one ulcer. There were 27 participants (14%) who had ulceration on both legs.

3.3.7.1: Episodes of ulceration

For many people, leg ulceration appeared to be a cycle of healing followed by breakdown, with some people enduring up to 20 - 30 episodes of ulceration (See Figure 3.5), with a median duration of 55.5 months (range 3 – 642 months; IQR 23 – 125). The number of ulcer episodes ranged from one to 30 with a median of three (IQR 5 – 28). People in Wigan and Bolton reported fewer episodes of ulceration, (mean of two episodes), with participants in Stockport having the highest mean number of episodes (five). Accurate recall of the exact number of previous episodes of ulceration is less likely when a person has had a large number of ulcer episodes. Hence the median number of episodes in each area is a more useful measure of the chronicity of ulceration in the population recruited to the study (Table 3.9). It is worth noting that, whilst some individuals cite only one episode of ulceration, it may have been present for many years as opposed to healing and breaking down again as has happened for those individuals citing several episodes.

Figure 3.5: Number of episodes of ulceration

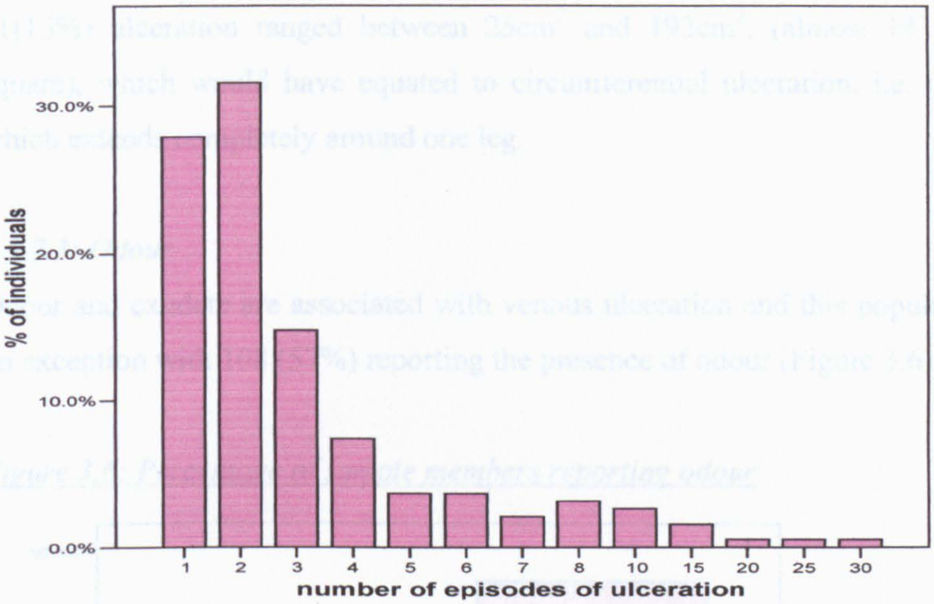


Table 3.9: Age and ulcer characteristics by area

Area	n	Median Duration of ulceration months (range)	Median Age yrs (range)	Median Number of episodes (range)	Median Size of ulceration (range)
Bolton	37	26 (3 – 435)	65 (24 – 89)	1 (1 – 8)	4 (1 – 192)
Cheshire	18	73 (4 – 459)	79 (41 – 93)	2 (1 – 8)	16 (4 – 100)
Countess	17	76 (18 – 590)	69 (40 – 91)	2 (1 – 15)	18 (1 – 100)
Oldham	19	38 (13 – 483)	78 (35 – 90)	2 (1 – 6)	5 (1 – 40)
Rochdale	6	80 (8 – 197)	58 (35 – 84)	2 (1 – 10)	13 (1 – 80)
Stockport	44	107 (12 – 642)	71 (36 – 91)	3 (1 – 30)	5 (1 – 25)
Southport	10	64 (8 – 259)	64 (41 – 87)	2 (1 – 7)	5 (2 – 36)
Tameside	14	77 (18 – 387)	72 (48 – 96)	3 (1 – 8)	10 (4 – 80)
Wigan	25	34 (10 – 286)	62 (26 – 85)	2 (1 – 5)	5 (1 – 60)

The ulcer history within this study would support that these individuals are suffering from chronic ulceration. More than 70% had their ulcer for more than six months and 25% longer than 24 months.

3.3.7.2: Area of largest ulcer

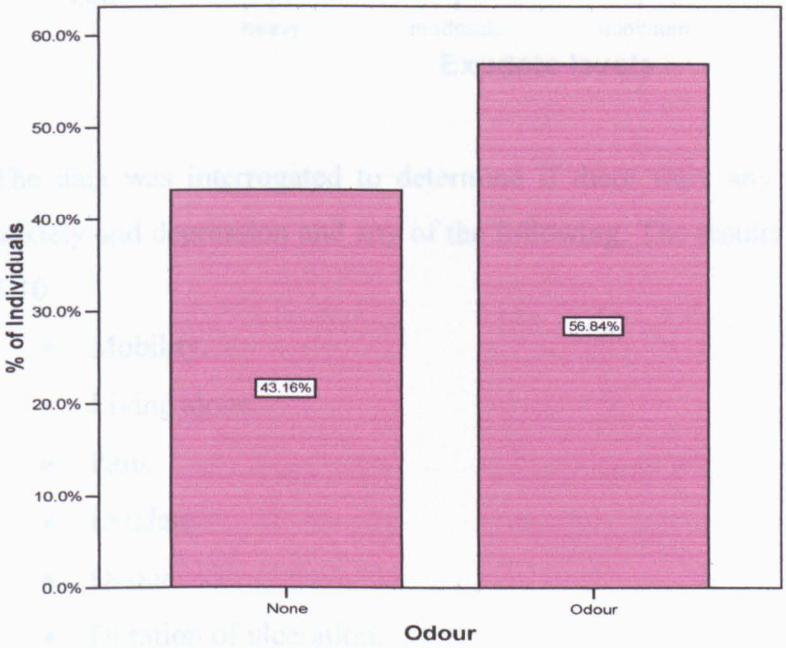
There was considerable variation in the size of ulcers ranging from $1cm^2$ to $192cm^2$ with a median size of $6cm^2$. 105 individuals (55%) had ulcers between

1cm^2 and 6.5cm^2; 54 (28%) had ulcers between 7cm^2 and 24.5cm^2. However, for 31(16%) ulceration ranged between 25cm^2 and 192cm^2, (almost 14 by 14cm square), which would have equated to circumferential ulceration, i.e. ulceration which extends completely around one leg.

3.3.7.3: Odour

Odour and exudate are associated with venous ulceration and this population was no exception with 108 (57%) reporting the presence of odour (Figure 3.6).

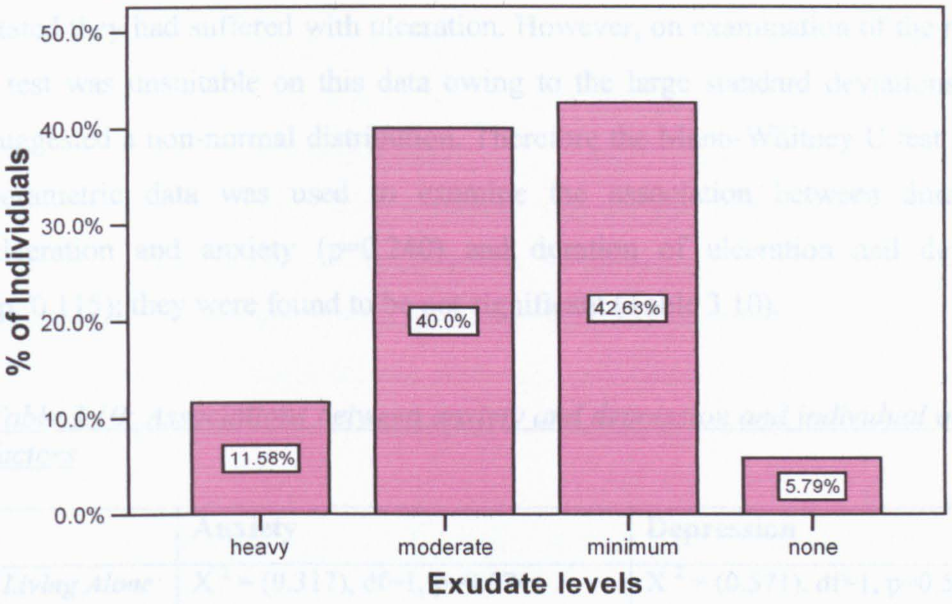
Figure 3.6: Percentage of sample members reporting odour



3.3.7.4: Exudate

There were only 6% of individuals (n=11) who had no exudate from their ulcer. For 22 (12%) the exudate level was heavy, whilst 157 individuals (83%) reported minimum to moderate amounts of exudate from their ulcers (Figure 3.7).

Figure 3.7: Exudate levels



The data was interrogated to determine if there were any associations between anxiety and depression and any of the following. The results are depicted in Table 3.10

- Mobility.
- Living alone.
- Pain.
- Exudate.
- Odour.
- Duration of ulceration.

Using data obtained from the first questionnaire, the Pearson chi-square test for independence showed there was no association between anxiety and living alone (p=0.574) or depression and living alone (p=0.571), or between mobility and anxiety (p=0.182) and depression and mobility (p=0.056). However, there was a significant association between anxiety and odour (p=<0.001) and depression and odour (p=0.002) and likewise between pain and anxiety (p=<0.001) and depression and pain (p=0.002). There was no association between exudate and anxiety (p=0.194) or depression and exudate (p=0.126). The data for duration of ulceration was continuous, referring to the number of months that an individual stated they had suffered with ulceration. However, on examination of the means, a t test was unsuitable on this data owing to the large standard deviations, which suggested a non-normal distribution. Therefore the Mann-Whitney U test for non-parametric data was used to examine the association between duration of ulceration and anxiety ($p=0.240$) and duration of ulceration and depression ($p=0.115$); they were found to be not significant (Table 3.10).

Table 3.10: Associations between anxiety and depression and individual and ulcer factors

	Anxiety	**Depression**
Living Alone	$X^2 = (0.317)$, $df=1$, $p=0.574$	$X^2 = (0.571)$, $df=1$, $p=0.571$
Mobility	$X^2 = (1.785)$, $df = 1$, $p = 0.182$	$X^2 = (3.657)$, $df=1$, $p=0.056$
Pain	$X^2 = (19.016)$, $df=3$, $p=<0.001$	$X^2 = (14.952)$, $df=3$, $p=0.002$
Odour	$X^2 = (19.507)$, $df=1$, $p=<0.001$	$X^2 = (25.737)$, $df=1$, $p=<0.001$
Duration	$Z = 1.176$, $p=0.240$	$Z = 1.574$, $p=0.115$
Exudate	$X^2 = (1.825)$, $df=1$, $p=0.194$	$X^2 = (2.367)$, $df=1$, $p=0.126$

3.4: Discussion

This section will focus on the major findings from Phase I of the study, but much of the discussion will be provided in the last chapter of this thesis, which also draws on the findings from Phase II.

3.4.1: Prevalence of anxiety and depression

The results of this study revealed high levels of anxiety and depression among individuals with chronic venous ulceration. A total of 52 (27%) scored as depressed whilst 50 (26%) scored as anxious, compared with (15% – 30%) of the general population (Hotopf *et al.*, 1996) as discussed in section 2.3. Affective disorders such as depression have been reported to occur in as many as 30% of elderly patients with chronic illnesses (Katon and Sullivan, 1990), with poor physical health cited as the number one risk factor for depression in later life.

The mean score obtained on the depression subscale of HADS (HADS-D) was higher than other reported samples of patients with breast cancer (Rodgers, Martin, Morse *et al.*, 2005), and renal disease (Martin, 1999), and similar to coronary heart disease (Barth & Martin, 2005) but lower than for psychiatric patients (Bedford, Grant & de Pauw, 1997). Previous reviews of prevalence rates (Herrmann, 1997) suggest that patients with chronic pain (including fibromyalgia and back pain) had a higher prevalence of anxiety and depression than patients with oncology, cardiac and neurological disorders. Comparisons are summarised in Table 3.11.

Table 3.11: Comparison of HADS anxiety and depression subscale mean score with other samples

Sample	**HADS Anxiety**	**HADS Depression**
Current sample of leg ulcer patients	*6.27*	*5.40*
Non clinical UK normative sample: Crawford (2001)	6.14	3.68
Musculoskeletal patients: Pallant and Bailey (2005)	8.14	9.26
Coronary heart disease patients: Barth *et al.*, (2005)	6.14	5.41
End-stage renal patients: Martin (1999)	6.90	5.20
Breast cancer patients: Rodgers *et al.*, (2005)	7.43	3.25
Chronic Obstructive Pulmonary disease rehab patients: Withers *et al.*,(1999)	7.10	5.80
Psychiatric patients: Bedford *et al.*, (1997)	13.90	9.90

3.4.2: Recruitment

Initially five clinical nurse specialists had agreed to take part in the study. Unfortunately in one NHS Trust the manager believed the time it would take nurses to recruit individuals was likely to have major implications on workload, despite assurances to the contrary based on the pilot study. In this instance, it would appear that the selected person was not the gatekeeper for this particular Trust and unfortunately were unable to recruit to the study.

3.4.3: Ethics

The heterogeneity of local ethics forms highlights the fragmented way in which the governance framework has been implemented, with variations in application requirements across NHS Trusts. The overall impact of applying for research governance in a multi-centred study was considerable in terms of time at the beginning of the research project and delayed the start of data collection by almost six months.

3.4.4: Demographic profile

The demographic profile of the sample of individuals in this study reflects the prevalence of ulceration in the adult population in the UK with 82% (n=156) aged over 55. There were more males than females in this study which, perhaps, contradicts the national profiles of a higher prevalence in females than males (Lees & Lambert, 1992). However, a dual case-control study by Scott *et al.* (1995), in America found that patients with chronic venous insufficiency were more frequently older males. Arguably this present study was interested in people with chronic leg ulceration and the fact that there were more males adds to the view that generally males are more likely to self-care for longer (Nelzen, 1997), seeking help much later in their illness trajectory than females, and therefore one might expect that there would be more males in the "chronic" population. This resonates with previous studies which supports the theory that men are reticent in seeking help from health professionals compared to females (Cook, Morris, Walker *et al.*, 1990;Galdas, Cheater & Marshall, 2005).

3.4.5: Ulcer history

While 53 individuals (28%) were experiencing their first ulcer, more than 65% reported having experienced between two and ten episodes, with four having more than 15 and two people having more than 25 episodes. A very similar picture is found within studies by Callam *et al.* (1985), who found that 28% had experienced more than ten episodes of ulceration. Nelzen *et al.* (1991b), reported 40% experiencing their first ulcer and 33% having had more than four episodes. It is worth noting that, although some people may only have one cited episode of ulceration, the ulcer may have remained open for many years, as opposed to healing and breaking down again for those individuals with several episodes. Moffatt (2001b,) also found that 60% of patients in her study reported having between two and ten episodes.

In this sample, 35% of people were either working or had worked in occupations which "may" have been a predisposing factor in the development of their ulceration, due to prolonged periods of standing: 26 were factory workers (14%); 19 cooks / chefs (10%); 18 hairdressers (9%); 23 police and nurses (12%) (Fowkes, Lee, Evans *et al.*, 2001;Tuchsen, Krause, Hannerz *et al.*, 2000). People in occupations which involve prolonged standing in warm conditions are at increased risk of varicose veins (Abramson, Hopp & Epstein, 1981), exposing the superficial venous network to higher pressures than normal (up to 90mmHg instead of 30mmHg). Approx 3% of people with varicose veins go on to develop leg ulceration (Morison & Moffatt, 1994, 1995).

The median age of the participants was 69, but four people reported ulceration developing in their twenties, 15 (12%) had developed their first ulcer before the age of 45 and 90 (47%) before the age of retirement. A similar picture was reported by Moffatt (2001b,) with 14% developing an ulcer before the age of 40. Likewise Nelzen *et al.* (1991), and Callam *et al.* (1985), reported that 50% of patients had their ulcer before retirement.

The mean duration of ulceration in the individuals who did not score as anxious was 113.34 months compared to a mean duration of 78.50 months for those individuals who did score as anxious. A similar picture was also found when depression and ulcer duration scores were examined, with a mean duration of 72.85 months in the depressed group, compared to a mean duration of 115.97 months in the non-depressed group. This tends to suggest that some form of adjustment may take place the longer an individual has ulceration and this is explored further in the interviews in Phase II of the study. Similarly Price and Harding (1996), found that ulcer duration of >24 months appeared to be related to healthier perceptions in terms of pain and general health. These results also resonate with the findings of Lindholm *et al.* (1993), and Franks and Moffatt (1998), who were unable to find evidence of longer duration of ulceration impacting on quality of life scores.

That ulcers can exist for a very long time has been found in a survey in Canada of 192 patients by Harrison, Graham *et al.* (2001), who reported that 60% of ulcers existed for more than six months and 33% of the patients had an ulcer for 12 months or longer. Similar long duration was found by both Callam *et al.* (1987), who reported a median duration of nine months and also Ebbeskog *et al.*, (1996), who reported on six months duration. More recently Moffatt *et al.* (2006), cited a median duration of eight months.

3.4.6: Pain

The problem of patients living with pain, which may not only be constant but also considerable, pervades the quality of life literature on leg ulceration. The Hofman study (1997), indicated that pain in leg ulcer patients was inadequately controlled – 69% cited that pain was the worst thing about having a leg ulcer. Studies consistently show that pain is the most significant predictor of depression, interfering with an individual's ability to function and causing inescapable stress (Blackburn-Munro and Blackburn-Munro, 2001). The results of the present study resonate with the literature on pain in that 73% of individuals suffered some degree of pain at some time of the day. It was therefore no surprise to find that there was an association between pain and depression ($p=<0.05$) and anxiety ($p=<0.05$). Because of limitations in the original design of the questionnaire, the data collected on pain was categorical which meant that it was not possible to show a true correlation with a scatter plot. However, a Pearson correlation tends to support a relationship between pain and depression, significant at the 0.01 level of

0.257. Pain is explored more fully in chapter five in the light of the findings from the qualitative data.

3.4.7: Odour

Odour from a heavily exuding wound is particularly distressing for patients and can lead to social withdrawal and, ultimately, isolation due to embarrassment (Douglas, 2001; Rich and McLachlan, 2003). Price (1996b) suggested that because smell carries such a social stigma, the effect can make the individual feel guilty and ashamed. If wet dressings are left on the skin, it can, not only lead to skin maceration causing soreness and pain, but is also an extremely unpleasant experience for the patient (Cameron, 2004).This population sample reinforced findings that odour is a major problem for patients and is strongly associated with anxiety ($p=< 0.001$) and depression ($p=< 0.001$). The level of exudate did not appear to be a significant factor but rather the associated odour was an issue. Odour is explored more fully in chapter six in the light of the findings from the qualitative data.

3.5: Internal reliability of HADS

The opportunity was taken to examine the internal consistency (also referred to as internal reliability) of the HADS, thus assessing the average level of reliability between all items comprising the scale measured by the questionnaire, by calculating Cronbach's alpha coefficients (Cronbach, 1951). Internal consistency is a measure of the degree to which each of an instrument's items measures the same characteristic. Cronbach's alpha statistic, for items with more than two available responses, provides a general estimate of how well the items on a test instrument measures the same phenomenon. It is based on the number of test items and their average inter-item correlations. If the questions within the instrument are measuring different concepts, they cannot be expected to correlate well with the overall score. The possible range of scores for alpha=0.0 – 1.0 with lower scores indicating less internal reliability. An alpha of ≥ 0.80 is recommended for well-established and widely used instruments (Higgins & Straub, 2006). Cronbach's alpha was 0.817 for the present data, with the item and scale statistics shown in Table 3.12, indicating good internal reliability.

Table 3.12: Cronbach alpha item and scale statistics

	Mean	**Std. Deviation**	**Variance**
Item Statistics			
Depression score	5.40	3.711	
Anxiety score	6.27	4.311	
Scale Statistics	11.62	7.398	54.723

3.6: Summary

The power calculation indicated a sample size of 246 people would be needed for this study. The smaller number of individuals recruited to the study sample (n=190) may have reduced the power of the results and, therefore, the ability to draw firm conclusions and comparisons with other populations. In addition, no specific diagnostic measure of anxiety or depression was used with the sample preventing analysis of the sensitivity and specificity of cut-off scores.

However, the results do add to an increasing literature on anxiety and depression in individuals with a chronic illness. The currently available literature in leg ulcers has developed predominantly as aspects of implementation projects or during randomised controlled trials. This is the first study to survey patients whose ulceration is chronic, for anxiety and depression in order to determine prevalence. We have learnt that a quarter of individuals with chronic venous ulceration display symptoms of anxiety and depression that has largely gone unrecognised. Pain and odour were the aspects of ulceration most strongly associated with a score of “caseness” on the HADS and it was interesting to contemplate if individuals might discuss these during interview.

The next chapter introduces the qualitative aspect of the study, exploring the philosophical underpinnings of phase II of the study. Whilst data on both anxiety and depression was collected in this first phase of the study, the aspect of major interest is depression, and thus anxiety is not pursued as a sampling criterion for Phase II as will be discussed further in the chapter four.

Chapter 4

Phase II: Living with a chronic leg ulcer

4.1: Introduction

This chapter outlines both the methodology used for this phase of the study, which explores 20 individuals' experiences of emotional distress, and chronic venous ulceration. It provides a rationale for the use of hermeneutic phenomenology adopted in this study and its' evolution within the qualitative tradition.

In this chapter I discuss the issues associated with data collection and analysis. Through the use of biography, together with excerpts from my journal, I aim to make my concerns, "prejudices" and position clear. This is in recognition of the fact that my historical, cultural, personal and professional background (Gadamer, 1976) influenced my approach to the study, data collection, analysis and presentation of quotations. This chapter discusses the issues associated with data collection and analysis, as well as ethical issues arising from the study.

4.2: Qualitative methodologies

There is increasing recognition of the contribution of qualitative research to health care (Faltermaier, 1997). Indeed, the importance of employing qualitative studies within the NHS is stressed by Murphy (2001). If policymakers and practitioners are to have some understanding of the context into which new policies are introduced, she asserts, then descriptive detail is necessary. Qualitative methodologies offer researchers investigating the social world, ways of understanding both human experience and the complexity of this world from the perspective of those who live within it (Janesick, 1998;Proctor, 1998). Researchers using this approach generally support the notion that "the perceptions of the researcher and other participants in the 'socially constructed' world are intricately interwoven" (Grbich, 1999, p.5), and are interested in issues such as the meaning people bring to a particular phenomenon, for example living with a leg ulcer.

Miles and Huberman (1994), and Hammersley and Atkinson (1995), view the researcher as the "research instrument" with an acceptance that researchers cannot "escape the social world in order to study it" (Hammersley & Atkinson, 1995, p.17). The focus of qualitative work, therefore, is on the descriptions of people's experiences and relationships, and the interpretations they place upon these. Consequently, qualitative studies are particularly useful for the study of areas about which little is already known. This is particularly pertinent for this study, where little is known about the experience of depression for individuals with chronic ulceration.

4.3: Philosophical underpinnings

Qualitative research is underpinned by philosophical and theoretical aspects which include: constructivism, symbolic interactionism, critical theory and hermeneutics. These have yielded a variety of approaches to social inquiry, such as ethnography, phenomenology, case studies, and grounded theory. The differences between these various paradigms have been noted by a number of authors (Creswell, 1998;Denzin & Lincoln, 2000;Murphy, Dingwall, Greatbatch *et al.*, 1998) who have described how differences in perspectives hinge on the nature of reality, what it is possible to "know", and how what is known can faithfully be rendered (Miles and Huberman, 1994). The theoretical approach acts like a lens through which we view the world (Patton, 2002, p.543) and is linked to our personal beliefs, backgrounds and philosophies (Morse, 1994).

4.4: Tensions, contradictions and hesitations

Confusion may ensue for those wishing to adopt an interpretive paradigm because of the inconsistent and interchangeable use of terminology within qualitative texts (Bailey, 1997). When you are trying to familiarise yourself with differing approaches, the conflicting perspectives can (and do!) cause discomfort and lead to the nagging doubt that you are "not doing it right" (Miles and Huberman, 1994, p.14). This can, as suggested by Miles and Huberman, consume more energy than the research process itself and entail a certain amount of "ontological gerrymandering" (Woolgar & Pawluch, 1985).

4.5: Methodological framework

As a novice to qualitative inquiry I did expend a vast amount of energy, which led to discomfort and the nagging doubt that I "wasn't doing it right" (Miles and Huberman, 1994, p.14). I also spent time in unravelling some of the conflicting perspectives, described by Woolgar and Pawluck (1985) as "ontological gerrymandering". Creswell (1998), and Morse and Richards (2002), discuss the congruence between the question asked, and the method selected, when making the critical decision of selecting the methodology best suited to answer the research question. As Sandelowski (2000), suggested:

> *"No method is absolutely weak or strong, but rather more or less useful or appropriate in relation to certain purposes."*
> (Sandelowski, 2000, p.335)

The aim of my study was to explore the lived experience of adults with chronic leg ulceration. As in most research studies, the research question guides the method (Patton, 2002;Schwandt, 2001). In this case, I was interested not only in the individual experience, but also how each person came to understand and accept that experience. I gravitated towards the inductive and interpretive framework of hermeneutic philosophy which incorporates the phenomenological philosophies of Heidegger (1962), Gadamer, (1975b), and van Manen (1990). The focus of hermeneutic phenomenology is toward illuminating details and seemingly trivial aspects within experience that may be taken for granted, with the goal of creating meaning and achieving a sense of understanding. Phenomenology was developed as a critique of, and an alternative to, the traditional objectivist ideology of modern science (Kvigne, Gjengedal & Kirkevold, 2002).

4.6: Phenomenology

Hermeneutic phenomenology offered me a framework that supported what I have always sensed to be true, but was unable to articulate: That understanding does not happen in isolation, but involves a complex process that includes a variety of interconnected exchanges. However, as I was to soon realise, I had further complex issues with which to grapple, since the phenomenological "method" of research developed from a philosophical movement that has many perspectives, and has thus resulted in multiple interpretations of phenomenological philosophy expressed within the literature. Whilst a complete review of all phenomenologies is outside the remit of this study, it is nonetheless important to provide a brief overview of the different schools, to place the ultimate selection in perspective, and to discriminate between the different philosophical traditions. It also clarifies the point often made, that to speak of phenomenology is not to speak of a single unified body of thought (Walters, 1995b). Phenomenology is generally recognised as being descriptive (attributed to Husserl), or hermeneutic (attributed to Heidegger and Gadamer), with the Dutch school (e.g. van Manen) recognised as a mixture of both descriptive and hermeneutic. These are discussed in the next sections.

4.6.1: Descriptive phenomenology: Husserl

Husserl (1859 – 1938), acknowledged as the founder of phenomenology, sought to establish a science of phenomena as a science of the cognition of essences rather than of matters of fact. He conceptualised the individual as a detached subject in a world of objects, in keeping with the Cartesian subject-object dualism (or mind-body separateness), and is primarily concerned with epistemological issues.

The French philosopher Rene Descartes([1664]1972,) is commonly seen as being responsible for dualistic ideas about mind and body, known as Cartesian dualism, and he was particularly intrigued by the mind-body split. In 1664 he proposed a "pain pathway" – a theoretical approach which dominated thinking about pain for almost two hundred and fifty years. In Zohar, he is cited as saying:

> *"I rightly concluded that my essence consist in this alone, that I am a thinking thing...And although perhaps...I have a body with which I am closely conjoined, I have, on the one hand a clear and distinct idea of myself as a thinking, non-extended thing, and on the other hand, a distinct idea of my body as an extended non-thinking thing; it is therefore certain that I am truly distinct from my body, and can exist without it."*
>
> Zohar (1990, p.92)

Husserl's eidetic or descriptive phenomenology, which is also transcendental, encompasses notions of "pure consciousness". It is proposed that researchers can, and must, transcend their natural attitude and suspend their beliefs about the existence of the objects of experience. Husserl used the mathematical metaphor of bracketing (epoch or reduction) for this suspension of beliefs, which is solely for the purpose of allowing description to be carried out in the most undistorted way possible (Ashworth, 1996), in order to reveal the lived world's structure of the person. What remains is the "transcendent ego", the pure consciousness, free to discover its true meaning, or its essence.

Husserl introduced the concept of "live-world" or "lived experience". He claimed that this life-world is not readily accessible because it involves what is taken for granted or things that are common sense. Husserl wanted to bring to light the ultimate structure of the consciousness (essences).

I would agree with Merleau Ponty (1962 / 1997), who believed that complete reduction is not possible because a researcher's consciousness is engaged "in the world" and, as such, is a perpetual process which cannot be transcended. The Cartesian notion of mind-body separateness is challenged with the view that we are embodied rather than being minds that possess a body: a person is an indissoluble unity. As both a nurse specialist, and previously, a district nurse managing patients with leg ulceration on an almost daily basis, it would have been impossible to suspend my beliefs and experiences. Indeed it was these experiences that brought the research question to the fore. As van Manen (1990) noted, a defining characteristic of phenomenology is when the researcher "turns to a phenomenon which interests them and commits them to the world".

4.6.2: Hermeneutics and phenomenology: Heidegger

Heidegger (1889 – 1976) challenged philosophers, from Plato to his contemporaries, on the historical assumptions that the only way of knowing in the world was by detached contemplation. He was Husserl's student and disagreed with Husserl's need, and indeed ability, to bracket presuppositions. It appears that, while both Heidegger and Husserl would agree that "intentional consciousness" was a phenomenon worthy of further exploration, they differed on how they felt this exploration should transpire and the purpose in exploring this phenomenon.

We start to see the dissolution of the absolute Cartesian boundary between self and world. Consciousness is first and foremost "intentional": it is always consciousness of something. We are not Cartesian subjects: there are no fixed and immutable boundaries between self and world. When trying to develop an understanding of another's world, Heideggerian hermeneutic phenomenology, based on an existential perspective, presupposes prior understanding on the part of the interpreter (researcher), refuting the Husserlian belief that it is possible to bracket one's being-in-the-world and therefore one's own preconceptions or theories in the process of phenomenological inquiry (Johnson, 2000;Walters, 1995a). It is the interviewer's background, prior knowledge and preconceptions of study phenomena, which are interconnected with the research and, ultimately, influence how one not only responds to participants but also approaches data generation and analysis (Lowes & Prowse, 2001).

As part of the research process, interviewers acknowledge and document their preconceptions, and the possible effects of these preconceptions on the interview structure, and participants' responses (Rodgers & Cowles, 1993), as portrayed in section 4.8. The researcher is thus considered inseparable from assumptions and preconceptions about the phenomenon of study; these are then explicated and integrated into the research findings ((le Vasseur, 2003;Lopez & Willis, 2004).

Hermeneutics or "the science of interpretation" (Allen & Jenson, 1990, p.241), is concerned with the complex description which emanates from people's detailed stories of their experiences in their everyday understanding of being-in-the-world. Hermeneutics has evolved from its ancient origins as a distinct discipline of the critical interpretation of biblical texts to include integration with several additional disciplines, including the existential aspects of Heideggerian and Gadamerian philosophy (Allen and Jensen, 1990). "Being" is the world existence, the primordial condition that allows everything else to happen. Heidegger contends that we are "thrown" into our world as beings (small b) at birth. Heideggerian researchers maintain that participants' experiences and interpretation of "being-in-the-world" are embodied in a background of linguistic and cultural traditions that can only be understood and interpreted by another "being-in-the-world" – namely, the researcher (Crotty, 1996;Leonard, 1989). Heideggerian phenomenologists propose that all knowledge originates from people who are already in the world and who seek to understand others also already in the world.

Heidegger challenged the foundations of knowledge by shifting from a philosophy concerned with epistemology, knowing, to one primarily concerned with ontology, being. Heidegger does not concentrate on phenomena but rather tries to uncover "being" as structures of human life itself (Koch, 1998). Ontology is about understanding the state of "being" and what it is like "to be" in any given situation. Heidegger describes the ability and potential "to be" as "Dasein". The basic meaning of "Dasein" is "being there", the requirement of which is to be conscious of one's existence. Dasein is Heidegger's way of referring both to the human being and to the type of being that humans have. Koch, (1996a) reports that the Dasein concept of a person's "being-in-the-world" necessitates a view that the person and the world are co-constituted, this being an indissoluble unity, indicated in texts by the hyphenation of "being-in-the-world". As such, an individual makes sense of the world from within their existence, not while detached from it. Therefore, it would make sense to say that only individuals experiencing ulceration could be considered eligible for this study; they have to "be" in the world of ulceration.

The natural standpoint of human beings is to be in the world where we are always interpreting the things we encounter and experiences that we have. Heidegger's intent was to make visible what kind of knowing occurs when one is involved in the situation, not standing outside it (Benner & Wrubel, 1989). By examining day-to-day lived experiences, Heidegger sought to expose some of the possible meanings of "being". The goal is not to predict or even to explain, but rather to understand and discover new meanings that may have previously gone unrecognised because of their perceived "everydayness". Cultural and social processes may be part of those experiences but they are not the objects of interest as they might be for sociologists or anthropologists (Schwandt, 1994).

The assertion in Heideggerian hermeneutics is that when "breakdown" occurs; that is, when the normal ebb and flow of everyday experiences goes awry, the taken-for-granted-ness of daily living vanishes. We are presented with a unique possibility for reflection and for new understandings to emerge. Leg ulcers are both the literal breakdown of the skin – the person's external barrier to the world – and the figurative breakdown of the embodied self. Leg ulcers cause chronic illness, and being chronically ill is a different way of "being-in-the-world" than being healthy. Patients can provide a personal view of living with leg ulcers and the experience of the care received, so that professionals who care for these individuals may be more empathic and understanding of their experiences.

Heidegger places emphasis on a person's history or background (historicality) of understanding, as one's background or situated-ness in the world (Koch, 1995). Historicality includes those things a culture gives a person from birth and is handed down, presenting ways of understanding the world. In Heideggerian phenomenological research, interviewers' backgrounds, prior knowledge and preconceptions of study phenomena are interconnected with the research, influencing their responses to participants, data generation and analysis. Heidegger says:

> *"[...A]n interpretation is never a presupposition-less apprehending of something presented to us (rather) interpretation will be founded especially upon fore-having, fore-sight and fore-conception."*
>
> (Heidegger, 1993, p.123)

Heidegger referred to these three concepts as fore-structures, with fore-having referring to background experiences from the life-world that makes interpretation possible. By fore-sight he was interested in experiences, which ultimately provide us with a viewpoint from which we can make interpretations; whilst fore-conception referred to experiences that create expectations about what might be anticipated in an interpretation (Geanellos, 1998).

Researchers subscribing to Heideggerian philosophy acknowledge that they can only interpret something according to their own beliefs, experiences and preconceptions, which are a legitimate part of the research process and should not be left out. Indeed, it is imperative that researchers work out their fore-structures, in terms of the phenomenon under investigation, and make them explicit. This could be viewed as a shortcoming in some research projects where it is omitted (Walters, 1995a). If this process is not worked through then there is a real danger of simply utilising interviews to confirm one's own foreknowledge, assumptions, bias and beliefs rather than the essence of the phenomena under investigation.

The interpretive process is achieved through a "hermeneutic circle" which moves from the parts of experience, to the whole of experience and back and forth again and again to increase the depth of engagement with, and the understanding of, texts (Annells, 1996). The hermeneutic circle is explained more fully in the section on Gadamer. Schleiermacher(1833/1977), who coined the term "hermeneutic circle", believed that:

> *"Complete knowledge always involves an apparent circle, that each part can be understood only out of the whole to which it belongs and vice versa."* (Schleiermacher, 1833 / 1977, p113)

Interpretation is seen as critical to the process of understanding. Claiming that to be human is to interpret, Heidegger (1962) stressed that every encounter involves an interpretation, influenced by an individual's background or historicality. Hermeneutics is an interpretive process that seeks to bring understanding and disclosure of phenomena through language: language was a mode of being that revealed Being. Heidegger also placed great emphasis on language, considering it to be more than an instrument used for the manipulation of thoughts and ideas. Rather, language had a hermeneutic character in that understanding became possible through language. It was postulated by van Manen (1990) that human experience has a semantic organisation. Humans encode their experience of the world, society and cultural institutions by means of language. Social practices may, therefore, be read as text as they reveal lived experience. Hermeneutics means interpretation: Heidegger posits that understanding and interpretation constitute our foundational mode of existence.

4.6.3: Hermeneutics and phenomenology: Gadamer

Gadamer (1900 – 2002), a student of Heidegger, similarly believed that it is not possible to lose one's pre-understanding, as everyone always has a pre-understanding of the topic in question. Gadamer (1979) reminds us:

> *"[...W]e must always already have a horizon in order to place ourselves within a situation."*
>
> (Gadamer, 1979, p.271)

In his *magnum opus*, *Truth and Method* (1989 / 1960), which contributed enormously to the field of hermeneutics, Gadamer argued that experience, culture and prior understanding render the scientific ideal of objectivity impossible; it is only through one's pre-understandings that understanding is possible. If one does not recognise one's pre-understandings, there is a risk that one will fail to understand or will misjudge meaning. For Gadamer, the hermeneutic circle brings three major concepts to the fore: prejudice, play and the merging of horizons. He uses the term "prejudices" to refer to pre-understanding; prejudices are the conditions by which we encounter the world as we experience something. We can only come to understand or make sense of the world (interpret) through our own past. In conversation with others, the combined past then creates a new understanding. Chadderton (2004) states that the hermeneutic circle:

> *"Exemplifies the circularity of play, the temporality of truth, the integral part played by pre-understanding in understanding and the coming together of interpreter and text in the fusion of horizons."*
>
> (Chadderton, 2004, p.69)

Research carried out in a Gadamerian tradition is developed from a desire to achieve a deep understanding of a phenomenon. Gadamer believed that philosophy was of no use unless it could be understood. He eschewed his discipline's reputation for excessive abstruseness. The essence of the question, according to Gadamer (1990), leads to the opening up of possibilities for this understanding. He emphasised the influence of the right questions for elaboration of the hermeneutic situation. That means the initial research question influences the whole research process. He further stated that there is no understanding without the activity of questioning. According to Gadamer, the narrow relation between questioning and understanding gives sense to the hermeneutic experience. He asserted that language is always interpretation, arguing that not only is there interpretation involved in *what* we experience, but also in the language we choose in *sharing* this experience. These were particularly important aspects to remember when considering the interviews.

For Gadamer, the major aim of a conversation is to allow immersion into the subject matter. Therefore a conversation between researcher and participant is a suitable method of achieving understanding of a phenomenon of interest. Understanding will appear through the fusion of horizons of participant and researcher. As suggested by Phillips (2007), we need to allow ourselves to be challenged by the “different-ness of the other person”. Horizon is the field of vision, which includes and comprises everything that can be seen from one perspective (Gadamer, 1990).

Gadamer viewed interpretation as a fusion of horizons (perspectives), a dialectical interaction between expectation of the interpreter and the meaning of the text. Questioning, including self-questioning, is an essential aspect of the interpretive process as it helps make new horizons and understandings possible. Understanding and interpretation are bound together and interpretation is always an evolving process, thus a definitive interpretation is likely never to be possible (Annells, 1996).

Gadamer understood hermeneutics as a process of co-creation between the researcher and participant, in which the very production of meaning occurs through a circle of readings, reflective writing and interpretations. It is only through constant reworking and revisiting of prior interpretations, a movement between parts and wholes, that it is possible to make sense of the human condition (Gadamer, 1975a).

4.6.4: Dutch School of phenomenology

The Dutch school is a combination of descriptive and interpretive phenomenology, which is used by scholars such as van Manen. It is the belief of van Manen (1990, p.9), that hermeneutics aims to interpret experiences within a given context without classifying them. This is in contrast to "pure" Husserlian phenomenology which seeks to describe meaning.

Hermeneutic phenomenology validates the position that understanding is shaped by internal and external influences, is guided by language, and results from the co-creation of new understanding through dialogue. While phenomenology is concerned with how one "orients to the lived experience", the hermeneutic component is concerned with how one "interprets the texts of life" (van Manen, 1997). Hermeneutic phenomenology suggests that neither experience nor interpretation can exist without the other (Heidegger, 1996). Experiences are revealed through the act of interpretation, using language in the form of words or some other symbolic form of expression. This form of communication and understanding relies on interpretation.

The individual themself uses interpretation; first to develop self-understanding and again when sharing the experience with others. It is further argued by van Manen (1997), that in applying this philosophical approach to a research method, the transformation of a person's unique experience and meaning into text also includes further interpretative efforts by the author and the reader: the interpretation is ongoing. Hermeneutics is described as a method, which facilitates interpretation of texts in context where "texts" refers to sources of information in addition to the written word. van Manen states that:

> *"The aim of phenomenology is to transform lived experience into a textual expression of its essence in such a way that the effect of the text is at once a reflexive re-living and a reflective appropriation of something meaningful."*
>
> (1990, p. 35)

4.7: Methodological selection

The idea of accessing people's day-to-day experiences of emotional distress, in individuals with chronic venous ulceration, is thus consistent with hermeneutic phenomenology. From this perspective "nothing can be encountered without reference to our background understanding" (Leonard, 1989, p.47). I believe it is truly impossible to select hermeneutics without phenomenology, but it may be possible to select phenomenology without hermeneutics. However, for the reasons outlined above I believed that the most appropriate methodology to help answer my research question was the use of a mixture of phenomenology and hermeneutics.

Phenomenological researchers need to acknowledge how their presence within the research field and their own *a priori* assumptions may impact on data collection, analysis and reporting (Mays, Roberts & Popay, 2001;Murphy *et al.*, 1998). It was important, therefore, that I recognised and challenged my own preconceptions, remaining critically aware of the relationship between myself as the researcher and the research environment (Hutchinson & Wilson, 1994). Indeed, one of the basic tenets of hermeneutics is not to develop a procedure for understanding, but to clarify the conditions in which understanding takes place (Gadamer, 1994) and this can be achieved through reflexivity.

