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**CHALLENGING THE MYTHS:
THE LIVED EXPERIENCE OF CHRONIC LEG ULCERS**

A thesis presented in partial fulfilment of the requirements
for the degree
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ABSTRACT

Leg ulcers are a chronic condition that affects a significant number of New Zealanders. While the management of the ulcers themselves has received much attention in the nursing and medical literature, little is known about what it is like to live with chronic leg ulcers, and how they impact on quality of life.

A review of the nursing literature relating to leg ulcers reveals a focus on wound management, and a failure to appreciate the perspective of these patients. It is frequently stated in the nursing literature that these patients deliberately delay the healing of their ulcers to ensure continued contact with the nurses.

This exploratory study utilised Heideggerian hermeneutic phenomenology to examine the experiences of five men and four women with chronic leg ulcers, revealing the comprehensive nature of the suffering that accompanies this condition. Much discomfort and distress is caused by the ulcers themselves, which is then compounded by the problems associated with the treatment regimes.

The presence of ulcers impacts on virtually every aspect of daily life. Study participants had worked hard to minimise that suffering, with the differences created by the ulcers becoming part of a taken-for-granted way of being-in-the-world. They desperately wanted their ulcers to heal, and were prepared to do everything they could to achieve this. But the potential benefits of some treatment regimes must be balanced against the ongoing disruptions that such regimes would cause to their ability to lead a reasonably normal life.

This study challenges the myths that surround patients with leg ulcers, and highlights the need for health professionals to move from a focus on wound management to understanding the specific needs of each individual within the context of their daily life.

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CHAPTER ONE

INTRODUCTION AND OVERVIEW

How chronic illness shapes our lives is not well understood. Aside from medical how-to books, there are few published accounts of such illness, precisely because of its invisibility. ... There isn't even a vocabulary to describe what it is like.

Register (1987, p. x)

This is a study about the illness experiences of nine individuals who have chronic leg ulcers.

I first became aware that leg ulcers were a significant problem when I began working as a district nurse six years ago. Within a very short time I realised just how much of my day was spent dressing leg ulcers, and how difficult it was to heal these wounds permanently, if at all. My interest in leg ulcers initially originated from a desire to increase the effectiveness of my wound management practices, partly because of the sympathy I felt for these patients, but also to reduce the demands they made on nursing time and resources.

Leg ulcers are defined by Cullum (1994, p. 3) as "tissue breakdown on the leg or foot due to any cause" and it is this definition that has been adopted for the purposes of this study.

I became aware that I knew little of the developments in wound management that have taken place over the past decade in particular, and when the opportunity arose during my university studies to undertake a literature review on a topic of my choice, leg ulcer management was an obvious selection.

Around the same time, again as part of my university studies, I was introduced to the phenomenological work of Benner and Wrubel (1989). I became increasingly aware of the importance for nursing of understanding patients' experiences of illness, and how little was currently known of these experiences.

When I began the literature review I originally regretted my choice of topic, for there is a vast amount of literature relating to leg ulcers. Gradually I came to realise that despite all this literature, these mountains of words, virtually nothing existed on the patients' perspective of the experience - on what it was like to live with these ulcers. Everything I was reading about leg ulcers was related to what health professionals saw as the problems, such as the prevalence of ulcers and the difficulties of wound management, the financial expense associated with their treatment, and how efforts to heal the wounds were thwarted by patients wanting the ulcers to continue so as to maintain contact with the health professionals. Little attempt had been made to understand the illness experiences associated with this condition, an understanding which would facilitate the provision of patient-focused, not wound-focused care.

I began talking to patients with leg ulcers, and realised that although I might have been visiting them on a frequent, even daily, basis for many months, I actually knew little of how their ulcers had impacted on their lives, and how they had coped over the years. A preliminary fieldwork study of these patients' experiences increased my awareness of the impact of this condition, with their stories revealing sometimes decades of chronic suffering because of their ulcers. But participants in that fieldwork study also demonstrated a resilience arising from a philosophical acceptance of the situation that had allowed them to carry on with life.

This present study sought to build on to those preliminary findings, exploring in more detail just what it is like to live with chronic leg ulcers.

This exploratory study used phenomenological research to examine the experiences of people living with chronic leg ulcers. As little material exists related to this topic, phenomenological research can be used to "help us discover what is there in that world, to name it, and to grasp at some meaning and understandings" (Munhall & Oiler, 1986, p. 38).

Nursing as a profession has yet to establish what the needs of people with chronic leg ulcers are, and whether existing nursing practices are meeting those needs. Madjar (1991) outlines the contribution of phenomenological research to nursing, with "descriptions, exemplars and paradigm cases that depict the reality of human experience and nursing practice in a way that statistical manipulation of values assigned to operationally defined variables cannot do" (p. 66).

This phenomenological examination of the lifeworld experiences of persons suffering from leg ulcers will provide rich descriptive data to guide the provision of appropriate nursing practice.

THE SIGNIFICANCE OF THE STUDY

While there are no published New Zealand studies of the prevalence of leg ulcers in this country, overseas studies indicate open ulcers in 0.15% of the general population, with a history of ulceration in approximately 4% of the population over 65 (Callam, Harper, Dale & Ruckley, 1988). In a recent Australian study (Baker, Stacey, Jopp-McKay, Hoskin & Thompson, 1991) 46% of participants had ulcers that had been present for more than 26 weeks, with 76% of all study participants having also experienced previous ulceration.

It is the chronic nature of the leg ulcer experience that presents the real challenge for both individual patients, and their health care providers. The advances made by modern medicine have increased the incidence of people living with chronic

illnesses (Gerhardt, 1990). There is growing recognition of how illness disrupts the taken-for-granted way of being-in-the-world, and the importance of understanding the patients' perspective of that experience. Garro (1994) reminds us that patient narratives must be seen not just as the story of an illness, but as "the story of a life altered by sickness" (p. 775).

Paterson (1986) discusses how the close association between nursing and medicine has resulted in nursing knowledge grounded in natural science, with "knowledge gained about the acute illness experience [being] almost solely based on the perspective of the nurse (or other health professional)" (p. 3). The perspective of the body as a scientific object means that "clinical decisions are based upon external interpretations, not upon the meanings and coherence of the body as constituted by the patient" (Gadow, 1985, p. 36).

Register (1987) states "... the major lesson I learned: chronic illness, though ever-present, is not what matters most in people's lives" (p. v). Nursing should be examining illness experiences - when that experience "becomes the whole situation, and the other aspects of the person's life may fade into the background" (Benner & Wrubel, 1989, p. 80). Nursing also needs to examine how that illness experience is managed by the individual and all the others involved in the situation to enable some degree of normal existence to be obtained.

As described by Packard, Haberman, Woods and Yates (1991), nursing theory development relating to the psychosocial care of people with chronic illnesses has been limited mainly because of the implicit assumptions made by researchers in relation to illness experiences. It is often presumed that chronic and acute illness experiences have a very similar impact on people's lives. Morse and Johnson (1991) consider that nursing is "beginning to listen more attentively and to give credence to the patient's perspective. ... This refocusing of health care ensures that the patient is treated as a person, that the family is included in the care, and that the care is humane" (p. 341).