4.8: Personal reflection

I needed to set out my perspective and background to allow others to review the influences that have played a part in shaping this study. The explication of my personal beliefs also made me, as the investigator, more aware of the potential judgments that might have occurred during data collection and analysis. A central idea within Heideggerian phenomenology is the recognition of the researcher's contribution in the process of interpretation, and the need to make explicit at the outset of the study the researcher's preconceptions (Parse, 1996). Similarly Denzin (1989, p.23) commented that "value-free interpretative research is impossible" due to the fact that every researcher brings "preconceptions and interpretations to the problem being studied" Interpretations are made in light of the researcher's theoretical perspective (Parse, 1996).

My background as a nurse spans 27 years. During this time I have worked continuously within the NHS, but also worked part-time for ten years within a higher education setting. My clinical role included working in general medicine and care of the elderly, as well as 11 years as a district nurse and 12 as a clinical nurse specialist (CNS) in leg ulcer management. It was during my time as a district nurse that my interest in wound care and, specifically, leg ulcers began. I undertook a Diploma and Degree in Health Studies, followed by an MSc, which allowed me to focus on the management of leg ulcers by district nurses. It was about the same time as commencing the MSc that I established a nurse-led leg ulcer service within the community in an attempt to improve care delivery to this marginalised group of patients.

I worked part-time as a nurse specialist in leg ulcers and also part-time as a lecturer employed specifically to develop and teach a leg ulcer course. During this time I pursued my interest in tissue viability by studying for a postgraduate diploma in wound healing and tissue repair. Over the course of my studies I developed a strong sense of the importance of evidence-based practice but I was equally aware that the patient's voice often gets lost, and wanted to pursue further the psychosocial aspects of wound management.

I felt that, undoubtedly, I had improved care for patients with leg ulcers, but there were patients still attending clinics after seven or eight years. Their lives had changed dramatically over the period of ulceration; yet, I truly did not understand the psychological impact that ulceration had on these individuals. As can be seen, the main influence on my interest in leg ulceration comes from my work as a CNS working with adults experiencing leg ulcers. It is important to mention that, in a way, their voices have also been included in this project. Although they have not been directly involved in the research per se, I owe much to the people who chose to share their experiences and struggles. Their stories had an impact on me, and I believe they also influenced the discussions between the individuals in this study and myself.

4.9: Recruitment of participants

The participants were purposively selected (Patton, 1990, pp.371 – 381) from the 190 participants identified in Phase I (Denzin and Lincoln, 1994; Morse, 1991). Purposive sampling is defined as:

> *"Judgmental sampling that involves the conscious selection by the researcher of certain subjects or elements to include in the study."*
>
> (Crookes and Davies, 1998)

As discussed in chapter three, participants in Phase I completed a baseline questionnaire together with HADS to determine "caseness" of depression. Participants were informed in Phase I that they may be contacted at a later date to be interviewed. Participants were not chosen in order to be representative, but because of their expert knowledge and experience of living with venous ulceration. As suggested by (Koch, 1994), in order to increase the diversity of the people who were selected, a mix of males and females from different areas were included.

4.10: Sampling criteria and method

Whilst there are no set rules on sample size in qualitative enquiry (Holloway & Wheeler, 1996;Sandelowski, 1995a), it is nonetheless important that any sample must be appropriate ("from whom") and adequate ("how much"), as the sample will have a profound effect on the ultimate quality of the research (Morse, 1991). The sample size is not determined by the need to ensure generalisability, but by a desire to investigate fully the chosen topic and provide information rich data (Grbich, 1999). Generalisation is not the aim – reaching a new or better understanding is. What matters is gaining rich data, data that illuminates the question to be answered or explored. The size of the sample is considered adequate when interpretations are visible and clear, new informants reveal no new findings and meanings from all previous narratives become redundant (Benner, 1994). Sandelowski (1995) suggested that a good principle to follow is:

> *"An adequate sample size in qualitative research is one that permits – by virtue of not being too large – the deep, case-oriented analysis that is a hallmark of all qualitative inquiry, and that results in – by virtue of not being too small – a new and richly textured understanding of experience."*
>
> (Sandelowski, 1995, p.183)

The validity, meaningfulness and insights generated from qualitative inquiry have more to do with the information-richness of the cases selected and the analytical capabilities of the researcher than with sample size (Patton, 2001), although Cohen, Kahn & Steeves, (2000), do suggest that larger samples provide more variety of expressions. Sandelowski (1995) suggests that in interpretive phenomenological research it is possible that from fifteen to twenty descriptions of a larger experience may be needed in order to ascertain its necessary and sufficient conditions. It is also worth considering the point highlighted by Morse, (1995), that frequency of occurrence is irrelevant as qualitative inquiry involves valuing variation over quantity. It is more important for the researcher to "know it all", than to hear things repeatedly. A considered decision was taken in accordance with the above discussion, that the sample should be no less than ten and no more than twenty patients.

The aim in participant selection in phenomenological and hermeneutic phenomenological research is to select participants who most likely possess characteristics relevant to the phenomenon being studied (Mays & Pope, 1996), i.e. have lived experience that is the focus of the study. In this case a chronic leg ulcer that may have caused participants some distress according to the results of HADS in Phase I. The participants must be willing to talk about their experience, and diverse enough from one another to enhance the possibilities of rich and unique stories of the particular experience (van Manen, 1997). It was therefore important that participants had first-hand experience of the phenomena of interest and were willing, and able, to reflect and provide detailed experiential information. I also needed to select some participants who might provide contrasting or "negative case" narratives (Streubert & Carpenter, 1999).

4.10.1: Criteria for inclusion in the interview sample

Taking the above into consideration, 20 participants were purposively selected from Phase I to be interviewed according to the criteria in Table 4.1, with the HADS depression subscale score (HADS-D) from Phase I the primary starting point. People in Phase I were considered to have reached "caseness" if they scored ≥9 on HADS-D and 18, from a possible 52, people who scored as "cases" were selected. A further two people were selected as negative cases having scored less than nine on HADS-D and with no history of depression.

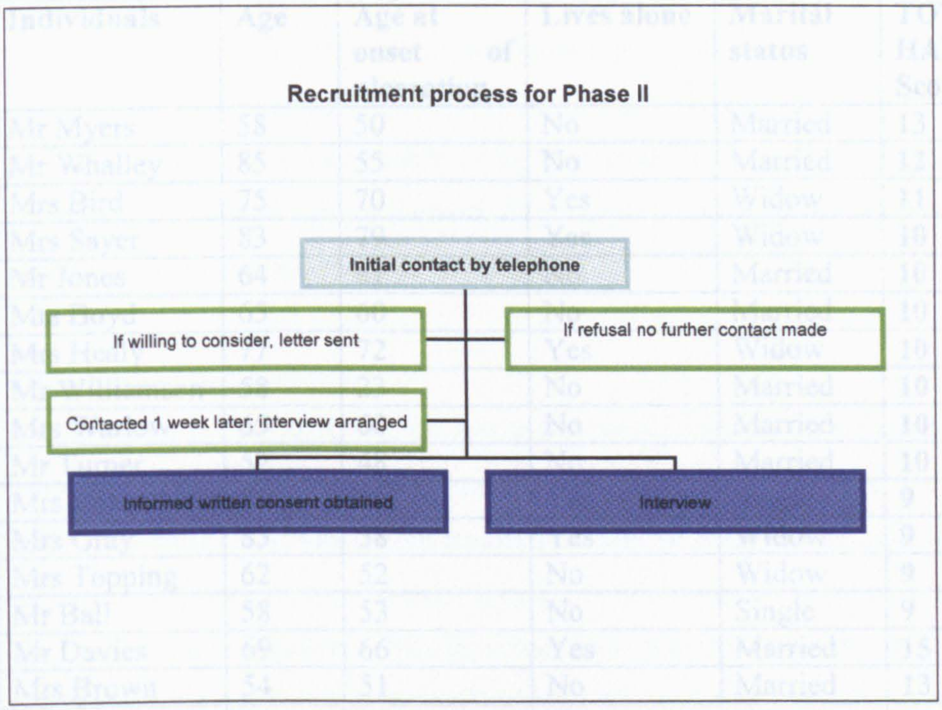
It was important that all participants met criterion two and this was applicable when, initially, I contacted two nursing homes to interview two elderly participants (aged over 90). The staff of the home felt that they would be unable to be interviewed for this period of time due to failing health.

Table 4.1: Criteria for interview sample

Criterion	**Rationale**	**Number of participants**
1a) Depression score of ≥9	No medical diagnosis of depression	14
1b) Depression score of ≥9	History of diagnosis of depression	4
1c) Depression score of <9	No medical diagnosis of depression	2
2) Willing to be interviewed for at least 30 minutes (all to fit criterion)		
3) Chronic open ulceration or chronic ulcer healed within previous 2 months (all to fit criterion)		

Whilst the aim is not to obtain a random sample, as discussed earlier, nonetheless I felt that it was appropriate to ensure that there were individuals from the NHS Trusts involved, and a mix of males and females to ensure as clear an understanding of living with ulceration was obtained. I was also influenced by the results of Phase I and felt that it would be useful to have a mix of ulcer durations (ranging from two to 35 years). Obtaining agreement from participants to be interviewed was not quite as straightforward as I had naively anticipated: some people declined to be interviewed, stating they were either too busy or just did not wish to be interviewed. As noted above, two people were aged over ninety and living in a nursing home and so were excluded on that basis (as outlined above). Three individuals had moved and four had been admitted to hospital, at the time of contact, with unrelated problems. One eligible patient had early dementia and it was believed (by his carer) that the nature of the condition could limit the depth of communication required, as well as his understanding of the experience. The recruitment process of participants for Phase II of the research is outlined in Figure 4.1.

Figure 4.1: Recruitment process for Phase II



4.10.2: Characteristics of sample

A total of twenty people consented to participate in this study and to share their stories with the researcher. These were interviewed between January and December 2004. In total, 12 women and eight men were interviewed: two from Oldham, five from Bolton, one from Cheshire, two from Rochdale, three from Stockport, four from Tameside and three from Wigan. The ages ranged from 52 to 86 with a mean of 68 years, 12 were married, six widowed and two single. There were 16 people with active ulceration whilst four had healed within the previous two months. All were English speaking, but represented a variety of socio-economic backgrounds, from factory workers to professionals, although 13 were now retired (eight due to their ulcer, five due to age). Four people were housewives, one person received incapacity benefit and the remaining two still worked. There were six people who lived alone whilst the others lived with spouses or family members. Characteristics of the twenty individuals selected and their HADS-D score can be found in Table 4.2.

Table 4.2: Characteristics and HADS-D score of sample

Individuals	**Age**	**Age at onset of ulceration**	**Lives alone**	**Marital status**	**TOTAL HADS-D Score**
Mr Myers	58	50	No	Married	**13**
Mr Whalley	85	55	No	Married	**12**
Mrs Bird	75	70	Yes	Widow	**11**
Mrs Sayer	83	79	Yes	Widow	**10**
Mr Jones	64	61	No	Married	**10**
Mrs Boyd	65	60	No	Married	**10**
Mrs Healy	77	72	Yes	Widow	**10**
Mr Williamson	58	23	No	Married	**10**
Mrs Warlow	65	60	No	Married	**10**
Mr Turner	52	48	No	Married	**10**
Mrs Ruane	86	81	Yes	Single	**9**
Mrs Gray	83	58	Yes	Widow	**9**
Mrs Topping	62	52	No	Widow	**9**
Mr Ball	58	53	No	Single	**9**
Mr Davies	69	66	Yes	Married	**15**
Mrs Brown	54	51	No	Married	**13**
Mrs Kay	72	60	No	Widow	**12**
Mr Owen	57	27	No	Married	**10**
Mrs Hall	69	42	No	Married	**7**
Mrs Smith	75	73	No	Married	**4**

4.10.3: Consent

The principle of respect for human dignity incorporates the right to self-determination and the right to informed consent. This necessitates potential participants being given adequate and understandable information about the study and affording them the power and free choice whether or not to participate. Participants in this study were provided with a full explanation of the purpose of the study and details of what would be involved if they agreed to participate.

All eligible participants (n=20) were sent a letter inviting them to take part in the study accompanied by an information sheet (Appendix Four), written in a style that accorded with the requirements of Multi-Centre Research Ethics Committee (MREC). The letter provided background information and a choice of dates and times for the interview. I arranged to contact the individual by telephone approximately one week after the expected receipt of the letter to answer any queries, and reinforce verbally any information the participant might have required, as well as to arrange a suitable date and time for the interview to take place. At the outset it was made clear to individuals that they were not obligated to participate but, should they wish to do so, they could withdraw at any time without detriment. I obtained signed consent from those who agreed to take part in the study prior to commencement of the interview.

4.11: Ethical considerations

As described in chapter three, all research studies conducted within the NHS are required to meet certain ethical requirements and the principles are the same for both quantitative and qualitative research. A key requirement of ethical codes is that the importance of the research objective is in proportion to the inherent risk to the participant. However, the personal and sensitive nature of qualitative interpretive research raises several ethical issues, which are discussed in the following section. Participants can also expect to be reassured that any data collected during the course of the study is kept in the strictest confidence so that no one, other than the researcher, can link responses to an interviewee.

4.11.1: The principles of beneficence, justice and respect

It was necessary to demonstrate that the ethical principles of beneficence, justice and respect for autonomy and human dignity of persons in nursing research (Beauchamp & Childress, 2001;Polit & Hungler, 2001) would be maintained throughout the study. Ethical behaviour has been described as a practical, dynamic and interpersonal activity, and depends on striking a balance between the rights of the individual participants, the risk of exploitation and the wider purposes of the research (Seymour & Singleton, 1999). It has been suggested by May (1991) that researchers need to take into account that interviews may stimulate self-reflection, appraisal or catharsis and considerable self-disclosure on the part of the informants and thus due consideration must be made regarding the informants' well being.

The principle of beneficence can be seen to encompass dimensions such as freedom from harm, exploitation and risk. Above all the maxim is "to do no harm" (non-maleficence) (Polit & Hungler, 2001). Thus, whilst a qualitative interview could be emotionally charged and distressing for some participants, for others it might be a validating and therapeutic experience (Kvale, 1996). Little is known about the impact in-depth interviewing has on study participants; often in-depth interviews can raise emotive issues and general anxieties. The potential for harm is therefore less visible in qualitative work (Lipson, 1994) and may vary in degree. However, researchers have a duty to treat participants in a non-exploitative way as they can be "wronged" even if not "harmed" (Murphy & Dingwall, 2001).

Evidence from previous interview studies has shown that some participants feel that telling their stories can be stressful, whilst others find it a positive experience (Brannan, 1998;Finch, 1984). It should not be an implicit assumption, however, that participants find it beneficial to talk about their experiences (De Raeve, 1996). Researchers have an obligation to consider how their research could impact on participants (Murphy & Dingwall, 2001;Silverman, 2000), bearing in mind that harm is possible at any stage. I thus endeavoured to conduct the interviews in as sensitive a manner as possible, remaining alert for signs of discomfiture or distress, and prepared myself to handle these therapeutically. Participants were reminded that the interview could be terminated if they wished, at any time without censure. If a participant became upset I would offer to switch the tape off and / or stop the interview (The taping of interviews is discussed in section 4.12.1).

The rights of individuals participating in research are paramount, and Burns and Grove (1995) describe this as the right to determine the time, extent and circumstances in which private information is shared. In this present study many people said they were grateful for having the opportunity of being listened to, of being able to tell their story, and they hoped it might help others in a similar position. Mishler (1986, p.131) found that individuals suffering from health problems often need a non-judgmental listener to whom they can voice their grievances and express their feelings.

Although some would argue that the potential for harm in qualitative research is of a different order to that in experimental studies, this does not mean that harm is not possible. However, harm is more likely to be emotional or psychological in nature. For example, stress may be incurred as a result of discussing sensitive issues and it may not always be possible to identify these sensitivities in advance.

Some authors suggest that many application forms for ethics committees, with their biomedical focus, often expressed in a prescriptive list, fail to take into account the ethical considerations required for qualitative inquiry, and consequently a study may not be deemed ethical simply because it manages to meet these requirements (Murphy & Dingwall, 2001). Other ethical considerations also need to be identified and addressed, not only at the point of recruitment to the study, during data collection and analysis; but also prior to the publication and presentation of research findings (Hammersley & Atkinson, 1995;Miles & Huberman, 1994).

Consideration was also given to the location of the interview, as this can potentially be significant. It is important that participants are interviewed where the experience takes place or where they feel most comfortable, usually their own homes, thus enabling participants to express themselves more freely and honestly. Therefore, participants were asked if they wished to be interviewed at home, and all agreed this was their preferred option.

Ethical issues within qualitative studies therefore raise a number of considerations that cannot simply be addressed by responding to a number of predetermined criteria, or by simply getting participants to sign a consent form (Murphy *et al.*, 1998). Instead, researchers need to be conscious of the imbalance of power between themselves and those they study. Researchers may undertake studies for a variety of reasons, including their own professional advancement, and they invariably set the agenda in terms of the research question posed and the means adopted to study it. Findings or implications from the study are also grounded in the researcher's beliefs (Silverman, 2000). Nonetheless, researchers have a responsibility not to treat participants merely as a means to an end (Murphy & Dingwall, 2001). Having said this, power differentials need not lead to exploitation (Murphy & Dingwall, 2001) and the sensitivities of study participants must be at the fore.

Lipson advises:

> *"[...T]hat we inform ethical decisions with cultural sensitivity, awareness of our own ethical values and how strongly we need to impose them, and trust in our own gut feelings about what is right in the immediate situation and whether there will be later repercussions."*
>
> (Lipson, 1994, p353)

4.12: Interviewing in hermeneutic phenomenology

Participants were viewed as co-researchers and therefore the term "generated" is used rather than "collected" since it infers that the researcher and the participants made data together. It also places emphasis on working *with* participants rather than *on* them, thus giving credence to the notion of reciprocity between the researcher and the participants (Reason, 1998).

The aim of this study was to elicit stories of individuals' experiences of living with chronic venous ulceration, and to "generate" meaningful descriptions. These stories were obtained by interviewing individuals. There are three forms that an interview can take (Fielding, 1993): the structured interview, which follows the same format for each participant; the semi-structured interview, in which the researcher asks the same major questions but has freedom to alter the sequence and probe for more information; and finally the unstructured interview, where questions are replaced by a short list of broad topics. In keeping with hermeneutics, a largely unstructured approach was adopted, since hermeneutic interviewing is interpretive and not governed by predetermined questions. It is important that the phenomenon under investigation directs the conversation instead of it being established by predetermined questions.

4.12.1: Preparation for interview

I developed a quite formal and almost ritualised process, of preparation for interview in order to avoid any unnecessary problems (Grbich, 1999). I checked the recording equipment, e.g. batteries and microphone, at least two days prior to interview, so that if needed I could access replacements. I spent time at the participants' homes "arranging" furniture, where necessary (with their permission), so that the equipment was sited in the best possible place.

When planning interviews, attention must be given to the dress code and setting. Fontana and Frey (1998), highlighted the importance of deciding how to present oneself as this can have a profound effect on the success, or failure, of the study. Throughout this study, I presented myself as a researcher and a nurse, emphasising that I did not work in any of the geographical areas in which I was conducting the interviews.

At the start of the interviews each participant was offered the opportunity to ask questions before signing the consent form agreeing to take part in the study. All participants were asked prior to the interview if they were willing to have the interview tape-recorded. I concurred with Hammersley and Atkinson (1995, p.157) who suggested that the physical act of writing may have obscured non-verbal behaviour, such as eye contact and facial expression. Consent in qualitative research may need negotiation as unforeseen events may occur which the subject may not wish revealed (Polit & Hungler, 2001). Informed consent is only partial, the nature of qualitative research is exploratory and there is no hypothesis (Holloway & Wheeler, 1996). I did not take informed consent for granted, but offered participants a chance to decline to be interviewed at this stage (Fontana & Frey, 1994). I took the opportunity to reinforce issues of confidentiality, transcription, storage and ultimate destruction of the tape. As discussed in section 4.11.1, I always informed the participant that they could terminate the interview at any point and I would never question their decision. This practice ensures that participant control is kept to a maximum (Gbrich, 1999) and that process consent is maintained (Carlisle, 1997). To help reduce the researcher-participant power imbalance (Parnis, Mont & Gombay, 2005), everyone was given a choice of venue for the interview, and all opted to be interviewed in their own home. The interviews were undertaken at a time that suited individuals, with two taking place in the evening after work.

Interview guidelines were prepared, and were required, as part of the ethical approval process (Appendix Six). However, the schedule was brief in nature and acted as a guide only, containing a number of key topics to facilitate exploration of general ideas. Patton (2001) suggests that the purpose of interviewing is to find out what is in, and on, someone else's mind by asking questions in a way that encourages informants to provide their own answers in their own words, and giving them leeway to diverge into other areas of their experience (Rose, 1994). The guide thus allowed flexibility to pursue emerging ideas (Britten, 2000). According to Kvale (1996), a good interview question should contribute thematically to knowledge production and dynamically to promoting a good interview interaction. Therefore, the questions were aimed at focusing the participant on their experience of living with chronic leg ulceration and the emotional impact this has had for them.

Another aspect of preparation was focussing on the act of listening as fully as possible. This involves minimising the number of distracting thoughts or questions. Being very interested in the participant's experience was of great assistance in offering close attention and the other non-verbal aspects of eye contact and tone of voice.

4.12.2: Additional phenomenological considerations

The phenomenological interview, based on the philosophy of Heidegger, incorporates the researcher's preconceptions in the generation of data. Indeed, this is a defining characteristic of the Heideggerian phenomenological interview and research process. When using a phenomenological approach, the interviewer gives form to the interview. Such interviews are not conducted, but participated in by both the interviewer and the person (Sorrell & Redmond, 1995). The central role of the researcher as well as the participant in the creation of data is a key factor in the Heideggerian approach (Koch, 1995).

Conversational in nature, the hermeneutic interview proceeds using active listening, question and answer (Geanellos, 1999). Gadamer insists that we come to an understanding through discussion, in talking something through with another, and insists that speech is the "medium of the hermeneutic experience". As with any conversation, neither person knows exactly what will emerge. The aim of the interview, therefore, is to come to an understanding (Gadamer, 1960 / 1989). In keeping with phenomenological tradition, the interviews were guided by the participants, with the assumption that they would describe what was meaningful to them (Kvale, 1996). If the questions were predetermined, this in itself would have imposed my pre-understandings onto the phenomenon, thereby closing down the possibility for different understandings. In this regard Gadamer reminds us that:

> *"The essence of the question is the opening up and keeping open of possibilities."*
>
> (Gadamer, 1979, p266)

Whilst listening to the story, I tried to get a sense of the experience from the participant's perspective; thus I tried to remain open to what they were telling me. I had to remain vigilant that I didn't just go into the interviews almost searching for what "I wanted to see" – or try to find what I was looking for in what people were saying. As phenomenological methodology seeks to avoid, as far as possible, structuring or influencing the story that each subject has to tell, questions were kept to a minimum with the function of assisting the patients involved to "tell their story". I was guided by the view that the ideal interview occurs when:

> *"The interviewer's short descriptive questions and/or clarifying statements provide an opening for a respondent's lengthier and detailed descriptions."*
>
> (Thompson, Locander & Pollio, 1989, p.139)

By listening and being open to what I was hearing, I was able to transpose myself into the participant's world... into the other's horizon (Gadamer, 1960 / 1989). Openness is critical and the exchange may be entirely open, with few direct questions asked (Koch, 1996b). The reason for this is to encourage the interview process to stay as close to the lived experience as possible. Kvale (1996), cautioned that it is important to look for not only what is "said", but what is said "between the lines". Hence, verbatim does not necessarily capture all of what is "really said" in an interview. The importance of paying attention to silence, the absence of speaking and the silence of the unspeakable has been supported by van Manen (1997). During the interview I was able to devote my attention to note observable data not revealed by audio taping alone. It was particularly useful to pay attention to facial expression, as sometimes the face inadvertently can both "conceal" what must remain hidden and "reveal" what one wishes would "remain" hidden (Caputo, 1987). Hence, the use of a reflective journal is vital to record material not obvious on the transcripts.

The aim was for the flow of conversation to be controlled by the individual. However, I also concurred with Cohen (2000), who suggested that the best way to elicit narrative data is to aim for the interview to resemble a conversation. Gadamer (1960 / 1989), also suggests it is by asking questions that the being of what is talked about is broken open, with questions providing a sense of direction.

In order to be able to ask a question, one must want to know something about something. However, whilst asking a question can imply openness, it can also limit the boundaries of what is going to be talked about. Geanellos (1999), discusses the significance of questions, recognizing that a poorly asked question predetermines a direction, whereas a genuine question allows the conversation to go in many directions. It was thus important that in asking questions I did not limit the boundaries by questions that were either too leading, or too narrow, in focus. However, as a caveat to boundaries, it is worth remembering that neither the interviewee, nor the interviewer, can predict the course of an interview in advance.

4.12.3: The interviews

All interviews started by asking people to talk about with whom they lived, to describe when they first experienced ulceration, and what they perceived to be the cause. Starting in this way appeared to put people at their ease and formed a basis for discussion of other issues. Whilst I did not ask specific questions, a conversation cannot proceed unless there is some dialogue. The probes used (for the purposes of clarification) and the prompts maintained a focus on the experience and depended entirely on the flow of the conversation (Koch, 1996). Commonly used probes were: *"Can you tell me more about that?" "Can you give me an example of that?"* Prompts sometimes consisted of repeating what individuals had said, or asking them to expand further on their experiences, as well as the use of "why" questions which allowed me to access interpretive understanding (Koch, 1993).

I explored my own experiences whilst conducting the interviews, noting down the nature of interactions to increase my awareness of events. The main issues that arose during the interviews were maintaining a non-therapeutic relationship and not intervening in the care received. During the interviews some participants asked for advice. I was aware that I should not be involved in a therapeutic relationship with participants. I reported on the current research evidence available, but stressed the need to discuss any changes to treatment with their nurses or GP. In this way I do not believe that my role as researcher fused with that of my role as a health professional.

Despite some initial nervousness, at least on the part of the researcher, the aim of providing a relaxed interaction process where the individuals could talk openly about experiences seemed to be achieved, as all participants spoke freely. However, during two interviews participants became overtly distressed as the emotion of recalling experiences overwhelmed them. I asked if they wanted me to switch the tape off and / or if they would prefer us not to continue, or at least to continue in their own time. My comments and questions were only a very small component of the verbal interaction. Most people spoke at length, with interviews lasting between 45 and 75 minutes. When material was either repeated, or no new thoughts were occurring in the conversation, I asked more closed questions to bring the interview to a conclusion and / or just stated we were approaching the end.

On reflection, most of the interviews felt as if they were successful (in terms of eliciting the individual's story). However, there was one interview where the participant responses were stilted and short and remained so, despite probing. There were also some occasions following an interview, and listening to the tapes, where I felt I could have handled the situation better and probed further. On reflection, and after discussion with supervisors, this was considered part of the learning process of conducting this type of research and happened early in the data collection period.

4.12.4: Confidentiality

I assured individuals that the study would be confidential and that they would never be identified directly, although my thesis (and subsequent publications) would involve the presentation of direct quotes from interviews. Audiotapes were coded, with no identifying information on them. The transcripts were also coded, and each person was given a pseudonym to maintain confidentiality. The tapes, all personal information including names and addresses, and participant research files were kept in locked cabinets at all times when not in use by the researcher.

4.12.5: Debriefing

At the end of the interview people were invited to ask questions, or add anything they may have felt was missed or left out of the interviews. Some people asked again about the research and what would happen to the information they had disclosed. There were three people who asked for specific advice regarding their ulceration, which I duly provided. I reiterated my thanks to people for taking part and for sharing their stories with me.

4.13: Reflective journal

Following the interview, notes were made about my own feelings, thoughts and impressions arising during our interaction. These were recorded in a journal and used to aid the interpretation of data. In the hermeneutic tradition, field notes are recorded before, after and around, but never during, the event. I also included notes on my immediate impression acquired during the interviews, such as intonation or body language. The journal was maintained throughout the study and incorporated reflections and interpretations of my experiences and understanding within the context of the study. My experiences were equally as important as those of the study participants in enriching interpretation (Drew, 1989) and are the basis of the hermeneutic tradition (Ricoeur, 1981). Getting into the hermeneutic circle necessitates the keeping of a reflective journal (Smith, 1999). My own development of thinking about the topic, and the needs of individuals, as well as the sources for these perceptions, have been included in the following chapter in order that the reader might identify the potential sources of influence in the process of interpretation of the data.

As discussed earlier, the hermeneutic circle is a metaphor taken from Heidegger to describe the experience of moving dialectically between the part and the whole, where each gives the other meaning. Gadamer also claims that language and history supply the shared sphere in the hermeneutic circle:

> *"Understanding is circular then. Because within the 'circle' the meaning comes to stand..."*
>
> (Palmer, 1969, p.87)

The hermeneutic circle is a "place" where the dialogue occurs, where parts of the text are related to the whole, and where both parts and whole inform the understanding of the other. The circle is meant to represent the "art of understanding" (Annells, 1996, p.707), as through every act of understanding, something different comes to be (Gadamer, 1976).

The use of a reflective journal is one way in which a hermeneutic circle can be engaged, moving back and forth between the parts and the whole of the text. Consequently, reflective journals are used to explicate preconceptions throughout the research process. There is a need to ensure that any preconceptions are acknowledged, transparent and incorporated into the entire research endeavour. The diary has proved to be a useful tool in writing up this thesis, enabling me to review my thought processes at different stages of the study.

4.14: Data analysis

This section describes some of the processes, and assumptions, which were made in relation to the data, through the hermeneutic approach to interpretation and analysis. Strategies utilised in data sorting and interpretation must be made explicit. It is considered of fundamental importance that any reader should be able to follow clearly the interpretive "trail" so as to facilitate understanding of the consequent interpretation. The study can be shown to be dependable when the reader is able to follow the decision trail of the researcher throughout the study. The ability to audit the decisions made is paramount, and leaves no room for ambiguity around choices made by the researcher (Guba & Lincoln, 1989). In this study, value was placed on the use of an interpretive framework that allowed informants to "speak for themselves", but guided the presentation of findings to bring out the key issues as raised by them, and bring these together across the sample.

Colaizzi's (1978), framework for analysis initially guided the extraction of themes and the search for commonalities. However, his approach is characteristic of Husserlian phenomenology and functions outside of the hermeneutic circle, as he ignores the part of researchers in generating the data, and proposes conducting the analysis based only on the perspectives of the participants, even though he described himself as an existential phenomenologist. In this chapter I have discussed and criticised Husserlian phenomenology, which would appear closely related to objectivity and positivism, and grounded in Cartesian principles. Husserlians purport to describe the phenomenon as it appears. I would contest, however, that it is difficult to separate description from one's own interpretation.

4.14.1: Analysis framework

In order to get into the hermeneutic circle, I needed to use my own experience as data, being aware of my background, and whenever possible, demonstrate the interaction with individuals' stories. These prejudices are brought to the analysis of interview data (Gadamer, 1976) and thus Colaizzi's framework (See Appendix Seven) would need to be modified for use with this study. Indeed, Colaizzi himself suggested that his steps for interpretation are by no means definitive and should be applied with some flexibility by the researcher. Taking his advice on board I therefore looked elsewhere for guidance and found van Manen (1990), (See Appendix Seven) offered a flexible structure to approaching "human science research" which was also considered to facilitate the analysis. Further, I did not return to the participants for guidance, clarification and validation, as suggested by Colaizzi (1987), for the main reason that each conversation would provide me with a new story, and this process could continue *ad infinitum*.

My framework for analysis, summarised below, ensures that the researcher is an integral part of data generation. The framework utilises parts of both Colaizzi's framework, with his ideas of "significant statements", and also van Manen's structure which aims at presenting rich and evocative descriptions of lived experience.

4.14.2: Using the framework

Step 1: Turning to a phenomenon which seriously interests and commits us to the world; a total immersion in reflection upon the possible meanings.

In order to engage in hermeneutic phenomenology we must be influenced by phenomena that seriously interest us and commit us to the world (van Manen, 1997). This would include a sense of prejudice (pre-judgment), as described by Gadamer (2003), which welcomes and seeks to incorporate what the researcher themself brings to the process. Within this context, van Manen challenges us to conduct our research by investigating experience as we live it, rather than as we conceptualise it.

The phenomenon in this case is the emotional distress of living with a chronic leg ulcer which, as reiterated throughout the thesis, arose from my own concern that, as health professionals managing patients with chronic leg ulcers, we had somehow failed to comprehend the emotional impact and disruption to an individual's way of being-in-the-world.

An audio typist transcribed the taped interviews. I checked these typed transcripts against the original tape for accuracy and contextual information, such as non-verbal cues, of which the audio typist would have been unaware. This was a valuable process of becoming familiar with the data and could be construed as the data preparation phase, overlapping temporally and contextually with data collection, analysis and interpretation as suggested by Sandelowski (1995b). All narratives were read numerous times following transcription and prior to commencing any coding. This assisted in developing familiarity with the texts, and their basic conversational content, and further sensitized me to emotions and possible meanings underlying the spoken word. During this phase, a list of key topics and storylines began to emerge.

Immersion took place through the constant iterative process of reading, reflecting, re-reading and further reflection. All the transcripts were read for a sense of the whole, in order to acquire a feeling for them and to become familiar with the text. Field notes were taken directly after the interview and added as a memo to the participant's file. These field notes contained observations as to ease of communication, setting and social context of the participant and non-verbal behaviour. Reflexive notes were also written, about my feelings towards the participant and the interview context.

Step 2: Reflection of own experience to aid understanding of the phenomenon.

As opposed to bracketing my experience, this was brought to the process of eliciting the emic perspective and to facilitate entry into the hermeneutic circle. This enabled me to spend some time in reflection of my own experiences of looking after people with leg ulceration in clinical practice. This included preliminary and ongoing reflections and writing in a journal. My experiences, both as a district nurse and then as a clinical nurse specialist, were selected. I had already formulated some assumptions and expectations about what the emotional impact of living with a leg ulcer may be like and these are made explicit:

(i) That the smell and pain of ulceration constitute a large part of the anxiety and distress suffered by patients with leg ulcers.

(ii) That the treatment provided by health professionals is a cause of anxiety and discomfort per se, namely compression bandaging.

(iii) That patients make active decisions not to concord with treatment because it causes such a disruption to their lives.

These experiences and assumptions were incorporated into the analysis process, in the same way as any clinician, would read the findings of this thesis, with experiences of their own clinical encounters in mind.

Step 3: Extracting significant statements.

The third step for Colaizzi: return to each "story" in order to extract from it phrases or sentences that directly pertain to the investigated phenomenon (Colaizzi, 1978, p.59). I returned to the "parts" by examining the transcripts line by line to isolate "significant statements" in the text. In other words, key parts of transcripts, which seemed to capture an essential aspect of the experience, were identified and labelled. I continually asked myself how and why I considered these statements essential to an understanding of emotional distress. I asked of the data "what matters?" and "what is it like?" for this individual. In this way I extracted significant statements from the transcribed interview and thus participated in generating the data. Each interview transcript was analysed separately in order to extract significant statements. Aspects of experience that reoccurred within a story, or in those of other individuals, were given the same labels.

Step 4: Maintaining a strong and oriented relation to the phenomenon.

I turned my full attention to the phenomenon in order to take understanding beyond any superficial level that may be achieved by brief or temporary interest. The orientation arises from a dual role of being both a nurse and a researcher. Throughout the steps taken I would constantly reflect on my own experiences with individuals and my own prejudices on the phenomenon. I endeavoured to merge my own understanding of the phenomenon with the meanings I felt were arising from the text. I thus made no attempt to "bracket out" (in the Husserlian sense) my own foreknowledge, since bracketing and hermeneutic analysis are mutually exclusive.

I analysed the text to explain the structure of the interview by dividing it into meaning units, each consisting of either a sentence, several sentences, a paragraph or several paragraphs with similar meaning in relation to the aim of the study. The meaning units were transformed, through condensation, to give a formulated meaning concerning experiences of living with a chronic leg ulcer.

Step 5: Describing the phenomenon through the art of writing and rewriting; giving expression through language to that which has been understood.

Rewriting is part of the process of thoughtfulness and of the development of understanding. Writing and rewriting are acts of interpretation and thinking themselves, and indeed this has been a useful process in ensuring true interpretation and representation of the data.

Step 6: Balancing the research context by considering parts and whole.

The researcher's account does not get lost in detail and retains a grasp of the original question and overall purpose of the analysis. The relationship of parts of the text to the whole remains a question during analysis with aggregation of "parts" and "wholes" of total data incorporating reflective diary notes and literature.

In detailing a process for interpretation, I acknowledge some "tension" between Gadamer's rejection of "method" and the need to demonstrate rigour in the study. Relatively, in stating that a six step analytical process is utilised, this does not mean that hermeneutic principles are being contravened, or that a strictly linear process is used throughout. The approach remains faithful to its hermeneutic philosophical foundations by a flexible non-sequential, "backwards and forwards" movement amongst the text and by constant reflection on "parts" and "wholes" within the data via constant "re-visiting" of transcripts and reflective diary. This then maintains a continuous interplay or "ongoing conversation" (Koch, 1999) with the text and myself, ensuring that analysis is reflective, reflexive and circular (van Manen, 1990, p.91).

Benner (1985), describes how hermeneutic interpretation:

> *"Entails a systematic analysis of the whole text, a systematic analysis of parts of the text, and a comparison of the two interpretations for conflicts and for understanding the whole in relation to the parts and vice versa."*
>
> (Benner, 1985, p.9)

It is this shifting back and forth between a background of shared meaning and focused experience, within that background that is known as the hermeneutic circle, described by Thompson (1990) as a "metaphor used to describe the experience of moving dialectically between part and whole":

> *"Phenomenological themes are not objects of generalisations; metaphorically speaking they are more like knots in the webs of our experiences, around which certain lived experiences are spun and thus lived through as meaningful wholes. Themes are the stars that make up the universes of meaning we live through."*
>
> (Thompson, 1990, p.243)

4.15: Computer Assisted Qualitative Data Analysis Software (CAQDAS)

The use of computer-assisted data analysis software is controversial (St John & Johnson, 2000;Weitzman, 1999). It has been suggested that researchers utilising computerised data analysis software may find a distance from the data that affects analysis. It is important that the researcher who intends to employ computerised data analysis understands the research methodology, and selects the software that has the best fit to the project. My criteria for selection were as follows: application to phenomenological data analysis procedures, ease of use and support services and / or networks.

I firmly believe that the long-term benefits of learning to use these programmes, and incorporating their use in the research study, would compliment the traditional hand analysis method of hard copies of data management. The Nvivo software data management system was chosen for its ability to store, retrieve and question the data (Richards, 2005). However, the software despite its title does not possess any analytical powers but merely provides facilities to assist the researcher in the examination of features and relationships (Gibbs, 2002). The programme was originally developed to assist researchers with theory generation in grounded theory (Bazeley & Richards, 2000;Gibbs, 2002). Nonetheless, the developers of the programme state that it can be used successfully with other research methodologies.

There were both pros and cons of using hand versus computerised data analysis: what did not work well was the time involved in learning how to use the programme, which was approximately three months of almost daily use before I felt confident enough to actually perform analysis. I also experienced some distancing from the data itself, as it felt akin to a process of fragmentation of the data, to the point where I found it necessary to return to the transcripts and re-read them, helped by a highlighter pen.

Of primary importance was the availability of an audit trail as to when and why analytic decisions were taken in the study. The software management programme also enabled me to keep a personal research diary that proved beneficial in keeping a log of reflexive issues. I chose to write the findings in a way that I believe is clear and provocative, and which opens the door to multiple understandings. In effect, I took the following words to heart:

> *"Language is the basis for understanding even in the scientific world. Because language is so important, we urge you to say what you want to say when you write; let your meaning come through loud and clear, and feel free to ignore the prescriptions and proscriptions that are often associated with science writing. If it seems appropriate to you to use the pronoun 'I' then use it; there's no reason to refer to yourself through some contortion*

> *like, "the present researcher" in service of a crazy notion of objectivity...It is part of the craft of research to use language with care and precision, your language must make sense to you and to your readers."*
>
> (Barritt, Beekman, Bleeker *et al.*, 2004, p.133)

4.16: Conclusion

This chapter has explored the development of hermeneutic phenomenology and outlined the considerations involved in qualitative inquiry, and my decision to select hermeneutic phenomenology as the preferred method of enabling me to answer the "what" and "how" questions in addressing the issue of living with a leg ulcer. I have provided the steps tackled in selection and recruitment of the sample for interview, together with the ethical issues and principles involved in interviewing people in the NHS. The interview process is described in some detail so that the processes and decisions made are transparent to the reader. The analysis framework is explained so the reader is confident the decisions made throughout the analysis process are based on my philosophical position.

As discussed in section 4.10.2., twenty people were selected for interview based predominantly on the HADS-D scores from Phase I (see Table 4.2). The findings from the interviews are presented in the following three chapters, with chapter five setting the scene and introducing 20 individuals whose being-in-the-world had been significantly affected by ulceration. Pernicious pain, odour, loss of self-esteem and confidence, embarrassment, anxiety and depression punctuate the lives of this group of individuals. Their stories reveal lives lived on the perimeter of activities and events, not fully engaged because of ulceration. Whilst the focus is predominantly based on the findings from the interviews, it will also be integrated with the results of the HADS-D depression subscale.

The real voyage of discovery
consists not in seeking
new landscapes
but in having new eyes

Marcel Proust

The next three chapters aim to help the reader understand and interpret the perspective of individuals who have to live with ulceration. It is important that healthcare professionals, other people with chronic ulceration, and the people who care for them, hear these voices and validate the experiences.

Health care professionals need to be informed of the day-to-day experience of people living with ulceration so that practice can be improved and the body of knowledge not only expanded, but also developed.

Chapter 5: Living in a world you don't want to be in

"Pain is a more terrible lord of mankind than even death itself."
Albert Schweitzer

5.1: Introduction and overview

The 20 respondents in this study were living in a world they didn't want to be in because of their chronic venous ulceration. Their being-in-the-world had been significantly affected by ulceration, and its associated consequences, causing private anxieties and agitations which they shared as they told their stories. Stories sometimes that sounded like ones of survival rather than of living. A brief profile introduces the 20 people (provided with pseudonyms), who gave up their time, and whose experiences informed both this researcher and the research. This is then followed by a demographic outline. These provide some background information, which helps in understanding the unfolding story. On a presentation note, data is presented as verbatim text in italics, with the pseudonym of the individual provided and the number refers to the sentence in the transcript.

This chapter focuses on pain, as this was the over-riding symptom of ulceration made explicit in most of the stories. People are forced to live in a world they don't want to be in, a world of uncontrolled and uncontrollable pain and suffering which impacts on their ability to get on with their lives, both physically and emotionally.

5.2: Participants

Twenty individuals were purposively selected (chapter four) according to their HADS-D score in Phase I (Table 4.2). In order to ensure a deeper understanding it was necessary to ensure that there was a breadth of experiences from which to draw. I therefore introduce the individuals in the three groups selected to interview as per the following criteria and outlined in Table 5.1.

- Fourteen individuals with HADS-D score ≥ 9 and no history of depression.

No history of depression means that an individual has never been previously diagnosed with, or treated for, depression.

- Four individuals with HADS-D score ≥9 and history of depression.

A history of depression in this study refers to individuals who have been diagnosed by their General Practitioner (GP) as depressed and treated with antidepressants.

- Two individuals with HADS-D score ≤8 and no history of depression.

Table 5.1: Individuals with HADS-D score ≥9 and no history of depression

Name	**Age first ulcer (years)**	**Illness Trajectory (years)**	**No of Episodes**	**Duration latest Episode (months)**
Mr Myers	50	8	3	42
Mr Whalley	55	30	4	53
Mrs Bird	70	5	3	57
Mrs Sayer	79	4	2	13 (Healed)
Mr Jones	61	3	1	36
Mrs Boyd	60	5	2	36 (Healed)
Mrs Healy	72	5	1	60
Mr Williamson	23	35	6	133 (Healed)
Mrs Warlow	60	5	1	60
Mr Turner	48	4	1	48
Mrs Ruane	81	6	3	38
Mrs Gray	58	25	7	24
Mrs Topping	52	10	4	68 (Healed)
Mr Ball	53	5	3	32

My data analysis revealed both diversity and similarity among the participants' lived experiences. Given this reality, what seemed important to me was to acknowledge and retain the uniqueness of each person while searching for commonalities among the experiences in order to provide a comprehensive understanding. Tables 1 – 3 help to illustrate the ulcer trajectory of the individuals in each group and are provided to help in the development of a comprehensive understanding. The tables include the age of the individual at the onset of their first episode of ulceration and the length, in number of years, of ulceration. Information regarding the number of episodes of ulceration is provided, as well as the duration of their most current episode. There are four people whose ulcers have healed but, as discussed in chapter two, this does not mean they are cured.

Mr Myers

This 58-year-old gentleman has not worked for many years due to Parkinson's disease; he developed bilateral ulceration eight years ago. He lives with his wife and numerous pets in a semi-detached house close to local shops and amenities. He has no history of depression and scored 11 for the depression subscale.

Mr Whalley

Although he is now 85 years of age, Mr Whalley was working part-time until the age of 80 at a local DIY store when bilateral ulceration finally forced him to retire. Mr Whalley lives with his wife in a semi-detached property ten minutes walk from the town centre. He developed his first ulcer at the age of 55 and has had ulceration on and off for 30 years. He has no history of depression, scoring 12 for depression.

Mrs Bird

This 75 year-old widow lives alone, but in the same block of flats and on the same floor as her twin sister. She started with ulceration when she was 70 and, whilst the current episode has almost healed, they never remain healed for longer than approximately two months. She has never been diagnosed as depressed and scored 11 for depression

Mrs Sayer

This 83 year-old retired mill worker lives alone in an upstairs warden-controlled flat, following the death of her husband 12 years ago. She is fully mobile and lives an independent life. Her second episode of ulceration has been healed for almost six weeks, having lasted for 13 months. Mrs Sayer has no history of depression, scoring ten for depression.

Mr Jones

This 64 year-old man was forced to take early retirement from his job as a security guard due to ulceration. He lives with his wife in a terraced house in a quiet cul-de-sac on the outskirts of the town centre. He has a three-year history of ulceration, during which time the ulcer has never healed. Mr Jones scored ten for depression; he has no medical history of depression.

Mrs Boyd

Mrs Boyd is a 65 year-old housewife, married with grown-up children and grandchildren. She has a five-year history of ulceration with the current episode open for two years. Mrs Boyd has never been diagnosed as depressed and scored ten for depression. Her ulcer has been healed for almost six weeks, after three years duration.

Mrs Healy

This lady is 77 years of age and lives in a pensioner's bungalow since the death of her husband five years ago. She rarely goes out as her mobility is limited due to ulceration which has lasted for over three years. Mrs Healy has no history of depression, scoring 13 for depression.

Mr Williamson

This 58 year-old retired chip shop owner has had ulceration on and off since he was 23. He lives in a large detached house in a quiet cul-de-sac close to local shops and amenities with his wife and one grown-up son. His last episode of ulceration has been healed for four weeks after a period of almost 11 years. Mr Williamson has never had a medical diagnosis of depression and scored ten for depression.

Mrs Warlow

Mrs Warlow is 65 years old, married and lives in a large bungalow in a secluded cul-de-sac. She still works part-time in the family business doing the books and wages. Her ulcer has been open for almost five years. Mrs Warlow has no diagnosis of depression and scored ten for depression.

Mr Turner

Mr Turner is a 52 year-old married car mechanic living with his wife and two children in a modern semi-detached property on a housing estate. He started with ulceration at the age of 48 and his ulcer has never healed in that period. Mr Turner has no history of depression and received a score of ten for depression.

Mrs Ruane

Mrs Ruane is an 86 year-old spinster who lives alone in a large semi-detached property in a small village. She is a retired factory worker, now virtually housebound due to ulceration which first started six years ago. Her current, third, ulcer has been present for 38 months. She has no previous history of depression and scored nine for depression.

Mrs Gray

Mrs Gray is an 83 year-old retired factory worker who was forced to retire early due to long standing ulceration, dating back over 25 years. She is a widow and lives alone in a pensioner's bungalow on a small estate close to local shops and amenities. This is her seventh episode of ulceration and her ulcer has been open for more than two years. Mrs Gray has no history of depression, scoring nine for depression.

Mrs Topping

Mrs Topping, now 62 years of age, has been a widow since the age of 44 and developed her first ulcer when she was 52. Her most recent episode of ulceration has been healed for five weeks. She has been a housewife since she married and looked after her five sons, one of whom still lives at home. There is no history of depression and Mrs Topping scored nine for depression.

Mr Ball (W19)

Mr Ball is a 58 year-old retired factory worker who lives with his nephew in a terraced house in the centre of a village. He was forced to retire at the age of 54 because of his ulcers, which constantly break down within two to three weeks of healing. He scored nine for depression and has no history of depression.

An interesting aspect to consider is the mean age of the above group when they first started with ulceration, namely 58 years of age (range 23 – 79), with a median duration of current ulceration of 3.5 years and a median illness trajectory of five years. Ulceration tends to be viewed as a problem of the elderly, but as can clearly be seen from this group, people can have their first episode at a much younger age at a time when they are also trying to cope with work.

There were four individuals interviewed with HADS-D score ≥9 and a history of depression as shown in Table 5.2.

Table 5.2: Individuals with HADS-D score ≥9 and a history of depression

	Mr Davies	**Mrs Brown**	**Mrs Kay**	**Mr Owen**
Age first ulcer	66	51.5	60	27
Illness trajectory (years)	3	2.5	12	30
No of episodes	1	2	3	6
Duration latest episode (months)	36	7	132	109

Mr Davies

This 69 year-old gentleman, although still married, lives alone in a warden-controlled flat. He is a retired civil servant with limited mobility, due to arthritis as well as ulceration. He has suffered with bilateral ulcers but now has an ulcer on one leg, which has been present for nearly three years. He has been depressed in the past due to his ulceration for which he was prescribed antidepressants. He scored 15 for depression.

Mrs Brown

This 54 year-old is the main carer for her disabled husband, who suffered a dense stroke three years ago. At one point, Mrs Brown had bilateral ulceration that lasted for seven months resulting in depression for which she was prescribed antidepressants. She scored 13 for depression.

Mrs Kay

Mrs Kay, now a 72 year-old widow, was forced because of ulceration to retire at the age of 63 from her job as a shop assistant. She lives with her mentally disabled son in a semi-detached house where she manages to do all the shopping and household chores herself, despite a long history of ulceration. She has been previously diagnosed with depression due to leg ulceration and received a score of 12 for depression.

Mr Owen

Fifty-seven-year-old Mr Owen is married with two grown up daughters, one of whom still lives at home. Forced to retire from his job as a coach driver at the age of 29, due to repeated ulceration, he has not worked since, as his ulcers have never healed for longer than six months at a time. He has been on antidepressants for many years because of his leg ulceration and scored ten for depression.

Two individuals were interviewed as negative cases, with HADS-D scores of ≤8 and no history of depression as depicted in Table 5.3.

Table 5.3: Individuals with HADS-D scores of ≤8 and no history of depression

	Mrs Hall	**Mrs Smith**
Age first ulcer	42	73.5
Illness trajectory (years)	27	1.5
No of episodes	8	1
Duration latest episode (months)	57	18

Mrs Hall

Mrs Hall lives with her husband and son in an upstairs flat close to the town centre. She is 69 years of age and has had ulcers on and off since she was 42. She eventually had to retire because of the deterioration in her ulcers, at 60, from her factory job, even though she had wanted to continue for another five years. Mrs Hall has no history of depression, receiving a score of seven for depression.

Mrs Smith

Mrs Smith is 75 years of age and married, living in a terraced house with her husband since their return home from abroad nine years ago. This coincided with the start of health problems culminating in ulceration 18 months ago. Mrs Smith has no history of depression, scoring four on the depression subscale.

Fourteen people in the study had recurrent ulcers, whilst for six this episode was their first experience of ulceration. Two people had more than one ulcer on one of their legs and four had experienced bilateral ulceration. The current ulcers had been present anywhere from seven months to twelve years, although ulceration per se had been part of many of their lives longer than they cared to remember; so long in fact it was hard to recall a time without ulceration.

5.3: Living in a world of pain

Pain associated with leg ulceration has been described by Smith *et al.* (2000), as one of the most significant and universal features of living with a chronic wound. One of the major aspects of ulceration for people in this study was pain, leaving people inhabiting a world they don't want to be in. A world that comprised the physical grip of pain, the revolving door of pain which affected sleep and a pain that was more than skin deep: pain became an intensive reminder of their ulceration. I reflected if pain came to the fore of interviews because it was one of my assumptions. However, most people spoke spontaneously about pain, as it was an overwhelming symptom of ulceration for almost everyone. Only two people did not speak about pain and even after prompting, whilst admitting to suffering with a degree of pain, they spoke about odour being the main symptom for them.

The physical and emotional pain endured by sufferers of leg ulceration is explored in this section, a pain that seems to impact on every aspect of their lives. The pain is described by some people as worse than any pain they have ever endured:

> *"It was like nothing I've ever experienced before... I'd sit at the table and I'd just start crying because of the pain."*
>
> Mrs Warlow: 11

I use the term endured to denote that pain has much more than a physical impact; it affects day to day functioning, having a significant impact for many on their psychological state. Pain was found in Phase I of this study to be significantly associated with depression ($p=0.002$, $x^2=14.95$). In order to fully appreciate what people are experiencing, it is necessary to have some context-related background information.

It has been proposed that there are three distinct dimensions of pain: perceptive (physical sensation); reactive, (psychological); and cognitive (Sofaer, 2000).

1. Perceptive component: this gives information on how much the wound hurts and what it feels like (i.e. the physical sensation of having a wound): *the physical grip of pain.*
2. Psychological aspect: this relates to the emotional impact of having the pain, how the patient feels. Fear, anger, anxiety, sorrow, depression, irritability and fatigue are all common feelings which may exacerbate, or be exacerbated by, the patient's pain response: *the revolving door of pain and is more than skin deep.*
3. Cognitive dimension: this is concerned with the attitudes and beliefs people have about their pain, what they believe to be the cause of their pain and the strategies they use to cope with it. Patients who have previously been subjected to painful dressing changes may remember this pain and become anxious at the prospect of further unrelieved pain (Pasero, 1998): *more than skin deep and living in Limbo.*

As will be seen from this chapter, these are not mutually exclusive aspects of pain but involve considerable overlap so that any divisions are used simply to help gain a deeper understanding of the world of ulceration.

5.4: The physical grip of pain

Pain is not a single sensation varying in intensity, but rather a complex sensation with a variety of qualities, and people can find it difficult to describe their pain mainly because its nature and intensity vary so much, not only between individuals but also for a person over time. People in this study were no different and, despite the fact pain caused them a great deal of suffering, it remained a subject that in many ways was difficult for them to articulate. Congruent with Heideggerian philosophy, McCaffery's (1979) statement that "pain is whatever the experiencing person says it is", was the basis on which the lived experience of pain was interpreted. It was as if no words for them could adequately convey the pain that they had to endure:

> *"[...I]t was a horrible pain. The pain would just come on for no reason. You could be just walking across the road and the pain... you had to stop dead. And there was a tear welled up in your face, you know... it was indescribable the pain."*
>
> Mrs Kay: 43

This difficulty in articulation of pain is conveyed by 57 year-old Mr Owen, who had evidently been asked on numerous occasions to describe his pain, since, without any prompting from myself he almost shouted at me, daring me to ask him to describe his pain:

> *"[...P]eople say to you describe the pain but you* ***can't*** *[his emphasis] describe a pain... How can you describe what pain is? How can you describe how bad it is... it feels like it's on fire all the time, that's how bad it is."*
>
> Mr Owen: 21

For him, pain was the worst thing about having an ulcer. It slowly eroded his enjoyment of things as he often found it difficult to focus or engage in even simple activities, such as watching the TV or reading. These are activities considered as distractions or ways of relaxing, but for many individuals with ulceration the unrelenting nature of pain prevents them from even doing that: there is no escape. Unfortunately, Mr Owen wasn't alone in this situation as 12 people stated that, for them, pain was the worst thing about having an ulcer, because of the impact of the pain on their ability to get on with their lives. However, two people (Mrs Sayer and Mrs Healy), did not feel as if pain was a significant factor for them. Other symptoms, such as the bulk of the bandages and the odour, were more important for them. These are considered in chapter seven.

People in this study utilised a number of sensory descriptors to describe their ulcer pain: "sore", "nerve pain", "stabbing", "like toothache". They also used affective descriptors, although less often than sensory descriptors such as "sickening", "horrendous" or "excruciating". It is important to note how the individuals have described the pain; they quite often refer to "someone" inflicting the pain:

> *"[...I]t is as if someone was scraping it, at times it's been as if... it's like needles, lots of lots of needles pricking at it, and another time as if somebody has got a razor blade we will say and scraping the top off... [T]his goes on and on and on."*
>
> Mrs Boyd: 4

Whilst the body has a ubiquitous presence in all aspects of our daily lives, it escapes our consciousness most of the time, particularly in health – we are embodied. The body, and in particular one part of the body, is not the focus for us every day. However, for many individuals the ulcerated leg, and not the body, has become the object of reflection: they constantly referred to "the leg"; the leg and ulcer appear to be controlled by "someone" and this permeates many accounts:

> *"[...A]nd if you imagine someone with a red hot darning needle sticking it in you, stabbing and burning at the same time."*
>
> Mr Ball: 47

It is as if this part of their body has become alien or detached from them, yet at the same time demands their full attention because of the pain and suffering inflicted by ulceration, almost as if "ulceration" has metamorphosed, assuming characteristics capable of inflicting pain. There is an overwhelming sense of loss of control, of disembodiment; "the leg" is something that is no longer viewed as part of them because they can no longer control how it behaves:

> *"[...Y]ou just felt as if someone had a digger and was digging right into you... [S]omeone digging a hole into your leg."*
>
> Mrs Kay: 7

Similarly, pain as an integral part of ulceration cannot be controlled; it happens at the most unexpected times and places:

> *"[...T]he pain would just come on for no reason... you could just be walking or sat reading and it would take your breath away... [T]he pain was unbelievable."*
>
> Mrs Warlow: 43

This loss of control finds echoes in the way they lead their lives, as is evidenced in the following chapters. Some of these accounts of their pain are reminiscent of accounts of torture chambers where individuals are subjected to low level yet continuous and rhythmic torture with familiar rings of the "dripping tap syndrome"; illustrated by Mr Owen when he said:

> *"[...Y]ou can just sit in here and its throbbing and throbbing, its just throbbing and throbbing going like a pulse."*
>
> Mr Owen: 87

The pain has been absorbed into his very being and even throbs, almost in synchronisation, with his pulse. These graphic descriptions do not appear in text books on venous ulceration as a "normal" and expected aspect of the pain associated with ulceration, which makes them somehow all the more poignant.

> *"I can't stand the pain I go through sometimes... [I]t's like somebody getting a knife, a pointed knife and going and jabbing you and then tearing you apart with a knife."*
>
> Mrs Smith: 11

The only positive aspect was the fact that the gaps between episodes of pain were far enough apart to enable Mrs Smith and her husband to venture outside the home. Unlike Mr Owen, she did not complain of constant pain but did seem to have some respite.

The following graphic account is somehow made all the more disturbing because it is told by a frail, elderly 86 year-old lady living alone, not only made housebound in the latter years of her life because of her ulcer, but also having to endure excruciating pain which intensifies her experience of ulceration:

> *"[...O]h yes very painful... sometimes you describe it as a dagger being turned round in your leg...* ***[Y]ou have the pain if you touch it, and you***

> ***have the pain when you don't touch it*** *[her emphasis], like an apple corer... it feels as though someone has been trying to take the middle out."*
>
> Mrs Ruane: 30

It was interesting that she emphasised the uncontrollable, and unpredictable, nature of ulceration pain when she stressed that the ulcer hurt, regardless of whether it was touched or not. If there are no triggers to pain it becomes impossible to predict when and where the pain will start, and how you can ease it or prevent it. Mrs Ruane used an analogy of coring an apple to try to explain the depth of her pain.

Most people nonetheless, found it difficult to explain what, for many, was a daily occurrence. Implicit in their difficulty with the articulation of pain was the fact that people knew it was impossible to "feel" someone else's pain:

> *"I keep repeating it but nobody knows how painful it is."*
>
> Mrs Kay: 28

As stated by Illich (1975):

> *"Pain in its essence, can neither be rationally understood, nor physically shared."*

This was inherent in most of the stories, and portrayed in their difficulty in articulation. The only way to help someone else get anywhere near understanding was by using examples of everyday objects, which most people know and use such as a knife, apple corer or cheese grater, but portrayed as instruments of torture or punishment:

> *"[...I]t feels as if someone's got a mini cheese grater with a sharp edge and they're twisting it round inside that area."*
>
> Mrs Bird: 7

They intuitively knew that just saying they were in pain would not provide an understanding of their pain experience; you could only truly understand or empathise if you had experienced it yourself:

> *"But you know, it's ever so difficult to explain to somebody and I feel absolutely sure that nobody really, unless they have got one, can really*

> *know how it feels because I would rather do anything than have that [pain].*"

Mrs Brown: 25

Similarly Mr Owen, still only 57 but having experienced 30 years of ulceration, summed up people's lack of understanding when he said:

> *"Eh occasionally you think I wish somebody else could feel it just to know what it is like you know and you don't really wish it on somebody no you don't but you think they don't understand how painful it is no idea."*

Mr Owen: 28

What a terrible indictment of one's fellow human beings who must display a complete lack of understanding let alone empathy of people's plight, for seven people to verbalise this same feeling of not truly being understood. To emphasise the point even more, some people alluded to the fact that they wouldn't wish ulceration on their "worst enemy"; you "may" wish lots of things on your enemies but ulceration would be just one step too far:

> *"They are terrible things to have, absolutely terrible. I wouldn't wish them on my worst enemy really they are that bad."*

Mr Whalley: 5

5.5: Revolving door of pain

Living with pain of chronic ulceration implies a life of limitations on a day-to-day basis. It is a different kind of life from the one led during good health. Life changes for people who develop leg ulcers quite considerably, effecting a transition from our normal phenomenological mode of bodily "dis-appearance", i.e. a body which "passes us by in silence", in Sartre's terms, to instead a state of corporeal "disappearance" (i.e. a dysfunctional appearance), becoming a focus of everyday life. Many of the accounts of pain endured are evocative, often tempered with a tone of despair and futility, a pain that at times appears unrelenting and all consuming epitomising the destructive force of ulceration"

> *"[...Y]ou can't express the pain that you get with them. It is that bad, you don't know where to put yourself, you don't know where to put your legs, you don't know what to do with them they are that bad."*
>
> Mr Whalley: 17

People seemed to experience pain, not as a one-off episode but as a cyclical and recurrent feature of various stages of ulceration, as described earlier by Mr Owen and Mrs Brown, never truly knowing when it was going to strike next. Like going in and out of a revolving door of pain, trapped in a world of pain, which few people seemed to understand. People sit down to relax at the end of the day to read or watch television, but still there is no peace, as evidenced by Mrs Kay who said:

> *"If you were sat watching television... all of a sudden you got this grinding pain in your leg, tears well up in your face and you just got up and walked out of the room... because you knew you were going to cry."*
>
> Mrs Kay: 65

Mr Owen's world had changed dramatically at the age of 29 when, due to bilateral ulceration, he was no longer able to continue work as a coach driver. Thirty years on he still grieves for a life lost to ulceration. He has been forced to lead a life, which he doesn't enjoy: being at home and looking after the house. His life-world is dominated by unsuccessful efforts to cope with and control his pain: *"Whatever I do causes pain"* he said. It would seem obvious from these five words that he must have tried various things to prevent, or at the very least stop, his pain, but all to no avail. He appeared to be trapped in "catastrophic thinking" about pain as he displayed magnified effects of pain with a minimum ability to cope and, a great deal of disability for a relatively young man (Keefe, Rumble, Scipio *et al.*, 2004).

Suffering and the body become deeply intertwined and shaped by pain: ignoring the body is not possible. The body forces itself into awareness by appearing unforgettable through its disturbing presence. There was an overwhelming sense of being gripped by the physical limitations of the pain from the ulcers. It reflects how the consequences of a chronic illness, such as leg ulceration, overshadow the individual's possibilities and resources and the main experience is the limitation that follows. The despair was expressed in comments such as:

> *"[...B]ut it's that painful at times if I had a knife I would cut the bloody thing off. Yeah... you can just sit in here and it's throbbing and throbbing."*
>
> Mr Owen: 15

This appeared to be the sentiment of someone at the end of their tether, who has tried everything he can think of. Prolonged suffering, in which the present moment may seem like an eternity, erodes human dignity: an hour of pain and discomfort can seem as long as a day of pleasure (Auten, 1986). Mr Whalley describes feeling trapped by the pain from his ulceration. His account describes a loss of control because of the constant and unrelenting nature of pain. He is an 85-year-old gentleman who had managed, at the age of 71, to secure himself a part-time, early morning job, tidying up at his local DIY store. It was a job he really enjoyed, he told me, and described in detail some aspects of this work and, for a fleeting moment, his demeanour changed as he relayed the enjoyment he derived from his job, which also provided him with some extra money to supplement his pension.

> *"I had to give up my job because I couldn't get to work... well I had to give it up and I enjoyed it, I really enjoyed it, and I just had to forget about it, I had to give it up."*
>
> Mr Whalley: 30

The following account came after he had explained to me his final day at work, when he realised that he was unable to continue. Ulceration, in particular the pain, had finally snared him, trapped him in its web. It was hard to miss the futility and innate sense of "giving in", especially when he emphasised his pain for the third time in a matter of ten minutes:

> *"The pain is that strong you know... you think about it you know, its there, it's always constantly there.... Oh it really affects you there is no two ways about it .The pain it really gets at you and you can't do a thing really you know. You are absolutely stuck with them, they more or less know they*

> *have got you and they are not going to let go kind of thing. Oh it does get you down, you hit rock bottom actually."*

Mr Whalley: 16

It felt as if he had been fighting a battle to keep going for many years with his ulcers but unfortunately ulcers and pain were the victors. As the pain severity worsened there was a parallel decline in his ability to function, and he finally gave in to the realisation that he could no longer carry on working. He had tried taking various pain killers but the pain seemed to be refractory to treatment and started to interfere with other daily activities such as mobility:

> *"[...T]hey are no good painkillers, they don't do anything, they don't kill the pain, the pain is too severe. Once you get a really bad ulcer you cannot control that pain no matter how many pain killers you take."*

Mr Whalley: 46

He was by no means the only person to be adversely affected by pain. Mr Jones and Mrs Gray, although not quoted here, were also affected by pain to the point they were forced to retire earlier than they had anticipated. Restrictions to daily life are pursued in chapter seven when their voices are heard: to add them here risks repetition since they have not articulated anything different and they are not quite so clear in their expression as other people who are quoted several times. Pain for most appeared to be a central part of living with a leg ulcer causing them distress, despair, frustration and often depression; as depicted in the following quote from Mrs Kay:

> *"Well as I say, some days the pain was worse than others. Some days you thought oh the pain you know, then I would be sat having my breakfast and then burst into tears something like that. Oh yes. Really got... it did... well it made me depressed."*

Mrs Kay:35

5.6: Night pain and interrupted sleep

Sleep is considered a universal, basic need for health and survival and is also believed to be essential to the healing process (North, 1990), with sleep deprivation impairing tissue formation. The descriptors used by some people were graphic, they talked about being kept awake all night because of the pain which felt like someone scraping the ulcer with a razor blade, or stabbing it with a red hot darning needle:

> *"I wasn't sleeping. It was really bad it was, you would just get relaxed in bed and then... it was like someone with a red hot darning needle sticking it in you."*
>
> Mr Ball: 47

Living with frequent episodes of pain, which just come on for no apparent reason, again emphasises a lack of control. It also reinforces that these individuals are equally at risk of pain at night. In this study, sleep deprivation was certainly an issue. *"I couldn't sleep"* was repeated by 16 people, with many individuals having their sleep interrupted by a sudden onset of pain, which added to the burden of ulceration:

> *"The pain was so intense... I could cope with most things but this was this was just destroying. I couldn't sleep so me sleep pattern was up the pole, I was getting I was cat napping for an hour or so at a time and then I'd be up."*
>
> Mr Davies: 18

People already exhausted from a day in pain go to bed, hoping for some relief, but the frustration, despair and pain continue, as revealed in the following excerpt in which Mr Whalley struggles to make me understand that the pain he has to endure at night is as bad, if not worse, than the pain he has to endure during the day:

> *"Oh definite, you can't get off to sleep at all, there is no way you are going to sleep with pain like that, you can't explain how deep that pain is. You know how severe it is...you just lay there and it seems as if the night is never coming to an end."*
>
> Mr Whalley: 16

That "never ending" night appeared to allow time to focus on aspects such as their leg ulcer, *"you just think about it more"* was something Mrs Hall said. It was during the night when the pain was so severe that Mr Whalley's mind began to work overtime:

> *"[...T]he pain is that bad, it frightens you because you don't realise that pain can be like that... you wonder whether gangrene is setting in."*
>
> Mr Whalley: 1

As noted by Solnek and Seiter (2002), disturbed sleep patterns can also be used as a reliable indicator of depression, with insomnia one of the most common complaints. His concerns about gangrene are addressed later in this chapter but illustrate here the extra burdens that ensue for people already in a state of physical pain so bad it frightens them. How cruel then, that they have the added mental anguish that something much more sinister is happening.

Lack of sleep seemed to make coping in the day that much more difficult and, as articulated by Mrs Kay, makes even the thought and desire to start the day a difficult prospect. The following excerpt illustrates the significance of lack of sleep on an individual's ability and desire to cope with the following day:

> *"Well you just stay in bed a bit longer it's all you can do, rest. It did keep me awake at night I must admit. It's no good... I just felt... like staying in bed forever, but I thought life has to go on."*
>
> Mrs Kay: 38

It is easy to miss the sheer futility that emanates from the last seven words of the quote from Mrs Kay: note the lack of desire for life itself to go on. The true meaning of their lived experience often came as much from what they didn't say as much as from what they did. Fear, overwhelming tiredness and no desire to get out of bed and even start the day graphically illustrate an impact on these individual's quality of life. It is not just physical fatigue, but mental fatigue, which has the hallmarks of depression:

> "[...*A]t night that is when it plays me up... and if you don't get any sleep for a few nights on the run you think to yourself I can't cope."*
>
> Mrs Boyd: 40

A person's daily being-in-the-world is often disrupted by lack of sleep and interrupted sleep. Closs (1992), noted that pain disrupts sleep, causing fatigue which then significantly reduces pain tolerance and the situation becomes like a pendulum swinging between pain and exhaustion.

> *"I just was tired, sometimes I was so tired from no sleep I would just fall asleep in this chair."*
>
> Mr Ball: 14

People acknowledged that they were more irritable and perhaps difficult to live with than they were prior to having an ulcer and that this was mainly due to a sustained lack of sleep. They verbalised the various strategies they had developed in an attempt to cope, not only with the pain but also with the lack of sleep. Many resorted to napping in the day or staying in bed that bit later if they could. Some of the individuals spoke about getting up in the night and reading, making themselves a hot drink or taking an extra pain killer.

> *"I'd watch the television I'd try and read I'd try, I'd count sheep I'd do all sorts of things. [E]rm, and so then I'd be very irritable and still* ***no*** *[his emphasis] sleep."*
>
> Mr Davies: 16

I could sense the desperation that he felt trying to get to sleep at night, to forget, or at least distract his mind from his ulceration, but still sleep often eluded him. Other people had asked their doctors for sleeping tablets which brought their own inherent problems such as not wanting to get up out of bed until the middle of the afternoon the following day, mainly because people had tried to sleep first and, as a last resort, taken sleeping tablets in the early hours of the morning so that the tablets did not take effect until much later. In other words, medication had been prescribed or dispensed, possibly minus adequate explanation.

5.7: Coping with pain

As described earlier, people developed strategies to cope with a lack of sleep. There was one particularly desperate tactic described by Mr Ball, who felt the only way he could cope with the pain at night was to resort to self-harm. He actually is grateful, as you will see from this extract, for his psoriasis, which in itself would be hard for most of us to accept. Yet it would be difficult not to see it as a coping strategy for managing his ulceration.

> *"[...W]hen that [ulcer] was very bad at night, and there was a patch of psoriasis round here [indicating the back of his arm], which was a bit sore so I'd aggravate it and make it worse... I would make it more sore if you know what I mean and doing that, over rid that [the ulcer]... I mean, you might never have heard of it but as kids if you banged your elbow my dad used to say bang your other one and you will forget it and it works. Common sense really. If you bang your elbow, you bang that one you forget about that, that one is now sorer. This was the same you see, doing this [picking at psoriasis], but I could control that because it was up to me how often I did it. Until that [leg ulcer] stopped stabbing. That is how I managed that one... sometimes. For which I was grateful for the psoriasis."*
>
> Mr Ball: 47

In my reflective journal I noted that I really couldn't believe what I was seeing; he had evidently suffered from a sleepless night as the psoriasis looked angry and had obviously been bleeding due to his constant picking. He caught my stare and in that instant I felt I saw the pain that had driven him in the night to such extreme measures, he just nodded and carried on with his story.

Fifty-eight-year-old Mr Williamson had to actively make an effort to function, despite the pain, using an active coping strategy through the distraction of his chip shop business with which he persisted until eventually he was in a position to sell the shop. In his case, it was a cognitive process in which he learnt to tolerate, or at least to, "put up with" the effects of chronic ulceration in order to gain some sort of normality in his life.

> *"[...W]ith your business there is always something going on, so you would have all that interest going on in your mind... that keeps your mind ticking over on different things... If you were sat in the house you would be thinking ulcer, ulcer, ulcer all the time, whereas* ***I had*** *[his emphasis] to go and get on with my life and get it sorted out."*
>
> Mr Williamson : 30

He was involved in thinking and engaging in an activity unrelated to his health problem (Endler, Kocovski & Macrodimitris, 2001), and this appeared to help him to function despite the pain and to cope, at least most of the time. It has to be remembered that it was ulceration which ultimately forced him to sell his shop. Most people in this study reflected a tendency to rely on passive strategies, such as pain-contingent rest, i.e. rest taken in response to the level of pain experienced, or avoidance of activity.

> *"[...S]ome days it was really painful to walk about and them days I used to just sit and put my leg up... on a bad day I used to give it [the house] a quick tidy up and just sit with my foot up."*
>
> Mrs Hall: 39

5.8: Uncontrolled or uncontrollable pain

Despite having excruciating pain, there were some people who seemed almost to go out of their way to avoid taking painkillers. In some cases the sedating affect, which although welcomed at night, was a nuisance during the day. However, in other cases it was due to the belief that somehow painkillers would be bad for them. Participants were unable to rationalise their decision, apart from having an overwhelming concern about "getting hooked on painkillers". Painkillers should be taken as a last resort, as portrayed in the following two excerpts. It was also interesting that Mrs Warlow used the number of pain killers she required as a marker of the condition of her ulcer:

"I kept thinking you know if I can do without [painkillers] *that I'm a step nearer."*

She actively did without painkillers even though she described the pain as:
"Like nothing [her emphasis] I've ever experienced before, I couldn't put my heel to the floor."

Mrs Warlow: 11

It was noteworthy that only two people spoke about nurses raising the issue of pain relief with them and, interestingly, not one person mentioned the nurse as someone to turn to, in times of excruciating and unrelenting pain, for advice. The role of the health professional in the management of pain is an issue explored fully in chapter seven.

The following extract from Mr Turner depicts a man who verbalised how he was desperately trying to continue working as a mechanic, living constantly with the anxiety that he may not be able to continue with his job if his ulceration did not improve. He was married with two children and not working was out of the question: how would he keep his family and home? He explained that he couldn't even take time off from work as he did not receive any sick pay. The poignancy of the following quote lies in the fact that he was just trying to "get through" the day, not enjoy it, but just be able to keep going:

> *"[...I] was in a hell of a lot of pain, pain wise at work, I was getting a bit... at the end I accepted taking these tablets [pointing to a box of analgesia], nobody wants to take painkillers, but at the end I thought at least it is getting me through the day."*

Mr Turner: 10

In some cases, individuals did not achieve pain relief with the use of the analgesics they had been prescribed:

> *"It [pain] is more or less uncontrolled. You can't control it, once you get a really bad ulcer you cannot control that pain. No matter how many pain killers you take."*

Mr Whalley: 46

Pain can have a devastating effect on people as can be seen from the stories in this chapter. Pain is dehumanising, as portrayed by 85 year-old Mr Whalley, who had the following to say about the impact of pain for him:

> *"[...W]ell it made you feel useless... I had to depend on the wife doing everything for me, I couldn't even get to the toilet, I was crawling on my hands and knees to get to the toilet they were that bad you know."*
>
> Mr Whalley: 6

The last time he had been expected to crawl on his hands and knees was in the trenches during the war: this time he was fighting a very different kind of battle. In the words of the ethicist Edwin Lisson "Disease can destroy the body, but pain can destroy the soul". In other words, pain can destroy autonomy, intelligence, self esteem and joy which certainly resonates in the stories of these sufferers. Pain had undoubtedly caused a breakdown in Mr Whalley's sense of self, evidence of a breakdown in the normal "smooth functioning of the body" (Benner & Wrubel, 1989, p59). It had become, instead, a body over which he appeared to have very little control and about which he was visibly upset during the interview. It was made more poignant by the example he gave of not being able to get to the toilet. We learn from a very early age that socially acceptable behaviour is the ability to take oneself to the toilet.

5.9: Pain of ulceration as the chronic condition

For some, the pain itself had developed into *the* chronic intractable illness with the ulcer taking second place. The pain interfered with their normal functioning and caused almost inescapable stress and this aspect is explored further in chapter seven. The strength, uniqueness and pervasiveness of the pain experience is captured in the following verbatim quotes from Mr Whalley and Mrs Brown. Quotes that also depict the all-encompassing nature of ulceration and the almost obsessive focus on their legs:

> *"When they [ulcers] are bad you know they are bad and the pain is absolutely constant day and night it never eases off. That pain never eases off when they are bad... they are really painful and if feels as if it is pulling*

> *all the time. You can't really explain the pain... you don't know where to put your legs, anything... there is no peace."*
>
> Mr Whalley: 10

And again, pain's unrelenting nature is graphically described by Mrs Brown:

> *"No, no. Because it was there, the pain was there all the time you just couldn't forget it, you could not forget it. Sometimes you just couldn't help bursting into tears, you just feel so terrible."*
>
> Mrs Brown: 70

Pain seemed to render most individuals almost speechless yet, ironically, their bodies were almost crying with pain. It was difficult for them to rationalise the pain they had themselves, which ultimately meant that talking about or explaining the pain to anyone else was difficult. Scarry summed this up in the following sentence when she defines it as an experience that is utterly "un-shareable":

> *"Physical pain – unlike any other state of consciousness – has no referential content. It is not of or for anything. It is precisely because it takes no object that it, more than any other phenomenon, resists objectification in language."*
>
> (Scarry, 1985, p.5)

People used their pain experience, above any other symptom, as a barometer to judge the progress or deterioration of the condition of the ulcer:

> *"[...W]hen you have a good day and then you go back again that is very worrying and very stressful... you know... you think I was alright... something is going wrong."*
>
> Mr Turner: 11

People interpreted a decrease, or absence, of pain as a sign they were progressing or healing, and would build their hopes up accordingly. The fact that Mrs Boyd's ulcer was still leaking was not as important a measure, in her eyes, as the level of pain:

> "[...B]efore I went on the Thursday I was thinking to myself, oh this is good, it wasn't paining me at night, it was still leaking a bit but wasn't paining, I thought this is good." Mrs Boyd: 38

A similar feeling is expressed by Mrs Hall:

> *"[...I] would have days when it weren't too bad because that is the time I would think I wonder if it is beginning to heal because it feels really good this week."*
>
> MrsHall: 59

The ulcer "feeling good" meant no pain, Mrs Hall explained to me. Conversely, the consensus view was that the "unexpected" onset of pain, or an increase in the pain experience, was taken as an early warning signal of potential infection, or at the very least deterioration in their ulcer. Most people knew, as portrayed in the following quote from Mr Whalley, that an infection in an ulcer would delay progress and result in an increase in pain, to be welcomed with dread:

> *"[...S]ometimes they don't hurt you at all, you can walk about, you can do anything... then they get infected and the pain starts and they get really bad... then you know you are in trouble."*
>
> Mr Whalley: 8

Infection has a recognised link to pain severity in ulceration (Mallet, 1999).
People generally felt that no one appreciated just what they had to endure, because this sentence of pain and its sequelae was not obvious from their demeanour. There is often a mismatch between how we look and how we feel and we try to almost "keep up appearances"; an aspect explored further in chapter seven in the section, *Keeping up appearances*. According to Madjar (1997), pain can create a gulf between those who are in pain and those who are not.

I noted in my reflective journal for December 2005 that in recounting their stories I was aware that pain was etched certainly on the faces of several of the individuals, and they became overtly upset to the point that even on recounting their stories at times it might be with tremulous voice and eyes filled with tears.

For most of the individuals, the accounts were more than just stating that they had pain; it went much deeper, into suffering, leaving them feeling imprisoned, unable to get on with their lives; this aspect is discussed more fully in chapter seven. Many suffered from deep emotional and psychological pain that impacted on every aspect of their lives, serving as a constant reminder of their condition. This is portrayed by Mrs Warlow, where it is hard to disentangle which aspect of pain makes her spontaneously burst into tears at the table:

> *"Well I thought why has this happened to me? All I want to do is get on with my life and I didn't want to be ill, which I was... you know... many, many times, you know... I'd sit at the table and I'd just start crying for the pain."*
>
> Mrs Warlow: 27

The following journal extract for February 2004 may assist with the answer.
Outside it was damp and miserable and inside the house offered no warmth or happiness. The house was deathly quiet and very dismal; my footsteps echoing on the cold tile flooring as I crossed the hall into a tiny room overlooking the overgrown back garden where Mrs Warlow had been sitting, waiting for my visit. The house and garden were lapsing into a state of disrepair, which seemed to be an extension of the despondency and despair in her story.

Pain was a constant reminder of the ulcer and its sequelae, appearing throughout individuals' accounts and having a profound effect on their lives. Six individuals were widows and most people had suffered from the pain of bereavement of a loved one (partner, parents, siblings, friends), been the main carer for a disabled partner or relative or, like Mrs Brown, coped with both. Despite these major life events, Mrs Brown was able to illustrate her illness trajectory with a specific event, which she articulates as being one of the worst times in her life. The pain impeded her mobility and this restriction in activity seemed to send her into a state of darkness and despair; it was almost too much for her to bear:

> *"Last Christmas Day I was trying to do our dinner in here and I could hardly walk about, it took me all my time walking from one side of the kitchen to the other, I was that bad, oh I was ill and the pain, I've never*

> *known pain like it, shocking, absolutely awful, I'd cry, oh it used to upset me... it was one of the worst times of my life I think that, really very painful ulcers, they are horrible things... I felt like I was going out of my mind sometimes... I just felt like running out that door and running and never coming back."*
>
> Mrs Brown: 14

It was as if there was some form of "bodily alienation" or "betrayal" at work (Bendelow & Williams, 1995;Williams, 1996). She had always made Christmas dinner and assumed that this particular Christmas Day would be no different, despite her ulceration. However, this normality had been disrupted and she found it difficult to bear. Christmas Day celebrations were put on hold as she suffered another day of unrelenting pain, driving her to the edge of despair.