Coulehan (1992, p. 361) asserts that "the patient's story must become a major focus of teaching and research". There is an absence of stories by people with chronic leg ulcers, an absence that seriously restricts the ability of health professionals to assist with the minimization of suffering and the attainment of comfort for these individuals and their families (Morse & Johnson, 1991).

This phenomenological study will reveal some of those stories, allowing health professionals to understand more of the everyday aspects of this illness experience within the context of each individual's unique circumstances.

The question for this study was -

What is it like to live with chronic leg ulcers?

The objectives for this study were -

- **to increase the understanding of health professionals about the experience of chronic ulcers.**
- **to ascertain which aspects of the chronic leg ulcer experience are the most distressing for the person.**
- **to identify how district nursing practice could better meet the needs of these patients.**

LEG ULCER MANAGEMENT IN THE NEW ZEALAND CONTEXT

It is difficult to provide an outline of the management of leg ulcers in New Zealand, as there is almost no New Zealand literature on this topic. Leg ulcer treatment is not standardised between the Crown Health Enterprises (formerly Area Health Boards), and there are no national treatment protocols or training courses.

My understanding of leg ulcer management in this country is based on my clinical experience as a district nurse; discussions with district nursing and university colleagues; a review of the limited New Zealand literature, and attendance at wound management and district nursing conferences. Young (1989) identifies the paucity of New Zealand literature relating to district nursing. The lack of objective data on which to base any analysis therefore means that the following outline of the management of leg ulcers reflects my own experiences, and understanding of the practices of the district nurses from the area in which this study was conducted. Practices may well vary considerably around the country.

As in overseas countries, the majority of chronic leg ulcers are managed in the community, mostly by district nurses (Morris, 1984), although some of the more short-term ulcers may be dealt with by the practice nurses working with general practitioners. Patients may self-refer to the district nurses, or else are referred on by hospitals, outpatient clinics, or general practitioners. While some of the hospital or clinic referrals will specify exactly what treatment is required for the ulcer, the referral from a general practitioner is more likely to simply state "leg ulcer, please treat".

The initial assessment of all patients is undertaken by a registered nurse, and a nursing care plan developed. The use of objective wound assessment tools, such as that devised by the English Wound Care Society (Flanagan, 1994, p. 84), is not yet common, although their use by nurses specialising in wound management is more likely. At the present time access to a Doppler ultrasound, which is used as part of the assessment of the blood supply to the lower limb (Cameron, 1991), is restricted to hospital inpatients, or those attending outpatient clinics.

A nursing policy on compression therapy is currently being developed by the Crown Health Enterprise in whose area this study was undertaken. This should result in the wider use of Doppler ultrasounds by district nurses. I am aware that in some other parts of New Zealand Dopplers are routinely used by district nurses as part of their assessment of leg ulcers.

Both registered and enrolled nurses are involved in the delivery of nursing care to the patient. They make the majority of decisions about wound management, such as the frequency of dressing changes and the selection of dressings and bandages. The district nurses are divided into teams of registered and enrolled nurses. These teams may be based on the allocation of distinct geographical areas, or structured in relation to acute or ongoing care. At times patients will be transferred between the various teams.

General practitioners normally have little input into the day-to-day management of leg ulcer patients. District nurses refer patients back to the general practitioners when wound infections occur; if there is a sudden deterioration in the ulcer; and in desperation when "everything" has been tried without success so that a specialist referral can be obtained. A minority of leg ulcer patients are admitted to hospital for treatment of serious wound infections that are unable to be managed in the community, or for surgical procedures such as skin-grafting, vascular surgery or occasionally amputation of a limb.

There are presently no formal education programmes specifically dealing with leg ulcer management available for district nurses. Educational opportunities occur on an irregular basis. The most common sources of information for district nurses are discussion with colleagues; wound care journals; attending wound care and district nursing conferences; and from the presentations of various wound care product companies.

STUDY OVERVIEW

Chapter One has provided an introduction to the study topic, outlining how the study question arose. Leg ulcer management in the New Zealand context has been described, and the importance for the nursing profession of understanding illness experiences has been discussed.

In **Chapter Two**, the literature relating to leg ulcers and their management is reviewed. While there is little New Zealand literature, the vast amount of literature from other sources that exists on this topic meant that only key articles were utilised for this review. The literature on the terminologies used to categorise various illness/disease conditions is also reviewed, revealing the confusion that presently exists in the application of those categorisations.

In **Chapter Three** the selection of the phenomenological method for this study is justified, and the study design and methodology are outlined. Ethical issues relating to this study are discussed, including the measures taken to protect the anonymity and privacy of study participants.

Chapters Four, Five and Six use the existential lifeworld themes of lived body, lived other, temporality and spatiality to describe the chronic suffering that constitutes the leg ulcer experience, while Chapter Seven integrates the study findings in a description of the adaptations that study participants have made to allow normality to be re-established.

In **Chapter Four** the physical impact of leg ulcers is detailed. The suffering accompanying living with a body that is out of control is described, and the contribution of treatment regimes to that suffering identified.

The alterations in family relationships caused by the ulcers are detailed in **Chapter Five**. New relationships must be developed and maintained with health professionals, while ulcers may cause disruption to social and work activities.

The inter-relationship between temporality and spatiality is described in **Chapter Six**. Previous experiences with leg ulcers shape the way current ulcers are experienced, offering both hope and despair for the future. Requirements for personal space are increased by the need to prevent both the aggravation of existing ulcers, or the accidental creation of a new ulcer, such as by a blow to the leg. The presence of ulcers heightens the awareness of the ageing process, with that process itself considered by the study participants to be a factor in delayed wound healing.

In **Chapter Seven** I describe how study participants learned to adjust to their chronic ulcers. Considerable work is required to minimise the impact of the ulcers, enabling the differences the ulcers create to become part of the taken-for-granted way of being-in-the-world.

The significance of the study findings will be discussed in **Chapter Eight**. The experiences of the study participants in relation to wound management are examined, gaps in existing nursing practice identified, and areas for further research suggested. Myths about non-compliance with treatment are challenged, and the nurse-patient relationship scrutinised. The importance of focusing on the person in the situation, rather than the wound, is stressed. This chapter concludes with a discussion of the limitations of this study.

CHAPTER TWO

LITERATURE REVIEW

This chapter will provide an overview of the literature relating to leg ulceration. While little has been published in New Zealand, there is a vast amount of international literature available on this topic, and it is beyond the scope of this chapter to review it all. The focus of this study is on the experiences of patients with leg ulcers, not wound management. Not all of the literature relating to the management of leg ulcers has been able to be reviewed because of its unavailability in New Zealand. Instead, key nursing and medical literature will be reviewed to outline the epidemiology, aetiology, and management of leg ulcers.

As this study is dealing with an illness experience, the literature relating to chronic illness and disease will also be reviewed, examining the terminology used to categorise these conditions and the confusion that exists in the ways these labels are applied or used interchangeably.

LEG ULCERS

The History of Leg Ulcers

For over two thousand years leg ulcers have been a part of human experience dealt with by medical practice (Baker & Stacey, 1994). The first written reference to varicose veins dates from the Ebers papyrus of 1550 BC, with Hippocrates being one of the first to recognise the relationship between ulcers and varicose veins (Shami, Shields, Scurr & Coleridge Smith, 1992).

Ryan (1987) describes the management of leg ulcers from that time on, there being:

many who believed that ulcers were the proper exit for bad humours and that healing of the ulcers should be delayed by the physician as long as possible by opening up an issue [outlet] in the other leg or by blood letting (p. 2).