There was an unquestionable association between pain and depression for Mrs Brown (who scored 13 on the HADS-D subscale), as pain impacted on her ability to cope with activities of living, such as cooking, as evidenced in the above excerpt. It was at this period in her illness trajectory that her doctor prescribed antidepressants, which she still takes.

Constant pain, lack of sleep and anxiety are ingredients that can result in atrophying weariness, together with changes to an individual's temperament, making them shorter tempered than normal – not only with themselves but also in relationships with family, friends and work colleagues. In the words of John Milton, in *Paradise Lost*:

> *"Pain is perfect misery; the worst of evils and excessive overturns of patience."* (2003, Book VI, lines 462 – 464).

This lack of patience is exemplified by 52 year-old Mr Turner who scored ten on the HADS-D subscale, and who found the pain made him "sharper" with people than he would normally be, exemplifying what suffering can do to people:

> *"I must admit pain wise; you are a little bit sharper with people. I wasn't going mad at everyone but I used to like with the wife and the boss at work... hang on a minute... the boss at work... my leg is hurting just give me a minute."*
>
> Mr Turner: 5

There was a collective script, with people getting frustrated and some people admitting to "flinging things" in their anger in an attempt to "get it out of their system". The anger and frustration is not targeted at an individual but is an outward sign of the inner turmoil of trying to cope with unresolved pain which is both physical and emotional: every so often, pent up emotions reach boiling point and they find an "escape" and release of tension in out-of-character responses.

Mrs Hall is a 69 year-old lady on her eighth episode of ulceration, with her current ulcer present for nearly five years but, she assured me, almost healed. However, because ulceration has, on and off, been part of her life for 27 years, her story is a pastiche of a life-time of ulceration, and is peppered with aspects from various episodes rather than a picture of life just in the now:

> *"I think I got on their nerves [family] really because I used to be so nasty... if it were a bad day I had a nasty side, and I think they got a bit fed up with it [laughs]. But I used to say if you knew how much it hurt."*
>
> Mrs Hall: 37

Similarly Mrs Brown, who describes herself as a placid person "normally", said:

> *"I used to get upset but I used to get mad as well, I used to get really nowty sometimes you know, it weren't me at all, because I've always been very placid really, but it was the way it used to affect me, sometimes I used to say to Fred I could smash everything in here... I used to get like that."*
>
> Mrs Brown: 35

People constantly alluded to the limited control they had over the symptoms of ulceration and it was this inability to control just when, and why, the pain would start that drove some people to the edge of despair.

5.10: Fear of gangrene

Pain seems to eat away at the very core of these people: "*I was a different person altogether*" stated Mrs Brown, but pain seemed to weave its insidious web through all the individuals "making" them portray out-of-character behaviour, affecting their capabilities and testing their tolerance levels. Constant and unremitting pain in the day, spilling over to night time when one expects to recharge one's batteries in preparation for the day ahead, results in individuals who are exhausted, short-tempered, weepy, frustrated, angry and, in some cases, desperate. One such person was Mr Davies, who had reached a point where he truly believed that the only way to resolve the pain and odour was to have his leg amputated, a factor he discussed with his daughters and, ultimately, his GP:

> *"[...I] felt that there was only one answer to get rid of the ulcer with its pain and smell, was to get rid of the damn leg... I said [to the GP], I can't put up with more years of this thing, I'm not prepared to do it. I said in fact I will go over to B and Q and rent myself a chain saw."*
>
> Mr Davies: 25

In many ways his "logic" was understandable. If he had managed to have his leg amputated three years ago when it was excruciating and in a terrible mess, he argued, by now he may well have been pain-free and able to mobilise with a prosthesis.

I was to be reminded of my own influence over the conversations that took place with the individuals; that they were more than interviews. They were also discussions, through which people continued to understand their experience of ulceration. This came to the fore when pursuing statements, such as that made by Mr Whalley, as referred to earlier when he was unable to sleep:

> *"It really is, it frightens you at times because you don't realise that pain can be like that."*
>
> **JJ: So when you say frightened, what is going through your head?**

> *"Well all sorts, you wonder whether gangrene is going to set in, you know, you wonder whether you are going to have to have skin grafting to get over if, it does, it frightens you to death really."*
>
> Mr Whalley: 18

It was something he hadn't even discussed with his wife, the fear that the uncontrolled pain meant he might develop gangrene. This was not an isolated thought from a single individual that there may be something sinister happening (to their ulcer), but was pursued by seven other people, and varied between cancer, gangrene and losing a leg due to poor circulation. Individuals in other studies and literature report living with uncertainty and fear about chronic illness. Mishel (1993), described uncertainty of outcomes with chronic illness and its treatment as "emotionally painful". Thoughts of "sinister" changes to their ulcers seemed to proliferate at times when the pain from ulceration appeared relentless and uncontrollable, as exemplified by Mr Williamson, who developed an infection resulting in *"unbelievable"* pain and odour. Although increased pain and odour are signs, to a clinician, that a wound "may" be infected, they represented something far more sinister to Mr Williamson as demonstrated in the following verbatim quote:

> *"I got an infection and it really knocked me, the pain was unbelievable as was the smell and all this horrible stuff coming out of my leg and I thought gangrene."*
>
> Mr Williamson: 6

It is noteworthy that five individuals (two female, three male) lived with spouses, and had felt either unwilling or unable to discuss this fear with their partners. In the case of the two women (Mrs Smith and Mrs Boyd), they had both explained how involved their husbands were in their care:

> *"[...H]e [husband] gets angry because it's getting no better... he has*
>
> *dressed it for me numerous times over the years."*
>
> Mrs Boyd:15

Similarly with Mrs Smith:

> *"[...I] mean it pained, it hurt, he [husband] couldn't do enough for me, I mean he's been my right hand man through pain and everything."*
>
> Mrs Smith: 38

How strange, then, they couldn't bring themselves to talk about their fear of losing a leg. Two other women (Mrs Topping and Mrs Kay) lived with their sons and it somehow seems "acceptable" that fears aren't articulated to your children. Mr Turner was not only trying to address the pain and lack of sleep, raising concerns for him that he might lose his job, but he was also harbouring thoughts that his ulcer was cancerous:

> *"Another thing when I didn't know what it was I thought I might even lose my bloody leg, I was that worried... when I had all this pain and nobody would tell me what it was, that is when I was getting very very worried you know, so I didn't know... cancer of my leg is what I thought."*
>
> Mr Turner: 11

As was Mr Jones:

> *"[...Y]ou think that the ulcer is not improving and could turn into a cancer and then you'll have to... you'll have to lose your leg... oh yeah it's gone through my mind."*
>
> Mr Jones: 50

It was interesting that this was the first occasion that either of the men had been able to talk about their fears with anyone. Neither had felt able to talk to their spouses, or to the nurses. It also became evident that the nurses had never either noticed or pursued the fact that both men must have been anxious. Mr Jones spoke about probing and asking the nurses why the ulcer was taking so long and there was no improvement, but it appears that he had not raised the issue of cancer; neither had the nurses apparently reassured him that he did not have a malignancy in his leg ulcer. Patients' reluctance to disclose their experience of emotional distress to health professionals has been reported previously (Chew-Graham, Mullin, May *et al.*, 2002). Some of the issues concerning the nurse-patient relationship will be pursued further in chapter seven.

That aspects of suffering remain unspeakable as suggested by Frank (2001) would seem apparent in the aspects that people found difficult to verbalise, even to their nearest and dearest. As stated by Mrs Boyd, who thought at one time she might lose her leg:

> *"You get these things in your head and you don't say to anybody you think that is what it is."*
>
> Mrs Boyd: 24

Thoughts such as these were fanned into major anxieties if the individual knew someone who had "lost their leg":

> *"I felt upset... I really did, I felt this is never going to get better. I was, as I say I was frightened I thought I was going to lose my leg to my knee or something like that. I have known people who have lost their leg and then eventually died because of poor circulation in your legs."*
>
> Mrs Kay: 3

5.11: A world you don't want to be in

Ulceration seems to transport people into a world they don't want to be, a world dominated by increasing pain and suffering, which interferes with their day-to-day living. Pain impacts on people's ability to carry on with daily living and also on their ability to sleep. For some the suffering is almost relentless, whilst others do achieve some respite although often the episodes of pain are frequent. Pain weaves a web around the lives of these individuals so that ulceration takes control, and appears often at the most unexpected times and places. It is hardly surprising therefore, that pain itself can become the overwhelming feature and draws people into its web, making them feel trapped and causing people to feel depressed.

Mrs Brown's life had been turned upside down by the death of her mother and the severe disability her husband had been left with following a dense stroke. Having bilateral ulceration was the final straw as she found the pain unbearable, even worse than the back surgery she had endured in the past. She suffered depression as she found it increasingly difficult to look after her husband and cope with her ulcers; her doctor eventually prescribed her antidepressants. Mrs Brown admits that she is unable to enjoy things the same as she did before and that she is not as cheerful and outgoing as she used to be. These aspects were also significant when she completed HADS-D, for which she scored a total of 13:

> *"[...I]t was one of the worst times of my life... really painful ulcers... I just couldn't cope with my housework, looking after T, I was in so much pain it really got me down and depressed... I always seem to be crying."*
>
> Mrs Brown: 25

Mrs Brown was one of a number of people who used other medical problems to help define the pain of ulceration. Mrs Kay also referred to arthritis, in an almost tacit assumption that pain with arthritis is so well-known and understood, whereas ulcer pain clearly isn't:

> *"I have arthritis, but arthritis pain is nothing compared to that [ulcer pain]. No... no it isn't."*
>
> Mrs Kay: 28

Again, almost 45 minutes, later she reminded me with this statement:

> *"[...H]orrible, the most horrible experience I have ever known... felt like crying all the time that is how it was."*
>
> Mrs Kay: 81

This is the reaction of a 72 year-old widow, forced to retire earlier than she had hoped, for whom life has already been difficult, who still looks after her mentally disabled son. She finds it hard to sit and watch television, as the pain often makes its presence felt. Similarly, if she goes out shopping she can literally be brought to a standstill because of the sudden onset of pain. On completion of HADS-D, for which she scored 12, she noted she was unable to look forward, or to enjoy things the same as she did before. It was not surprising in interview when she said:

> *"[...O]h the pain, well it made me really depressed. I had to go to the doctors and he said you are depressed and gave me some tablets for depression. It was through my leg and particularly the pain, I knew I was depressed... it was a terrible time."*
>
> Mrs Kay: 84

> *depressed... it was a terrible time."*
>
> Mrs Kay: 84

Unable to carry out tasks that have previously been taken for granted, such as shopping, cooking and cleaning, are often the aspects which can have a greater impact than the inability to, for example, go away on holiday. They are the daily activities that cause us the greatest anxiety when we can't manage them, because they are such an integral part of day-to-day living, normally undertaken without causing pain and despair, and requiring little planning or forethought. For Mrs Warlow, who admits to being an active person, her account is rich in evidence of the extent to which her life has changed because of ulceration. She verbalises feeling mentally and physically slowed down because ulceration *"has got a hold on my life"*. She can't walk properly because of the pain and has lost interest in going anywhere, refusing to go away on holiday. She prefers to just sit at home for long periods of time on her own, as her husband works long hours. Often she is unable to focus on a book or the television, as she admitted in the HADS-D in which she scored ten. She stated that she would cry a lot of the time because of the pain, and that she felt depressed because of the dramatic change to her life, her ability to do things.

It is a world gripped by pain in which individuals' stories appear like tales of combat, in which they are trying to overcome the enemy of ulceration and limit its ruinous effects on their lives. There appears to be little control for their pain; the body is ever present, yet slowly the individuals feel they are losing control over their bodies as their legs no longer respond as they did before but take on characteristics of their own, constantly reminding the individuals of their presence:

> *"Like I say you get to rock bottom really, you just don't know what to do. The pain is that strong. Why have I got this, why have I got to put up with this pain It's there, it's always constantly there."*
>
> Mr Whalley: 62

Mr Whalley no longer enjoyed things the same, as he was unable to participate in the activities that he wanted to do, such as dancing classes and socialising with friends. He had lost enthusiasm and confidence and even started to feel useless as his independence was eroded by the limitations of painful ulcers. On completion of HADS-D he scored 12, with the only aspect he felt remained unaltered was the interest he took in his appearance, which was an aspect he refers to as important (See chapter seven).

5.12: Summary

This chapter has introduced the world of 20 people living daily with ulceration, some for months, but many for years. The stories told to me in the privacy of peoples' own homes revealed a collective script of the negative impact of ulceration on their lives, with people transposed into a world of pain, sleeplessness, anxiety, fear and depression. Only two people did not express feeling overwhelmed by pain. People spoke in metaphors, using household implements in an attempt to explain the, almost unexplainable, experience of pain. Life is changed dramatically both physically and emotionally by venous ulceration, yet it is a world so poorly understood, leaving people to feel largely ignored or disbelieved. There are no support networks; even support from family members and loved ones can seem to be limited.

Although 14 individuals were interviewed who had no history of depression, they had all scored ≥ 9 on the HADS-D subscale and their lives appeared to be punctuated by symptoms of depression due to ulceration. For many, unrelenting and unremitting pain emerged as the aspect of ulceration that eroded their *joie de vivre*, resulting in avoidance behaviours such as decreased activity and negative self-image (examined in chapter six). Loss of control, the inability to look forward to things, crying and mood changes are symptoms often equated with depression. However, depression for this group of individuals would seem to have gone unheeded and untreated. Listening to what people have said, it is incomprehensible how it can have remained undetected and this is considered further in chapter seven.

The four people taking antidepressants because of ulceration had realised themselves that they were depressed, and actively sought help from their GP. It was impossible to ignore the depths of despair in Mrs Brown's story as she felt like running away; Mr Davies had been driven to request amputation. These threads of despair weave throughout the next chapter moving me from the comfort zone of my own assumptions, and challenging my horizon, as I listened to the stories.

Mrs Smith and Mrs Hall, selected for interview as they had low HADS-D subscale scores, spoke about the pain they had to endure. Their lives were undoubtedly affected by their ulceration, but they did not appear to be driven to the same depths of depression evident in most of the other stories. The emotions of individuals appeared to result in avoidance behaviours, such as decreased activity and negative self-image, as will be explored in chapter six.

Chapter 6: A Life of Restrictions and suffering

The fundamental fact remains that it is illness, and not health,

> *"which 'objectifies' itself, which confronts us as something opposed to us and which forces itself on us."*
>
> (Gadamer, 1986, p.107)

6.1: Introduction

Chapter five highlighted the physical and emotional impact of pain, with pain seeming to beat like a rhythmic pulse throughout the day, often persisting long into the night. People are no longer "embodied" as their legs become disembodied and a focus of the pain driving some people to the edge of despair. Pain continues to work like a spider, weaving a web, traps its victims in a life of misery, despair and ultimately depression.

This chapter addresses the restrictive and relentless nature of ulceration, which manifests as suffering on an almost daily basis, either with physical pain or psychological and emotional pain. People experience the body as an obstruction in their daily lives as it will no longer respond as it did previously. Life changes for people who develop leg ulcers quite considerably, with the body losing its silence and instead becoming a focus, and an obstruction, in everyday life: from work through to social activities.

6.2: The body as an obstruction to daily living

The body becomes an obstruction in the individual's daily life. According to Merleau-Ponty (1962 / 1997), the body is the basis for human beings' perception; it is by means of the body that one has access to the world (Good, 1992). Many frustrations for the individuals came from the changes to their bodies resulting in the loss of ability to participate in normal family life in activities such as swimming, which was cited several times, as in this example from Mr Owen who was so frustrated at having to remain at the edge of the pool or just sit on the beach to the point that he no longer went away on holiday with his family:

> *"[...B]ecause whenever we went on a job to the seaside we always took our swimming trunks with us so that we could go swimming and enjoy ourselves as well and all that went out the window... I had to stop swimming"*
>
> Mr Owen: 9

The inability to join in activities (because of the body's obstruction), that many of us take for granted, gains in poignancy the more you hear it reinforced by different individuals. Mr Williamson likewise used swimming as an example of activities he had been forced to miss, because of the obstruction of his chronic ulceration:

> *"[...F]irst time I went to Spain... I were sat there, with this bandage on my foot... you sit at the seaside don't you, where most families are in the sea and you are sat there thinking, I can't go in the sea... I will just stay here on the beach and sulk."*
>
> Mr Williamson: 12

The poignancy is not in the activity per se but in the "exclusion" that ulceration causes: constantly sitting on the periphery of family activities, missing out on activities such as *"going in the sea with your kids"*; surreptitiously the ulcer takes control as the element of choice to do things is eroded. It was interesting that, for Mr Williamson, there did not seem to be any question that he would not continue to take his family on holiday, even though he was restricted from taking part in many activities. Many people were like Mr Owen or Mrs Hall, refusing to take a holiday because they were restricted; a decision which had subsequent implications for the family.

> *"I wouldn't have gone on holiday because I never knew how my ulcers were going to be during the week"*

said Mrs Hall – and six other people – signifying not only the unpredictable nature of ulceration, but also the loss of control in their lives: people constantly live in an environment of uncertainty because of ulceration. Mr Owen appeared to stop going on holiday because he was unable to swim, a decision which must have been difficult for the family to accept as he had three young daughters at the time **he** decided to stop going on holiday. It was not a family decision but one, Mr Owen admits, he took himself:

> *"[...I]t used to get me annoyed everybody swimming and I'm sat on the side looking at them... so we stopped going away."*
>
> Mr Owen: 39

This emphasises the all-consuming and encompassing nature of ulceration to the point that some people could only "see" the impact of ulceration on their own lives, appearing somewhat oblivious of the implications of their decisions for the family. It would appear, from what people said, as if they had begun to neglect other valued aspects of their lives such as family, friends and leisure activities. People were undoubtedly suffering from their inability to take part in activities previously enjoyed; as noted by Frank (2001), suffering is loss, present or anticipated. The experience of not being as involved in their worlds as before meant the sense of losing wholeness involving body and self, people spoke of feeling as if they were losing their grip over their bodies. Uncertainty also paralyses hope so that the individual only "exists". Although affected by past experiences, uncertainty is always experienced in the present with people unable to move forward with their lives (Penrod, 2001).

Mr and Mrs Whalley decided that attending ballroom dancing classes would be an excellent way of occupying some of their leisure time, as well as a good way of keeping fit. It was something they had always wanted to do but it had always seemed difficult to find the time until they both retired. What they hadn't planned for was Mr Whalley's leg ulceration as he suffered another acute episode, making attendance at dancing classes difficult. Accounts from participants contain references to shattered hopes and plans for the future, not just for the individual but also, as portrayed earlier, for the family, since the interference caused by leg ulcers extends to the wider family, particularly when they are living in the same house as the person with ulceration.

> *"My confidence went completely. I just didn't want to do anything I couldn't do anything. We were trying, well we had started dancing and we were doing quite well with it, but when these broke out of course that kyboshed that and we haven't been able to do anything for the past two years really in the dancing line because I can't get my shoes on properly, you know you have got to wear a larger shoe on account of all the bandages."*
>
> Mr Whalley: 3

Not only has Mr Whalley had to give up dancing, but so too has his wife. Initially, people were unable to go out because of the ulceration, but it would appear from what many individuals said as if this state changed into an unwillingness to go out. People didn't want to be the centre of attention because of their leg, they didn't want to look different to everyone else and draw attention to themselves if they went anywhere. Individuals stated that they started to lose the desire to go out, demonstrated here by Mr Whalley:

> *"It's horrible, horrible and it zaps... it takes your life away really because you can't do what you used to do by any means because it takes all the enthusiasm out of you, you lose all your confidence and you just don't* ***want*** *[his emphasis] to do anything, you can't do anything."*
>
> Mr Whalley: 2

This 85 year-old gentleman with a 30-year history of ulceration epitomises the cyclical process of acceptance, which was a recurrent feature in all the accounts, and the impact ulceration has had on his life. It is noteworthy that his emphasis has been placed on **not wanting** to do anything over not being able to do anything: emphasising the anguish that ulcers can cause. People constantly reinforced the dramatic alterations and "sacrifices" they had been forced to make because of the irruption of ulceration into their lives.

> *"Oh they do change your life definitely; your life completely alters. You get a bad ulcer and believe me your life changes completely: your life isn't the same."*
>
> Mr Whalley: 26

What is important to keep in mind is that these adjustments are rarely temporary, as a person with venous ulceration, even though the ulcer may heal, are never "cured" since the underlying condition remains present (Chase *et al.,* 1997). It merely goes into remission leaving individuals waiting for the next episode. Venous ulceration is not an event but a life-changing situation. The ulcer, if it does heal, always seems to leave both a mental and a physical scar. As stated by Mrs Boyd:

> *"[...I]t just seems to go on and on forever and there is no end."*
>
> Mrs Boyd: 21

Chronic ulceration undoubtedly separated the person in the present from the person in the past, shattering images of the person in the future. This resonates with the work of Corbin and Strauss in the following excerpt:

> *"Who I was in the past and hoped to be in the future are rendered discontinuous with who I am in the present. New conceptions of who and what I am, past, present and future, must arise out of what remains."*
>
> (Corbin & Strauss, 1988, p.10)

Likewise, it is a life-changing situation for family and friends who miss out on holidays and social activities and not just the individual. Bury (1982), suggested that disease not only disrupts structures of meaning, but also relationships and material and practical affairs. An extreme example of the impact on the wider family was provided by 69 year-old Mr Davies whose wife of 47 years left him because he had become unbearable to live with: *"I was a grumpy, grouchy, miserable old sod."*

Certainly there was a tension evident (from our conversation), in the marriage of Mr Davies; likewise Mr Owen also felt that he *"might as well not be married"*, laying the blame firmly and squarely with his ongoing ulceration problems:

> *"She [his wife] won't come near me in case she touches me leg and she hurts me leg."*
>
> Mr Owen: 46

He claims that prior to ulceration his life was *"perfect"* and that:

> *"There couldn't have been a better family at one stage."*

There appeared, from what people like Mr Owen said, to be a constant yearning for previous lives. Following many episodes and years of ulceration he felt that his life was different as illustrated when he said:

> *"[...I]t has changed and by God it gets me really down at times... you just try and plod on."*
>
> Mr Owen: 74

Ulceration restricted social activities, as depicted earlier, previously enjoyed by family and friends, with a marked withdrawal by individuals from social life. People socialised less because of self-inflicted restrictions it would seem, often, as opposed to an actual restriction: it is not so much an "inability" to leave the house as a loss of "desire" or "fear" of accidental injury to the leg, as articulated by Mr Owen:

> *"I don't even go out at nights now... I sit in here all the time, I know I make myself restricted... my wife goes out but I don't like going in case I get my leg knocked. Yeah you are scared of anybody knocking your leg, you are scared of anybody banging your leg because you don't know if it's going to set another ulcer off."*
>
> Mr Owen: 33

For some people, the joy of an activity was lost in the precision planning which formed part of any decision to even, for example, go to a concert or the theatre. There are so many "obstacles" which would have to be navigated, such as getting on the bus, or obtaining a seat with leg room where they would be least likely to sustain an injury from people going past them. People felt that they had to *"adjust life according to my foot"*, and the ability to do anything spontaneous was completely out of the question, as some places were more "dangerous" than others for people with ulcerated legs: any outing required strategic planning and forethought. Yet, on the other hand, it was equally difficult for people to plan anything too far in advance, since ulceration does not necessarily get better in a progressive manner and it would be impossible to predict either the condition of the ulcer or how your general state of health might leave you feeling; you could never be sure what the ulcer was going to do next. Uncertainty involves different aspects as related by comments from individuals. For people with a chronic illness, such as ulceration (and its treatments), uncertainty encompasses duration, pace and frequency (Weiner & Dodd, 1993). Arranged activities may have to be cancelled or, at the very least, re-arranged because of a "bad" day. People thus started to withdraw even further from social possibilities because the status of their ulcer could not be predicted from one day to the next:

> *"You never knew from week to week how you were going to be."*
>
> Mrs Ruane: 51

It is hardly surprising then that some of the individuals became disinclined to do anything; there was a definite reluctance on behalf of most individuals to get on with things, especially if they necessitated effort, because quite often they had to be cancelled or put on hold. Mrs Bird referred quite aptly to a "lethargy" that even affects the mind:

> *"Yes, a sort of lethargy that even affects your mind... oh I can't be bothered doing that, I'll leave it until another day... just a reluctance to get on with things."*
>
> Mrs Bird: 10

This "biographical disruption" (Bury, 1982), which means that the structures in daily life become disjointed, was, for these individuals, often a matter of adjusting from a very active to a more passive life. For some people, the fact that it limited what they could do was the worst thing about having a venous ulcer. The more active the life an individual had lived prior to ulceration, the more difficult acceptance and adjustment seemed to be; often eliciting the "why me?" question.

> *"I've always been sporty and active, walking, cycling, tennis and I think then why should this happen to me?"*
>
> Mrs Bird: 4

The "why me?" question is itself an expression of grief: as noted by Ricoeur, suffering is always expressed in form of lamentation.

> *"How long? Why?... why me?... why did this person die of cancer, and not that one? Why do children die? Why is there so much suffering, far beyond ordinary mortals capacity for suffering?"*
>
> (Ricoeur, 1955, p.252)

Lost activities mentioned included walking, going to the theatre, socialising with friends, swimming, shopping, going on holiday, dancing, baking and decorating.

> *"Whereas at one time you would think oh I will go so and so, you can't you have to think twice."*
>
> Mrs Healy: 12

People actively considered if the activity was worth the effort that would be required, both physically and emotionally, almost like a cost-benefit analysis. Other significant barriers to leaving the home were not just the appearance of the bandages, but the problems with footwear caused predominantly by the bulk of the bandages: ultimately these impacted on their being-in-the-world.

> *"I like going shopping... but it did stop me from going shopping because I had to wear this horrible big shoe and I felt really everybody looked, I always imagined everybody were looking at it."*
>
> Mrs Hall: 43

These barriers are addressed in more detail in the next chapter in "prisoner to treatment". The experience of not being as involved in the world as before means the sense of losing wholeness involving body and self (Charmaz, 1995).

6.3: Obstruction to work

An aspect which became overtly important, causing major disruption to people's lives was the disruption to working patterns due to ulceration. Eight individuals had been "forced" to retire earlier than they had anticipated / hoped because the symptoms and debilitation of ulceration made maintaining work impossible for them. Five people had developed ulceration after retirement and these proved to be significant aspects to consider when analysing the findings.

- Individuals forced to retire due to ulceration (Table 6.1).
- Others, which includes two people who are still working and one gentleman on Incapacity Benefit (Table 6.2).
- Women working in the home, plus people who developed ulcers post-retirement and now working in the home (Table 6.3).

Table 6.1: Individuals retired due to ulceration

Name	**Age first ulcer (years)**	**Illness trajectory (years)**	**No of episodes**	**Duration latest episode (months)**
Mrs Gray	58	25	7	24
Mr Jones	61	3	1	36
Mr Williamson	23	35	6	133 (Healed)
Mrs Kay	60	12	3	132
Mr Owen	27	30	6	109
Mrs Hall	42	27	8	57
Mr Whalley	55	30	4	53
Mr Ball	53	5	3	32

The median age of onset of ulceration in this group of eight individuals is 54 (range 23 – 61) with a median duration of 26 years (range 3 – 35).

Mr Owen, still only 57, had been "forced" to retire from his job as a coach driver at the age of 29. He was still unable to accept the premature end of his working life as a coach driver.

> *"[...W]ell I had no choice really 'cos I was restricted as to what I could do. I could hardly walk around, let alone drive a coach, I had to go up the stairs on my backside at times... [T]he doctor said if you don't give up work you will end up in a wheelchair."*
>
> Mr Owen: 8

This "loss of control", first alluded to in chapter five, finds echoes in many other aspects of Mr Owen's life to the point it was almost a list of "lost" activities he could no longer engage in, including swimming, digging the garden, decorating, shopping, socialising at night. It was difficult to disentangle the aspects actually "controlled" by the ulceration, from others, such as socialising at night, which could be interpreted as a self-inflicted restriction or choice, an aspect discussed later in this chapter. Similarly, Mr Jones was also unhappy that ulceration meant he was no longer able to continue with his job as a security guard, which he explained was a bitter blow to him.

> *"I had to retire from my job early because of it [ulcer]... I couldn't do the job... I was a security guard, I couldn't walk round properly and eh... and do my patrols and do me job... and I enjoyed me job so that really depressed me."*
>
> Mr Jones: 8

A similar employment issue difficulty was experienced by 58 year-old Mr Ball, also a security guard, who was unable to carry on with his job and forced to retire. Unfortunately, as evidenced in the following excerpt, most people appeared scarred by premature retirement:

> "[...*Y]ou go from meeting people, doing different things at work and enjoy... erm if you enjoy a job you know it makes it all worth while and then suddenly you've had to opt for Tricia on the television, daytime telly and shopping with the missus."*
>
> Mr Jones: 62

The impact of being forced to retire early varied in intensity from individual to individual, but for some it was a devastating blow. It would appear that, for many people, you had to be able to work in order to be valuable. Certainly for Mr Jones and Mr Whalley their self-concept was strongly linked to this notion. For so many people work is viewed as part of the basic scaffolding of life, being a source of social support and providing a structure to the day. Having to give up work seemed to prompt basic existential questions such as "who am I without work?" Mr Whalley evidently believed that he was nothing without his ability to work. It appeared to provide him with a sense of purpose and belonging and the loss of his job had a devastating impact on his self-esteem.

> "[...*Y]ou have to give up your job because you can't get to work obviously, you can't drive... oh I was very annoyed about it... you have to give it up*

> *and you have nothing left... you have nothing left really. You are finished... you have nothing to look forward to."*
>
> Mr Whalley: 39

Stansfeld and Rasul (2007) suggest that unemployment acts like a life event, with depression as the immediate reaction. It was apparent that Mr Owen, Mr Jones and Mr Whalley had engaged in very few activities outside work and consequently felt as if they had *nothing* when ulceration forced them to retire; but it also seemed to erode their capacity to look forward to anything or retain hope, which is also a future perspective. This was evidenced in chapter five in the case of Mr Owen who seemed to have given up on even trying to have a holiday or socialising. There was a pervading air of no longer feeling needed or valuable, together with a sense of loss and deep suffering. As noted by Frank:

> *"Suffering is loss, present or anticipated... At the core of suffering is the sense that something is irreparably wrong with our lives."*
>
> (2001, p.355)

Not only did people become unemployed as a result of ulceration, but they were also dealing with the onset of a physical illness, coupled with a degree of disability – both powerful risk factors for depression (Bruce, 2002). Ulceration appeared to interfere with their role performance and they found it difficult to change roles, perceiving it as a loss of independence rather than a change in circumstances. The eight individuals who described being "forced" into premature retirement (Table 6.1) all verbalised that they felt depressed because of having to give up work. It is interesting to note that they admitted to not enjoying things as much as they did before and felt that they did not have a lot to look forward to: this mirrors their scores in the HADS-D on similar questions. It appeared to be more a case of "pressure" to leave. For example, Mrs Kay spoke about feeling angry regarding the treatment and attitude to ulceration she received at work. The fact that she was not allowed a chair to sit down, just now and again, if her leg was particularly troublesome, or the shop was quiet. Mr Jones referred to the fact that he wasn't offered any kind of other job within the workplace which he "may" have been able to do, or indeed just time off work to get a little bit better. This general lack of understanding of ulceration appears throughout many of the accounts and is explored more fully in chapter eight.

It was interesting to compare Mr Williamson and Mr Owen who had both started with ulceration when they were in their twenties. Mr Williamson did have occasions when the ulceration was so bad that he had to take time off from work as a chip shop owner, and did wonder if he was going to be able to carry on:

> *"[...Y]ou are in the chip shop and you are thinking oh Christ how long can I carry on... I'm in pain... but you have the two kids to bring up, a house, a mortgage and everything to pay... I got upset emotionally inside, but you just have to keep going."*
>
> Mr Williamson: 2

Mr Owen was advised by his doctor to give up work as a coach driver. Undoubtedly he would have been unwise to continue with this line of work, especially as he had already had two episodes of deep vein thrombosis. However, the doctor's advice seems to have been interpreted to mean giving up work altogether, as he admits that he never tried to obtain any other form of employment. Mr Owen appeared to give up on most things as referred to earlier – he no longer even tried to take his family on holiday or to look for any form of work at all. Ulceration had definitely trapped him in its web and he admitted to feeling depressed and to obtaining antidepressants from his GP.

> *"It's so severe at times, well it gets you down having to drag it round at times; I told the doctor I felt really down... he agreed I was on a real downer and gave me some tablets."*
>
> Mr Owen: 87

People with exuding and painful ulcers are "ill", yet there appears in practice to be very little recognition of this fact, as noted by Mrs Hall:

> "[...*Y]ou see that is another thing about ulcers, the doctors don't put you on the sick with them, you still have to work with them, even though you are in pain and haven't slept.*"
>
> Mrs Hall: 24

It is true that numerous people with leg ulceration do continue to work, as I know from my own clinical practice, and this is certainly evidenced in this study (see Table 6.2).

Table 6.2: Working and Incapacity Benefit Group

	Mrs Warlow (Working)	Mr Turner (Working)	Mr Myers (Benefit)
Age first ulcer (years)	60	48	50
Illness trajectory (years)	5	4	8
No of episodes	1	1	3
Duration latest Episode (months)	8	48	42

In many cases, continuing with work is not out of choice but out of necessity. People have family to consider, a mortgage etc. to pay. Yes, "lives" per se have continued, yet the people I spoke with did not feel they were "living" the life they wanted, they had been transposed into a "world they did not want to be in" as portrayed in this account from 52 year-old Mr Turner, married and with children to consider.

> "*[...]I don't get paid if I'm off; I run the house... the financial side of it. I thought I would... seriously at one time; I was so close to having to pack work in. Come three o'clock in the afternoon I just couldn't stand the pain... it got me down I must admit.*"
>
> Mr Turner: 24

These mirror exactly the concerns articulated earlier by Mr Williamson who also had to force himself to work because of financial responsibilities. Mr Turner's body was a definite obstruction to daily living, he was made aware daily of "having" a body. I would argue that most of the general public who work are not considering agonising pain at three pm on a working day on a daily basis, and worrying about how long they will be able to continue in work because of pain. Not only did Mr Turner have to cope with his ulcer on a daily basis but he also had the added anxiety of trying to keep his job. It was noteworthy that only Mr Turner's employer was reported as showing any understanding or sympathy. Mr Turner described how his boss was the person who suggested seeking professional help and offered to pay half the cost of a private appointment.

Individuals **do** consider themselves to be "ill", particularly during an acute episode, as stated by Mrs Warlow: *"I was ill, I would be crying because of the pain... I wasn't right"*. As leg ulcers are not "legitimised" by doctors, then the general public (who may have never had ulcers), do not consider them to be a chronic illness, they remain "just a leg ulcer" and this perhaps explains some of the attitudes demonstrated by employers, work colleagues, friends and even family.

6.4: Work inside the home

Originally viewed as separate groups, Table 6.3 was re-conceptualised as two parts of one main group. While five people post-retirement continued to work, this was work inside the home. There were four women who "elected" to work in the home either through preference, as in the case of Mrs Boyd and Mrs Healey, or because of circumstances as in the case of Mrs Topping who was widowed at a young age with a family of six boys to look after. Latterly, Mrs Brown was also unable to continue working as she had her disabled husband to look after.

Table 6.3: Working in the home

<table>
<tr><td colspan="5"><i>Women working in the home who developed ulcers</i></td></tr>
<tr><th>Name</th><th>Age first ulcer (years)</th><th>Illness trajectory (years)</th><th>No of episodes</th><th>Duration latest episode (months)</th></tr>
<tr><td>Mrs Brown</td><td>51.5</td><td>2.5</td><td>2</td><td>7</td></tr>
<tr><td>Mrs Boyd</td><td>60</td><td>5</td><td>2</td><td>36 (Healed)</td></tr>
<tr><td>Mrs Healy</td><td>72</td><td>5</td><td>1</td><td>60</td></tr>
<tr><td>Mrs Topping</td><td>52</td><td>10</td><td>4</td><td>68 (Healed)</td></tr>
<tr><td colspan="5">Mean age on developing an ulcer was 59 (range 51.5 – 72)</td></tr>
<tr><td colspan="5"><i>Ulceration post retirement: now working in the home</i></td></tr>
<tr><td>Mrs Ruane</td><td>81</td><td>6</td><td>3</td><td>38</td></tr>
<tr><td>Mrs Sayer</td><td>79</td><td>4</td><td>2</td><td>13 (Healed)</td></tr>
<tr><td>Mr Davies</td><td>66</td><td>3</td><td>1</td><td>36</td></tr>
<tr><td>Mrs Smith</td><td>73.5</td><td>1.5</td><td>1</td><td>18</td></tr>
<tr><td>Mrs Bird</td><td>70</td><td>5</td><td>3</td><td>57</td></tr>
<tr><td colspan="5">Mean age on developing an ulcer was 74 (range 66 – 81)</td></tr>
</table>

It is important to remember those people who do "unpaid" work in the home, like housewives. It is, however, beyond the remit of this study to enter into the debate about the use of market concepts to describe non-market work (Blackburn, 1999). The term is used here not to undermine the important work done, predominantly by women, but also that done by men within their own homes (Oakley, 1974). Rather, it is used to ensure that readers are aware of the work that people do in the home, but to delineate it from work outside the home. Ulceration undoubtedly had an impact on this group, and their ability to continue with work in the home; in this study this pertained to the women only. For the five people developing ulceration at a mean age of 74 years, their focus had shifted from paid employment capability issues, to their ability to perform jobs within the home. Twelve people verbalised the impact of ulceration on their ability to do everyday tasks and just how bad that made them feel. Instrumental activities of daily living, such as housekeeping tasks and grocery shopping, are tasks that physically and cognitively are somewhat more complicated and more difficult than self-care tasks but are also necessary for independent living. Many individuals alluded to their inability to undertake many essential activities of living and home maintenance, which now required reliance on others

> *"[...Y]ou have to get somebody else to do the job you wanted to do yourself... I wanted the decorating done, I can't climb the ladders. I can't afford to climb the ladders, I won't I'm frightened in case something happens."*
>
> Mr Davies: 31

This limitation in physical role was identified by individuals as a devastating blow when they had previously been independent.

> *"I could do anything at one time... and I'd have a go at anything... and then I couldn't... it was as though it got a hold on my life."*
>
> Mrs Warlow: 15

People were no longer prepared to take any risks at all for fear of what they perceived to be the potential impact on their legs and / or ulceration. Shopping, which Mrs Ruane verbalised as *"the only good part of housework"* was off limits for many, certainly in bad weather, because of problems of having to wear unsuitable footwear. Several women had to rely on members of the family for their shopping. They had tried going themselves but found they either couldn't walk very far, or were so slow that if they accompanied a family member, invariably they would squabble because the family member perceived they were walking too slowly.

> *"I couldn't walk far, my sister used to say oh why are you walking so slowly, and I said I can't go any quicker and she wasn't pleased... I just*

> *stopped going in the end unless it was absolutely essential and she got what I needed."*
>
> Mrs Warlow:20

People found it difficult when their "roles" were eroded or changed, particularly women, when their partners had to take over the housework.

> *"I can't even do the cleaning, and I feel so disgusted with myself because I can't do the cleaning in the house."*
>
> Mrs Smith: 22

Women generally view the house as their "responsibility", as depicted by Mrs Hall who describes a period during which her ulceration was so bad she was forced to stay in bed for four weeks:

> *"[...I]t was absolute murder, you can see all your responsibilities... fellas don't clean like you, like a woman and I could see things wanted doing; it drove me mad."*
>
> Mrs Hall: 40

Mrs Warlow, a 65 year-old lady, had started with ulceration at the age of 59 following a bad road traffic accident. She has been hospitalised on two occasions because of her ulceration. Mrs Warlow, an independent woman, describes how she "normally" enjoys being very active doing her own decorating and jobs around the house, but has been reduced to sitting crying at the table.

As I continued to read the stories over and over and listen again to the voices of the individuals, I was struck by the gradual erosion taking place in their lives; an erosion of not only the ability to do things but also the desire. For many, uncontrolled and unrelenting pain as described in chapter five, had diminished their quality of life and made them hesitate about participating in activities of daily living for fear of worsening their ulcer which would, they all believed, result in increased pain. Everything is so much more of an effort, as described in the following passage by Mrs Bird:

> *"I used to be such a positive person... but now there is a reluctance to get on with things because everything is so much more difficult, it has taken the joy away from doing things."*

Mrs Bird: 13

6.5: Relationships

Social, and often family, relationships began to suffer as the avoidance behaviour escalated and added to the emotional burden of ulceration. It was sad to hear examples such as that expressed by Mrs Bird of the impact on family relationships.

> *"I used to go and see my daughter and grandchildren every week... but I can't manage the trains and luggage with my leg... and that is a great sadness because I know she needs help and I want to help her but I can't."*

Mrs Bird: 35

Eight people alluded to "strain" in their relationship with their partners because of ulceration mainly due, it would appear, to a lack of understanding as evidenced in the following from Mrs Warlow:

> *"Oh it did put a strain on... and the other day he [her husband] said... 'just get yourself right, do you not want to walk properly again?'"*

Mrs Warlow: 29

She was visibly upset at the thought that her partner appeared to accuse her of not wanting to get better. Mrs Hall had even written to a leg ulcer clinic to try and obtain further information which she could show as "evidence" not only to friends, but also family because:

> *"I used to think that they thought I were putting it on."*

Mrs Hall: 19

People verbalised being upset by the lack of support from the immediate family and the suggestion that for some reason they did not want to get better, as if in some way the individuals could control the progress of the ulcers. It would seem that because ulcers remain "marginalised" by the health service they are categorised as "only a leg ulcer" which means they are perceived by the public as not being that bad. It is hardly surprising that people verbalised they had feelings of guilt or worthlessness, or started to question their own responses to ulceration.

> *"When I was working I didn't... well I wasn't able to do a lot. I had to... everybody had to muck in and help. And I felt guilty about it because I thought but I have only got a sore leg."*
>
> Mrs Hall: 39

Yet this was a 69 year-old woman who had endured "only a sore leg" on and off since she was 42 years of age and had managed to keep working up until the age of 60 combined with looking after the house and family. As stated by Mrs Bird:

> *"Anyone who hasn't suffered [with ulcers] has no idea of the pain and inconvenience... yes exasperation at the length of time for healing."*
>
> Mrs Bird: 73

Sometimes the reference to relationships was not quite as overt, as in the case of Mr Turner who offered that:

> *"I have been in tears a couple of times when I have been in the house on my own."*
>
> Mr Turner: 24

He had previously, as outlined in chapter five, harboured thoughts that his ulcer "might" be cancerous and that he had been unable to discuss this notion with anyone. He was also extremely concerned that he would be forced to give up his job. Yet here was a man who felt unable to speak with his wife because:

> *"[...S]he is hard, very hard if there is something wrong she will suffer and you would never know. So she expects everybody else to be like that."*
>
> Mr Turner: 30

Implicit in this sentence is Mr Turner's own suffering, predominantly in silence, almost trying to maintain the British stiff upper lip. His only release of tension was, therefore, to find a time when the house was empty, so that he could feel free to vent his pent up emotions. In times of illness or anxiety I would proffer that it is not that people necessarily "expect" their partners to be able to do anything. However, I would argue that one at least would hope for support and / or sympathy. It could also be argued that Mrs Turner's attitude may have been a calculated approach by her, in an attempt to prevent Mr Turner wallowing in self-pity and make him carry on. They needed his income – he had to carry on.

6.6: Vulnerability: fear of another ulcer

An overwhelming sense of fear weaves like a gold thread throughout the tapestry of individuals' accounts, having its foundations in the theme of *"vulnerability"*; this implies uncertainty in daily life because of the disease and its demands on life. In everyday activities the body subliminally reminds the people of their illness.

> *"Souffrir passé, avoir souffert ne passé jamais."*
> *"Suffering passes, having suffered never does."*
>
> (Bloy, quoted by Buytendijk, 1948, p.250)

It seems that the memory of ulceration remains crystal clear, unlike the appearance of other ailments, which are a transient "departure" from the healthy self, and therefore the memory of them fade without scars. Individuals like Mr Whalley admitted that

> *"You can't forget them; you can't forget what you have been through."*

This sentence "speaks" volumes about the depth of suffering. Even when the ulcers had healed, people felt unable to forget their experiences; they were always wary of any trauma, even a scratch to their legs from objects or even other people, vigilance is always required. Fear of accidental trauma or re-ulceration was mentioned by all the individuals, but to varying degrees of intensity as identified in their stories. Mrs Kay spoke about feeling terrified at the thought of her ulcer returning:

> *"I have a fear of it coming back... oh yes you are always frightened of banging it, always frightened of knocking it on anything or falling... it's there in your head all the time, just be careful you don't knock it."*
>
> Mrs Kay: 73

She even gave a specific example of falling in the bedroom and immediately bursting into tears because she was so terrified that she might have sustained an injury to her leg. The thought she might, again, have to endure months and months of pain were too much for her to contemplate. It was evident that ulceration was not seen as something that was controllable, with the threat of a further episode being felt by the entire group: some individuals described not just awareness but almost an obsession fuelled by anxiety, as clearly articulated by Mr Whalley who verbalised the underlying vulnerability evident in most stories:

> *"[...Y]ou never forget them believe me, you can't forget them you can't forget what you have been through... you have **always** [his emphasis] got that feeling that it is going to break out again."*
>
> Mr Whalley: 26

Withdrawal from social life, as described earlier, was also partly linked to an avoidance strategy. Fear of sustaining an injury and enduring a further episode of ulceration, or the potential risk of deterioration to a current ulcer, were enough to make people unwilling to join in social activities where they "may" place themselves at risk. People seemed to constantly cogitate on the endless possible consequences of potentially painful threats, almost catastrophic about future pain experiences and their ability to cope.

> *"I miss going to the Town Women's Guild and coffee mornings... I couldn't go there in case I got my leg knocked."*
>
> Mrs Ruane: 55

People could no longer just have a scratch or a sore on their leg, in their mind it was automatically going to ulcerate, *"every time you get a pain"* offered Mrs Topping, you think it's coming back. Likewise from Mrs Hall:

> *"You are terrified, I know it might sound silly, but every little tiny itch on my leg or smarting I am petrified of it beginning to be another ulcer... I just hate having them."*
>
> Mrs Hall: 47

It is hardly surprising that, with this mind set, venturing out means exposure to potential injury. Respondents describe how everyday activities such as a trip to the supermarket become fraught with danger as the threat of pain and / or ulceration is ever present. Interestingly, this is shared by some relatives, reinforcing the impact of ulceration not just for the individual but also for the family. Mr Whalley states that when he goes shopping with his wife she is:

> *"[...C]onstantly saying watch that buggy, watch her with that buggy."*
>
> Mr Whalley: 2

These thoughts are particularly at odds with the reality of the causes of ulceration for the individuals in this study as no-one stated that their ulceration had been caused by supermarket-related trauma. I would propose that there are not many of us who are "terrified" at the prospect of going to the supermarket and yet so real was the fear of getting another ulcer that some people actually stated:

> "[*...S]upermarket shopping, that terrifies me it really does, and my husband is always saying 'watch out mind the trolleys'."*
>
> Mrs Boyd: 19

It is as if the shopping trolleys and buggies have taken on sinister characteristics, becoming more than inanimate objects. Care is always taken to protect the limbs, to a point where it must be impossible to focus on anything else other than the potential risk of injury. People appear to spend the whole time they are out scrutinising their surroundings for potential hazards:

> *"[...W]ell when you see somebody with a bag keep away from them."*
>
> Mrs Sayer: 36

The legs are constantly monitored for any signs that a new ulcer may be forming. As Mrs Kay emphasised:

> *"I am always looking at it [leg] every morning and think how is it doing... you have got to, you have got to look after it."*

The perceived "threat" of ulceration never seems to go away… the next ulcer is waiting in the wings.

> *"You are constantly watching it and you are constantly putting cream on; like I put cream on this other leg every day to make sure that the skin doesn't get hard, you know and you are constantly doing that once you get your legs right again and you are forever watching them."*
>
> Mr Whalley:36

For one respondent the fear of reulceration was so great that she stated she had contemplated suicide as a preferable alternative:

> *"I have said many a time, if I have got to start again with one [an ulcer] again, I would do myself in I really would... I can't go through this again... it just seems to go on and on and on for ever and there is no end."*
>
> Mrs Boyd: 19

This 65 year-old housewife "struggled" throughout the interview to maintain her composure. I offered to turn the tape off several times, but she wanted to continue and help make other people aware of the impact on her life, her being-in-the-world as a result of ulceration. I was aware that for many like Mrs Boyd, these narratives were "newly aired", and thus, that faltering, hesitation and upset were part and parcel of the first telling. That ulceration had caused her great suffering and left a deep scar was unquestionable. The memory of ulceration remained clear in her mind six weeks after her ulcer had healed.

I noted in my journal that I was totally unprepared for the comments made today; this challenged my assumptions. I have witnessed first hand the change in people attending the leg ulcer clinic where I work. I was aware that people "suffered" physically and mentally with ulceration but I had no idea just how much.

6.7: Vulnerability: fear of malodour

> *"Well like I say it takes all the beauty out of it because you cannot do anything, you cannot go anywhere, you can't go and mix with friends because of the smell... you are frightened really of going out, whether people can smell anything like... it zaps all your confidence."*
>
> Mr Whalley: 3

Whilst leaking, wet leg ulcers, I would propose, are regular occurrences to nurses managing patients with leg ulceration. For people experiencing their first episode of ulceration it is vital to remember this is a **new** experience for them. However, it is an experience, as reinforced by Mr Whalley, which has an all-consuming impact on an individual's ability to get on with everyday living. Once again, ulceration has demonstrated an ability to "control" and restrict activities, irrespective of the number of episodes. For some individuals, oozing wounds and wet bandages were the worst thing about ulceration, preventing them from socialising. Whilst there was an actual risk of odour in some cases, nevertheless, for many the potential risk was enough for them to curtail activities, which for individuals like Mrs Healy were already limited.

> *"It [ulcer] limits what you can do... it makes you want to hide. Because if you get into a room and someone says oh there is a funny smell here,[long pause]... it might not be you, but oh God is it? You feel conspicuous."*
>
> Mrs Healy: 11

Mrs Healy is a 77 year-old widow who lives alone in a pensioner's bungalow. She has difficulty leaving the house because of ulceration, and has reached a stage, where she admits, that she has *"become like a recluse"* because of the difficulties (real or potential) caused, not only by ulceration, but also by their treatment. This will be explored further both in this chapter and in chapter seven. Symptoms are not always immediately visible, or obvious, to the onlooker as in the example given by 58 year-old Mr Myers. It was only after he had been stood with a group of people for a while, that several of them started to complain about a smell, making him hover momentarily between "disavowal", pretending not to notice others' attention, and "avowal" when he would openly acknowledge the odour, and therefore his disability, in an attempt to diffuse the situation (Scambler, 2004). To tell or not to tell was his obvious dilemma:

> *"[...T]he worst thing about them is when they smell, you can't go out, they smell that strong and its... once in the bar people went phew... what's that smell? I thought should I stand my ground and ignore it or shall I slope off and then they are going to say it must have been him."*

He paused for a few seconds and looked away before adding:

> *"So I just sort of sloped off."*

Mr Myers: 12

It became apparent to me, not only from what Mr Myers said, but also from Mrs Healy's comments, the fact that they both assumed that any malodorous or unusual smell was obviously them, rather than anyone or anything else. It is as if the overwhelming nature of ulceration results in a myopic view, meaning they are unable to see beyond the ulcer to even consider that the smell could be caused by something else: the ulcer becomes all consuming. Ulceration is the cause of the effect. It was likely that for both of these individuals they had been told previously that their ulcer did indeed smell, therefore any smell thereafter must be them. This was evidenced when Mr Myers suddenly added:

> *"Even the wife you know, when you get out of bed... she has gagged."*

Mr Myers: 12

It was hardly surprising that the next time there was the "hint" of a foul smell, Mr Myers immediately concluded it must be him and never waited to explore if, in reality, it was. Mr Williamson, who owned a chip shop, was especially sensitive to any risk of smell from his ulcer as this would obviously be an unacceptable situation in the shop, potentially jeopardizing his business. He provides a specific example of being able to smell his own ulcer on an occasion when he was taking the family on holiday down to Cornwall by car:

> *"We were going on holiday to Cornwall and as the air conditioning was working in the car you could get this drift of a smell coming up from your leg…it was disgusting… like something decaying…like a dead rat"*

Mr Williamson: 8

It seems inconceivable that, even whilst driving down for his holiday, the ulcer should make its presence felt, pervading the very air he breathed. There is no holiday from ulceration. It was interesting to note that he never mentioned if any of his family members were able to smell his ulcer. This was a similar situation for Mrs Warlow, who was certain that her husband must be able to smell her leg. She believed the smell was like "dead flowers" and, one particular evening, repeatedly asked her husband if he could smell anything because she was so convinced that the terrible smell was from her leg.

> *"[…O]ne night we were having our meal and I could smell dead flowers and I asked my husband if he could smell my leg… when we went to bed I could still smell dead flowers and I asked him again if he could smell my leg."*

Mrs Warlow: 26

Having had the answer once from her husband that he couldn't smell her leg did not appear to ease her concern, so she insisted on asking him three times that one evening because, she admits, she was so obsessed about it smelling. Although both Mr Williamson and Mrs Warlow complained about a smell, they admitted that family members did not substantiate this. However, it could also be that family members do not wish to hurt the feelings of these individuals and so deny being able to smell the ulcer. Mr Davies also complained of malodorous wounds that likewise caused him embarrassment and distress and impacted on his self-esteem. He admits that he became insufferable to be with because he got so frustrated and angry:

> *"I realised that I smelled like the clinic smelled... I didn't want to go to keep in touch with friends... you would get a whiff of yourself and think God... I was miserable and morbid and then occasionally I would get so frustrated I would be verbally very aggressive."*

Mr Davies: 12

Changes in the body's capacities to behave as expected often elicit dramatic repercussions in self identity (Charmaz, 1987). Mr Davies was expressing his experience of changing from a predictable body to an uncertain one. It was interesting that he referred to himself as if he was "rotting away", since Mr Williamson and Mrs Warlow used similar descriptions of decay, as did Mrs Hall. I wondered if they were also referring to "dying" inside, an emotional death.

> *"I used to wake up at night and I could smell it, you know it used to make me feel really depressed. Yes terrible. Like dying flesh, you know a really bad smell...like something dead in the same room"*

Mrs Hall:12

It sounded as if the foundations of Mr Davies' life, as he knew it, were crumbling subsequent to his ulceration: his wife of 47 years had left him, his mobility was severely limited and he admitted that he was depressed, something which was echoed in his HADS depression score of 15.

> *"I was uncomfortable because I felt that this leg was offensive to people. So I was in a sort of catch 22. If you could smell yourself rotting away you know it's horrible it's a horrible thing. Its like, it's worse than any horror movie. To just have part of you that will not respond it won't heal."*

Mr Davies: 20

Once again lack of control raises its head, and disembodiment is apparent in Mr Davies' last sentence. He desperately tried to mask the smell but the exudate seemed to be everywhere, despite using plastic covers and protectors

> *"[...T]there was so much exudate from it, although we put plastic covers and protectors, still this exudate... bedclothes, the bedding, the room was beginning to smell evil."*
>
> Mr Davies: 12

It would be interesting to know if, in reality, the room did smell as he described or whether the smell was "in his nostrils" and implanted in his memory, so that any stale smell conjured images and thoughts of the smell from his ulcer. On the other hand, terrible smells can start to impregnate materials and linger in the air long after the original source of the smell has gone. This concern about the smell of his ulcer was massaged, as discussed in a later section, by the problems he had with personal hygiene.

I was left in no doubt, from what I heard, that ulceration had impacted greatly on the lives of individuals such as Mr Davies leaving a very bitter taste and smell. The ulcer was not only destroying their flesh, but destroying their very lives and undoubtedly their being-in-the-world. The problem with odour seemed to be compounded, for many, by difficulties with personal hygiene. A daily shower or bath tends to be part of everyday routine practice, so to have to limit that to a couple of times a week, or even worse, to not at all, was a major restriction for most people.

> *"I felt unclean, I couldn't get clean. I shower daily and then I couldn't shower because of the dressings which had to stay on for a week. I felt like I would imagine how the old lepers used to feel... I felt like I needed a bell because of the horrible smell."*
>
> Mr Davies: 12

This 69 year-old gentleman's self esteem was at rock bottom. He didn't want to go out because of the discharge and smell from his ulcers and the final straw was the fact that he was unable to shower because of the restriction of the bandage regimen. It was particularly difficult for Mr Davies, a large gentleman who admitted to perspiring profusely. A "normal" part of his daily life was to shower twice a day and to reduce this to not at all had a devastating impact. Problems with personal hygiene were not restricted to Mr Davies, but were a symptom of the treatment rather than the ulcer.

6.8: Personal Hygiene

The ability to shower or have a bath was aggravated not by the ulcer per se, but by the restrictions of the bandage and the extraordinary lengths to which people went, not to get the bandages wet, but to actually "enjoy" having a bath:

> *"I wrap a towel around it and then plastic to keep it dry, so I have one leg out of the bath and one leg in."*
>
> Mrs Healy: 29

What is astonishing is the fact that this is a 77 year-old lady who lived alone. The potential risk of her getting in and out of the bath when she is alone raises one's anxiety levels, let alone adding plastic bags and limited movement due to a bandaged leg. Hanging legs out of baths appeared to be a common method of having *"half a bath"* as Mr Myers described it. There appeared to be a few mishaps with this method and often saturated bandages were the result, but people still did not appear to feel they could ring the nurses and ask for the bandages to be changed, as discussed further in chapter seven. Not all the individuals alluded to problems with personal hygiene, nonetheless those who did unanimously spoke of it as "quite a performance". Some individuals had tried the plastic bag method and resorted to having a "full wash" at the sink and waited for the nurses to wash their feet when they had the bandages changed. Other people made "arrangements" with the nurses in the clinic, which allowed them to have a shower or bath just prior to having their bandages changed. If you were unfortunate enough to have bilateral ulceration, it appeared to be completely out of the question to attempt to attend to one's personal hygiene with a shower or bath.

Since commencing the thesis it is noteworthy that many commercial companies have now produced a waterproof cover to wear over bandages. This is available on the Drug Tariff for the health professional to prescribe. The cover provides a waterproof seal so that people can at least shower without the worry of wet bandages.

Whichever the chosen way of attending to their personal hygiene it was evident, on listening to individual's stories, that undoubtedly it was quite a performance. Not the, almost, subconscious task which most of us take for granted, and certainly something we do not have to forward plan. As reiterated throughout, these are individuals who have had their current ulcers for anywhere between seven and 68 months; for them the problems with personal hygiene were articulated as being huge.

6.9: Loss of control

Individuals are limited on a daily basis as to what they are able to do and they feel forced to accept this situation. They have, as Mr Jones suggested, little power to change it:

> "*...[T]here's nothing you can do really about it is there I mean that's the situation you are in. so there's nothing... you can either... if you can't accept the situation what can you do?*"

He hesitated for several minutes as if he were questioning me. However, he was sat looking down at the pencil he was rolling over and over between his fingers. I just waited and he continued:

> " *You know you go I think you go deeper and deeper and deeper... you go into a deep depression. If you can't accept the situation you are in I think you would go further than the mile you really would get depressed.* "
>
> Mr Jones: 63

It is a constant inability of these individuals to regain control of so many aspects of their lives that gains in poignancy as each story is "truly" listened to. The ulcer has already cost people, like Mr Jones and Mr Ball, their jobs and in many cases a person's ability to socialise. In reality, what people seem to be grappling with is the lack of control they appear to have over so many aspects of their lives due to ulceration. This is not a linear process of acceptance but also, like the grieving process, goes in cycles, with some never completing the stages but getting overwhelmed or "stuck" in one phase.

> *" I think on the whole when you know you've got one and you think oh no and it's a feeling of sadness and resignation, frustration oh, weariness... I think oh well, resignation I suppose... well there is nothing you can do about it is there, I mean that is the situation you are in."*
>
> Mrs Bird: 30

The unrelenting nature of ulceration has forced many of the individuals to live in a world akin to limbo, a world of uncertainty in a region on the border of hell, where they are left feeling as though they are trying to survive in a condition of neglect or oblivion, feeling disregarded or forgotten. Limbo is derived from the Latin *limbus* meaning hem, hedge or boundary, and although it has religious connotations limbo is also used colloquially to refer to any status where someone / something is left "in the lurch" awaiting another action to enable progress. People with ulceration have been "left in the lurch". They are waiting for the ulcer to, at the very least, improve but also to heal. They have to deal with uncertainty, an emotion somewhere between hope and despair related to an unknown future perspective. However, unlike limbo where there is supposed to be no sense of punishment, these individuals stories are tinged with pain, both physical and psychological. People speak about existing rather than living.

> *"I just exist and that's all, just exist... if I didn't have the ulcer now that's quite a different story, I think I would live it up. I would be happy love."*
>
> Mrs Gray: 50

People struggle to come to terms with their situation and desperately try to carry on with their lives, but it is an obvious uphill struggle for most. For some individuals, even accessing the treatment itself was problematic since some people were expected to attend leg ulcer clinics rather than having home visits by the district nurse. Mrs Warlow described getting to the clinic as:

> *"[...A] nightmare because I couldn't drive because of the pain and the bandages, we had a manual car and well you know I just couldn't press the clutch down... people say oh we'll give you a lift... but it was too long term, it just took away all my independence and I got quite depressed."*
>
> Mrs Warlow: 14

This situation is undoubtedly compounded by the recurrent nature of ulceration, just as the stage of "reluctant acceptance" is reached then, perhaps, another episode of ulceration ensues which sends the individual in a spiral back to the beginning of the cycle again and again. Mr Jones referred to the potential depths of despair and depression to which one could be driven because of ulceration. Mr Turner referred to this desperation in a different way. Religion was not a subject that I alluded to at all in the interviews so the following off the cuff comment by Mr Turner was quite alarming:

> *"You say a prayer of a night I can assure you, you pray. I believe there is somebody up there. I did, I used to get down on my knees and pray, to try and get some sanity into my head you know."*
>
> Mr Turner: 15

As Mr Turner was the final interview that I conducted it was not possible to pursue this with any of the other individuals. It was apparent that he wasn't praying for the ulcer to heal, but rather for peace of mind. The impact on his ability to cope, psychologically and emotionally, with ulceration on a daily basis was evident in his prayer. There was so much churning in his mind: the pain and its impact on his ability to work; his concerns about cancer. If he lost his job how would the family cope? It is not a case of worrying about the ulcer but the potential impact of ulceration on daily living.

6.10: Putting on a brave face

For those who in some way come to acceptance, it is a reluctant acceptance, almost as if they are living a lie and they try and mask their true feelings to other people. People spoke about putting on a brave face, like picking up a mask they could put on to disguise their true feelings, even when they were in pain, or feeling overwhelmed by their ulceration, as confirmed by Mr Owen:

> *"You've just got to keep smiling and keep a happy face on it."*
>
> Mr Owen: 58

However, some time later in our conversation, he admitted that:

> *"[...D]eep down you are not happy, you are sad, really sad but you have just got to pretend because you are restricted."*
>
> Mr Owen:70

It was an interesting comment. There seemed to be a constant need to hide their true feelings, almost keeping the British stiff upper lip. Mr Owen had greeted me with a smile and had initially appeared to be a cheerful individual. This veneer was soon gone and the sadness and despair so evident in his story was also portrayed in his demeanour. This could be an inherent part of the difficulty with family friends, how can people be expected to know which is the real face and which is the mask?

As mentioned in chapter five, people often said that they "wouldn't wish it on their worst enemy" because of the pain, but it was also said of the way ulceration restricted them so much:

> *"I wouldn't wish it on my worst enemy I tell you that, I wouldn't... because it fastens you down so much."*
>
> Mrs Healy: 20

Mrs Healy has been made housebound by ulceration. She stated that she could cope with living alone, although she missed her husband because initially after his death she was able to get out. Ulceration, complicated the situation by restricting her mobility, allowed depression to creep into her life.

> *"[...I]t's so depressing and you feel as if you are tied down with everything, it limits what you can do... if you let yourself go down under if you know what I mean you just... it just makes me feel totally depressed."*
>
> Mrs Healy: 15

People found the loss of independence difficult to accept, and the restrictions on their life unbearable, as the restrictions of ulceration vacillate between private concerns such as personal hygiene to public worries caused by the potential embarrassment of discharge and odour. Pain appears to conspire with discharge and malodour to make coping with some days an endurance test. People have internal concerns about how best to cope with activities of daily living such as attending to personal hygiene and cooking and cleaning. For some these are daily milestones before they can even consider socialising, or going to work. Add to these external factors, such as reactions by family, friends and general public and it becomes easier to grasp why many individuals articulate a downward spiral into despair and depression, particularly if they can see no end to ulceration, no light at the end of the tunnel.

> *"[...I]t has really changed my life as though it has got a hold on me and taken away all my independence and I got quite depressed and I didn't want to go out or do anything."*
>
> Mrs Warlow: 14

Many people spoke about feeling "really low" and the fact that they were unable to look forward to things as they previously did. It was noteworthy that, on completion of the HADS-D, this was a significant contributor to their overall depression score for 11 people, while only one female felt her ability to look forward to things had not altered.

6.11: More than skin deep

The individuals' accounts were more than just stating they had pain in their ulcer, it went much deeper than that. The pain left them feeling imprisoned, almost as if the ulcer had trapped them in its web. They were unable to accept what had happened, particularly if they had led an independent and fulfilled life, but were now literally forced to spend hours and hours at home unable to get on with their lives, grieving for a life lost to leg ulceration and, for some, living with fear.

> *"I could do anything at one time... and then I couldn't and it was as though it [the ulcer] got a hold on my life, I couldn't get on and live how I wanted to live."*
>
> Mrs Warlow: 15

Mr Jones, a 64 year-old forced to retire because of ulceration, also grieved a lost life:

> *"[...I]t's just I don't feel, I don't feel, I don't feel like I was before I had the ulcer. You know I can't... it's something you can't put into words June, it's just a feeling you have see. You know it's just the way you were and the way you are now."*
>
> Mr Jones: 32

It was clear that Mr Jones was still in the middle of a grieving process, finding difficulty in reaching a point of acceptance as he still missed work.

I could almost "feel" the grief; it seemed to fill the air I noted in my journal. We were both sat at the kitchen table, but his demeanour oozed sadness as he sat with his head down, turning a pencil in his hand over and over. At times it was evident that he found it difficult not only to articulate his feelings, but also to even reflect as he was today.

Pain from ulceration meant that this group of people were left feeling unable to carry on with their lives until the pain had gone. There was an overwhelming sense of feeling disregarded or forgotten, together with a loss of control over their bodies. People found it difficult to remain positive and "carrying on" was out of necessity rather than an active decision as illustrated by the respondent who said that:

> *"[...Y]ou just get on with life you've got to do... like everything else you get used to it, though it's not what you would want to be doing, but you've*

> *got to accept it, if we didn't we would all be bobbins wouldn't we – you see we would all finish up in a mental home."*
>
> Mr Williamson: 12

Likewise, Mr Jones also "reluctantly accepted" that he had to carry on because there was no other choice. He didn't want to be at home all day watching the TV or going shopping with his wife, he wanted to continue working but the pain dictated otherwise, taking control and limiting his options.

6.12: Summary

This chapter has continued to explore the symptoms of ulceration, with particular emphasis on how they impact on daily living and the restrictive nature of ulceration. The body has become an obstruction, becoming disembodied, due to "the leg" which becomes a primary focus impeding previously taken for granted aspects of daily living. The ulcer takes over people's lives as their ability to control aspects of their lives is gradually eroded, every aspect of life appears to be punctuated by loss.

A chronic health problem such as leg ulceration simply continues day after day, often invisible or misunderstood, not only by the general public but, it would seem, also by some health professionals. Despair, frustration, anger, fear, isolation and sadness are all part of the unseen experience of chronic ulceration, leaving individuals in a state of uncertainty about the future. Eight people spoke about being forced to retire earlier than they had anticipated, two were made housebound; people lost interest, confidence, ability and / or desire to socialise. Individuals were left in a constant state of "vulnerability": living in fear of someone or something causing a trauma to the leg or ulcer, fear of pain, fear of amputation, fear of people being able to smell the ulcer and fear of further ulceration.

People have difficulty doing even small jobs around the home due to the restrictions of ulceration. Sheer exhaustion adds to their problems, since people are often subjected to interrupted sleep. Exhaustion also results, in many cases, to a loss of control over emotions. Friendships and relationships are put to the test, in some cases with poor outcomes. Living with chronic ulceration means more than simply having dressings and bandages renewed, but even this can be a harrowing experience, as described in chapter seven. Ulceration necessitated changes to people's lives, largely underestimated, not only by the individuals themselves, as well as families and friends, but also by many health professionals, which is explored in chapter seven. People have expressed feelings of helplessness, hopelessness, guilt and worthlessness throughout this chapter as well as poor self-esteem, which are all considered to be core symptoms of depression.

Chapter seven explores what happens in the clinical encounter, is it the therapeutic experience we would hope it should be for individuals whose lives have already been so dramatically affected by chronic ulceration? It is politically incorrect to speak of compliance, since that indicates a power stance taken by the health professional. Health professionals are challenged to involve people in decisions regarding their care, empowering them to concord with an agreed treatment plan for their care and management. These issues are discussed in the next chapter and how they relate to the reality of the situation and their impact on the individuals on the receiving end.

Chapter 7: Abiding by the Rules

> *"The difference between strife and serenity often depends on the meaning and interpretation of a word, yours"*
>
> (Calnan, 1983)

7.1: Introduction

This was a challenging chapter to write since, predominantly, the findings were initially not "seen" as I realised I was largely addressing my own assumptions as to the lived emotional experience of living with ulceration, albeit in a different way to previous research. Issues such as pain, discharge and malodour were the "obvious" textbook (and biomedical) aspects of the chronic ulceration trajectory, but there transpired to be another vital component. Once I had moved beyond just observing the data and really entered into the lives of the individuals, I was able to see the impact of the clinical encounter for individuals on the receiving end of care. It felt akin to a light being switched on, illuminating aspects which individuals were somewhat uncomfortable about revealing, and I was told, in a variety of ways and guises, that their encounters with health professionals formed a pivotal part of their lived experience, leaving either a painless stain, or a painful scar.

There were multiple experiences, including my own as a nurse, discussed in chapter four, together with those of the individuals, that impact on the findings in this chapter. The experiences of individuals included, not only those of day-to-day living, but also their experiences of the clinical encounter. As discussed in chapter six it is likely that, for many of the individuals, these were untold, and therefore untested, narratives. Throughout the telling of their stories, people had hesitated, become visibly upset and agitated, questioned and challenged me, as they delved into hitherto unspoken territory. The fact most people knew I was a nurse carried its own mixed benefits. Whilst it is likely, it may have made many people temper some of their comments about nurses they had previously dealt with. Equally, I believe some people "needed" me to know what the clinical encounter can truly be like. My role as a nurse, nevertheless, helped me to uncover the essence of their encounters. It also helped in my understanding, and emphasises, not only the importance of addressing my biases and assumptions, but also the need to be as reflexive as the storytellers themselves.

In chapters five and six, the individuals spoke about suffering related to their ulceration: days of pain, problems of wet and smelly wounds, and restrictions on footwear and choice of clothing, plus the inability to leave the house. The list appears endless, as does the restriction of activities previously outlined in chapter five; lives were put on hold waiting for the controlling and all-consuming ulceration to heal. However, there also appeared to be suffering related to the care these individuals received. At some stage of their illness individuals were either advised, or sought help of their own volition, to manage the ulceration, resulting in a myriad of experiences for these vulnerable individuals, not all of which were positive.

There was unanimous agreement amongst the individuals of the importance of somewhere / someone to turn to. However, there was disparity amongst the individuals as to the quality of the "care" they received, not only physically but also psychologically. The lack of understanding of their own chronic illness is explored as it is inexorably linked to care by health professionals and disempowerment.

7.2: Lack of understanding

Good communication requires the ability to give sound advice including answering questions, solving problems and inspiring confidence. However, it is also difficult to question if one is not informed or in possession of limited knowledge about a subject. Salvage (1992), in her conceptualisation of "new nursing" states that:

> *"[...P]artnership includes enhancing the patients' knowledge and skills through giving information, maximizing their independence, respecting and giving patients choice and understanding patients' individual needs."*
>
> (Salvage, 1992, p.12)

As will be discussed later in this chapter, time and opportunity to pursue information, or air anxieties with the health professional, appeared to be limited. This simple question of cause of ulceration unleashed a variety of emotions, which drew me into the lives of these people on their emotional journeys through ulceration.

As an ice breaker at the beginning of each interview, I asked people to tell me about how, and when they got their ulcer. This resulted in a myriad of tales of traumas ranging from a knock to the leg, to unusual bites whilst on holiday abroad. What was initially conceptualised as an ice breaker ultimately provided valuable data pertinent to the illness trajectory. Ulceration seemed rarely to be attributed to a long-standing problem with veins, such as deep vein thrombosis, a recognised risk factor for ulceration (Nicolaides, 2000). Only five people mentioned a prior medical problem that might have contributed to their ulceration but, even then, the explanation was somewhat vague, as shown in the following quote from Mrs Kay:

> *"My ulcer started, I was a shop assistant, I was standing all the time, I have had poor circulation because I had four miscarriages, and the last one it was, it was dead inside me and it was a dead weight and that caused me most of my problems."*
>
> Mrs Kay: 3

The astounding aspect to consider is the duration of illness trajectory for these individuals. Mrs Kay is now in her twelfth year of ulceration, and her third episode. Yet, these individuals do not appear to have a true understanding of their illness. This seems at odds with the expert patient agenda (DoH, 2001c), yet is congruent with the poor profile of leg ulceration and thus limited knowledge and understanding by the general population about leg ulceration. Mr Whalley, (with a 25 year history), and Mr Owen, (with ulceration for more than 30 years), both realised that problems with their veins "may" have been a contributing factor. However, they were unable to clarify how the two were related. Mrs Brown, with a two–and-a-half-year history, reinforced this viewpoint, when she mentioned cellulitus as linked although, in contrast, Mrs Hall (27 year history), believed (correctly), that a prior thrombosis was the culprit. Cellulitis is a common complication of venous ulceration, but not a primary cause, unlike venous thrombosis (as discussed in chapter two), which can be a precursor to ulceration.

Does this mean there has been an assumption made on the part of the health care professional that individuals possess a true understanding of their illness? Or do professionals believe that it is not necessary to ensure understanding? For some, there was a sense of "unfairness", particularly if they had been active; almost a belief that if you haven't kept yourself fit and active, then you "deserved" an ulcer.

> *"...I think there's frustration as well as the pain... [long pause]... eh a bit of anger why has it happened to me? I've always been sporty and active; walked, tennis, hockey, cycling, biking and I think why should it happen you know."*
>
> Mrs Bird: 4

It was almost as if she felt she had been wrongly "convicted", and should therefore not have received this sentence of ulceration, which is deserved if you haven't led an active and healthy life, but not, if like her, you have. There is a pervading sense of feeling betrayed by their bodies. Some individuals made comments such as:

> *"Before I had one [an ulcer], I had heard of a leg ulcer, but I never knew what they were."*
>
> Mrs Kay: 3

This simple statement resonated throughout everyone's story, even though it may not have been stated as directly as did Mrs Kay. Rather, it tended to be referred to obliquely in the ways people attempted to manage their ulceration with plasters or strips of lint for protracted periods of time without obtaining help, as demonstrated by Mrs Topping and Mr Turner. It would seem that there is a general "ignorance" about ulceration, a condition that has not been given the status of other chronic diseases. It became evident that many of these individuals still did not truly comprehend ulceration, even though it had necessitated a fundamental rethinking of peoples' biographies.

Fifteen people were coping with a recurrent episode of ulceration, yet all referred to their first episode, which in some cases was over 25 years ago, and what had triggered that particular episode. The most likely explanation is that people perceived there was a difference between who they were in the present, living with ulceration, and who they were in the past, in an unencumbered body. This was definitively marked by the first episode of ulceration.

People referred to various "traumas" and their surprise that the "cut on their leg" wouldn't heal like other injuries they had received in the past. Ones that had successfully responded to, previously tried and tested, remedies such as Germolene™ and a sticking plaster. Mrs Topping alludes to this fact when she told me:

> *"I got a scratch on holiday and kept putting a plaster on it."*

I would suggest that the first episode of ulceration can be a surprise to many people, as they would not automatically assume they, in fact, had a venous ulcer, rather than just a traumatic wound, which should heal quite uneventfully. The time frame before seeking advice can thus be variable, it depends often on whether the individual knows someone else who has suffered with something similar, and this may prompt them to seek help earlier. There appeared to be either an initial denial that the trauma could result in something other than a "simple" wound, or the fear that it represented something more sinister. Anecdotal reports suggest that individuals with leg ulceration may harbour concerns associated with the cause of the ulcer, as historically the cause has been linked to conditions such as syphilis (Morison & Moffatt, 1994). Fears such as these may delay individuals from seeking treatment.

Is this perhaps, what prompts some people to try and self-manage before being forced, often by someone else, to face up to the situation and get some help? It was interesting that it was predominantly the men who continued for a protracted period of time, to manage themselves before seeking help, particularly those men who were still working. Mr Turner gave me details of his daily dressing regimen that took place in a dirty workshop, before he reluctantly accepted help.

> *"I had discharge from the ulcer, but I had to keep a dressing on, I was putting lint and that on it. You know... before I knew what it was... this is why it all got out of hand. I was cutting pieces of lint, when I used to go to work, tape them and put the lint: I used to have to have a mirror to see where it was you know at the back, because they said that if any fibres or anything... this might upset things, there are all sorts of bloody germs and that in there isn't there?"*
>
> Mr Turner: 18

He was finally approached by his employer, who suggested he should seek professional help, rather than continue as he was. Mr Whalley similarly, until the ulcers had reached large proportions and were almost unbearable for him, continued to try and manage before he finally gave in to having some help.

> *"Dr said oh you have got two stinkers there, and he played holy war actually, I said I know I have left them a bit too long, he said you certainly have, because I tried to carry on working and then at the finish I got that way that I went to work one morning, did my job a treat, no problem, got in the car, came home but to try and get out of that car that morning, I bet it*

> *took me 20 minutes to try and get out of the car and that was when I realised I had let them go too far."*

Mr Whalley: 11

It is important from an ulcer-healing perspective, that an individual seeks advice and treatment as soon as possible, since size and duration of an ulcer are predictors of healing time. The larger, (greater than $10cm^2$), and longer, (duration of more than 6 months), an ulcer is present before commencing with compression therapy, the longer it will take to heal (Margolis, Berlin & Strom, 1999). It is also possible that an ulcer left untreated for months or years "could" undergo malignant change, known as a Marjolin's ulcer (Morison and Moffatt, 1994). However, from an individual's perspective the size and duration did not appear to be significant factors for them; what seemed to matter, was if the ulceration started to interfere with their ability to carry on with their lives, as exemplified by both Mr Whalley and Mr Turner.

People were upset and frustrated by the inability to plan anything as there is no known endpoint. The inability of an individual to look forward to things is considered to be one of the hallmarks of depression and, indeed, is one of the HADS-D screening questions for depression. It seems to be a catch 22 situation for these individuals; to be able to look forward to something necessitates the ability to plan the event. People frequently spoke about being unable to plan anything because you never knew how the ulcer would be. Mrs Warlow, who developed ulceration at the age of 59, had expected the ulcer to heal by the time she was 60:

> *"[...W]e were going to go away when I was 60... but 60 came and I was no better and these last few years have gone and now I'm 65... I want to get on with my life but I can't at the moment, I can't even wear ordinary shoes."*

Mrs Warlow: 34

There is a sense of futility in these few sentences where she speaks of not being able to go away but it is the last six words that convey so much more, just added at the end, that you almost miss them. It is as if she has moved her own goal posts, from the ability to go away on holiday, to a more important daily issue of being able to wear her own shoes again. People appeared to be caught up in what Jobling (1988) calls the "sysyphus syndrome". Like Sysyphus, who was condemned by the gods to roll a boulder up to the top of the hill only to see it roll down again, so individuals go through many rituals of treatment regimens, only to find the condition of the ulcer has changed very little.

7.3: The paradox of care

People expect or, at the very least, hope they are not treated like another "item" scanned through on the conveyor belt, with scant attention being paid to the "item", yet this is how they describe their experiences. Sometimes, the nurses appeared to be solely concerned with getting on with the task in hand, rather than communicating with the individual and yet communication can make, or mar, a person's illness experience (Wilkinson, 1999).

> *"I mean there are times when I have to go to the clinic and I've thought...they don't care here, I'm just another on the... conveyor belt that's it."*
>
> Mrs Bird: 65

> *"[...S]ometimes at the clinic they were so busy that they never really had time to talk to you very much, it was just a case of doing your leg and out and the next one in you know."*
>
> Mrs Brown: 42

The reflexive device of "making excuses" for nurses, about how busy they are, was very common. As stated earlier, this may have been partly due to the fact that most people knew I was a nurse and, therefore, may not have wished to be over-critical of nurses. I was to be reminded of the work of Elias, a sociologist writing in 1985:

> *"It is perhaps not yet quite superfluous to say that care for people sometimes lags behind the care for their organs."*
>
> (Elias, 1985)

The "treatment" sounds efficient, as the dressings and bandages are changed as per protocol, albeit in a mechanistic and ritual way it would seem, from the descriptions of some individuals. Undoubtedly, all the individuals were being "cared for" if one considers Gaut's definition, as no one stated that they did not receive treatment:

> *"'Caring for' involves tasks that maintain health and facilitate survival but which can be done in apathy and indifference."*
>
> (Gaut, 1983, p.315)

The technical function of performing the dressing was done, but little or no care was given. However, the presence of a human and / or personal element is questionably absent from the accounts of some of the respondents, with no evidence of communication, comfort, reassurance or participation, as evidenced in the following excerpt from Mrs Topping. It was interesting that she referred to experiences approximately three years ago, when she felt there was time to talk:

> *"[...W]hen I was going three years ago there used to be time for the nurses to talk to you."*
>
> Mrs Topping: 10

but now she states:

> *"[...N]ow you just go in, they take your bandages off stick your leg in a bucket put some stuff on and bandages and you're off."*
>
> Mrs Topping: 10

Comments such as these implied it was the nurses who controlled the amount of interaction and discourse, between themselves and the individuals, which not only has echoes of a power imbalance, but also makes it appear as if the nurses are not interested in anything other than the "leg" as the "dys-functional" part (Kralik, Koch & Webb, 2001). It also reinforces the dominant biomedical approach espoused in comments such as the following from a senior physician at St Thomas' Hospital who observed:

> *"What a lot of valuable time would be saved if our patients could be taught that all we want to hear from them is an account of their symptoms as concise as possible and chronological."*
>
> (Cassidy, 1938, p.177)

The experiences of many individuals fell short of being "cared about", which involves concern and a valuing of the other as well as a positive attitude towards the individual and a commitment to care (Gaut, 1986). As discussed in chapters five and six, here we have 20 individuals who have unequivocally demonstrated that they have struggled, and are still struggling, both physically and psychologically, with ulceration. There has been little to suggest, from the stories of these individuals, that they received help emotionally to cope with ulceration. This is despite the fact that healing, let alone a cure, was unlikely to be a realistic option for many of them.