The history of leg ulcer treatment, and the advances made in understanding the physiological processes that result in leg ulceration, are detailed by Negus (1991).

Allen (1988) describes how a leg ulcer does not exist as a clinical condition, being instead:

only an indication of the skin's failure to cope with the intolerable stress of an overwhelming pathological condition, sometimes locally, sometimes in the rest of the leg and sometimes in the whole body. It is the last stage in a heroic struggle against superior odds, not an abject surrender to a minor assault (p. 62).

Leg ulcers are most commonly associated with venous or arterial disorders. Venn and Fox (1987) suggest that venous ulceration is due primarily to venous hypertension associated with valvular incompetence, often resulting from damage caused by a deep vein thrombosis. Ertl (1993a, p. 679) describes the characteristics of venous ulcers, with the slow development of a relatively shallow ulcer occurring in the gaiter area. Arterial ulcers, associated with peripheral vascular disease or a blockage in an artery, are typically small ulcers with a pale base, but may be so deep that fascia and tendons are exposed; with elevation of the limb resulting in considerable pain. While they may be present on any part of the limb, they are normally found on the foot and bony prominences.

Venous disorders account for approximately 60-80% of all leg ulcers (Ertl, 1993a), while there was evidence of arterial insufficiency in a quarter of the participants in the study by Callam, Harper, Dale and Ruckley (1987). Arterial disease may exist in isolation, or in conjunction with other disorders. Allen, Hourston, Shorey, Ward and Thomas (1993) found 16% of patients attending a nurse-supervised leg ulcer clinic had mixed aetiology ulcers.

Less commonly, leg ulcers may also be associated with neuropathies arising from diabetes or multiple sclerosis; autoimmune disorders (rheumatoid arthritis); endocrine (myxoedema) and haematological (sickle cell anaemia) conditions; neoplasms and infections (tuberculosis, syphilis) may also contribute to leg ulceration (Allen, 1988).

Prevalence of leg ulceration

Limited information is available about the prevalence rates of leg ulceration. Negus (1991) suggests that the paucity of epidemiological studies "probably reflects a general lack of interest in a chronic, non-fatal condition which mainly affects the elderly" (p. 11). Cullum (1994) defines the difference between **incidence** (the number of new cases of disease occurring in the at-risk population during a specific time period) and **prevalence** (the number of cases of disease present in the at-risk population at a point in time) in epidemiological studies. Cullum continues by discussing how the epidemiological studies of leg ulcerations to date have been of prevalence only. There are difficulties comparing findings because of a lack of consistency in relation to criteria for inclusion in these studies, such as the exclusion of foot ulcers from some studies. As leg ulcer incidence increases with age, the composition of the study populations can also affect findings, but in general study findings are strikingly similar (Nelzen, Bergqvist & Lindhagen, 1994).

There are several large epidemiological studies that are frequently cited in the literature. In a survey of approximately one million people, the Lothian & Forth Valley Leg Ulcer Study (Callam, Ruckley, Harper & Dale, 1985), revealed the prevalence of open ulcers in the general population as being 0.15%, while 3.6% of the over-65 population had a history of ulceration. Closer to home, an Australian study by Baker and Stacey (1994) identified a point prevalence of ulcers of 0.11% among a population of 238,000, with a male:female ratio of 1:1.9.

Although the incidence of leg ulcers increases with age, it is not a condition confined exclusively to the elderly. Callam, Harper, Dale and Ruckley (1988) reported that over 50% of participants in their study had their ulcers before retirement age, with 42% experiencing a moderate or severe restriction to work and leisure activities. The Swedish study of a population of 270,000 by Nelzen et al. (1994) identified that over 50% of first ulcers developed before the age of 65 years, with 22% of venous ulcers present before the age of 40 years.

While the total numbers of people with leg ulcers may be relatively small, it is the chronic nature of the condition that makes these ulcers so significant for the individual concerned, and also for the health professionals involved in the management of the ulcer. The lengthy duration of the ulcers, and the repeated episodes of ulceration, were demonstrated by Baker, Stacey, Jopp-McKay, Hoskin and Thompson (1991). Of their study participants, 76% had experienced previous ulceration, of these 28% had experienced more than 10 episodes of ulceration, while 46% of the current ulcers had been present for longer than 26 weeks. Over 50% of the participants in the study by Nelzen et al. (1994) had current ulcers of more than one year's duration, with 20% of those ulcers being larger than 10 cm in size.

Management of leg ulcers.

Overseas studies indicate that the majority of leg ulcers are managed in the community. The limited information available indicates that this is also true for New Zealand (Morris, 1984). Moffatt et al. (1992) observed that "the treatment of leg ulceration has been delegated predominantly to district nurses, with poor healing despite their hard work" (p. 1389). Studies by Cornwall, Doré and Lewis (1986) and Ertl (1992) identified district nurses as having sole responsibility for the treatment of 62% and 71% respectively of all leg ulcers.

The treatment of leg ulcers can form a significant part of district nursing caseloads, as frequent dressing changes may be required over many years. According to Moffatt et al. (1992) over one fifth of leg ulcer patients are treated daily, and half have dressings changed more than twice weekly. A Swedish study (Lindholm, Bjellerup, Christensen & Zederfeldt, 1992) found that leg ulcers managed in the community were dressed on average 3.8 times a week, with foot ulcers requiring dressing changes 5.9 times weekly. In one of the few New Zealand studies of district nursing (Higgins, 1983), 14% of clients had wounds or ulcers, with wound management comprising 18% of the total nursing cares given. In my own district nursing practice, approximately 20% of my workload is related to leg ulcer treatment.

Rudolph (1983) describes the enormous body of literature about the treatment of chronic problem wounds, little of it scientifically based. Walsh and Ford (1989) discuss the lotions and agents used by nurses to treat wounds, and suggest that "some of the remedies used verge on witchcraft and have as much to do with professional care in the 1990s as a cauldron full of newts' livers and bats' feet" (p. 27).

Leg ulcers are usually left to heal by secondary intention, consisting of granulation and the formation of scar tissue (Stotts, 1986). Cuzzell and Stotts (1990, p. 35) describe how "scientifically dubious methods" of wound care, such as the use of mud to treat pressure ulcers, have now given way to wound care based on a science of tissue biology. There is now a bewildering variety of modern wound care products available for use on leg ulcers, including film membrane dressings; hydrocolloids; alginates; and hydrogels. Each of these groups of dressings are designed for specific stages/classifications of wound healing. Morgan (1991) outlines the difficulties of selecting the most appropriate wound care product when so many products are available, but there are few published studies comparing products within the same groups.

Compression therapy, increasing deep venous return and reducing venous hypertension, is the mainstay of the treatment for venous ulceration (Ertl, 1993a), but must be avoided in ischaemic ulceration where it can cause tissue necrosis. Callam, Ruckley, Dale and Harper (1987) report on the hazards of compression therapy, and recommend that a full assessment is undertaken before the commencement of compression therapy, including Doppler ultrasound. A Doppler ultrasound is used to assess blood flow to the limb, and for establishing an ankle pressure index (API), with compression therapy not advised if the API is less than 0.8 (Cameron, 1991).

It is not possible within the scope of this chapter to provide a detailed review of the assessment and treatment principles for leg ulceration. Accurate and ongoing assessment is the key to effective leg ulcer management (Ertl, 1993b). Flanagan (1994, p. 76) states that an holistic approach is vital in this assessment, and should include the multiplicity of factors that influence wound healing, including the identification of patient needs and problems.

Again there is an extraordinary amount of literature on wound management in general, and leg ulcers in particular, including some from New Zealand - Morris (1993), Watt (1993), and Wallace (1993). Wallace details a comprehensive approach for selecting the appropriate wound dressing, including the need to assess the patient's general condition; an understanding of the factors that affect healing; and the accurate assessment, classification and staging of the wound. She continues by listing the characteristics of the ideal wound dressing, and stresses the importance of ensuring that the dressing chosen is comfortable during use, and should not cause pain when the dressing is being changed.

Attitudes towards leg ulcers

Allen (1985) states:

The real problem about leg ulcers is their reputation. The term conjures up a picture of overweight old ladies, with grossly swollen legs and massive discharging ulcers, whose nurses are condemned to a treadmill of daily visits to change unpleasant dressings (p. 49).

The chronic nature of the wounds, and the difficulties inherent in achieving a permanent cure, have obviously been the source of considerable frustration for some health professionals. That frustration has at times been evident in attitudes and beliefs expressed towards people with leg ulcers. In particular, there is an oft-quoted belief that many leg ulcer patients do not want their ulcers to heal because they will lose contact with the district nurses, and may in fact deliberately prolong treatment (Ertl, 1992; Hamer, Cullum & Roe, 1994; Lindholm et al, 1993; Wise, 1986b). The comment by Wise (1986a) is typical - "her ulcer has healed twice in the past two years but recurred within two months of healing. ... so it is probably a factitious [not natural] ulcer which she uses to ensure regular contact" (p. 39).

As the following quote from a case study example by Antrobus (1982) shows, the rejection of a specific treatment regime may be considered by the health professional to be evidence of the patient not wanting the ulcer to heal, rather than an indication that the treatment regime itself may be unacceptable:

I feel the reason Mrs G rejected the use of the constrictive medicated bandages was the fact that the nurse visited only twice a week to apply them, whereas the other dressings necessitated daily visiting and Mrs G looked forward to our visits (p. 353).

An alternative explanation may have been that the 'constrictive' bandages were rejected because they were uncomfortable.

The belief of some health professionals that many leg ulcer patients do not want their ulcers to heal is illustrated by Cullum (1994) with further examples from the literature, and she comments (p. 62) "and yet *there has been no evidence published to substantiate these impressions*" (original emphasis). Flett, Harcourt and Alpass (1994), in a New Zealand study, examined the psychosocial aspects of chronic leg ulceration in the elderly, and found no evidence that social isolation was causing those patients to deliberately prolong their ulcers.

Some health professionals have demonstrated considerable sympathy towards the plight of people with chronic leg ulcers, acknowledging the distress that is associated with constant pain, discomfort and odour (Cameron, 1991). Taylor and Hoile (1986) discuss the effect of varicose ulcers on elderly patients, which:

... cause immense suffering to these old people who are often also in chronic ill health from a variety of causes... . In addition to the pain, discomfort and unpleasant discharge that causes distress over many months or years, the associated smell may cause loss of social contacts, with resulting loss of independence (p. 33).

The cost of leg ulcers

Leg ulcers can prove costly for both the individual patient, and the health care provider. Earning capacity for the individual may be restricted (Callam et al., 1988), and there can be associated treatment costs, such as prescription charges and medical fees.

An appreciation of the financial costs associated with chronic leg ulcers is becoming a motivating force for health care providers to establish more effective treatment regimes as treatment incurs considerable expense. Bosanquet (1992) estimates approximately £400,000,000 was spent in the United Kingdom yearly (1990-91 prices) on what he describes as "an orphan service involving long-term recurrent therapy" (p. 44).

While no New Zealand figures are available, Baker and Stacey (1994) suggest costs of approximately \$A365,000,000 - \$A431,000,000 incurred for the treatment of venous leg ulcers alone in Australia for the 1991-1992 period.

The human costs associated with living with chronic leg ulcers have been largely ignored by researchers (Hamer et al. 1994). There is limited acknowledgement of the problems associated with the ulcers, such as wound odour, pain and loss of mobility, with Riordan (1991) describing how those problems may themselves trigger off further health problems in elderly patients. To date, there has been very limited research into the quality of life for people with leg ulcers (Cullum, 1994). Hamer et al. (1994) have released the preliminary analysis of an essentially quantitative study into this topic, revealing that over one third of their 155 participants described pain as being the worst aspect of having a leg ulcer, yet this is an area of leg ulcer management that has received scant attention from both practitioners and researchers.

A quantitative study by Lindholm et al. (1993) utilised the Nottingham Health Profile to assess the impact of chronic leg ulcers on 125 patients attending the Department of Dermatology for treatment of their ulcers. This study revealed a significant impact for male participants in the areas of social isolation, physical restrictions, emotional reactions and pain, while the impact was less marked for female participants. Participants with ulcers of shorter duration reported more problems than participants with a long ulcer history, and the authors suggest that this may be because adaptive mechanisms develop to facilitate acceptance of the condition.

Finally, in a very recent study, Hyland, Ley and Thomson (1994) describe the development of a self-report quality of life questionnaire for leg ulcer patients they constructed following focus group discussions with 22 ambulatory patients who had leg ulcers. The conversations of the focus groups were classified by the authors into four categories - pain, restriction of activities, mood and feelings,

and preoccupation with ulcers and treatment. Varying levels of pain were reported by the patients, with pain limiting some activities, especially walking. Social activities were also restricted by the possibility of potential injury in crowded situations, while the need to have dressings changed limited absence from the home, such as going on holiday, with embarrassment appearing to be a significant factor. A variety of moods and feelings were described by the patients, including feeling unclean because of the ulcers. These patients also reported uncertainty over treatment, with some referring to different health professionals offering conflicting advice.

The questionnaire that was then constructed by Hyland et al. (1994) on the basis of the focus group findings was trialled with a further 33 leg ulcer patients. A refined version was subsequently administered to another 55 patients, of whom approximately one-third reported negative emotions and substantial functional limitations because of their ulcer(s). The authors conclude by suggesting "patient management is likely to be most effective from the perspective of a biopsychosocial interaction" (p. 298).

Trends in the management of leg ulcers

The unfortunate district nurse found herself trapped in a situation where she was looking to the doctor for expert advice, the doctor was hoping that the nurse had a trick or two (known only to nurses) up her sleeve and the patient was pathetically trusting that both of them knew what they were doing.

(L.Brown, personal communication, cited in Allen, 1985, p.56).

While previously district nurses have had few treatment options available to them, the treatment of leg ulcers is becoming increasingly sophisticated, with the development of new generation wound care products, such as the alginate and hydrocolloid dressings, and a variety of compression bandages and stockings. The range of treatment options now available, coupled with the technology available to assist with more accurate diagnosis and assessment of wound

aetiology, is making it extremely difficult for district nurses to remain up to date with the latest treatment options.

The rapid developments in leg ulcer management have provided some challenges for nursing education. Surveys have been carried out to establish the education needs of district nurses in the United Kingdom (Ertl, 1992; Roe, Luker, Cullum, Griffiths & Kenrick, 1993), and various specialist leg ulcer courses developed (Allen, 1985; Moffatt & Karn, 1994).