What a terrible indictment of nursing, a position which purports to be the epitome of a "caring" profession: nurses have endeavoured to promote caring as not only inextricably linked, but also as the core of nursing (Cortis & Kendrick, 2003;Morse & Johnson, 1991); and the essence of our work (Miller, 1991). Caring is the most consistent theme in defining nursing (McCance, McKenna & Boore, 1999) and its almost undisputed central function (Leninger, 1991;Watson, 1985). Benner and Wrubel (1989, p.398) also suggest that caring is the *"basic way of being in the world"*, from which all nursing practice evolves. In Morse's Science of Comforting model (1994) she makes explicit that the focus of nursing is comfort, which is the direct manifestation of caring and the ultimate goal of caring and nursing that is not steeped in a conveyor belt mentality.

Communication, integral to caring, is also considered to be a core clinical skill, an essential component of clinical competence (Silverman, Kurtz & Draper, 1998). If, for the individual, the encounter with the health care professional is one of almost indifference, then there is clearly no time or value placed on evaluating an individual's understanding – a prerequisite if education is to be successful (Arnstein, 2004). Implicit in education and understanding is empowerment of the individual. Healthcare staff until recently, were considered to know what was in a patient's best interests and thus able to make decisions on their behalf (Kennedy, 2003). The RCN sees empowerment as a desirable, if not essential part of nursing care (RCN, 2003) and go on to describe it as a central part of nursing, congruent with current national healthcare policy which aims to shift the balance of power from healthcare staff to patients (DoH, 2001b, 2001c). People need information about their health to be empowered to make informed decisions about the variety of options available to them (Feste & Anderson, 1995).

If there is no evidence of caring, this must infer that individuals are offered no comfort. Caring is the human effect which is present during the act of comforting and which motivates and initiates comforting actions (Hawsley, 2000). People feel comforted if nurses are responsive to their needs, it helps to make them feel secure and safe. Unfortunately, there were several examples provided by individuals where nurses appeared to be oblivious to the emotional needs of people in their care, displaying a lack of understanding or empathy with many of the individuals; an attitude tantamount to benign neglect. Mrs Topping verbalised that it was unacceptable to ring the nurses for the dressings to be changed, with echoes of feeling controlled by the nurses.

> *"[...Y]ou can't phone up and say can you change it, can I come in and you change it... you're not allowed."*
>
> Mrs Topping: 78

This also resonates with the viewpoint of Tweedale (2002), who argued that the culture of paternalism engendered in the healthcare profession is difficult to fundamentally alter. In general, patient empowerment is perceived to be a good thing but becomes blurred when an individual asks staff to follow a course of action, which is in conflict with their own perspective. Mrs Brown had actually requested if she could have her leg redressed in the week because of the discharge and revealed she was not only self-conscious, but also uncomfortable:

> *"...I used to say could I not come more often then they don't get as wet. I used to say look when people see all that stain it looks terrible... a big wet stain coming through the bandages."*
>
> Mrs Brown: 17

It is as if the nurses were listening, but not truly "hearing" the individuals, with power remaining firmly with the health professional. In this scenario, the nurse has clearly failed to perceive the meaning and feelings of Mrs Brown; in other words, lacked understanding and empathy. The health professional appeared it would seem to believe that they knew best, irrespective of what the individual thought was best for them. A further aspect to consider is the "potential" damage to the surrounding skin from such a wet wound as discussed in section 2.8.4. Whilst no individuals actually used the term "empathy", they referred to traits which, according to Morse, Bottorff, Anderson *et al.,* (1992), form the basis of empathetic communication, words such as "understanding" and "sympathy". This is further discussed later in the chapter.

As Mrs Brown spoke, I noted in my journal, that I couldn't help but be drawn to look at her bandages. I noted leakage on the outside of the bandages, with dressing renewal not expected for several days. This was a on a hot day in the middle of June.

In that one sentence, quoted above, this 54 year-old lady was verbalising her problems with exuding ulcers, not merely because of the physical discomfort of wet bandages (which would also feel much heavier), but mainly because she was embarrassed that other people would notice, an important factor in people's lives (Salter, 1997). It seems incredible that such a request is turned down. It may take weeks to find the right moment to even "summon the courage" to ask the nurses to reconsider their treatment regimens. For the request to be met with a resounding "no" must be devastating. In other words, the concerns of the individual are given no more than lip service. This was not an isolated example as four other individuals had similar experiences.

These comments concur with the views of McCormack (1993), and the findings of Henderson (2003), in which the nurses believed they knew best and did not allow patients to decide their own care. These comments also stand in stark contrast to the evident rhetoric about the active involvement of people with chronic illness in decisions about their disease management (Paterson, Russell & Thorne, 2001;Thorne & Paterson, 1998). Likewise, these experiences do not reflect policy agenda in the UK government regarding the focus of patient involvement in health care decision-making (Entwistle, 2000;NHSE, 1996).

The evidence in the literature advises health professionals that compression bandages can be left in place for seven days, as they retain their pressures for this period of time. However, what the literature and guidelines (RCN Institute, 2006) do not imply is that this decision should ignore requests from individuals who have concerns. It is not always easy for individuals to query the care they receive from health professionals, and I would suggest that for some it could be a difficult decision, hardly surprising when the request is ignored. The outcome for individuals in this study was to resort to plastic sheets and towels to protect the bedding at night, as indicated by statements such as this from Mrs Healy:

> *"And when I went to bed I had to put a towel over the bedding and towel over my leg because it was all over the sheets... it was always wet: the stuff I have thrown away."*
>
> Mrs Healy: 51

It was difficult for me to truly comprehend the following statement from Mrs Topping, regarding her thoughts about the treatment she received, particularly in times of difficulty.

> *"[...Y]ou can't do anything if you are having problems but put up with it. You couldn't take it off and you couldn't phone up and say can you change it they won't."*
>
> Mrs Topping: 25

There is evidence that concern about alienating staff through non-compliance is well grounded (Li, 2004). Mrs Topping's viewpoint echoes experiences verbalised in chapter five regarding dressing changes, where some nurses appeared "reluctant" to accept individuals self-report of pain. Again, it would appear many nurses quote the evidence like a mantra that the bandages have to remain in place for a week. This is not meant to be at all costs and certainly not if the person is having problems. It is difficult not to interpret all of these, as examples, which merely reinforce the continuing imbalance of power between health care professionals and patients, with evidence used by some professionals, to reinforce compliance, which does not take into consideration the individuals' needs or desires.

What also appeared lacking, from what the individuals told me, was any explanation from the nurses as to the rationale for a once a week treatment. Yet, had time been taken to provide that information, then it may well have reduced anxiety and distress, and increased coping abilities in some individuals (Field & Adams, 2001). Information and involvement are at the heart of a patient-centred approach to health care (Coulter, 2002). This again can be a tactic to maintain control, as knowledge is empowering. Therefore, withholding knowledge can only have the opposite effect.

People felt they were not treated as individuals, or sometimes even seen as a person, arguably the hallmarks of caring, but as groups of people with leg ulceration for which there is a "one fits all" treatment. This is also portrayed in the fact that, interestingly, all 20 individuals were being managed in multi-layer compression therapy (although other regimens are available), which caused many individuals more distress, I would suggest, than the ulceration itself. The nurses managing these people need to be open to their suffering so that, as a consequence, individuals feel the nurse is co-experiencing and understanding what things mean for him or her. Nurses also need to take heed of the NHS Improvement Plan (DoH, 2004b), the government's strategy for modernising the health service. This places great emphasis on putting patients and service users first, by providing more personalised care, and advises health care professionals to take a holistic approach to patients' health and well being, not simply focusing on illness. Unfortunately, just publishing a document will not bring about a change in entrenched behaviour.

7.4: Professional autism

In essence, this includes the nurses' perceptions, and understandings, of the person trying to live with chronic ulceration, and how well this has been achieved as seen through the eyes of those on the receiving end of care. It encompasses the notion of "empathy" (alluded to earlier), described by Reynolds and Scott (Reynolds, Scott & Austin, 2000), as an essential prerequisite of nursing practice. It is fundamentally about being in tune with the needs of the individuals.

> *"Empathy is the ability to perceive and reason as well as the ability to communicate understanding of the other person's feelings and their attached meanings."*
>
> (2000, p.226)

Unfortunately, there were many instances cited where nurses did not appear to be in tune with the suffering of the individuals. There appeared to be an inability on the part of some nurses to empathise with individuals, and it therefore became difficult for the nurses to help the individuals understand, or cope, with their ulceration, demonstrated in the following statement from Mrs Brown:

> *"[...T]hey'd just wrap you up and I'd be hurting and I could hardly walk, but yet you had to come out and carry on."*
>
> Mrs Brown: 35

This felt akin to "professional autism", where the nurses were unable to see the impact of their actions and treatment on the individuals. People left the clinical encounter feeling unhappy, frustrated, and uncared for, in a world already turned upside because of living with the symptoms of a chronic illness. When individuals stated that they were treated in an almost dismissive manner, they were equally critical of the clinicians.

Mrs Brown expressed that sometimes she felt upset by the way the nurses treated her. People referred to both the nurses' verbal and non-verbal communication. For example, Mrs Brown described one nurse as being "off-ish" on frequent occasions when she went to the clinic for treatment, because the outer bandage had been removed by Mrs Brown herself. The nurse is making very clear, by her non-verbal behaviour that she is the person in charge, and that Mrs Brown should do as she is told. Mrs Brown tried to explain she was in agony and couldn't sleep, and she would only consider removing the outer bandage if she really had to, but the nurse displayed her displeasure.

> *"[...S]he wasn't really very pleased you know and said I see you've took it off, you know really off-ish with me, you always had to do what they [the nurses] said."*
>
> Mrs Brown: 43

It is surely difficult to feel empowered when you are not allowed to have a say in decisions about your own needs, when someone else makes assumptions about what your needs are (Sines, 1995). This is a further clear example of the fundamental difficulty encountered, when individuals try to alter the balance of power in their favour by following a course of action other than that recommended by staff. Mrs Brown had already articulated, in chapter four, the difficulty she had with pain and exudate, and how she became angry when nurses kept telling her, or even expecting, that she would be able to rest. It was almost as if the nurses were "blaming" her for the non-healing of her ulcer. This is congruent with the findings of Madsen (1992), and Pinder (1995), who comment on the tendency, on the part of some health care professionals, to blame those with chronic illness for the symptoms they experience.

The professional attribution of negative stereotypes to patients who are perceived to be uncooperative, difficult or demanding is well established (Bendelow, 1996;Dixon-Woods & Critchley, 1999;Li, 2004). What appeared evident from some stories was the extent to which the nurses were influenced by a biomedical framework (section 2.3.1), with emphasis on the "dys-functioning" part of the body. In a biomedical model, rest and leg elevation would be the advice to assist in venous return and reduce pressure, regardless of the psychological impact (Kralik *et al.,* 2001). Many nursing authors have argued that an important distinguishing factor between nursing and medicine is the recognition that patients are more than their disease or illness (Liaschenko, 1998;Reynolds *et al.*, 2000). Nonetheless, it would seem from the stories of these individuals that some nurses continue to find this somewhat challenging to implement. It is far easier to deal with the physical treatment of the ulcer than to address psychological needs and, it would seem, they often remain ignored.

People like Mrs Brown were struggling, mentally and physically, to fit ulceration into the context of their lives and, in Mrs Brown's case, looking after her severely disabled husband and the home, virtually alone. People with chronic illness will often work through an adaptive decision-making process (Paterson *et al.,* 2002), similar to a cost-benefit analysis, and may ultimately take a course of action that differs from some of the advice given to them by the health professionals as the suggested course of action is not something that will fit into their lives. The question is: should they feel as if they have been "punished" for doing this?

This reinforces that some health professionals seek to retain the balance of power in their favour and believe that people should comply, rather than concord, with treatment regimens. It appeared from the stories of the participants that, in some cases, nurses were continuing to use a biomedical model in their approach to care and not "hearing" the individuals' illness experience; the person seems to have faded into the background. This only seeks to intensify the disembodiment already articulated in the stories of these individuals. The healthcare professionals were also portrayed as unwilling to listen and accept the individuals' account of their condition or the level of their pain. Mantyselka, Kumpusalo & Ahonen, (2001) reporting on concordance between patients' assessments of pain intensity and that of GPs' found that the more severe the pain as assessed by patients, the greater the non-concordance with the GPs' assessments which were at least two units lower than the patients' rating. This was certainly exemplified in the following excerpt from Mrs Boyd who strongly believed the nurses labelled her as non-compliant.

> *"[...T]here was a new sister and I got really upset one day because I got the impression that she was saying I wasn't trying hard enough... but if you got the pain I got then you would have tolerated* ***anything*** *[her emphasis] that was going to do it good."*
>
> Mrs Boyd: 9

Mrs Boyd became visibly upset at this point, on recalling the situation with a senior member of staff, who had evidently made her own judgement as to what Mrs Boyd should, and shouldn't, be able to tolerate. There was a collective script of people being asked about their pain, which individuals stated was recorded by the nurses, but not necessarily addressed. There was the viewpoint that, if the nurse didn't "offer" painkillers, then you don't really need them. The individuals on the receiving end of care clearly did not appear to be entitled to make any decisions about their care. Generally, the individuals in the study said they appreciated those nurses who displayed signs of sympathy in the way they dealt with them. It became evident, that "being told" what to do, was not appreciated, and only succeeded in the nurses being labelled as *"cocky,"* or *"off-ish"*.

Patients are aware of the negative stereotypes and strive to avoid them, as indicated by people's "acceptance" of the treatment they received. Individuals did actively strive to avoid being labelled, by behaving "appropriately" and occupying the role of the "good" patient competently (Bastian, 2003;Salmon & Manyande, 1996;Werner, Widding Isaksen & Malterud, 2004). The "good" patient is positive, stoical, co-operative and uncomplaining (Pollock, 2007).

There were occasions in which the individuals were told about other people who *"had really bad ulcers"*, as if the individual had no right to complain because there were people deemed by the health professional to be a lot worse off than them.

> *"[...T]hey would say we have seen a lot worse than this... they probably had, mine were probably nothing compared to some people's. But to me they were a big thing... it were my ulcer and it was me suffering."*
>
> Mrs Hall: 54

It must be terrible, for a nurse to make you feel as if you have no right to complain about your ulcer, because other people have ulcers that are bigger, or much worse than yours. This only serves to exemplify that people are not treated as individuals.

Nonetheless, there were some nurses who did appear to be "in tune" with the individuals because of their mutual affinity as human beings, communicating a sense of trust during the dressing procedure. People appreciated staff that showed an interest and involved them in decisions regarding their care, as described by Mr Jones, who described feeling reassured.

> *"[...I]t's important to feel as if the nurse is really taking an interest, it's a big lift for you if you feel they care and want your leg to heal... and for nurses to discuss treatments with you as well is very important to me."*
>
> Mr Jones: 49

Similarly Mrs Healy stated:

> *"Psychologically you feel better knowing that somebody is taking an interest in you and they want your leg to heal you see."*
>
> Mrs Healy: 46

Mr Jones expanded, in great detail, the discussion that took place between himself and the nurses, and with one in particular, whom he referred to by her first name. It was interesting that throughout, where nurses appeared to be "trusted", they were called by name. Otherwise, they were referred to as either "they," or "the nurses". It almost felt as if the individuals' attitude to the nurses mirrored the way the nurses treated them, so that if they were dealt with in a distant, or dehumanising, way then they were referred to in a less than deferential way. Feeling a strong sense of support from health professionals, appeared to be of paramount importance, and seemed to have the effect of enhancing comfort and reducing anxiety and uncertainty. The experience of Mr Jones was not an isolated case. Indeed, seven people including Mr Myers, believed that nurses showed a genuine interest in them as individuals:

> *"All the time they are doing your legs the nurses are talking to you and they do make you feel a lot better... actually I used to feel better when I had spoken to them."*
>
> Mr Myers: 51

Individuals seemed to feel reassured and secure when they sensed that the nurses were there for them. People referred to some of the behaviours, which according to Morse *et al.* (1992), form the basis of empathetic communication – emphasising the process of emotional engagement of the nurse with the patient. According to Morse *et al.* (1992), sympathy is a first-level empathetic response and is a verbal and non-verbal expression of the nurse's own sorrow or dismay at the individual's situation.

It seemed important to individuals that nurses communicated their recognition and understanding of the individual's situation. It appeared to make a difference to know someone understood. Morse *et al.*, (1992) refer to this communication as second level empathetic communication response. This type of empathy is considered to be "patient-focused" and results in patients feeling secure and reassured. There were some individuals who also made no comment on the care they received and this may be because it either wasn't an issue for them, or that the caring went unrecognised. It is likely that caring is expected and thus taken for granted by many until such times, as it doesn't happen.

7.5: Prisoner to treatment

What is often a devastating blow to individuals who seek professional help is the impact of the treatment itself, which in all cases was multi-layer compression bandaging, on their ability to live life as before. Treatment has become part of the problem, as well as the solution since, for Mrs Brown, the bandages were a continual reminder that she looked "different", a view shared with some anger by others such as Mrs Kay.

> *"If you just have one bandage on your arm you know it's cumbersome, but to have four, you can't imagine what four bandages on your leg is like* ***can you*** *[her emphasis]. They bandage it from there [pointing to toes], all the way up your leg and right up to just below your knee."*
>
> Mrs Kay: 48

I tried to reflect whether the vehemence with which she asked the question was directed to me as a health professional, or simply reinforcing what she had previously stated, that no one could truly understand unless they have experienced it for themselves.

People were unanimous in their agreement, that the bandages caused them problems, and that they were an issue for them, with many verbalising that multi-layer compression bandages were the worst thing about having a leg ulcer. The bandages restricted people's ability to do so much, making them feel encased, not free. Mrs Smith likened wearing bandages to *"carrying a tree trunk around"*, while Mr Jones felt it was *"like having your leg in a bed"*. Mrs Brown said:

> *"[...I]t's so uncomfortable all the time, you just felt like your leg was in a vice all the time with this pressure bandage."*

Mrs Brown: 20

In health, the presence of the lived body is taken for granted (Leder, 1990), whereas, in illness, people become aware of "having" a body and "feeling" different (Madjar, 1997, pp. 58 - 59). This is displayed in the following excerpt from Mrs Brown, who is definitely aware of having a body and feeling different:

> *"I didn't go out a lot, I didn't want to go anywhere you know, I used to think everybody was looking at me, because...all the wrappings, they put a layer of cotton wool all around as well, that was to soak any fluid up, altogether you have five layers on, my leg looked massive you know... I felt so embarrassed."*

Mrs Brown: 25

If people had managed to forget about their ulceration prior to treatment, forgetting about "the leg" was now virtually impossible. The treatment compounded to ensure that the leg became a daily focus in their lives, impacting on their ability to continue with their lives, with simple activities like going to the shops becoming major expeditions for many. Spontaneous decisions to slip your shoes on and go to the shops were no longer an option. Not only did they have pain, discharge, odour and the bulk of the bandages to contend with, but they were also subject to the vagaries of the weather, often opting not to go out at all if it was raining or snowing, because of their inability to wear "normal" footwear.

> *"Your ability to go out depends on the shoes that you can get for your feet as well... One minute it's pouring with rain, and the next the sun is shining, so you have to be able to have a pair of shoes that you can go out in any weather."*

Mrs Smith: 46

As you read the following passage from Mrs Healy's conversation, it needs to be with awareness that this situation had been continuous for the past three years. It is not a problem that requires a short-term solution, this was an on-going problem, which started to interfere with her ability to leave her home and socialise. She admitted that she was now virtually housebound as a direct result of the treatment. A particularly important factor for this lady, who also lived alone and admitted to being lonely, there were some weeks when the only person she did see was the district nurse to change her dressings.

> *"Well... It limits what you can do... you can't get into your ordinary shoes. When it's wet and cold I can't go out because I can't get my feet warm or I get wet... I had to adapt a shoe. I had one right shoe on one foot and that [cut out slipper] on the other, and then fancy going out when there is snow on the ground and your toe is bare. I found, it limited me, it more or less tied me down."*
>
> Mrs Healy: 13

It could be argued the she "may" not have gone out in any case, but this was a 77 year-old lady who, prior to ulceration had, she explained to me, "hardly ever been in" and had belonged to several committees and social groups which she no longer attended.

Many spoke of having trouble walking because of their chronic ulcers, either due to pain like Mr Whalley and Mr Owen, or because of loss of function, due to the site of the wound which restricted ankle movement, like Mrs Warlow and Mrs Kay; but often due to the treatment regimen itself.

> *"Oh yeah because I just couldn't cope, I couldn't cope with my housework, looking after Tom, I was in so much pain, I could hardly walk, you imagine, I mean both my legs were wrapped up at first... I was walking around stiff like, I could hardly walk... this pressure bandage it's so uncomfortable."*
>
> Mrs Brown: 23

People talk about searching all over town to find footwear, not only to fit them, but which they can also tolerate. Two individuals even resorted to buying two pairs of the same shoes in different sizes, so that they could make one complete pair, which would enable them to walk more easily and would also look better. There is also the added risk of potential falls, not just outside, but also within the home, particularly for the elderly in ill-fitting shoes or slippers as illustrated by Mrs Ruane:

> *"I had to be very careful in the kitchen because I couldn't get my shoes on with all those bandages... I had to hold onto everything so I wouldn't skate you see. It gets slippery."*
>
> Mrs Ruane: 39

This then made tasks such as making a meal, or even a cup of tea, difficult and potentially hazardous. Fear of falling was something verbalised by six individuals and all related to ill-fitting footwear. Another aspect to consider for people on a pension, or out of work, is the cost of buying another pair of shoes that would possibly be no use to them once the ulcer has healed.

As discussed earlier, what appears to confound the situation for most of the individuals, was the length of time the ulcers took to heal. Unlike a prison sentence, where the duration of sentence is announced, these individuals are left in a state of Limbo waiting for the ulcer to heal as there is no known endpoint to their sentence.

> *"[...I]t's just a case of your leg being encased in all these dressings, you feel imprisoned, trapped, you never feel free and its four years now so that is a long time."*
>
> Mr Jones: 7

Mr Jones admitted he asks the nurses every week how long before he heals to which, the nurse admits, she is unable to tell him as there is no way of knowing. She can tell him if it is looking better or worse, but not when it will be healed.

Similarly, Mr Whalley worried about how long he was going to be *"stuck with these ulcers"*.

7.6: Keeping up appearances

A major factor mentioned by all twelve women was the impact on their appearance of the treatment. For women, bandages seemed to be a double edged sword, not only were the bandages so bulky that they were unable to wear their "normal" footwear, but they had to resort to buying unattractive shoes that, in addition to being several sizes too big, didn't co-ordinate with any clothes they had:

> *"[...A]t the moment I can't wear no decent shoes and as far as skirts, I have loads of skirts I can't wear them because I wear trousers which is a good thing for me, hides the bandage... I would love to wear skirts, but I can't get my shoes on you see to match my skirts."*
>
> Mrs Gray: 17

Another person noticing the bandages was unacceptable, as this was a visible stigma interfering with their self-image. Visibility plays an important role in producing negative social reactions (Joachim & Acorn, 2000). When completing the HADS in Phase I, all the women had noted they still took an interest in their appearance, confirmed by what they said in interviews. For example many of the women, including those on a pension, saw a professional hairdresser once a week. Appearance mattered greatly as verified by Mrs Brown:

> *"...I've always sort of tried to keep myself nice and dress nice... sort of in a way proud of yourself, and when you come to something like this, it's awful... it had a terrible affect on me you know."*
>
> Mrs Topping: 33

It was important to be able to go out looking as smart as possible: it seemed to affect, not only how they felt about themselves, but also how others perceived them:

> *"[...H]aving to wear dumpy horrible flat shoes. I don't wear high heels, but just something that co-ordinates with what you've got, instead of having to have something that comes out of, oh I don't know, what you can say, like the old institutions you know."*
>
> Mrs Bird: 56

Mrs Bird's use of "institution" was interesting, and perhaps linked to a fear of association with a cultural stereotype of people from an "asylum", who were visible to "normal" people through having not just "odd" clothes, but often an unconventional way of dressing.

It remains a source of puzzlement that some women found it preferable to maintain their "normal" footwear on the unaffected leg, and an odd and oversized shoe or slipper on the ulcerated limb, rather than having a pair of shoes that matched.

> *"...I either wore a big horrible shoe or a bedroom slipper on my bad leg... and I felt everybody looked."*
>
> Mrs Hall: 43

This "may" be related to a desire for normalisation, keeping a foothold so to speak, in the door of the "normal" world. This resonates with the comment by Donnelly (1993, p.6), that people with chronic illness live in "the dual kingdoms of the well and the sick". Mrs Brown who had searched the shops exemplified this, desperately trying to get something to fit her bandaged foot, and resorted to wearing a man's shoe on one foot in order to accommodate the bandages. The resultant appearance had an unquestionable impact on her self-esteem to the point where she admits she no longer wanted to socialise or indeed even leave the house at all.

> *"[...] I didn't go out a lot, I didn't want to go anywhere like that you know, I used to think everybody was looking at me and thinking 'oh look at her*

> *legs'... I had a size nine men's shoe on one foot, and my normal shoe on the other, it's the way you look, as well as what you feel, it's awful... when you come to something like that, it's awful."*
>
> Mrs Brown: 29

The aesthetic appearance of the dressings and bandages were a source of concern. Jones, Farina and Hastorf (1984), refer to six dimensions of stigma impacting on interpersonal roles, with aesthetic qualities as the fourth dimension. This refers to the extent to which a condition affects the appearance of a person. This has direct relevance to the effect of the treatment options for individuals with ulceration. Women mentioned how unattractive their dressings were, and that they should be hidden or concealed from others. "Covering" is an attempt to minimise the effect of the stigmatising condition (Goffman, 1963b). Women often wore trousers or alluded to the fact that they had not worn a skirt, or dress, for years because of the ulcer, a form of "selective concealment" (Scambler & Hopkins, 1986).

> *"Well no you see, when you have got those horrible bandages on, well, I felt I couldn't wear skirts, so I had to wear trousers all the time, which I do now. Just to cover the bandage up, it's horrible, and thick, and wasn't very glamorous... I think I was trying to shut it away."*
>
> Mrs Kay: 37

The women did not want to draw, nor be the focus or centre of, attention, preferring to merge into the background, or at least not command attention because of their ulceration; it would be almost like wearing a prison uniform. There would appear to be a constant "need" to, in some way, "hide the leg", this alien part of the body the individual has no control over. The preferred solution is to hide it not only from others, but also from themselves:

> *"...it's sort of too noticeable for me to want to walk about like that, so therefore I've had pants on for the last six years... I think it would draw too much attention to me if I walked about with as skirt on."*
>
> Mrs Warlow: 21

This meant that the desire to socialise or even to leave the house was, for many, eroded, as there was a distinct withdrawal from social life and they became veritable prisoners. It is almost as if people thought that they would be socially disqualified because of their ulceration. These perceptions seemed to add to the physical and psychological burden of ulceration, impacting on their being-in-the-world.

> *"I like going shopping... but it did stop me from going shopping because I had to wear this horrible big shoe and I felt really everybody looked, I always imagined everybody were looking at it."*
>
> Mrs Hall: 43

Similar thoughts by Mrs Brown were given voice when an acquaintance she met at bingo walked up behind her and started to laugh loudly, and tell her she looked like a mummy from the back *"...you see how people react to the way you look... it's the way you look as well as what you feel, it's awful"* was all she could say to me. This meant she would not go anywhere new, only to places like bingo where she already knew people. She did not want to have to cope with people looking at her, or risk further comments.

The bandages aggravated all the women, restricting their activities and impacting on their body image. The treatment seemed to cause obstacles at every turn, which at times appeared insurmountable, even dressing for the day felt like something else people had to cope with. People seemed to vacillate between hope and frustration. Women talked about the fact that they could no longer just go to the wardrobe and select whichever item they wanted to wear. They couldn't wear stockings or certain types of tights, or their preferred footwear. On a day-to-day basis this meant that getting ready for the day had taken on a whole new dimension, based not on a colour scheme or the weather, but rather on the "theme" of concealment as far as possible. Although the weather dictated, for some, because of the problem of footwear, if they were able to go out at all:

> *"[... I]f you ever want to go any where, you've got this dirty great big lump of stuff on your leg and you can't even get a pair of stockings on and it's very frustrating to think that you can't dress up and go out because of them, because they are so, so ugly the dressings."*

Mrs Smith: 27

However, appearance was not something for which females had the monopoly, as noted in the following excerpt from Mr Whalley:

> *"You can't dress up like you used to dress up on account of the bandages and shoes."*

Mr Whalley: 5

Footwear was a problem for the men also, as described by Mr Williamson, particularly if he had been stood up all day working. If he then put on a suit to go out he found he either had to wear sandals or resort to cutting shoes.

> *"[...S]ometimes I couldn't get a shoe on at all, no way, which depresses you really because you are going out dressed up and you have a pair of sandals on. I mean joking apart, you do get a bit taken back sometimes when the Velcro comes lose and they start flapping about. I have got some shoes that I have cut right down, and cut the elastic off, so I could get in them you know. You know you do all kinds of things, just to keep going don't you."*

Mr Williamson: 40

He emphasised on numerous occasions that he just "wanted to keep going", he was not prepared to give in to ulceration but tried to retain some sense of "normality". Other people, like Mr Owen, gave up trying to get into shoes after years of ulceration and almost a lifetime in bandages:

> *"...I can't wear a proper pair of shoes they have got to be trainers and one size up because of the bandages."*

Mr Owen: 34

Similar to Mrs Bird, referred to earlier, Mr Ball also mentioned that he didn't want to have to wear footwear which reminded him of either an older person's home or institutions:

> *"I refused to wear those fold over Velcro things because they reminded me of old peoples' homes and institutions, that type of thing."*
>
> Mr Ball: 17

Mr Owen also noted that he couldn't wear "proper" trousers and he had likewise been forced to wear trainers:

> *"I can't wear a proper pair of trousers it has got to be a tracksuit with a wide bottom."*
>
> Mr Owen: 35

What a cruel irony that he should find he is forced to wear trainers and tracksuit bottoms, arguably items of clothing that one associates with fitness and sports. Here is a gentleman who admits to even walking much slower than his family when they are out as a group.

7.7: Unequal partnership

There is constant talk of concordance, rather than compliance, with treatment, as if somehow semantics changes the thinking, and indeed behaviour, of health professionals. Unfortunately, there were more incidents cited of nurses trying to retain power in decisions made about treatments than examples of true partnership in care. Mrs Brown felt that even if she did say or request anything then it was ignored, as evidenced earlier in her request for changes of dressings in the week. She admitted that, on several occasions, she had redressed it herself out of desperation because her bandages were wet through and very uncomfortable. Odour and exudate were damaging to people's sense of image and self-esteem, limiting the desire to go out. This was further aggravated by the treatment, not simply in terms of physical bandaging, but also in terms of attitude and actions of clinicians. Unfortunately, she has been reprimanded for this behaviour despite her desperate and heartfelt explanations.

> *"...I really got mad because I always felt that they were telling me what to do all the time and it was so hard."*
>
> Mrs Brown: 40

This is not an isolated case. Mrs Boyd had also been in a situation where she was in agony with the dressings and so changed them only to be told:

> *"[...D]on't touch it, it is meant to last a week so you need to persevere and keep it on the week."*
>
> Mrs Boyd: 12

Mrs Brown was unhappy at the way she was spoken to. She articulated that the nurses were constantly telling her what to do and talking down to her, as demonstrated in the following quote. This was a lady almost at the end of her tether, trying to cope with a severely disabled husband and, at one point, bilateral ulceration. She was responsible for the maintenance of the house including shopping and cooking, and found the advice she was given unrealistic in her circumstances:

> *"[...L]ook at your legs, they are red... you are not resting enough she [the nurse] said, and they [the nurses] used to talk to me as though I was a little girl."*
>
> Mrs Brown: 40

This sentiment was echoed by Mrs Kay who spoke of being "patted on the head" by the nurses when she tried to talk to them about how she was feeling; an act that has connotations of both patronisation and also disbelief in what the person is saying:

> *"...I did talk to them, but then I got worked up and started crying so she came and patted me on the head."*
>
> Mrs Kay: 41

People commented that they had been warned not to remove any of the layers of bandage, or that in extreme circumstances **only,** they could remove the top layer **only** but only *"if you are in agony and it's really hurting".*

It appears to be the no pain, no gain mentality:

> *"It's not them that is suffering, it's me that's suffering, it's alright telling me to put up with it and I'd come home and I'd cry you know and I'd say how can you put with the pain, in agony like that."*
>
> Mrs Brown: 18

On one visit to the clinic, Mrs Brown had commented that *"my leg is no better, it's still hurting me"* to which she received the following rather curt response from the nurse:

> *"Well you shouldn't keep touching it, it's our job, leave it alone."*
>
> Mrs Brown: 49

It was astonishing and disheartening at the same time to hear nurses "blaming" people for the non-healing of the ulcer. It is hardly surprising to hear comments such as "they don't understand" levied at the nurses when they display such a lack of understanding.

The clinician's "control" extended beyond the clinical encounter, with individuals verbalising about being afraid to remove bandages, even though they were painful or soaked in exudate, for fear of reprisals and repercussions at their next appointment or visit.

7.8: Continuity of Care

People described the importance to them of sequential encounters with the same, or not more than two or three nurses, as it helped to facilitate trust and provide them with a sense of predictability and coherence in an otherwise unpredictable illness journey. This is referred to by Haggerty, Reid, Freeman *et al.* (2003, illness journey. This is referred to by Haggerty, Reid, Freeman *et al.* (2003, p1220), as "relational continuity of care" in which there is "an ongoing therapeutic relationship between an individual and one or more providers". Never seeing the same person twice led to feelings of insecurity and frustration at having to re-tell their story each time they went for treatment. Mrs Boyd also alludes to the fact that, because for her there is no continuity, the nurses ask her all the time how it is.

> *"Every time you go it's a different nurse... you never seem to see the same nurse and then they are saying to you, what do you think, how does it seem to you?"*
>
> Mrs Boyd: 7

This was not an isolated viewpoint. Eleven people mentioned the importance of continuity, of at least having the same person alternate weeks, and lack of continuity was an issue for four of these individuals. One of the reasons cited was the fact it is not unusual for nurses to have differing ideas and opinions on the "best way" the ulcers should be managed.

> *"I started on one dressing and then the next week it was someone else and they said oh I think this is better and that happened the week after."*
>
> Mrs Boyd: 12

This appeared to be more of a problem for the six individuals whose care was managed by district nurses, as the individuals may have visits by nurses they have never seen before, as exemplified by Mrs Brown:

> *"Then this particular day another one came and I didn't know her either and she said 'oh what a mess... you're not resting enough with this leg you've got to rest and get it up' and I saw red and told I had a sick husband and nobody to help me, how can I rest?"*
>
> Mrs Brown: 40

Nurses who visit patients regularly get to know the individuals and their family circumstances, and even though the individuals may have heard the same advice from their "regular" nurses, often this advice is tailored for the individual.

People who attended specialist clinics predominantly were more positive about the care they received and the importance of the clinic.

> *"It's very important you know to have somewhere you can go, someone to turn to who understands and will do something for you."*
>
> Mrs Hall: 51

Again there is an emphasis on being understood as an individual, not as part of a group of people with ulceration. However, many of the individuals recognised that the dedicated leg ulcer clinics offered what is referred to as management continuity, described as a "consistent and coherent approach to the management of a health condition that is responsive to a patient's changing needs" (Haggerty *et al.*, 2003, p.1220).

7.9: Dreading the change

Unfortunately, for some patients they could attribute some of their pain to the treatment and specifically to the actual procedure of dressing change. In phase I, of the 73% of people who complained of pain, for 57% of them the pain was worse at dressing change. Dressing change succeeded only in exacerbating, rather than ameliorating, the pain, becoming not only a physical but psychological ordeal for them with some actually stating that they dreaded having their dressings changed. Cleansing in a bucket of water was painful for some as articulated by Mrs Brown.

> *"[...P]utting it in water, that was awful you know, you're so sore and they are hurting so much, and then they stick your leg in water... then, she'd get her tweezers, and she'd start rolling skin off my leg, all dead skin, from*

> *over the ulcers, oh... [pause] and they were so painful, because you're like, near the nerve endings."*
>
> Mrs Brown: 11

This concurs with the findings of Vuolu (2006), who concluded that even ulcer cleansing in a bucket of water can cause pain if the limb is immersed / withdrawn too quickly. It seems unbelievable that a patient should have to tell a nurse not to pull a dressing off which has dried out and adhered to the wound. Dressing change, to have fresh dressings and bandages applied, should be a procedure that brings relief, not something, which is dreaded and becomes a harrowing experience. This is a perverse flip side to an intervention that is supposed to have a therapeutic intent.

> *"[...B]ut many a time, when they were bad, I used to go, and all the things were stuck, the pads used to be stuck to my legs, and you can imagine, that when you've got sore legs, and I used to say 'don't pull it, don't pull it, I can't stand it'."*

At this point she hesitated for quite some time, and was tearful, almost as if she was actually reliving that moment again, before she continued:

> *And it would take your skin away, it was really bad... I used to be in agony, I used to dread going."*
>
> Mrs Hall: 12

As a health care professional, it is sometimes too easy to forget that not everyone understands the causes, or pathway, of their pain. In fact, listening to these individuals' accounts, it made me wonder whether the nurses looking after them had any understanding, let alone any empathy, for their situation. I could not help but be reminded of a quote from Kuhn, Cooke, Collins *et al.*, which states:

> *"Patients expect ineffective pain relief and their carers ensure they are not disappointed."*
>
> (1990, p.1678)

This suggests either a professional callousness or, I would contend, a "professional autism". Both are traumatic and damaging to the individual concerned.

> "[...*A]nd I couldn't bear... you know, dressings were horrendous. I'd like be bouncing up and down nearly hitting the ceiling.*"
>
> Mr Davies: 18

It could be said, from the reports of the individuals, that there was "reluctance" on the part of some nurses to accept the individuals' self-report of pain. With people being told, for example, that they were extra sensitive. How does this fit with Margo McCafferey's definition of pain?

> *"Pain is whatever the experiencing person says it is and exists whenever he says it does."*
>
> (McCaffery, 1968)

A definition with which most nurses, I would argue, are familiar. The following, from Mrs Bird, does not exemplify an understanding of that definition.

> *"[...T]hey get the forceps out, and I think, here it comes and they've got to take the scab off... oh God [pause], I mean I have cried several times, because it hurt* **so** *[her emphasis] much... and they tell me I am extra sensitive... it is terrible and I think each time oh not again please."*
>
> Mrs Bird: 3

Previous experiences of pain that have not been well managed can lead to anxiety as noted above, and negative perceptions of potentially painful events. It was interesting to realise that the simple action of a nurse picking up a pair of forceps was automatically linked to pain. Especially as forceps are regarded as a hand-held instrument, for grasping or holding objects, not an instrument for inflicting pain. In Krasner's model of chronic wound pain (Krasner, 2001) she refers to this type of pain as "cyclic acute wound pain" as it accompanies regular procedures performed by the health care practitioner. Poor pain management can result in the negative effects of depression, anxiety and helplessness.

7.10: Summary

Writing this chapter has been both a challenging, as well as humbling, experience. In the previous two chapters I felt able to accompany, to a degree, these individuals on their journeys, not only because of my clinical experience of dealing on a daily basis with individuals with ulceration, but also due to the growing literature on ulceration. The depth of people's anguish and their levels of depression have at times, however, been both revealing and disturbing.

I was to be humbled, disappointed and saddened by their experiences of the clinical encounter. The treatment itself left people in pain and discomfort, or made them virtually housebound either due to embarrassment, odour, or the vagaries of the weather. People should be able to come to a clinical encounter safe in the knowledge that their pain will not be accelerated, and leave feeling better. Sadly, in many cases, this was not the reality. Instead, for some people, it became a traumatic and painful encounter adding to their downward spiral into depression.

This chapter has emphasised the ignorance surrounding the appreciation of leg ulceration as a chronic condition that is both mentally and physically disabling. The divide between the perspective and aims of the health professional in the management of ulceration, and that of the individual, does not appear to be diminishing. There is evidence from the stories of individuals of the maintenance of a biomedical model with "power" remaining firmly in the hands of the clinician despite the rhetoric of government legislation.

It has been difficult to listen to criticisms of fellow nurses and even harder to commit these findings to paper. Nonetheless, it is important that as clinicians we understand the impact of the clinical encounter for the individual in terms of mental and physical suffering. It is vital that as clinicians we do not underestimate the potential role we can play in ameliorating the suffering and helping to improve an individual's quality of life. Whilst we leave the words of the individuals at this point, it is not only impossible, but also wrong, to leave their voices behind as we move to the final chapter. In writing these chapters I have had to be selective as to the data to represent, which is a reflection of my intrinsic role within the research process. Equally I had to be selective in the aspects that I took forward to the final chapter. I found that was also a difficult decision, as I realised that it could imply that I believed one aspect of the chronic ulcer trajectory was more important than other. I believe that my ultimate selection was true to the voices of the individuals in articulating the aspects that helped to explain their emotional distress and ultimately depression.

I return to the conception of the study prompted by my own clinical practice and concern for patients with chronic venous ulceration for whom cure was not a realistic objective. Many of these individuals verbalised “feeling low” and “fed up”, and I began to question if the symptoms they were expressing were in fact a co-morbid depression which might impact not only on their quality of life, but also on the healing of their ulceration and their physical and mental health. My aim therefore in the next chapter is to ensure that I have clearly articulated the evidence provided by the individuals who shared their stories.