While not yet common in New Zealand, in some countries multi-disciplinary community clinics are becoming a cost-effective and efficient means of achieving wound healing (Bosanquet, 1992; Moffatt et al. 1992; Moffatt & Oldroyd, 1994). Strong emphasis is placed on the education of specialist nursing staff, skilled in the accurate assessment and systematic research-based treatment of ulcers, with the development of clearly-defined treatment protocols, such as the Charing Cross Hospital four-layer high compression bandaging systems.

While impressive results are being reported by some clinics, the long-term outcomes are not yet clear. Moffatt et al. (1992, p. 1392) acknowledge that approximately one-fifth of legs had reulcerated within six months of healing with their clinic regime, a figure that increased to one-third by the end of twelve months. It appears that leg ulcers will remain a challenge for health professionals for the foreseeable future.

As previously mentioned, there is an enormous body of literature relating to various aspects of leg ulcers and their management, much of which has been beyond the scope of this particular literature review. Anyone wishing to examine this subject in more depth is referred to a literature review, commissioned by The British Department of Health and compiled by Cullum (1994), which has recently become available. Entitled 'The Nursing Management of Leg Ulcers in the Community: A Critical Review of Research', this comprehensive document

reviews medical and nursing literature published between 1965 and the end of 1991.

CHRONIC ILLNESS

There is an extensive body of literature relating to chronic illness/disease, but unfortunately this literature demonstrates a lack of consistency among the definitions that are used, and in their application.

There appears to be reasonable consensus about the term **disease**, with its focus on objective biomedical phenomena, defined by Benner and Wrubel (1989) as "the manifestation of aberration at the tissue, cellular, or organ levels" (p. xii). Robinson (1990) considers that "diseases may be characterised by their unique pattern - their course - which they are deemed to follow through the unfolding of (biomedically) observable signs and symptoms over time" (p. 1173), while Mechanic (1978) suggests "the concept of disease usually refers to some deviation from normal functioning that has undesirable consequences because it produces personal discomfort or adversely affects the individual's future health status" (p. 25).

There is general agreement over the subjective nature of the concept of **illness**, described by Benner and Wrubel (1989) as "the human experience of loss or dysfunction" (p. xii), and Conrad (1990) as "the social and psychological phenomena that accompany ... physiological problems. Illness is a profoundly social phenomenon, that may or may not rest on disease as a foundation" (p. 1259). Diamond and Jones (1983) suggest that "illness denotes phenomena that are apparent to the ill person only" (p. 5), and that when that illness is communicated to others, becoming a social phenomenon, it is called **sickness**.

Brody (1987) outlines the components of sickness, including a change in social roles; an unpleasant interruption to body and self; the requirement for medical intervention; and being abnormal in relation to reference group functioning.

Other categories that may be used in relation to health/illness are **disability** (activity restriction), and **handicap** (social disadvantage) (Bury, 1988). Mechanic (1978) cites the definition of **impairment** used by the National Center for Health Statistics, 1975 as "chronic or permanent defects, usually unchanging in their nature, resulting from a disease, injury or congenital malformation" (p. 182).

There appear to have been few attempts to specifically define the term **chronic illness**, although this is a term in wide usage. Anderson and Bury (1988) consider chronic illnesses "are generally conditions for which treatment of the underlying disease process is not available; the emphasis of care and rehabilitation is therefore more on enhancing and sustaining the quality and fullness of life than on reordering the disease process" (p. 2).

Benner and Wrubel (1989) describe chronic illness as "either continually needing to be treated and managed, or only intermittently requiring treatment" (p. 136). Strauss (1987) outlines the prominent characteristics of chronic illness, such as their long term, uncertain nature; the expense of treatment required; the presence of multiple disease; and the frequency of conflicts over interpretation and management, but he fails to formally define what chronic illness actually is.

In her discussion of what she calls the **interminably ill**, Register (1987) challenges metaphors and language that casts the chronically ill as victims or walking embodiments of disease, stating that an active response is demanded by illness.

Chronic illness may be conceptualised in terms of a systemic disease or as a progressive condition. Larkin (1987) states that while acute disease may be localised, chronic illness is "often the result of many causes interacting over the course of time and affecting a relatively larger part of the body" (p. 536). This idea of chronic illness as being only applicable to systemic disease processes is not uncommon - for example, arthritis, multiple sclerosis and diabetes frequently feature in literature relating to chronic illness. Smeltzer (1991) discusses the usefulness of multiple sclerosis as a model for chronic illness, because of the progressive disability and unpredictability that is characteristic of this disease.

One of the most comprehensive definitions of chronic illness is given by Lubkin (1990) as "the irreversible presence, accumulation or latency of disease states or impairments that involve the total human environment for supportive care and self-care, maintenance of function, and prevention of further disability" (p. 6). Purportedly a definition of chronic illness, this definition clearly leans heavily on a disease model, and it is difficult to see where subjectivity has a place.

This blurring of the definitions of disease and illness is common. The 1956 American Commission on Chronic Illness (as cited by Strauss, 1975, p. 1) describes chronic disease as:

All impairments or deviations from normal which have one or more of the following characteristics: are permanent, leave residual disability, are caused by non-reversible pathological alteration, require special training of the patient for rehabilitation, may be expected to require a long period of supervision, observation or care.

This definition is used by Strauss to introduce his text on chronic illness and the quality of life, and it appears that, along with many other writers, he uses the terms illness and disease interchangeably. Not infrequently the term 'chronic illness' may in fact have nothing to do with the subjective experiences of people with a chronic disease/condition.

All the terms are labels that are applied to people, but a different perspective is obtained when personal accounts of ill-health are examined.

Understanding an illness experience from the patient's perspective has the potential to enhance the care that health professionals can offer their patients. Such understandings are compromised when the inconsistent application of terminologies makes it difficult to differentiate between subjective experiences of illness and objective descriptions of disease.

Brody (1987) states that "the precise meaning of the distinction between disease and illness has been much discussed, but never resolved..." (p. 21) , and chooses to tell stories of 'sickness' as this is the term that implies a social dimension. Morse and Johnson (1991) describe how health professionals are beginning to "listen more attentively and to give credence to the patient's perspective" (p. 341). It is this perspective that is undertaken in this study. By utilising phenomenological research methodology, this study is able to clearly describe the illness experiences of nine individuals with chronic leg ulceration.

Benner and Wrubel (1989) in their phenomenological examination of illness, discuss the role of symptom experience, and how "every illness has a story - plans are threatened or thwarted, relationships are disturbed, and symptoms become laden with meaning depending on what else is happening in the person's life" (p. 9). This study will examine the **stories** of the individuals who agreed to participate in this study, and demonstrate the lived reality of the illness experience.

SUMMARY

This chapter has reviewed a small amount of the enormous body of literature that exists relating to leg ulceration. Following a brief outline of history, aetiology,

and treatment of leg ulcers, consideration was given to the attitudes demonstrated towards people with leg ulcers. A failure by health professionals to acknowledge the impact of the chronic nature of this condition, and the impact of treatment regimes, has been demonstrated by attitudes which are frequently unsympathetic to the plight of these patients.

The confusion in existing definitions of illness and disease and their application has been discussed. While purportedly seeking to portray subjective illness experience, many of these definitions are still essentially descriptions with a disease focus, rather than the accounts of individuals and their lives.

In the following chapter, the selection of phenomenology as the most appropriate research methodology to reveal the stories of people living with chronic leg ulcers will be discussed, together with a detailed description of the research process that has been used in this study.

CHAPTER THREE

RESEARCH METHODOLOGY AND DESIGN

The vast majority of the literature on leg ulcers reviewed in the previous chapter has been from the perspective of the health professional, with scant regard given to the subjective experiences of those suffering from this condition. Little is known about what it is like to live with these chronic open wounds, and how lives are altered by their presence. The appropriateness of existing nursing practice in relation to people with leg ulcers is unclear, and the potential contribution of nursing in this area has yet to be identified.

Hermeneutic Heideggerian phenomenology, in providing both the philosophical foundation for this study, and as the guide for the research design, will facilitate the examination of this particular illness experience to further such understanding.

As described by Benner and Wrubel (1989), understanding the experience of illness is fundamental to nursing practice:

Understanding the meaning of the illness can facilitate treatment and cure. Even when no treatment is available and no cure is possible, understanding the meaning of the illness for the person and for that person's life is a form of healing, in that such understanding can overcome the sense of alienation, loss of self-understanding, and loss of social integration that accompany illness (p. 9).

In this chapter the history and assumptions of phenomenology will be described, with particular attention paid to the phenomenological view of the person. The design of this study will then be outlined, including details of the study participants, ethical considerations, data collection and analysis.

THE PHENOMENOLOGICAL VIEW OF THE PERSON.

Benner (1994) describes the goal of interpretive phenomenology as being to "respectfully understand the lifeworld, critically evaluating what is oppressive, ignorant, or troublesome from the perspective of the participants and identifying sources of innovation and liberation within everyday practices" (p. 123).

Phenomenology arose out of the difficulties experienced by philosophers from Descartes onwards concerning perception and knowledge that result from the concept of the human being as a subject in a world of objects. Heidegger shifted the focus of phenomenology as originally founded by Husserl from considering problems of epistemology [how we know what we know] to questions of ontology [what it means to be a person]. Leonard (1994) suggests that the debates that currently exist in nursing concerning the appropriateness of specific research methodologies would be resolved if researchers first considered the importance of the ontological question, for "in asking what it means to be a person, we come to understand more clearly how we know the world" (p. 45).

The five essential Heideggerian phenomenological perspectives relating to being a person are outlined by Leonard (1994, pp. 46-55).

- (1) The first theme focuses on the relationship of the person to the world. World is "the meaningful set of relationships, practices, and language that we have by virtue of being born into a culture" (p. 46), with language articulating this world and revealing things to us. As the world both constitutes the self, and is constituted by the self, what a person can and cannot become is set up by the possibilities of that world. This world is taken for granted, only reaching our consciousness when it breaks down in some way.

- (2) Because a person is a being for whom things have significance and value we become involved in the world, with culture, language and individual situations giving rise to qualitatively different concerns. What a person finds significant and of value is only obvious in relation to the context of his or her world, and therefore research into health and illness must study the person in that context.
- (3) The person as a self-interpreting being refers to the fact that it is during the course of living a life that a person comes to be defined. These interpretations are facilitated by language and culture which, although so all-pervasive as to go unnoticed, make the world intelligible for us.
- (4) The view of the person as embodied differs fundamentally from the Cartesian view of the body as an object, for it is "the body that first grasps the world and moves with intention in the meaningful world" (p. 52). The body is our basic way of being in the world, and rather than just possessing a body, the person is embodied, allowing for understandings of situations in skilled, taken-for-granted bodily responses. These taken-for-granted skills are revealed to us in the breakdown of the body that is experienced as illness.
- (5) The person in time differs from the traditional view of linear time as a succession of moments. The phenomenological notion of temporality sees the person existing in a present that can be understood because of one's experiences in the past, and from which one is able to project oneself into the future.

NURSING AND PHENOMENOLOGY

The suitability of phenomenology as an appropriate research methodology for nursing is evidenced by the number of researchers now drawing on this method, such as Benner (1984); Benner and Wrubel (1989); Madjar (1991); and Rummel (1993). Swanson-Kauffman and Schonwald (1988) outline the increasing importance of phenomenology for the study of nursing phenomena, and how "knowledge of lived experiences of health and healing are legitimate topics of nursing inquiry" (p. 97). Benner (1985) states that the treatment of illness and disease, and health promotion, are concerns for nursing, and how "nursing requires access to concrete problems and dilemmas associated with health, illness, suffering, and disease and an understanding of the power of human practices, skills, and relationships that engender hope and promote healing" (p. 13).

Phenomenological inquiry provides the means of reaching such an understanding. Phenomenology is able to examine the disruptions to normal ways of being in the world associated with illness. Leonard (1994) states "it is nursing, more than medicine, that seeks to help the patient reclaim the sense of embodiment that allows for their taken-for-granted, unselfconscious transactions in the world" (p. 53). The focus of phenomenology on the unique experiences of a person allows for the provision of nursing care in which patient-identified needs are paramount (Jasper, 1994).

Thompson (1990, p. 229) outlines the contribution that hermeneutic phenomenology can make to the socialisation of nursing researchers themselves, allowing for better self-understanding; and facilitating an awareness of the social, political and ethical dimensions of the research process.

PHENOMENOLOGICAL RESEARCH METHODOLOGY

Van Manen (1990) describes how the emphasis in human science research is on "explicating the meaning of human phenomena ... and on *understanding* the lived structures of meanings" (original emphasis, p4).

Hermeneutic phenomenology was selected as the research methodology that would best facilitate this examination of experiences of chronic leg ulcers. Originally an academic discipline first developed within the field of theology, Thompson (1990) describes how hermeneutics is today known "as a contemporary philosophy that emphasizes the human experiences of understanding" (p. 230). There have been many interpretations and modifications of the phenomenological method originally proposed by Husserl. Hermeneutic phenomenology arises from, and is consistent with, Heideggerian phenomenology, and must be distinguished from the transcendental school of phenomenology associated with Husserl.

Van Manen (1990) describes hermeneutic phenomenology as a human science which studies 'persons', a term referring to "the uniqueness of each human being" (p. 6), with phenomenology being the descriptive element, and hermeneutics the interpretive. The interrelated phenomenological research activities outlined by van Manen (pp. 39-51) of orienting to the phenomenon, formulating the phenomenological question, and explicating assumptions and pre-understandings, have formed the basis of this study design.

Orienting to the Phenomenon

This study arose from my growing concern that health professionals had failed to comprehend the considerable disruptions to normal ways of being-in-the-world experienced by persons with chronic leg ulcers.

Considerable reflection and reading, informal discussions with persons with leg ulcers, and a preliminary fieldwork study on this topic, convinced me of the importance of making the stories of these people accessible to health professionals.

Formulating the Phenomenological Question:

The specific research question for this study was

What it is like to live with chronic leg ulcers?

The objectives for this study were to understand more about the impact of chronic leg ulcers on everyday life so that the realities of living with this chronic condition would be revealed to health professionals. I also wished to ascertain whether current nursing practice in general, and district nursing in particular, was meeting the needs of these persons.