Chapter 8: Discussion

"A sad soul can kill you quicker than a germ."
John Steinbeck, American Author 1902 – 1968

8.1: Introduction

The study conducted for this thesis was prompted by my clinical practice, and concern for patients with chronic leg ulceration for whom cure was not a realistic objective. Many of these individuals verbalised "feeling low" and "fed up", and I began to question if the symptoms they were expressing were, in fact, a co-morbid depression which might impact not only on their quality of life, but also on the healing of their ulceration and their physical health.

This concluding chapter begins by highlighting the key findings and the extent to which I was able to answer my own clinical question, and thus the objectives, of the study. The methods used will be discussed as well as the limitations of the study. This is followed by an overview of the study findings and how they provide enhanced understanding about a previously under-researched area. The implications of the findings will be discussed in the light of existing knowledge, in addition to how this research has added to our body of knowledge of leg ulceration and its potential sequelae. This chapter will also consider the implications for clinical practice and areas of further research. The contribution of this study towards the development of nursing knowledge and enhancing the understanding of patients' experiences is also explicated.

8.2: Key findings

Key findings from this study are as follows:

- There is a link between chronic venous ulceration and anxiety and depression.
- Venous leg ulceration shares the hallmarks of a chronic illness.
- There is an association between pain and odour, and depression in chronic venous ulceration.

- Chronic venous ulceration and depression are linked to decrements in quality of life.
- Many individuals live in a world they "don't want to be in", enduring the loss of "life" and self.
- The clinical encounter is not always helpful or positive.

8.3: The case for using a quantitative and qualitative approach

Freshwater (2006, p.181), stated that methods is about *"Finding the best approach to answering a question in the most robust manner"*. This was the ultimate starting point in the conceptualisation of this study. In the original design, the quantitative and qualitative components were seen as separate, essentially as two conceptually discrete elements of a single study. However, once the study began, I became aware of how my thinking about the qualitative data was continually informed and enhanced by the findings of the quantitative component, and how the results of this phase enriched my interpretation and understanding of my data.

During analysis of the interview data, I was influenced by the findings of the HADS, as well as the information collected in the questionnaire. This meant that aspects such as pain and odour (key findings in phase one), were highlighted and thus initially "seen" in the data. Nonetheless, the survey data also helped to shape chapters five to seven and deepen an understanding of the experiences shared by the individuals. I believe that the findings need to be viewed as a complete data set, helping in our developing understanding of the psychological impact of chronic ulceration. It is with this view in mind that I have taken the step of discussing both phases concurrently as I believe this enhances understanding. Whilst the quantitative data was analysed and represented in this thesis separately, it was impossible to put this data to one side during the interviews. Subsequently, the findings from Phase I are peppered throughout the qualitative presentation of data.

Using a survey in phase one enabled me to provide a clear impression to both the prevalence and scale of anxiety and depression in individuals with chronic venous ulceration, and the main contributing factors to a score of "caseness." The in-depth interviews in phase two followed a hermeneutic phenomenological approach to facilitate the exploration of the individual's experience. The quantitative phase provided answers about the size of the problem, and indicated some of the key factors associated with a high depression score on the HADS. The stories provided by the participants through their interviews permitted an understanding and interpretation of their experience. The information provided in this research supports the wondering and wandering which reflects the uniqueness, and the significance of, the inevitable individual process of coming to understand the lived experience of ulceration. This suggests that the lived experience included individuals' whole being, which influenced their meaning, or understanding, regarding ulceration.

Using a quantitative and hermeneutic approach together has enabled the value of both approaches to be illuminated. Research using the "society" method provides us with an understanding about health problems, but cannot tell us the way in which an individual understands their experience. The quantitative phase was an important way of not only determining prevalence, but also of obtaining a sample from which to purposively select individuals to interview. The results, of either phase in isolation, would not have added to our body of knowledge on emotional distress in chronic venous ulceration. The quantitative phase provided the skeleton structure, such as the factors that are associated with "caseness" of depression, whilst the hermeneutic approach added the meat to the bones, providing the perspectives of the individuals regarding these factors.

The phenomenological approach was the key, to uncovering participants' interpretation of the complex and dynamic process of integrating leg ulceration into their lives. Calman (2000, p.17) stated that stories:

> *"[...H]elp us to make sense of the world and able to bear some of the burdens which we face. They give meaning and structure to our daily lives."*

Illness and disease are not synonymous, but rather illness is the lived experience of the disease, reflecting the changes in an individual's state of being and social function: in other words, the impact factor of the disease itself.

8.3.1: The advantages of using a narrative approach

Each person's narrative, like their journey, was unique, even if the text as a whole highlighted many similarities and common experiences. This study illuminated the meaning of the participants' experiences of living with chronic venous ulceration. Gaining insights into people's perceptions, and issues which affect them, is important clinically, to enable us to try and meet individuals' needs; hermeneutics allowed the individual's experiences to take priority. As discussed in previous chapters, my data analysis revealed both diversity and similarity among the individuals' lived experiences. Given this reality, what seemed important for me was to acknowledge and retain the uniqueness of each individual while searching for commonalities among the experiences. Every illness has a story which is unique, regardless of how many people share that disorder (Alexander, Fawcett & Runciman, 1994). Hermeneutics allowed for the idiosyncrasies, as well as the commonalities, to be heard. While the aim of qualitative research is not about generalizing findings, but to generate new understanding that is comprehensive and logical, these results are relevant and could be transferred to other persons with chronic venous ulceration (Patton, 2002).

8.3.2: My role as a nurse

My clinical experience, together with my understanding of research in the field of leg ulceration, certainly helped me to gain a deeper understanding, and I thus concur with the view of Geanellos (1999), when she stated that her pre-understandings made understandings possible. However I also recognise that, on the other hand, they distracted me. I was so focused on the "obvious" that I sometimes missed the inherent meaning in what might have appeared like an off-the-cuff remark. I discussed these barriers and potential distractions in chapter seven. This is the paradox of hermeneutics, suggests Geanollos, as that which is potentially enabling (preunderstandings), is also potentially disabling. Gadamer makes this point when he says:

> *"We are always within the situation and to throw light on it is a task that is never entirely completed...this is not due to a lack in the reflection [as]...self knowledge proceeds from what is historically pre given...and hence both prescribes and limits every possibility of understanding". In this reality resides the possibilities and limitations of hermeneutic research."*
>
> Gadamer (1979, p.279)

8.4: Limitations of the study

As with any study, this study is subject to some limitations. These limitations are explored in relation to the study size and design. The sample size of 190 did not meet the 246 target provided in the sample size calculation, which means that Phase I of the study is underpowered, which may be considered to weaken the findings. However, the sample size achieved was relatively close to the calculated size needed, so the effects could be considered to be minimal. The prevalence only included people in receipt of care, whereas there are also people who self-treat for protracted periods of time, often purchasing supplies from their local chemist. It would therefore be advantageous to capture the opinions and experiences of this group of self-carers. Also, more patients now attend treatment rooms for dressing changes and were not targeted for this study.

It might be useful in future studies, to include a quality of life questionnaire and a further depression scale to enable analysis of the sensitivity and specificity of cut-off scores. A coping strategy questionnaire may be a useful addition, since pain was one of the factors most strongly associated with a high score on the HADS and may provide health care professionals with information regarding which coping strategy it may be helpful to pursue with an individual. Repeating the HADS in the context of a longitudinal study might similarly be useful to determine if the HADS score improves over time, or during periods of healing.

There were more men than women in this study, which differs from the demographics of leg ulcer populations generally, in which the picture is of a predominance of elderly females. The male perspective may be considered to be over represented in this study. However, it may simply be due to the fact that men tend to try and "manage" their symptoms for longer, thus affecting the chronicity of their ulceration. A finding that resonates with the general health literature as previously identified in chapter three. There is also evidence that men heal more slowly than women (Moffatt *et al.,* 1992).

Whilst it is only possible to see a relatively small proportion of the potential sample within qualitative studies, nonetheless it was important to ensure that a range of perspectives was represented. The strategy of sampling for Phase II, from the nine different NHS Trusts involved in the study and thus from 190 participants taking part in Phase I ensured that people were not merely "cherry picked" from my own area of clinical practice. However, this does not necessarily mean that all patients with chronic venous ulceration would display the traits or relate similar experiences. Nonetheless, it does suggest that their views and experiences were not an uncommon feature of the illness trajectory.

In this study I carried out one interview with each participant and, while this proved to be an effective means of capturing their lives at a particular time, I am aware that repeated interviews at intervals of four to six months might have provided an insight into their responses to the fluctuating pattern of chronic illness. In particular, it may have been possible to understand how their lives varied according to the healing, or deterioration in the condition of their ulcer, and enabled me to explore whether, and how, this may have linked to their overall feelings of wellbeing. Interviews throughout the year may also have been shaped by particular environmental changes, which include the weather (hot, rain, snow) and the time of year, which may have also influenced the expressed accounts of the individuals. However, a longitudinal approach may have led me to try to find consistency among stories instead of seeing them for what they are which are time-bound and temporal interpretations, thus any alteration or correction may simply be a new story. Also, the individuals were all at different stages of their healing cycle, in terms of previous episodes of ulceration, the severity etc. I believe that this study does give an insight into lived changes over time, and captures the diverse experiences of people suffering chronic leg ulceration.

All the participants in this study came from an ethnically "white British" background and I acknowledge that the inclusion of different ethnic groups may have raised other important issues. As discussed in chapter two, there remains limited epidemiological evidence describing the prevalence of venous ulceration by ethnicity (Franks *et al.*, 1997), which may also be a result of under reporting. However, after discussions with the nurse specialists in each NHS Trust included in this study, I was assured that at the time of the research they did not manage any individuals with ulceration from different ethnic groups.

8.5: Venous ulceration as a chronic illness

Throughout this thesis I have continuously emphasised the need for venous ulceration to be recognised, and therefore treated, as a chronic illness as opposed to "just a leg ulcer". Chronic venous ulceration, I would argue, has many of the hallmarks of a chronic condition but is bereft of any of the benefits. Leg ulcers do not have any "value" in the taxonomy of chronic illnesses and, certainly in my own experience, thus receive scant attention. They are subsequently poorly resourced by management, which seems to be reflected in their general treatment as an illness that does not require, or indeed receive, attention and sympathy. Pressure groups, the media and funding due to competing issues, as well as politicians appear to decide which illnesses or diseases should be given more or less sympathy. For example, chronic obstructive airways disease is:

> *"Linked in the public mind to smoking (so) that the image of a wheezing, coughing, breathless old man is often greeted with little sympathy."*
>
> (Williams & Bury, 1989, p.609)

There seems to be a mix of factors at play in the "benefit" arena of chronic illnesses. Firstly, there is policy, determined by mortality and economic statistics, giving rise to Government targets. Secondly, the unspoken public hierarchy of diseases, with its own rules regarding benefits – and which groups are most deserving. For example, cancer sufferers are conferred benefits which are not necessarily transferred to alcohol-related liver disease, with the latter subjected to the "blame" and "deserve" culture, underpinned predominantly, by "misunderstandings" of disease.

It is hardly surprising, therefore, that leg ulcers are viewed as relatively insignificant, perceived as a sore on the leg which should heal "normally" with a plaster. The end result, I would contend, is that many people will try and self-care, as identified in this study, for a protracted period of time before seeking professional help. As discussed in the thesis, people expend energy trying to conceal their ulceration and to cope as best they can in a society which appears to afford leg ulcers little value in the hierarchy of chronic diseases. This is a finding which resonates with a study by Nelzen *et al.* (1996), who suggests that leg ulceration, in people of working age, is often underestimated because they are self-caring. This perhaps goes some way in helping to explain how little is understood about the impact of ulceration in its potential to cause depression, as people continue to try and manage their ulceration. However, this has important implications since we know that the duration of ulceration prior to treatment significantly affects the response to therapy (Barwell, Ghain, Taylor *et al.*, 2000; Skere, Smith & Dore, 1992).

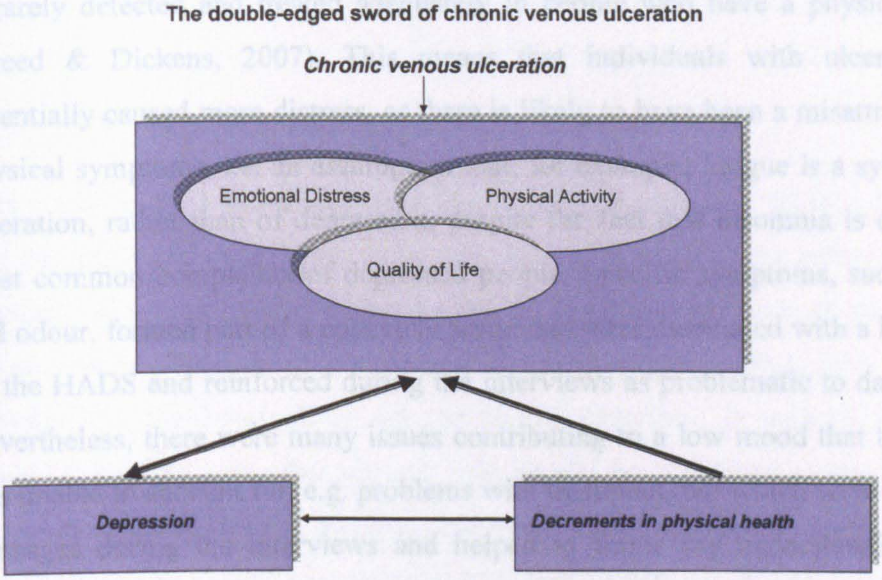
The literature review identified the shift in focus in healthcare from acute to chronic illness and the paradigm shift required in moving from a medical model with cure as the primary goal as cure becomes unattainable. Care rather than cure is the vital element for people with chronic illness. However, it would appear from the individuals descriptions of the clinical encounter, as if cure still remains uppermost for many health professionals when managing chronic ulceration. The paradigm shift in management appears to have bypassed leg ulceration with the focus remaining on the physical aspects, largely as diagnostic indicators. Health care professionals are thus left to either make assumptions on illness impact for people in their care or it would seem, in extreme cases, ignore that aspect whilst retaining a focus on the physical parameters.

8.6: Establishing the link between venous ulceration and depression

8.6.1: Changing demographics

During the course of this study I have reinforced the changing demographics with a projected increase in the older population to one billion worldwide aged 60 years or more by 2020 (World Health Organisation, 1999). This is likely to have major implications for services managing people with chronic ulceration, as we know the prevalence of ulceration increases with age. Likewise the risk of depression increases, particularly in people with a physical illness. The growth in the number of people potentially developing chronic venous ulceration can be convincingly linked to the growth of depression. It is also estimated that depression will become the second most important cause of disability worldwide (after ischaemic heart disease) by 2020. Depression not only impacts on an individual's mental health (emotional distress), physical functioning and quality of life, it also has major implications for physical health since it is known that depression is also a risk factor for hypertension (Davidson, Jonahs, Dixon *et al.*, 2000), hyperlipidaemia (Gary, Crum, Cooper-Patrick *et al.*, 2000) and heart failure (Abramson, Berger, Krumholz *et al.*, 2001; Wulsin & Singal, 2003). Miller (1996) has suggested that depression makes medical illness worse, whilst an increase in medical illness is a risk factor for depression. Therefore there is something of a double-edged sword with ulceration (See Figure 8.1). Not only is it long term and recurring, it is also a potentially disabling condition: in other words, a chronic illness. This study has found that people with ulceration may be at risk of depression and therefore a concomitant deterioration in physical health, which has implications for policy and practice, as well as for the individual.

Figure 8.1: The double-edged sword of chronic venous ulceration



In this study, a total of 190 people completed the HADS, out of which only 4% (seven) of people had previously been diagnosed as depressed despite the fact that 27% (52), people scored as depressed (HADS ≥ 9). This result highlights for the first time that there is under-recognition of the symptoms of depression in people with ulceration and therefore under-treatment. Are the symptoms of depression obfuscated by the symptoms of chronic ulceration as health professionals continue to use the biomedical lens with its myopic view of the individual? This resonates with the findings of Peveler *et al.* (2002), who noted that depressive illness is often undiagnosed, and untreated, particularly when it coexists with physical illness. The concern is that if depression remains undetected in diseases, such as coronary heart disease, that are UK Government targets, then what chance is there for people with a chronic illness such as leg ulceration? This emphasises the need for people with all chronic conditions, not just the pump-primed Government target diseases, including venous ulceration, to be routinely screened for depression, both by nurses and GPs, and treated accordingly.

It is well recognised that depression in the medically ill has an adverse effect on outcome, most notably health-related quality of life, combined with the fact that it is rarely detected and treated adequately in people who have a physical illness (Creed & Dickens, 2007). This means that individuals with ulceration are potentially caused more distress, as there is likely to have been a misattribution of physical symptoms, i.e. an assumption that, for example, fatigue is a symptom of ulceration, rather than of depression, despite the fact that insomnia is one of the most common complaints of depressed people. Specific symptoms, such as pain and odour, formed part of a collective script and were associated with a high score on the HADS and reinforced during the interviews as problematic to daily living. Nevertheless, there were many issues contributing to a low mood that the HADS was unable to account for, e.g. problems with treatment, but which were very clear messages during the interviews and helped to frame my understanding of the emotional distress endured by many people with chronic ulceration.

As nurses, we should not be concerned purely with the disease process, but also with people's lives, and the impact of that illness on their lives. In order to "look into" another's world and empathise with their experiences we have to actually enter that person's world. This can be achieved, not through the use of theories, but by listening to what the person says and how they make sense of their world. Levinas (1989) reminds us that it is important to recognise, and respond, to suffering but not to pretend to know the other's suffering. As stated by Johnson:

> *"The issue is not whether the events as the participants reported them happened exactly as they reported them. The issue is understanding how the participants experience these events."*
>
> (Johnson, 1997, p.201)

Whilst most people evinced a struggle to articulate the depth of their experiences, nonetheless, individuals poignantly described pain, discharge, odour and losing sleep as everyday occurrences – they are in pain, they can't sleep and it smells bad. For some individuals these led, ultimately, to embarrassment, fatigue, frustration, social isolation and, in due course, depression. Chronic leg ulcers caused pain, both physically and emotionally, for most individuals in this study, disrupting future plans, hopes and dreams.

8.7: Association between depression and pain

This study found a significant association between pain and anxiety ($p=<0.001$) and depression and pain ($p=0.002$), with individuals describing enduring, almost constant pain, and lives wracked by the unpleasant experience of pain. People unequivocally "blamed" their ulceration for the changes in their daily lives, and subsequently their outlook on life, as clearly described throughout this thesis. Some researchers argue that chronic pain should be viewed as a potent physical and psychological stressor that may influence mood (Von Korff & Simon, 1996). Thus pain can be viewed as a potential trigger of depressive illness.

Studies of chronic disease consistently show that pain is the most significant predictor of depression, interfering with an individual's ability to function normally on a day-to-day basis, creating struggles and causing inescapable stress (Blackburn-Munro & Blackburn-Munro, 2001). Both depression and chronic pain are known to be independently associated with decrements in quality of life and increased somatic preoccupation (Kroenke, Spitzer & Williams, 1994). It is vital therefore, that not only is pain accurately assessed, but that symptoms of anxiety and depression are as well, since there is an evident feedback mechanism between the three, with each feeding the other.

8.7.1: Living in a world of pain

This research identified that 73% (139) of the individuals in the Phase I sample, suffered some degree of pain at some time of the day, with many individuals stating that uncontrollable and unpredictable pain was, for them, the worst thing about having an ulcer. This adds to the growing body of literature that cites pain as a key issue for individuals (Douglas, 2001; Ebbeskog & Ekman, 2001; Kiernan, 2002; Nemeth, Harrison, Graham *et al.*, 2003).

It was evident in this study that, for many individuals, chronic pain had an emotional, as well as physical aspect, and that it was as much to do with the concomitant restrictions of pain on everyday life, as pain per se. It has been suggested by Bendelow and Williams (1998, p.155) that pain defies the Cartesian mind and body divide, where pain is viewed as a purely physiological entity. This has been demonstrated in the findings of this study, with pain eroding physical, social and emotional boundaries, interfering with every aspect of life. Pain punctuated the experience of ulceration for nearly all of the individuals in this study, and changed lives significantly, serving as a constant reminder of their ulceration, leaving people "living in a world they don't want to be in", a world of pain and suffering.

> *"Suffering is the unspeakable, as opposed to what can be spoken; it is what remains concealed, impossible to reveal; it remains in darkness, eluding illumination"*
>
> (Frank 2001, p.355)

Pain in chronic venous disease rarely appeared to be a one-off episode for the individuals in this study, but cyclical and most definitely a recurring feature of various stages of ulceration. Chronic pain, like their chronic ulcer, has become a situation for these individuals, rather than an event, having the power to impact severely on quality of life. Ulceration has been an everyday aspect of their lives for longer than some of them cared to remember, for some individuals between 20 and 30 years.

As identified in the literature review, pain in leg ulceration has been a feature reported on in most recent studies (Heinen, van Achterberg, Reimer *et al.*, 2004; Hofman, Ryan, Arnold *et al.*, 1997; Krasner, 1998) and reviews (Persoon, Heinen, van der Vleuten *et al.*, 2004). One of the hallmarks of previous studies, likely to be a reflection of the emphasis in care, is that the "consequences" of symptoms of ulceration has tended to take precedence over their "significance" for the individual in their daily lives. Importantly, this study has taken into account the significance, as well as the consequence of symptoms for individuals, meaning that what has been explored much deeper in this study is the emotional and psychological impact of symptoms such as pain; in particular anxiety and depression.

People found it difficult to remain positive, throughout what was often a protracted ordeal, finding it almost impossible to articulate their physical and emotional pain in such a way that others could truly appreciate what they have to endure. This was evidenced throughout chapter five and reinforced by Scarry in the following:

> *"Whatever pain achieves, it achieves in part through its unsharability, and it ensures this unsharability through its resistance to language."*
>
> Scarry (1985)

Some of the individuals did not appear to achieve pain relief with the use of analgesics, and this is congruent with the findings of other researchers (Ebbeskog, 2003). As suggested by Kolcaba (1994), the reduction of pain and physical discomfort may give the person a sense of peace and ease. Peace and ease, I would contend, were elusive factors in the lives of these individuals. People became so desperate that they felt amputation of the affected limb was the best option; they are "so sick and tired" of pain, to the point of seeing the GP, to request amputation of "the leg". What had for some, been an unspeakable, and therefore unshared fear (even with family), ironically became an option. These findings resonate with experiences of several other researchers (Bland, 1995; Kiernan, 2004; Walshe,

1995) where amputation was also raised as a preferred outcome. There were only two people for whom pain was not the most significant factor. This was because odour and discharge were symptoms which were so overwhelming for them that the physical pain of ulceration was, for once, not centre stage.

In this study, the experience of pain itself appeared to be the catalyst for a variety of psychological reactions including anxiety and depression, the cause of sleep problems, loss of self-esteem and social withdrawal, all of which can also exacerbate pain. Depression and sleep loss are known to lower the pain threshold. People complained of lack of sleep often because of pain, and a concomitant fatigue, which impacted on their ability to function as normal the following day. The combination of fatigue and pain has been acknowledged in previous studies (Hellstom, Persoon & Hallberg, 2004; Johnson, 1995; Michelson, Bolund & Brandberg, 2001) to be associated with reduced Quality of Life (QoL). Steen, Sonn, Hanson *et al.* (2001), in a study of older people, also report on the contribution of fatigue to low QoL. Fatigue is recognised to be a core symptom of depression (Table 2.5), with insomnia being one of the most common complaints of depressed individuals.

8.8: Decrements in quality of life

Depression alongside chronic pain has been associated with feelings of helplessness and loss of control (McDonald, Pasik, Dugan *et al.*, 1999). The importance of accurate diagnosis and reporting of chronic pain should not be underestimated. It is also important to recognise the part of intermittent pain in limiting functioning, causing sleeplessness and resulting in lost workdays. It is recognised that chronic uncontrolled pain can destroy a person's quality of life, and may even erode the will to live (Rolstad & Harris, 1997). This was an unexpected revelation in two interviews in the present study when individuals expressed suicidal ideation because of the impact of ulceration on their lives. It is worth remembering that, set against the remainder of the population, suicide rates are higher amongst older people, particularly males aged 75 and over (Clarke & Fawcett, 1992).

A clear message in this study was the difficulty most people encountered when trying to "carry on" with their lives because of the impact of pain, which changed their being-in-the-world dramatically. This resonates with the findings of Walshe (1995), when informants of her study felt they were not allowed to forget they had an ulcer because of the pain. Likewise Bland (1995), in her Masters thesis on leg ulcers of different aetiologies, focused on the protracted suffering of people with ulceration.

My interpretation is contrary to the perspective of Krasner (1998), who felt that patients were able to maintain a positive attitude and were thus committed to "carrying on despite the pain". Krasner's perspective implies an element of choice on the part of the individuals in her study, as if they actively chose to "carry on". Implicit in the term "carry on" is the notion that there is no change to circumstances and therefore day-to-day living, with people able to "carry on" as before. People in this study clearly verbalised that the routines and structures that provided their daily lives with a sense of structure and rhythm had collapsed.

In the present study, whilst some people continued to go to work, it was not out of choice. The majority of people found it impossible to carry on as before, as discussed in chapters five to seven, since life was consumed by the ulcer. People have had to get on with their lives because of mortgages to pay, family commitments; but not in the way depicted in studies by Bland (1995) and Krasner (1998) who believed that people "carried on" despite ulceration. People in this study articulated about "forever watching" their legs with the knowledge that they are never going to be "healed" and a resignation to a lifetime of ulceration and everything that is linked to that ten letter word. This has similarities to the findings of Chase *et al.* (1997), who spoke about the "forever healing" of venous ulcers. The impact of ulceration on quality of life is multi-dimensional, with significant limitations in activity and restrictions in participation clearly described by individuals.

One of the major differences between this study and previous research is the chronicity of ulceration as the entry point into the study. This may account for the differences in peoples' ability to "look forward" to things or "to carry on", reported previously in the literature. There was an intuitive awareness from individuals in this study that the best they could hope to achieve was a lengthier period of remission, as opposed to a cure, since they all referred to the risk and fear of reulceration. Many have long since abandoned the notion of a life without ulceration: what they appeared to yearn for was control of their symptoms. People were unable to look forward, as discussed in chapter six, because of a concomitant depression associated with their leg ulceration. The individuals in this study commented on the various aspects of uncertainty in their lives. For persons with a chronic illness, and its treatments, uncertainty encompasses duration, pace and frequency (Weiner & Dodd, 1993).

Uncertainty paralyses hope and the individual simply "exists". Although affected by past experiences, uncertainty is always experienced in the present with people unable to move forward with their lives (Penrod, 2001). Rowe and Kahn (1998, p.40) stated that the most important characteristic for successful ageing seems to be to "just keep on going" and suggested that a forward-looking approach, and active engagement in life, seem critical for growing old well. Thus, an ability to look forward has major implications for the health and emotional wellbeing of our increasing elderly population, and therefore for our future assessment and management of people with chronic diseases such as chronic ulceration. Pain and depression in elderly people appear to be strongly associated and may even intensify each other (Casten, Parmelee, Kleban *et al.*, 1995; Romano & Turner, 1995).

8.9: A world you don't want to be in

In the present study, it was as if the participants' bodies had become alien to them, no longer behaving as they had before. Leg ulceration had caused a breakdown: the body was no longer able to function in the habitual way. Activities were experienced differently, and the nature of the lived, or habitual body changed, necessitating new understandings. People described changes in taken-for-granted aspects of living. Simple, but important, tasks like getting in the shower or bath, became major hurdles. People constantly referred to what they used to be able to do, with the body of the past, including tasks such as cooking, or cleaning, to DIY and work; compared to now, with this broken body of the present, and mourned their loss. This is similar to what van Manen (1998, p.9) refers to as a "broken, disrupted or disturbed relation with the body", a characteristic of most chronic illness experiences. The body has become an obstruction in the individuals' daily life; this is important since it is by means of the body that one has access to the world (Good, 1992). Illness entails an awareness of changes in one's being-in-the-world (Madjar, 1997).

People explained to me how no longer any task seemed to be simple or everyday. The body refused to obey as it had in the past; it was now the dominant partner. Feelings of physical and emotional distress and a sense of altered self were profound sources of discomfort. As a multitude of symptoms confronted the individuals, so the body made its presence felt. The body "lost its silence", calling attention to itself. Chronic ulceration is a disembodying experience, a change to lived life. Rather than "being" their own body, people are confronted with "having" a body in a different way than when healthy. Everyday habits of ignoring the body were no longer possible.

People constantly referred to "the leg" as if it was a discrete appendage to the body, it was "something" over which they appeared to feel as if they had little control. It meant losing the familiar "feeling of myself" and experiencing a sense of discontinuity with the world. People perceived there was a difference between who they were in the past, in an unencumbered body, and who they are now. There was a pervasive feeling of being betrayed by their bodies, which involves not only "looking different to oneself and to the world" but also "feeling different" (Madjar 1997, pp.58 – 59).

The nature and perception of bodily deterioration is crucial in determining an individual's quality of life, as discussed in chapters six and seven. Healthy persons are at ease with their bodies in daily life, since the healthy body does not question its experience. In health, the presence of the lived body is characterised paradoxically by its absence – a healthy body is taken for granted (Charmaz, 1995; Leder, 1990). The body is the medium through which conceptions of self are formed. Body and self are inseparable, but not identical; the body is an aspect of self but in illness the experience of being-in-the-world is ruptured by incapacity (Gadow, 1980, p.174). Lawler (1993, p.59) proposed that in today's society we tend to:

> *"Focus on the body when it is not working properly and... during illness we hand it over to others for repair and care."*

In addition Gadamer(1986, p.70) implied that:

> *"Modern science and its ideal of objectification demand of all of us a violent estrangement from ourselves."*

People in this study appeared to be trapped in a world that they didn't want to be in. The stories presented are of people suffering with chronic ulceration, stories of survival rather than of living: they speak of endurance, frustration, anger, despair, sadness, resignation due to pain and odour, coupled with the disabling impact of treatment and the clinical encounter, which compounds their problems. People expressed overwhelming emotions of sadness, sorrow, hopelessness and gloom. Living with a chronic leg ulcer has a major impact on an individual's being-in-the world necessitating, for most, a change to their worlds. It means entering a world dominated by the symptoms and restrictions of ulceration: a lifetime sentence from which there appears to be little reprieve. Even appointments are a constant reminder of illness and help retain focus on ulceration, in a body that has betrayed them.

8.9.1: Loss of life and self

One of the key findings in this study was the concept of loss as the restrictive and destructive nature of ulceration weaved itself stealthily like a poisonous serpent through the lives of these individuals. It is hard to move forward towards acceptance if the individual still yearns for things of the past, especially the way they lived their life. Despite lengthy periods of ulceration there was little evidence in what people said of their adjustment or of restructuring their lives. This may be because the participants' new reality did not remain constant, as their ulcers alternated between periods of intact and broken skin. This was congruent with the findings of Keeling, Price, Jones *et al.* (1996), who studied the coping responses of patients, with both leg ulceration and diabetic foot ulceration, using the Coping Response Inventory. They found that, whilst patients utilised a whole range of strategies, these did not change over the study period, suggesting little illness adaptation was occurring.

I have emphasized throughout the course of this thesis the variety of "grieving" emotions people reported throughout their illness trajectory including disbelief, anger, frustration and depression with a sense of waiting, almost in a state of Limbo (feeling disregarded or forgotten), for their ulcers to heal. People experienced a journey that has much in common with the process of grief according to the traditional loss model of Kubler-Ross (1969): the initial disbelief or denial tinged with anger, sadness and possibly guilt that in some way they could have prevented it happening, plus the reluctant acceptance. A further major factor, I would contend, is that individuals do not appear to be involved in a discussion about the likely long-term prognosis of their ulceration. No-one appears to have been informed that his or her ulcers may never heal, which makes any form of adjustment an elusive state. Schopenhauer considers the agony of suffering to be greatly intensified by the extent to which it leaves us *"thinking about future and absent things"* (Schopenhauer, 1970, p.44).

In this study, loss was central to all the individual's experiences with ulceration. Loss of friends and diminishing social life; loss of job and income, are added extras to the loss of sleep as well as a loss of motivation and desire to do anything, or go anywhere. Loss of control likewise pervaded all aspects of chronic ulceration, from living with symptoms, obstructions to daily living, and even experiences with health care professionals. This resonated with the work of Charmaz (1987), who described how chronically sick people are involved in a constant struggle to lead valued lives and still maintain definitions of self that are positive and worthwhile. She considers the "loss of self" to be a powerful form of suffering experienced by the chronically ill. It is a hallmark of the chronic illness trajectory, and therefore of chronic ulceration.

Coming to terms with chronic ulceration, and thus the existence of a chronic illness within their lives, was an ongoing process as people mourned the loss of their "old" life. Life for these individuals will never be the same again. There was a disruption between the individual's definitions of self with regard to the past, present and anticipated future with plans and dreams shattered. Thompson (1998) noted that loss robs life of meaning when desired goals are no longer attainable. The impact of a chronic disabling condition on the individual was described by Bury (1982), as a "biographical disruption". Benner and Wrubel (1989) state that:

> *"A person with a long-term illness does not simply take a temporary leave of absence from life. One is forced to let go of life as it was lived...[With chronic illness] life is not so much interrupted as reshaped."*
>
> *(Benner and Wrubel, 1989, p.136)*

In a study by Kralik (2002), loss was central to all the women's experiences with illness. Likewise with Michael (1996), one of the main themes to emerge in a study of chronically ill adults integrating illness into their lives was "confronting loss". Halstead notes:

> *"Hope as an integral thread woven into the warp and weft of a lifetime, serves as a functional stabilisation in old age. In the older adult, the concept of loss is most destructive when it produces a loss of meaning in life. Loss of meaning and purpose, and therefore hope, is the ultimate loss in life – 'a living death'."*
>
> Halstead (1999, p.287)

People vividly described the grip that pain took on their lives and the downward spiral into despair. Different aspects of ulceration reinforce and amplify one another with loss of self in one area often spiralling into loss within another, with devastating and sometimes irreversible consequences. For example, pain and its impact on mobility resulted not only in a reduction in social activities but also, for some, in loss of employment. As identified in chapter four, poor mobility per se was not associated with depression. However the "impact" of poor mobility, which often resulted in exclusion from activities, did result in verbal reports of symptoms of depression expressed in the interviews.

Individuals in this study alluded to feeling a sense of hopelessness and to a loss of control not only over the ulcer but also over many aspects of their lives. People were forced to lead a life of restrictions, with constant constraints placed upon them by the unpredictable nature of ulceration, together with the discharge, odour and pain. This is further compounded by the treatment per se, which means trying to find suitable shoes to fit the bandaged foot, or in some cases feet. As suggested by Ebbeskog (2003), people start to feel imprisoned by the body and the bandage. Treatment has become part of the problem, as well as the solution, akin to what Jobling (1988) referred to as the "sysyphus syndrome" (section 7.2). Helplessness and loss of control can result from a loss of power to effect any change in their situation, and lead to an overwhelming sense of hopelessness. It becomes a futile exercise "hoping" for a cure, which would signal a return to the life they knew before ulceration. Not only are there physical limitations but also emotional restrictions, sometimes fuelled by fear of potential, rather than actual problems. They are vulnerable individuals whose lives are dominated by ulceration.

8.9.2: Forever watching

Leg ulceration appeared to dominate the thinking of many individuals, even if their ulcers had healed. They were fearful of the return of their ulcer and everything that goes with them, which partly explains the "forever watching" of the legs once the ulcer has healed. Although most people, as discussed earlier, seemed to be aware that the ulcer would return, nonetheless, they still hoped for even just a short period of remission when they could "press the restart button" and pick up life where they left off. People described their lives as though they had put them on hold, waiting for a time that may never happen, instead of living in the now. Initially setting out on this thesis I believed that people waited in Limbo for their ulcers to heal, when they would then be able to get on with their lives. Limbo, however, is perceived to be a "place" of waiting in which there is no sense of suffering, which is totally at odds with what the individuals in this study described; suffering was a key element.

Unfortunately it would seem that nurses may be complicit in this situation as people explained that the "non-healing" of ulceration was never addressed as a possibility, healing remained the primary outcome. Undoubtedly, people in this study had changed from "having" a body to "being" a body since they had lost "the silence" of a body in health (Merleau-Ponty, 1962). Ulceration and its sequelae shaped and dictated their daily lives, limiting their forward thinking or "hoping" ability. It is hardly surprising, therefore, that people displayed key symptoms of depression. What I would suggest as unacceptable, is that fourteen people scored as depressed according to the HADS and openly discussed symptoms of depression in interview, yet had received no treatment, as their depression remained undetected, and therefore, undiagnosed.

It has been shown in several studies that doctors and nurses tend to overestimate the incidence and extent of anxiety disorders, but seriously underestimate the incidence and severity of depressive disorders (Hardman, Maguire & Crowther, 1989; Seltzer, 1989), with the latter often being dismissed as an understandable reaction to physical illness. Nursing staff tend to recognise depressive disorders more frequently than medical staff, but still recognised only 50% in one study (Hardman *op. cit*).

8.9.3: On being ill

Ulceration imposed limitations for the individuals in this study with people having to make adjustments to their everyday lives. Many spoke of feeling "slowed down" and generally taking longer to complete activities, coupled with an inability to carry out certain tasks that were a large part of their lives prior to ulceration. It is inconceivable that a person who has an open wound which exudes, smells, is often excruciatingly painful, interferes with sleep and mobility could be considered "well". If an individual, with a chronic illness such as arthritis, has an acute episode it would not be unusual, I would suggest, for them to be recognised as "legitimately" ill and allowed time off from work to recuperate. Yet people in this study were not signed off from work. Their only option had thus been to resign from work earlier than they had wanted or anticipated due to the impact of their symptoms.

Participants in the present study described themselves as "ill", a finding at odds with those of Walshe (1995) but in agreement with Kiernan (2002). One of the key differences between this study, and that of Walshe, is the average age of respondents, namely 81 in Walshe's study compared to 61 in this current study. It may be that respondents in Walshe's study viewed pain and ill health as a normal part of ageing, as discussed previously, and therefore did not perceive themselves to be ill, only elderly. Walshe also suggests that people grade the level of "illness" according to whether you need to be seen by a doctor or receive treatment from a nurse. I would argue that, with the increased roles and responsibilities of nurses in diagnosis and treatment, this view would no longer hold true in today's NHS. Some participants in Kiernan's study, as in this study, had other conditions with serious implications for their overall health, but all considered "their leg ulcer to be more debilitating and restricting in comparison". Likewise in a quantitative study by Phillips *et al.* (1994), patients believed leg ulceration was their most significant health problem.

8.9.4: Obstruction to work

Employment is not only linked to financial reward but also provides a sense of purpose and belonging and is a fundamental component of how we define ourselves in the social world (Evans & Repper, 2000). Changes from a predictable body to an uncertain one are likely to raise existential questions around freedom, independence, control, invulnerability or mobility. Chronic illness involves a permanent alteration in the individual's way of life and an appraisal of that which may be hoped for in terms of function and health (Jerrett, 1994), and therefore for many, employment prospects. According to Corbin & Strauss (1987), chronic illness crashes into a person's life and separates the person in the present from the person in the past. This was definitely evidenced in several individuals' perceptions of themselves, with some expressing feeling no longer "worth" anything, and having nothing left now they were unable to work. This resonates with a study by Asbring (2001), who noted that finishing work impacted on an individual's feeling of worth. Loss of employment because of ulceration is not a new finding and resonates with previous studies of ulceration, which also identified that people experience problems maintaining employment (Phillips *et al.,* 1994; Roe *et al.,* 1996). What this study adds to our existing knowledge base is the significance of that loss of employment for individuals which, as discussed in chapter seven, had huge ramifications psychologically.

Work that is meaningful not only provides an individual with a feeling of satisfaction and fulfilment and provides a structure to the day, but it has also been linked with the promotion of positive mental health; Oxley (1995) noted:

> *"For people, work has psychological and economic benefits. Besides providing the source of money needed to attain a certain lifestyle, it can become a source of social contacts and self-esteem. Work is a place to spend one's time. A way to stay involved, active, to participate in society and feel included."*
>
> Oxley (1995, p.465)

Impairments in social function (Holyroyd, Stensland, Lipchik *et al.*, 2000), work function (Dolce, Crocker & Doleys, 1986) and functional limitations, for example limited mobility, restricted activity, are exaggerated when depression and pain coexist (Von Korff, Ormel, Keefe *et al.*, 1992). Pain severity and frequency, pain-related functional impairment, and diffuse pain are all associated with more depressive symptoms and more depression (Von Korff & Simon, 1996). For people in this study, the future was an unknown area because, although they feared that ulceration would continue to affect their lives, they did not know in what way. The future was not in their hands.

8.9.5: Body image

People explained, in great detail, their views about the impact of treatment. People verbalised about not wanting to leave the house because of the appearance of the bandages and being "forced" to wear ill-fitting shoes or even slippers. This was yet another example of the obstruction of ulceration to daily living. People expressed feeling self conscious of their appearance in the bandages, and started to lose their sense of identity as the focus was on their leg, not on them as an individual. Although people described, in some detail, their efforts to maintain their appearance, nonetheless, some individuals began to lose interest in their appearance; as their ability to select clothing to wear narrowed, so did their focus.

For some, there was also the fear that "someone" might be able to smell their ulcer. This bears hallmarks of Goffman's (1963) work on visible and invisible stigma which can result in bearers being discredited or discreditable depending on how immediately visible and recognisable the physical components. Oozing wounds and wet bandages ranked alongside pain as aspects that people considered were the worst thing about ulceration, and indeed were the factors associated with a high HADS-D score in Phase I of the study. It has been documented elsewhere in the literature about leakage of exudate and odour, as common occurrences for individuals with venous ulceration, for example Walshe (1995). This project contributes to our increasing understanding of these symptoms on quality of life (Price, 1998).