Explicating Assumptions and Pre-understandings

Van Manen (1990) warns that "our 'common sense' pre-understandings, our suppositions, assumptions, and the existing bodies of scientific knowledge, predispose us to interpret the nature of the phenomenon before we have even come to grips with the significance of the phenomenological question" (p. 46). Husserl originally suggested that one must 'bracket' everything that was known about the phenomenon, theoretically setting aside that knowledge. Van Manen considers that it is more appropriate to "make explicit our understandings, beliefs, biases, assumptions, presuppositions, and theories" (p. 47), so that those reading this study are able to assess whether these pre-understandings have indeed influenced the study findings.

Working as a district nurse, I have had considerable contact with persons with leg ulcers, and my interest in their experiences has been the focus of numerous informal conversations, and the subject of a small fieldwork study, prior to the commencement of this study. I had therefore already formulated some assumptions and expectations about what life with leg ulcers must be like, and these are now made explicit. At the outset of the study I had assumed:

- (i) That many aspects of this experience would be very unpleasant for these people, including pain, the smell of wounds, and the problems associated with bandaging.
- (ii) That having had ulcers heal in the past helps sustain hope that current ulcers will heal. Nevertheless there will be a significant degree of acceptance that the condition is chronic, and that when an ulcer heals the victory is likely to be only temporary.
- (iii) That these persons will be subject to much conflicting advice/information, and that much of that advice will be difficult to comply with, particularly the advice to rest the leg.
- (iv) That these persons will have considerable expertise about the management of their ulcers, but that expertise may not be acknowledged by the health professionals they deal with.

Data collection

This phenomenological study focuses on the experiences of nine people with chronic leg ulcers. Descriptions of these participants, the criteria for their inclusion in the study, and details of how participants were accessed for this study, are provided later in this chapter (pp. 39-44).

There are various methods of data collection open to phenomenological researchers (van Manen, 1990), including the use of observation, descriptions in literature, the use of diaries and journals, and non-discursive artistic material. The method of data collection for this study has been the use of hermeneutic interviews with participants who had experience of the phenomenon under investigation - chronic leg ulceration.

For this study, at least two interviews were held with each participant, with several participants being interviewed on three occasions. Interviews ranged in duration from one to three hours. All interviews were tape-recorded (with the permission of the participants), and transcribed verbatim by myself. All but three of the interviews were conducted in the homes of the participants, with the spouses of two participants present at the time of the interviews. The other three interviews were conducted in a hospital setting, as the participants were at that time hospital in-patients. All participants were offered a copy of their transcripts, with four participants taking up this offer.

Van Manen (1990) discusses the art of the researcher in the hermeneutic interview as being "to keep the question (of the meaning of the phenomenon) open, to keep himself or herself and the interviewee oriented to the substance of that thing being questioned" (p. 98). A semi-structured interview schedule had been designed for the initial interview. I began by asking each participant to tell me how long their current ulcer had been present, and without exception this one question appeared to be all the encouragement needed for participants to tell me their stories. I quickly learned to abandon my interview schedule.

Second and subsequent interviews were used to allow clarification of, and reflection on, the deeper meaning of some aspect of the previous interview, or raise issues that had not yet been covered. Field notes were recorded in a journal

after each interview, and included not only comments about areas that needed further clarification at a subsequent interview, but also recorded tentative study findings.

Bergum (1991) discusses how the term 'conversation' rather than 'interview' was a more appropriate description of the process used in her research, as the word 'conversation' "implies a discussion and best captures the attitude of this interaction. Like an interview, the conversation has a central focus, but it is not one-sided" (p. 61). I believe the term 'conversation' is also a more appropriate description of the interviews that were undertaken for this study.

Data analysis

The tape-recordings of the research interviews, the verbatim transcripts, and the fieldnotes I made about those interviews and the issues raised in them, formed the text that was analysed to discover the essence of what it means to live with chronic leg ulcers.

It would not be accurate to describe the process of analysis of this data as happening in an orderly manner, mainly because of the nature of hermeneutic analysis. 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" (p. 9). It is this shifting back and forth between a background of shared meaning and a 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" (p. 243).

The approaches of van Manen (1990, pp. 92-101) provided the framework for the analysis undertaken in this study. Initially each interview was read in its entirety several times, and the tape-recordings of the interviews were also listened to on several occasions to gain an impression of the sum of the experiences described by each participant.

Each text was then read selectively to identify statements or phrases that appeared to be of particular significance, and those phrases highlighted. Finally, a line-by-line approach was utilised to facilitate understanding of what was being revealed in the description of the experience. Emerging themes were then compared with the experiences of other study participants, commonalities and differences noted, and emerging findings taken back to study participants for their further reflection.

While some aspects of this lived experience were immediately obvious, such as the suffering that is inflicted by the presence of these chronic wounds, other important themes were more difficult to identify. As an example, it was obvious from their stories that the majority of the study participants had been able to reach some kind of accommodation in relation to this suffering. It was clearly more than just mere acceptance of the condition, but it required many readings of the transcripts, comparisons of the experiences of each participant, and line-by-line questioning of the data, before the nature of the work that is required to maintain a sense of normality was identified.

TRUSTWORTHINESS OF THE STUDY FINDINGS

The problems of establishing rigor in qualitative research were described by Sandelowski (1986). She suggested various strategies for ensuring the confirmability of qualitative research, including achieving auditability (the clear decision trail), and fittingness, strategies that have subsequently been adopted by

many qualitative researchers. Sufficient details are provided in this chapter to enable the research processes of this study to be visible to such scrutiny.

In a subsequent review of the issue of rigor in qualitative research Sandelowski (1993) reveals her belief that a preoccupation with ensuring the trustworthiness of qualitative research has meant that "we were more preoccupied with building fortifications against attack than with creating the evocative, true-to-life, and meaningful portraits, stories, and landscapes of human experience that constitute the best test of rigor in qualitative work" (p.1).

Leonard (1994) emphasises that interpretive inquiry is not simply just a description of a phenomenon but is "always concerned with some kind of breakdown in human affairs. Thus the ultimate criterion for evaluating the adequacy of an interpretive account is the degree to which it resolves the breakdown and opens up new possibilities for engaging the problem" (p. 60). I believe that the findings of this study do indeed meet that criterion as a picture has been painted of a view that has until now been invisible - the reality of living with chronic leg ulcers while trying to maintain a sense of normality.

Fittingness of the study was increased by the selection of participants who had considerable experience of leg ulceration, and who were able to fully articulate those experiences (Beck, 1992). The use of multiple interviews with the participants allowed for emerging study findings to be verified with each participant. Completed study findings were discussed at some length with several of the participants, who confirmed the findings as representing the lived realities of their lifeworlds.

Finally, Benner (1994) suggests in phenomenological interpretation that "if the interpreter's own views have not been challenged, extended or turned around, the quality of the account is questioned and the danger of just reading in preconceptions must be considered" (p. 101). Some of the assumptions I had

about this study topic have indeed been confirmed, such as the suffering that accompanies the experience of leg ulcers, and the difficulties of complying with treatment regimes. However, many aspects related to the experience of leg ulcers, and of which I was completely unaware, have now become evident to me.

These include the difficulty participants experienced in trying to control a condition that was largely beyond their control, and the work that is required to combat the suffering. I believe that my views were challenged as the study progressed, and this was reflected in my growing sense of awe at the courage displayed by these study participants, and their ability to lead meaningful lives in the face of protracted suffering.