This study also uniquely demonstrates the association between odour and depression in both phases of the research. It is more than people articulating having leakage of exudate, particularly at night, and having to pad the leg and place towels in the bed before they retired, to protect the bedding. Interestingly, whilst these were common occurrences, they were never dealt with, as individuals were left to manage as best they could. This study constantly asked people "How did that make you feel?" which is a unique approach compared to much of the leg ulcer literature. This approach has increased our understanding of the impact of symptoms rather than simply registering or acknowledging their presence.

Individuals with malodorous ulcers, arguably fall into Goffman's discreditable category, where symptoms are not always obvious to the onlooker (Joachim & Acorn, 2000). People then hover between disavowal, as discussed in chapter six, pretending not to notice others attentions, and avowal, when they would openly acknowledge the odour and therefore their disability in an attempt to diffuse the situation (Scambler, 2004). Levels of exudate have previously been found, by Price (1998), to cause distress and affect the quality of life. These findings are important as poor exudate handling is also recognised as a barrier to granulation and epithelialisation (Jones & Harding, 2001).

As evidenced in chapters six and seven, people expended an inordinate amount of time and energy in trying to appear "normal". There was a desire of people in this current study to, in some way, "hide" the unattractive dressings and bandages by wearing trousers to hide the dampness of the bandages. This finds echoes in the work of Walshe (1995), and Hyde (1999), as well as in the chronic illness literature. Kralik (2002) in a study of women in midlife experiencing a chronic illness described women using tactics such as wearing trousers. There was a pervading sense of people putting on a brave face, of "keeping up appearances", of trying to appear "normal" even when they felt unwell. It appeared to be a tactic people used to ensure they did not draw attention to themselves, and also resonates with findings in the chronic illness literature (Telford, Kralik & Koch, 2006). They guarded their "precious self-esteem" by camouflaging imperfect body parts. People in this study explained that they were left feeling quite despondent and low much of the time.

A person's physical appearance is important in most societies. Appearance affects how individuals feel about themselves and how others perceive and value them (McCall, 1990). Because societies seem to be obsessed with physical perfection, and most people are less than physically perfect, McGrowther (1996) questioned whether an underclass of less than physically perfect people is being created. "Damaged goods" is a term used to describe how popular culture portrays people with disabilities (Phillips, 1990). If people believe that illness is something private, or they feel shame or guilt about being the focus of care and attention, this can lead them not to disclose information or experiences (Charmaz, 1991).

An inability to wear "normal" footwear, pain, odour and exudate turned peoples' worlds upside down. Their being-in-the-world changed and there was an overwhelming focus on "the leg". Loss of self-esteem and ultimately confidence meant that for many they no longer looked forward to anything. The findings resonate with seminal work by Charmaz (1983), who likewise describes the ways in which the stigma associated with chronic disease may prompt people, not only to experience feelings of low self-esteem, but also to withdraw from activities such as work, or going out socially. Telford *et al.* (2006), concluded from their review that people with a chronic illness struggle with their self-identity. Day-to-day living for people in the current study was tinged with a sense of futility and hopelessness about the future, contributing to anxiety and depression. Each of the 20 individuals in this study has a unique illness career which involves stages of adaptation described by Leidy, Ozbolt & Swain (1990), as a psycho physiological process of stress management. In this process stressors become distressors and life, instead of seeming a challenge, increasingly seemed to involve "pervasive helplessness", and I would add hopelessness.

8.10: The clinical encounter

Having a leg ulcer has meant that at some stage of their illness people in this study have either been advised, or have sought help of their own volition, to manage the ulceration. This resulted in a myriad of experiences for these vulnerable individuals, not all of which were positive. Some individuals, particularly males, verbalised trying to self-care for a protracted period of time before seeking professional help, in the hope that this would help ease their pain and suffering. Unfortunately, there were people who spoke about "dreading" going to have their dressings renewed because of the expectation and it would appear, the often sad reality that it would be a painful experience. Nurses in this study continued to provide evidence of poor wound care practices, as noted by the comments of individuals. People spoke about dreading going for changes of dressing because of the fear of pain during the procedure. It was as if the staff heard but either didn't listen or were suffering from some form of "professional autism".

Whatever the best intentions of clinicians, individuals in this study spoke about having to beg nurses to stop a procedure because it was so painful, even putting the leg in a bucket of water was too painful for some to bear. Pain experienced by individuals seemed to be underestimated and was often aggravated by washing or cleansing the wound. These experiences resonate with the findings of earlier studies a decade ago (Hansson, Holm, Lilleborg *et al.*, 1993; Hollinworth, 1995; Krasner, 1995; Noonan & Burge, 1998; Walshe, 1995). Hollinworth (1995) found that dressing changes were a time of increased pain, but that analgesics were rarely offered. Moffatt, Franks & Hollinworth (2002), identified that, at dressing change, even burns ranked behind leg ulceration as the most painful wound. Hansson (*op cit*) and Krasner (1998), describe painful dressing procedures, such as debridement being used regularly in leg ulcer care.

Removing a dressing, and / or changing one, is the most common pain trigger with chronic wounds, (Hollinworth & Collier, 2000; Meaume, Telom, Lazareth *et al.*, 2004; Moffatt *et al.*, 2002) and the point at which the most severe pain is reported. A phenomenological study by Hyde *et al.* (1999), also reported that some patients found the dressing procedure was the time they experienced most pain with their ulcers. Nurses need to be aware that the pain experienced by some patients as a consequence of apparently innocuous stimuli, such as changes in pressure, or temperature (a condition known as allodynia), can be excruciating.

From the findings of this study, it would appear that health professionals continue to think that they, rather than the patient, can decide the degree of pain. It is important that health professionals bring prior knowledge, rather than prejudice, to an encounter with an individual regarding pain, but remain wary of stereotyping as this can, and does, lead to misunderstandings as identified in this study and reinforced in the literature (Sofaer, 1998). This is something which actually happened in the management of leg ulcers when for years it was deemed that arterial ulcers were painful, whilst venous ulceration was generally pain free (Buxton, 1987; Gilliand & Wolfe, 1991), despite the fact that most individuals, irrespective of ulcer aetiology, complained of varying degrees of pain and discomfort.

Individuals in this study constantly reiterated that people, including nurses, do not understand what they are going through and previous research suggests that, when compared to patient perceptions, nurses frequently underestimate pain severity (Field, 1996; Kuhn, Cooke, Collins *et al.*, 1990). These are important findings reinforcing the work of Pieper, Szczepaniak & Templin (2000), who found a correlation between QoL and wound pain. Contrary to the belief of some nurses, doing nothing is not avoiding harm. Not attending to an individual's pain may be causing harm through negligence (Copp, 1993). This situation is unacceptable now, as we have high quality evidence about what works in pain management (Bandolier, 2006).

Koch (1994) similarly noted that there is often a mismatch between what the patient reveals about their illness experience and what professionals hear. This is a stark contrast to:

> *"Pain is whatever the experiencing person says it is and exists whenever he says it does"*
>
> (McCaffery & Beebe, 1995).

It is also at odds with the findings of Moffatt et *al.* (2002), where practitioners stated that their main considerations at dressing changes are to prevent trauma and pain to the patient; it would appear that actions do sometimes speak louder than words. Likewise, a report by the World Union of Wound Healing Societies (WUWHS, 2004) claimed that there remains evidence of poor wound care practices which affect patients' psychological well-being subjecting them to painful wound care procedures as described in this study and raising stress levels. The Best Practice Statement *Minimising Trauma and Pain in Wound Management* (Gray *et al.*, 2004), is clear in its guidance to healthcare professionals, when it states that:

> *"There is a professional responsibility that wherever possible wound pain should be managed effectively according to the cause. For this objective to*

> *be achieved consideration should be given to pain from the wound prior to a dressing change. It is important that the pain experienced while wearing a dressing is assessed and this may inform the selection of future wound dressings."*

Pain and trauma at dressing change can delay wound healing, since there is a direct link between psychological stress and wound healing (Collier & Hollinworth, 2000), as discussed in section 3.8. Stress increases glucocorticoid levels, reducing inflammatory responses, and resulting in delayed wound healing. These are interesting findings when considered in the light of findings by Polignano and Rowan (1999) who found that those people not experiencing pain at the beginning of treatment with compression therapy, subsequently had higher wound healing rates than those experiencing pain.

From what people have said in this study, it remains a sad reality that nurses do not always accept the individual's verbal report of pain; reinforced in the literature by Henkelman, (1994), and Horbury, Henderson & Bromley(2005). People were complaining of chronic, rather than acute, pain but in the main described being treated for an acute phase as nurses tended to focus on the cause, and not necessarily the effects, of pain. Pain for the individuals in this study remained inadequately controlled and consistently underestimated and misunderstood by nurses, a feature apparent in earlier studies (Briggs, 2003; Hofman *et al.*, 1997; Hollinworth, 1995; Krasner, 1998), with little seeming to have changed since Walshe (1995) noted that health professionals often fail to enquire about pain.

It could be argued that the responses of healthcare professionals are not surprising given the fact that they are "trained" to listen to biomedical markers and cues regarding a decline in physical parameters, which form the basis for most leg ulcer assessments. However, the "impact factor" of symptoms such as pain and odour does not seem to be routinely interpreted, and therefore not transferred to the clinical encounter, as evidenced in the stories of the individuals.

The reality for people in this study was a pervading sense of loss of control, as the health professionals remained at times "oblivious" to, for example, their suggestions of an extra dressing change, and sometimes even appeared to be disbelieving of their suffering. These negative interactions with health professionals simply reinforced feelings of powerlessness and hopelessness verbalised by people in this study. The reports of the individuals here continue to provide evidence of an "expected" compliance on the part of health professionals, rather than concordance. As discussed later, this may be partly related to expediency in a time-pressured day. Some nurses, it would appear from the interviews, continue with the paternalistic method of issuing instructions rather than sharing the power and agreeing a treatment programme that best fits the individual. By taking a "power" stance health professionals, in effect, limit an individual's ability to participate in decisions relating to their care.

The political agenda informing practice refers to the "expert patient" and the emphasis on concordance and empowerment. The concept of person-centred care and involving people in decisions about their care and treatment has become increasingly important in UK health policy (DoH, 2005). However, whilst the semantics are different to the environment of professional paternalism implied by "compliance", it would seem that people are still expected to comply with a prescribed treatment regimen. As noted by Bergen (1992), and Booth, Maguire & Butterworth (1996), this often happens because nurses don't ask patients what they want or involve them in any decisions about their care. Dimond (2003), argues that failure to assess and manage the patient appropriately could be interpreted as a breach of the Human Rights Act 1998, and indeed inappropriate management of leg ulcers can lead to litigation (Culley, 2000).

It is essential that health professionals become sensitised to the experiences of individuals living with chronic venous ulceration. The reports of individuals in this research mirror exactly the findings reported in a recent paper by Millard, Hallett & Luker (2006), who described the attitude "overt non-involving" when community nurses, even when challenged, ignored patients' opinions, requests to change treatments and accounts of subjective experiences. It is, therefore, hardly surprising that people expressed feeling low. Pain perception is affected by physiological, emotional and environmental factors with each individual's perception of pain unique. Pain assessment should, then, take into account the person's perspective, which necessitates active listening and empathy on the part of the healthcare practitioner (Mangwendeza, 2002).

Another factor alluded to earlier is the time element in a busy clinic under pressure, and indeed this was referred to on several occasions by individuals in this study, especially by people with a long history of ulceration. When time is limited, the temptation is to be prescriptive and assume, as the healthcare professional, that "we" are in the best position to tell the person what to do. It is impossible to know with certainty if some of the behaviours displayed by nurses towards individuals in this study were based on a lack of adequate knowledge about pain management, or other factors such as lack of time. Arguably, as a result of reduced economic resources, an enhanced workload has been imposed upon nurses. Lack of time, because of staff shortages, and increased workload has been found in other studies to be the most common barriers to effective pain management (Schafheutle, Cantrill & Noyce, 2001). However, an interesting hypothesis to consider is that taking time to address pain may of itself lead to healing, both physically and emotionally, and therefore reduce demand.

The individuals in this study articulated two kinds of suffering: the suffering related to ulceration as well as suffering related to the care they received. This resonates with what Eriksson (1997) refers to as being *"reduced from a human being to being a physical body"*. People in this study clearly described the total focus on "the leg", where the leg was viewed as a malfunctioning part, making them feel like a disembodied individual.

In a recent study, Rushe and Cook (2006) consulted 96 patients and carers about what they considered makes a good nurse. The study identified that people expected to be shown "respect" and treated as "grown-ups" as well as being dealt with by nurses who cared, and took time to talk to patients. These are all arguably "traits", I would suggest, that did not appear, from what individuals reported, to be in abundance in the management of individuals with leg ulceration in the present study. Being patted on the head, as described by one individual, is not, I would suggest, treating someone as a "grown-up". According to the NMC (NMC, 2002), key skills of nursing include: use of effective communication, assessment, planning, intervention, evaluation of clients' physical, psychological, social and spiritual needs and participation in inter-professional working. Communication is the foundation of all interactions, especially "healing relationships" (Zoppi and Epstein, 2002). However, it is important to remember the observations by Curtis *et al.* (2004), that a patient's emotional state influenced their perception of the effectiveness of communication by the clinician – the greater the patient's level of depression, the poorer the communication rating.

However, it must be emphasised that there were some positive experiences expressed; when people felt they were listened to and subsequently played an active part in the decision-making process regarding their care. This was apparent where individuals spoke about having developed a relationship with the nurses, and where they felt as if they were treated as individuals. The development of a nurse – patient relationship is essential for the provision of quality patient care. Langewitz, Eich, Kiss *et al.* (1998, p.230), have defined patient-centred communication as communication which invites, and encourages, the individual to participate and negotiate in decision-making regarding their own care. People also feel the need to achieve and maintain a sense of control in their chronic illness, as this is fundamental to self esteem and quality of life (Taylor, Jones & Burns, 1998).

Being seen by the same nurse was important for people in this study. People appeared to need time to build up trust in the health professional, thus reducing an individual's stress and anxiety. Some people here even believed that their wound deteriorated when they did not see the same person. Over time, nurses develop a therapeutic relationship with an individual, a factor observed in previous studies by Husband (2001) and also noted in the work of Kiernan (2002), and Ebbeskog (2003). This, I would suggest, can also extend to include an understanding of the individual's ability to tolerate treatments. Fareed (1996), found that people felt reassured and secure when they sensed nurses were there for them in the physical, psychological, emotional and spiritual realms, and when nurses were accessible.

A Swedish study by Tornkvist, Gardulf & Strender (2000), revealed that assessments of patients' satisfaction with primary care were significantly related to technical quality of care, communication and personal relationships between patient and provider. Studies have underlined the importance of good communication with patients in aiding adherence to medical regimes (Sanson-Fisher, Campbell, Redman *et al.*, 1989), whilst other studies have documented that lack of communication gives additional fear and unnecessary pain and anxiety about their conditions (Frith, 1991). This was certainly reflected in expressions of fears regarding malignancy and / or gangrene.

Caring, competent and skilful nursing staff that showed interest by explaining treatment brought a sense of security to the encounter with individuals. In return, staff were respected and trusted as also explicated in a study by Ebbeskog and Emami (2005). Trust in a carer's competence can bring about a feeling of peace and ease in those who are suffering (Lindholm & Erikkson, 1993). Chipman (1991), also asserts that caring behaviours include the provision of comfort to patients and families. It is important that people are treated with empathy, genuineness and connectedness. The findings of this current study resonated with those of Walshe (1995), in which some people were not satisfied with treatment, whilst others were happy with the nurses professional qualities, and grateful that they had a good relationship with the nurse. It has been suggested by Eriksson (1997), and almost 40 years earlier by van Kaam (1959), that a patient longs for true communion with a nurse: moving beyond mere understanding to truly sharing a patient's world with all its experiences.

8.11: Conclusion

The work in this thesis clearly demonstrates that chronic venous ulceration bears all the hallmarks of a chronic illness, including the links with depression. Over a quarter of individuals with chronic ulceration presented with symptoms of depression, and although these symptoms are very much at the heart of the experience of living with chronic ulceration, depression goes largely undetected and undiagnosed.

The findings in this research have contributed to our understanding of the lived experience of venous ulceration. As a researcher, this has been a long journey of discovery for me of my seeing things differently and not just taking aspects of ulceration at face value. This research is underscored by previous research that has provided an enhanced appreciation of the physical symptoms of ulceration. This current study has added to our body of knowledge regarding the prevalence of anxiety and depression, with particular focus on depression as a global burden which is predicted to increase exponentially with our changing demographics. There is extensive evidence from both phases of the research of the association between pain and depression, and depression and chronic illness resulting in decrements in perceived quality of life. Gaining insight into patients' perceptions and issues which affect them is important to clinicians in order to enable them to meet individual's needs.

These are important findings: not only for healthcare professionals, but also for pharmaceutical companies involved in the manufacture of dressings, bandages and other devices to help healing and alleviate symptoms such as pain and odour. There is a need to address these issues, since these are factors which individuals stated as having a direct impact on their lives.

As nurses we routinely record information about the ulcer including size, duration, pain, levels of odour and exudate. However, we do not routinely record their "impact factor" for the individual and, ultimately, the action taken to try and address this, since there remains a focus on the physical parameters. This research has clearly identified that symptoms such as insomnia, fatigue, feeling low, have largely remained unheard by the health professional. Symptoms of depression appear to have been accepted as a natural, and perhaps expected, reaction to ulceration. It could be argued that clinicians strive to heal ulcers in the hope that all the "peripheral" symptoms will disappear, thereby negating the need to deal with them.

The findings offer health professionals, carers and researchers knowledge that can be reflected on and considered; as well as a deeper understanding which they can apply, not only in their interactions with people living with leg ulceration, but in care situations occurring in other settings. It is clear that pain remains at the core of the experience for patients despite the burgeoning literature, which has cited pain as a factor for more than a decade. Other symptoms, such as low mood, fatigue, and insomnia, are not a regular feature of the assessment process and it is therefore likely that depression will remain undetected and undiagnosed. Self-reporting screening instruments such as HADS cannot replace clinical assessment in the diagnosis of depression. They can, however, provide a valuable tool for nurses in their ongoing assessment of individuals with chronic venous ulceration. Since most people with leg ulceration are managed by nurses, it might be advantageous to provide nurses with a practical and easily administered screening tool to help identify early signs of potential emotional disturbances and depression in clinical settings where mood is not routinely assessed. Nurses need further education and training regarding pain management in leg ulceration and clear referral criteria for unresolved and intractable pain. They also require clear education and guidance on how to detect possible signs and symptoms of depression.

Implications for clinical practice and policy

It is important that these findings do not remain exclusively as conclusions within an academic piece of work but are disseminated to clinicians and policy makers. Unless this happens future researchers will make similar conclusions which state that little has changed in clinical practice with individuals continuing to suffer.

Some early findings from the research have been published in a journal which is widely read by nurses and also presented at an RCN International conference. However, it is vital that the findings reach the clinicians who are directly involved in the care and management of patients with chronic venous ulceration. This cannot be achieved by solely presenting at conferences and publishing in journals although this is an important aspect that needs to continue with thought given to both the journals and conferences.

I need to liase with other researchers and lead clinicians so that we have a much stronger case, with a robust evidence base, with which to raise the profile of chronic venous ulceration. The time for increased public awareness and increased investment in this chronic disabling condition is now, as we have clear evidence of the changing demographics of the population susceptible to not only leg ulceration but also depression. It is time for leg ulceration to be high on the policy agenda ensuring future investment enabling further research and improved outcomes for people whose lives are turned upside down by this disabling condition. Ulceration and its sequelae need to enter the public arena through increased media attention, so that sufferers no longer feel ostracised, stigmatised and isolated.

A physical illness such as chronic ulceration cannot alone account for persistent low mood, lack of interest and pleasure in activities. These are core symptoms of depression and anxiety, not core symptoms of chronic ulceration. Indeed, these are not cited in the literature on leg ulcers as common symptoms of chronic ulceration, but are listed in texts as common symptoms of depression. To have a leg ulcer as well as depression is a double burden. We know that 20% of ulcers will never heal, despite being treated with evidence-based care. More, therefore, needs to be done to assist people in facing the reality that their ulcers are unlikely to heal and thus help them to incorporate chronic venous ulceration into their lives. People are not "just" living with the marginalised illness of ulceration, but also it would seem with an undiagnosed and untreated depression in many cases. Treating the depression may not heal the ulcer, but could improve an individual's quality of life. Whilst cure may not be available, relief of suffering may be possible.

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Appendices

Appendix 1

Morbidity associated with leg ulceration

Appendix 1

Morbidity associated with leg ulceration

Study	**Year**	**Country**	**Methods**	**Sample**	**Findings**
Phillips T., *et al.*	1994	USA	Quantitative interviews	62	57% mobility; 65% severe pain; 68% negative emotions including fear, anger, depression and negative self image
Charles, H.	1995	UK	Phenomenology	4	Patients experience pain, loneliness, diminished human interaction, hopelessness, sleep disturbance
Hofman, D., *et al.*,	1997	UK & Sweden	Prospective study Prevalence & severity of pain	94	69% pain worst thing about an ulcer 64% severe pain
Chase, S., *et al.*	1997	USA	Phenomenology	37	Four main themes: forever healing; limits and accommodations; who cares; powerlessness
Chase, S., *et al.*	2000	USA	Survey	21	
Flett, R., *et al.*	1994	NZ	Matched control group	14 patients 14 healthy	Low levels of self esteem; pain and mobility
Krasner, D.	1997	USA	Descriptive qualitative study to understand pain	14	Pain worst thing about having an ulcer
Bland, M.	1995	NZ	Phenomenology	9	Patients coping mechanisms, patients want ulcer to heal
Walshe, C.	1995	UK	Phenomenology	13	Pain was overwhelming feature, leakage and smell
Hamer, C., *et al.*	1994	UK	Quantitative: NHP and short	88 patients	37% pain significant factor

			form McGill Pain questionnaire	60 healthy	Restricted mobility
Lindholm, C., *et al.*	1993	Sweden	Survey NHP	125	Men more affected than women: pain, energy and emotions
Franks *et al.*,	1998	UK	Survey NHP	758	Bodily pain, physical mobility; diminished functioning
Ebbeskog, B., *et al.*	2001	Sweden	Phenomenology	15	Social withdrawal, Body image
Price, P., *et al.*	1996	UK	Survey SF-36	55	Bodily pain, physical and social functioning
Douglas, V.	2001	UK	Grounded theory	8	Pain
Brown, A.	2005	UK	Phenomenology		Pain, coping, social disconnectedness
Husband, L. L.	2001	UK	Grounded theory	39	Pain
Hyland, M., *et al.*	1994	UK	Quantitative survey Focus group interviews	50 22	Pain, sleep, mobility problems Pain, restriction of activities, low mood
Hyde, C., *et al.*	1999	Australia	Semi-structured interviews	12	Pain, leakage, smell
Wissing, U., *et al.*	2002	Sweden	Philadelphia geriatric centre multilevel assessment	70 Patients 74 Healthy	Pain, mobility restrictions
Franks, P., *et al.*	2003	UK	Medical Outcomes SF-36 compared with normative data	118	Lower mean scores in social functioning, pain, role functioning
Hopkins, A.	2004	UK	Phenomenology	5	Biographical disruption, social implications, coping
Hareendran, A.	2005	UK	Interviews HRQoL (modified Skindex)	38	Pain, itching, altered appearance, sleep disturbance

Appendix 2

Phase I information sheet and consent form

THE UNIVERSITY
of LIVERPOOL
Health and Community Care Research Unit (HaCCRU)
Thompson Yates Building, Brownlow Hill
Liverpool L69 3GB.
Tel: 0151 794 4952

NHS

Information sheet for patients

Please read this document carefully

Study Title:
The prevalence and experience of emotional distress in patients with chronic leg ulcers

> **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.

1. What is the purpose of the study?

Venous leg ulcers, sometimes called varicose ulcers, are caused by poor blood return from the legs to the heart. Bandages applied from the toe to the knee speed the healing of venous ulcers by helping the blood return. However, this can often take weeks or months and can have a major impact on your day-to-day activities. Unfortunately, as some of you may have already experienced, leg ulcers, often recur. I would like to know how you feel during this time and whether having a leg ulcer has affected you emotionally, for example has it made you feel anxious or even depressed.

2. 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 leg ulcer and whether this has an affect on the healing of their ulcer.

3. Why have I been chosen/asked?

I wish to understand the impact of having a venous leg ulcer. This information can only be obtained from people like yourself who are actually experiencing the problem

4. Do I have to take part?

Your participation in this study is entirely voluntary. If you do agree to take part and then decide at a later time to withdraw then you are free to do so at any time without influencing your future care or treatment

5. What will happen if I agree to take part?

If you do agree to participate you will be asked to complete a short questionnaire that will take you no longer than 10 minutes to complete. I would suggest that you complete this in the clinic, although you may complete in your own home if you prefer. This will be sent directly to me at the University in a FREEPOST envelope, which you will be given to you with your questionnaire. Your nurse will also complete a short form containing details about your leg ulcer and some information on your medical history. This form will also have your contact details, as I may ask you to take part at a later stage in an interview. If the results from you questionnaire suggest you are experiencing emotional distress, I will inform you of this by letter, as you may wish to discuss this with your GP. I will also notify your GP.

Thank you for taking time to read this information sheet

If you require any further information or have any concerns while taking part in the study please contact

June Jones
Research Fellow/Clinical Nurse Specialist
Health and Community Care Research Unit (HaCCRU)

OR

THE UNIVERSITY
of LIVERPOOL
Health and Community Care Research Unit (HaCCRU)
Thompson Yates Building, Brownlow Hill
Liverpool L69 3GB.
Tel: 0151 794 4952

NHS

CONSENT FORM

Title of Project: The prevalence and experience of emotional distress in patients with chronic leg ulcers

Name of Researcher: June Jones

Please initial box

1. I confirm that I have read and understand the information sheet dated January 2003 for the above study and have had the opportunity to ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my nursing care or legal rights being affected. ☐

3. I understand that sections of any of my nursing notes may be looked at by the investigator (nurse) or researcher, where it is relevant to my taking part in research. I give permission for these individuals to have access to my records. ☐

4. I agree to my GP being informed about my involvement in the research. ☐

5. I agree to the researcher (June Jones), having access to my contact details. ☐

6. *I agree to my GP/ Named Nurse being informed if the research results suggest that I may be in emotional distress. I understand that I will also be informed by letter. ☐

7. I agree to take part in the above study. ☐

Name of patient	Date	Signature
Name of Person taking consent	Date	Signature

*N.B In the unlikely event of any major problems your GP/Named District Nurse will automatically be informed

1 copy for patient; 1 for researcher; 1 to be kept with notes

Appendix 3

Data collection tools

HAD Scale

We are aware that emotions play an important part in most illnesses. If we know about these feelings we will be able to help you more.

This questionnaire is designed to help us to understand how you feel. Read each item and place a firm tick in the box opposite the reply that comes closest to how you have been feeling in the past week.

Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought out response.

*Tick only **one** box in each section*

I feel tense or 'wound up':

Most of the time ☐
A lot of the time ☐
Time to time. Occasionally ☐
Not at all ☐

I still enjoy the things I used to enjoy:

Definitely as much ☐
Not quite so much ☐
Only a little ☐
Hardly at all ☐

I get a sort of frightened feeling as if something awful is about to happen:

Very definitely and quite badly ☐
Yes, but not too badly ☐
A little, but it doesn't worry me ☐
Not at all ☐

I feel as if I am slowed down:

Nearly all the time ☐
Very often ☐
Sometimes ☐
Not at all ☐

I get a sort of frightened feeling like 'butterflies' in the stomach:

Not at all ☐
Occasionally ☐
Quite often ☐
Very often ☐

I have lost interest in my appearance:

Definitely ☐
I don't take so much care as I should ☐
I may not take quite as much care ☐
I take just as much care as ever ☐

Reference Code: ☐☐☐☐☐☐☐☐☐☐☐☐☐
Area: ☐☐☐☐☐☐☐☐☐

HAD Scale

I can laugh and see the funny side of things:

As much as I always could ☐
Not quite so much now ☐
Definitely not so much now ☐
Not at all ☐

Worrying thoughts go through my mind:

A great deal of the time ☐
A lot of the time ☐
From time to time but not too often ☐
Only occasionally ☐

I feel cheerful:

Not at all ☐
Not often ☐
Sometimes ☐
Most of the time ☐

I can sit at ease and feel relaxed:

Definitely ☐
Usually ☐
Not often ☐
Not at all ☐

I feel restless as if I have to be on the move:

Very much indeed ☐
Quite a lot ☐
Not very much ☐
Not at all ☐

I look forward with enjoyment to things:

As much as ever I did ☐
Rather less than I used to ☐
Definitely less than I used to ☐
Hardly at all ☐

I get sudden feelings of panic:

Very often indeed ☐
Quite often ☐
Not very often ☐
Not at all ☐

I can enjoy a good book or radio or TV programme:

Often ☐
Sometimes ☐
Not often ☐
Very seldom ☐

Today's Date: ☐☐ ☐☐ ☐☐

Thank you

Please place in the envelope provided and either return it to the nurse in the clinic or pop it in the post.

The prevalence and experience of emotional distress in patients with chronic leg ulcers

Please complete all relevant questions in the spaces provided.

Patient Details **Date Completed:** ____________________

SURNAME: ____________________ FORENAMES: ____________________

DOB: ______________ AGE: __________ M/F: ______________

ETHNIC ORIGIN: ____________ MARITAL STATUS: ____________________

ADDRESS: ____

POST CODE: ______________ TEL NO: ______________ LIVES ALONE: Y/N

OCCUPATION/PREVIOUS OCCUPATION ____________________________

STUDY NURSE: ____________________ TEL NO: ____________________

NAMED DISTRICT NURSE: ______________ TEL NO: ____________________

GP: ____________________ TEL NO: ____________________

2. Medical History. Please tick as appropriate
Does the patient suffer from any of the following

	Yes	**No**
History of DVT	☐	☐
Stroke (CVA)	☐	☐
Hypertension	☐	☐
Heart failure	☐	☐
Depression	☐	☐
Osteoarthritis	☐	☐
*Other	☐	☐

* If OTHER, please specify……………………………………………………………..

3. Social History.

In the past 3 months has the patient suffered any major life event such as bereavement, loss of job etc, which may have had a negative impact on their emotional state? YES/NO

If YES, please specify____

4. Mobility Please circle the correct answer

Fully Mobile (Walks Unaided) YES/NO   Limited Mobility (Walks with Aid) YES/NO

Immobile (Cannot Walk) YES/NO   Has this made the patient housebound YES/NO

5. Pain (associated with leg ulcer) **Please tick as appropriate**

a) Pain level

0 No Pain ☐
1. Mild Pain ☐
2. Moderate Pain ☐
3. Severe Pain ☐
4. Overwhelming pain ☐

b) Is Pain?

Intermittent ☐
Continuous ☐
Dressing Changes Only ☐
At Rest ☐
Night Pain ☐
When legs dependent ☐
When legs elevated ☐

6. Leg Ulcer Details

1. On which leg does the patient have ulceration   Left ☐   Right ☐   Both ☐
2. How many ulcers does the patient have ☐☐
3. Ankle Brachial Pressure Index of limb with largest ulcer   ABPI ☐ · ☐ ☐
4. How many episodes of ulceration has the patient had ☐☐
5. When did the patient have their first episode of ulceration   Month ☐☐   Year ☐☐
6. When did the current episode of ulceration appear   Month ☐☐   Year ☐☐

7. Ulcer Specific History **Please complete in spaces provided.**

	Left Leg	**Right Leg**
1. Size – length (cms)/ width (cms)		
2. Exudate - amount (heavy/mod/min/none)		
3. Odour - none/some/offensive		

Appendix 4

Phase II information sheet and consent form

THE UNIVERSITY
of LIVERPOOL
Health and Community Care Research Unit (HaCCRU)
Thompson Yates Building, Brownlow Hill
Liverpool L69 3GB.
Tel: 0151 794 4952

Information sheet for patients (2)

Please read this document carefully

Study Title:
The prevalence and experience of emotional distress in patients with chronic leg ulcers

> **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.

1. What is the purpose of the study?

Venous leg ulcers, sometimes called varicose ulcers, are caused by poor blood return from the legs to the heart. Bandages applied from the toe to the knee speed the healing of venous ulcers by helping the blood return. However, this can often take weeks or months and can have a major impact on your day-to-day activities. Unfortunately, as some of you may have already experienced, leg ulcers, often recur. I would like to know how you feel during this time and whether having a leg ulcer has affected you emotionally.

2. 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 leg ulcer and whether this has an affect on the healing of their ulcer.

3. Why have I been chosen/asked?

I wish to understand the impact of having a venous leg ulcer. This information can only be obtained from people like yourself who are actually experiencing the problem

4. Do I have to take part?

Your participation in this study is entirely voluntary. If you do agree to take part and then decide at a later time to withdraw then you are free to do so at any time without influencing your future care or treatment

5. What will happen if I agree to take part?

Several weeks ago you completed a short questionnaire. I should now like to invite you to take part in one interview, which will take the form of an informal conversation between you and myself. This will take place at a time and in a place that is convenient for you. I would like to tape record the conversation to allow me to consider in detail your comments. You will not be identified by name on the tape recording. The contents of the tape will be kept strictly confidential. The audiotapes will be stored securely in a locked cabinet within a locked room for five years and then destroyed.

Thank you for taking time to read this information sheet

If you require any further information or have any concerns while taking part in the study please contact

June Jones
Research Fellow/Clinical Nurse Specialist
Health and Community Care Research Unit (HaCCRU)
University of Liverpool
Thompson Yates Building
The Quadrangle
Brownlow Hill
Liverpool
L69 3GB

Tel: 0151 794 4952

THE UNIVERSITY
of LIVERPOOL
Health and Community Care Research Unit (HaCCRU)
Thompson Yates Building, Brownlow Hill
Liverpool L69 3GB.
Tel: 0151 794 4952

CONSENT FORM (2)

Title of Project: The prevalence and experience of emotional distress in patients with chronic leg ulcers

Name of Researcher: June Jones

Please initial box

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

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my nursing care or legal rights being affected. ☐

3. I understand that the researcher will tape the interview, and I give permission for her to tape the interview ☐

4. I understand that the tapes will be transcribed and stored securely at the University of Liverpool ☐

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

Name of patient	Date	Signature
Name of Person taking consent	Date	Signature

1 for patient; 1 for researcher; 1 to be kept with notes.

Appendix 5

Letters

Draft letter to R & D Departments

Health and Community Care Research
Unit (HaCCRU)
Thompson Yates Building, Brownlow Hill
Liverpool L69 3GB.
Tel: 0151 794 4952

Name
Director of R&D
Address

Date

Dear Name

Re: MREC Study 02/8/106 The prevalence and experience of emotional distress in patients with chronic leg ulcers

I should like to register the above project with you, (which I have sent to LREC), prior to commencement of the study with the Tissue Viability Service. I am currently studying at the University of Liverpool for a PhD looking at 'emotional distress in patients with chronic leg ulcers'. The PhD is funded by the North West NHSE Regional Office for a duration of 4 years. I also work as a clinical nurse specialist in leg ulcers with Southport & Formby PCT where the research has been piloted.

The research has been driven by my own experience of managing patients with leg ulceration both as a district nurse for 13 years and also as a nurse specialist for the past 8 years. There is much more emphasis on the need to look at the psychosocial implications of chronic disease, this is an area which is under researched in the area of tissue viability. We have some evidence to indicate that by addressing the emotional distress we may accelerate healing of wounds, to date we do not know if leg ulceration is linked to emotional distress. This study aims to address this deficit in knowledge and provide vital information for practitioners looking after this group of patients.

The research is in two phases:
Phase 1: Quantitative phase which aims to determine the prevalence of emotional distress in patients with chronic leg ulcers across 5 areas in the North West. This phase will also provide the participants for phase 2. A total of 246 patients across the 5 areas are required for this phase (statistical advice was sought for power calculation). This equates to approximately 50 patients per area to be consented into the study.
Phase 2: Qualitative phase. During this phase up to 40 patients (maximum of 8 from Stockport), will be interviewed (some who score as depressed and some who do not) to explore further the pertinent issues that result in emotional distress for some, but not others.

I have had several meetings with Name of Nurse who is keen to help with the project. The North West MREC Committee has passed the project, and I enclose a copy of the final letter of approval.
I enclose a copy of the MREC submission and protocol, which will explain the study in detail, together with copies of the information sheet, consent and questionnaires.

Please can you also advise re obtaining an honorary contract with Oldham for the duration of the study.

I am happy to discuss any queries you may have regarding the project and can be contacted on my direct line @ Liverpool on 0151 794 4952 or via email to jonesje@liv.ac.uk

Yours Sincerely

June Jones
Research Fellow/Clinical Nurse Specialist

Appendix 5

Letter to GP
Informing of patient involvement in research

Date :
GP Name
GP Address

Dear Dr

Re: Patient Name and Address

Research :
The prevalence and experience of emotional distress in patients with chronic leg ulcers

This letter is to inform you that during their recent attendance at the leg ulcer clinic/home visit, your patient was recruited to the above study.

Research has demonstrated the impact of leg ulceration on quality of life (Price & Harding 1996). Nonetheless, more work is required on the experience of patients with leg ulcers who suffer emotional distress. The research is funded through the NHS North West Regional Office for a four year duration. The research has been approved by the Local Research Ethics Committee 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 at the above address.

Yours sincerely,

June Jones
Research Fellow/ CNS Leg Ulcers

Appendix 6

Interview topic guide

Appendix 6

Emotional distress: Topic Guide

- Introduce self
- I should like to understand what it is like to live with a leg ulcer
- Today I would like to talk to you about your views and experiences
- Everything you say is kept strictly confidential. We will not use your name and you will not be able to be identified from what you say to me today.
- Is it OK to tape record our discussion today? Good way of getting an accurate record of your views. The tape recorder can be turned off at any time.
- You don't have to discuss anything, or answer any questions that you are not happy with
- Consent (written)

The Interview

1. Basic Information

(I want to get a simple profile of the respondent – a bit of background)

- To start with, can you tell me a little bit about yourself – How old are you? Do you live here with anyone else? How long have you lived in this area?

- Can you tell me a bit about your general mobility? Are you able to go out on your own? Do you use sticks or a frame to help you get about? Is this because of your leg ulcer?

2. Leg Ulcer History

(I want to find out the duration of ulceration and how many episodes)

- Can you tell me some more about your leg ulcer? How long have you had an ulcer, have you ever had an ulcer before? Can you remember how it started? Were you able to get some help easily, or did you have to wait a long time to be seen?

3. Treatment

(I want to find out who looks after the ulcer, whether they go to a clinic or if the district nurse visits)

- Who treats your leg ulcer; do you go to a clinic to have your leg ulcer redressed or does the district nurse visit you at home?

- Can you describe to me a little bit about what happens?

- What do you think about this service – good/bad/indifferent?

- If good, what makes this service good/ what is it about this service that makes it good?

- If bad, what makes this service bad/ what is it about this service that makes it bad?

- How could these services be improved so that they are better for you?

4. Activities of daily living

(I want to find out if the ulcer impacts on their ability to do everyday activities such as cooking, cleaning, shopping, bathing)

- Can you tell me if your leg ulcer has caused you any problems with things like cooking, cleaning or shopping?

- What about having a bath or a shower, are you able to manage that? How does that make you feel?

5. Psychosocial aspects

(I want to find out if the ulcer stops them going out, whether it makes them feel 'depressed', what is the worst thing about having an ulcer, if pain or odour are issues)

- Can you tell me if you still enjoy doing the same things now as you did before you got your ulcer?

- Do you have any hobbies or interests, have these been affected by having an ulcer?

- Has your leg ulcer stopped you from doing anything that you wanted to do, if so why?

- What would you describe is the worst thing, for you, about having a leg ulcer?

- Is there anything you could think that would make it easier for you to cope with your leg ulcer?

- Could you describe any periods where the ulcer has caused you severe discomfort or pain?

6. Other Issues

- Is there anything else that you would like to discuss/ any issues about your leg ulcer that we haven't covered that are important to you?

Appendix 7

Analysis frameworks

Appendix 7: Analysis Frameworks

Colaizzi's Framework

Colaizzi's seven steps for the analysis of written descriptions:

1. Each subject's descriptions, known as protocols are read initially to acquire a general sense or feeling from the protocol
2. Once the general sense of the protocol has been determined, significant statements are extracted.
3. Formulated meanings are derived from significant statements and are compiled into clusters of themes
4. Returning to the protocols will validate the clusters of themes
5. If the clusters of themes are not validated by the review of the protocols, then a re-evaluation of the protocols will be conducted to re-identify significant statements, formulated meanings, revealing clusters of themes and again returning to the protocols for evaluation.
6. The process will be repeated to develop a summary of clusters of themes leading to the formulation of an exhaustive description of the investigated phenomenon
7. Validation: Return to each subject and ask if this analysis describes their experience

van Manen's Structure

1. Turning to a phenomenon which seriously interests and commits us to the world; a total immersion in reflection upon the possible meanings, the researcher fully committed to 'thoughtfulness' to the phenomenon being explored.
2. Investigating experience as we live it rather than as we conceptualise it; the researcher is bringing all of their experience to the understanding of the phenomenon
3. Reflecting on the essential themes which characterise the phenomenon: to make meanings and significance of experiences intelligible through uncovering and revealing what is hidden.
4. Describing the phenomenon through the art of writing and rewriting; giving expression through language to that which has been understood
5. Maintaining a strong and oriented pedagogical relation to the phenomenon
6. Balancing the research context by considering parts and whole.