STUDY DESIGN

Criteria for inclusion in the study

For this study, I was interested in learning how people lived with chronic leg ulcers, and of the routines and coping strategies they developed over time.

Seldom is there any indication in the literature of the length of time the condition must be present to be considered chronic - the National Center for Health Statistics (cited by Mechanic, 1978) describes chronic conditions as "having first been noticed more than three months before the week of the [clinical] interview" (p. 182). Baker et al. (1991) defined as 'chronic' a leg ulcer present for more than one month or longer, admitting that this definition was arbitrary "but embodies the notion of delayed healing" (p. 867).

In qualitative research, participants may be selected according to the needs of the study. Morse (1991) suggests that "the researcher may chose to interview informants with a broad, general knowledge of the topic or those who have

undergone the experience and whose description is considered typical" (p. 129). To facilitate an examination of the chronic nature of the leg ulcer experience, only persons with current leg ulcers that had been present for at least six months were considered eligible for inclusion in this study.

Accessing study participants

Permission for access to potential participants for this study was initially obtained from the General Manager of a large provincial Crown Health Enterprise (formerly Area Health Board), and subsequently from the managers of the domiciliary nursing service of that Crown Health Enterprise.

A meeting was scheduled with district nurses, and an information sheet (Appendix B) was distributed to those nurses, explaining the purpose of the study. Their assistance was sought in obtaining participants who met the criteria for the study but it was stressed to them that no pressure was to be put on any patient to participate. District nurses were assured that any comments made about them by the study participants would be handled in such a way as to ensure that specific district nurses would not be able to be identified in any subsequent reports on the study.

An introductory letter (Appendix C) and information sheet (Appendix D) were distributed by those district nurses to all those considered eligible for inclusion in the study, explaining the purpose of the study, and asking them to consider taking part.

The district nurses supplied me with the names of patients who were prepared to discuss the study further, and who had given those nurses permission to supply me with their name and telephone number. I then contacted those individuals by telephone and sought their approval to visit them to discuss the study further. Two of those people who had originally agreed to meet with me subsequently

decided, when I made the initial phone contact with them, not to be involved with the study, with one of them becoming particularly upset, telling me "that leg ulcers had ruined her life, and it was too awful to talk about" (Fieldnotes, 17 February).

The study participants

Van Manen (1990) describes how the methodology of phenomenology "tries to ward off any tendency toward constructing a predetermined set of fixed procedures, techniques and concepts that would rule-govern the research project" (p. 29). It was not possible to determine prior to commencing the study how many persons would need to be interviewed before the study was complete.

The stories of the nine participants that form the basis of this study represent a wide variety of experiences with leg ulcers. Following the completion of interviews with these nine people I became concerned that, within the constraints of the resources available to me, I would not be able to do justice to the stories of even these participants because of the volume of data already generated. Benner (1994) suggests that "sample size is limited by the size of the text that will be generated and the number of researchers available to analyze the text" (p. 107). After consultation with my study supervisor I decided to restrict the study sample to those existing nine participants.

I am conscious that even though it is now six months since the interviews were completed, the majority of the study participants still have current leg ulcers. I am acutely aware of their vulnerability, and of the importance of ensuring that their privacy and anonymity are preserved.

I believe that, despite the use of pseudonyms, providing a biographical profile of each participant, detailing specific information about the duration of their current ulcers, and the number of years they have experienced leg ulcers, would enable

them to be identified by nurses who knew them. Therefore, only limited, generalised information will be provided about the study participants.

There were five male participants in this study, whose ages ranged from 59 years to 81 years. The four female participants were aged between 56 years and 79 years. All participants had current ulcers of at least six months duration at the commencement of the study, although one participant subsequently had a leg amputated before data collection was completed. The current ulcers had been present for periods ranging from between six to twelve months duration for five of the participants; between three to four years duration for three of the participants, and one ulcer had been present for approximately six years.

Three of the study participants were undergoing their first experience of leg ulceration. Three study participants had experiences with leg ulcers that first began between three to six years previously; with the final three participants having ulcers present for most of the past 20, 43 and 47 years respectively. Three of the study participants had bilateral leg ulcers. The study participants had fifteen current ulcers between them. Three study participants lived alone, while the others lived with spouses or other family members.

No attempt was made to establish the aetiology of the current ulcers, as the focus of this study was on experiences of ulcers, not ulcer management. The district nurses in this study setting have received limited education on the assessment of leg ulcers, and do not currently have access to Doppler ultrasounds that would permit accurate diagnosis to be made. Several study participants had received conflicting advice in the past about the aetiology of their ulcer, or had been told that the aetiology was still uncertain. Study participants did not appear to consider it important to know what type of ulcer they had.

ETHICAL CONSIDERATIONS

The approval of both the Human Ethics Committee of Massey University and the Ethics Committee for the particular Crown Health Enterprise concerned were obtained for this study, and all conditions of those committees have been complied with.

All study participants were requested to sign a consent form (Appendix E) once their proposed role in this study had been clearly explained to them. It was clearly stated to participants that unwillingness to participate in the study, or withdrawal from the study at any time would not adversely affect their further care, so that they would not feel obliged to participate to ensure the continuation of their existing treatments.

Confidentiality and anonymity were maintained by not using personally identifiable information on any of the transcript material or interview tapes; by ensuring that only myself and the study supervisor had access to the interview transcripts; by keeping all interview tapes and transcripts in a locked cupboard, separate from the key to the codes used in those materials; and in the final report using pseudonyms and removing any details that might permit the identification of study participants.

I believe I have taken every possible precaution to maintain the confidentiality and privacy of study participants. However, I am particularly concerned to ensure that study participants have not prejudiced their future treatment by taking part in this study. I have therefore taken the liberty of withholding the pseudonym from several interview excerpts as an additional precaution in protecting the confidentiality and anonymity of the study participants.

Participants were assured that any information they divulged was not made available to their district nurse. Prior to commencing this study I had been aware that the potential existed for the identification of ethical concerns relating to the nursing practices described by study participants. There were no issues revealed during the study relating to the district nursing service that cannot be dealt with in the separate study report shortly to be forwarded to the Ethics Committee concerned. Details relating to either individual participants or staff will not be supplied in that report.

Provided anonymity and confidentiality were maintained, there were no potential long-term disadvantages to subjects participating in this study, but there was the possibility of some short-term distress when reflecting on the extent to which this condition had impacted on their quality of life. Study participants were warned of this, and mechanisms put in place to deal with it should it arise. Short-term advantages to participants were limited to the potential satisfaction arising from the awareness that they were sharing knowledge and experiences that were of interest to myself, and that their contribution will increase nursing knowledge of this experience.

Ethical considerations relating to the possibility of distressing study participants restricted some areas of questioning, such as discussing with participants whether they had ever considered that they could face amputation of their leg at some future date.

Hutchinson, Wilson, and Wilson (1994) suggest that while the risks associated with participation in qualitative studies for health research purposes have received attention, little has been reported of the potential benefits that may also be experienced. They cite benefits such as healing, empowerment, a sense of purpose, and catharsis being experienced by participants in such studies. No attempt has been made to establish whether the participants in this study experienced any benefits from their participation, although it was clear that the

majority of them enjoyed having the opportunity to tell their stories, and to assist me with this study.

PRESENTING THE STUDY FINDINGS

There are various ways in which phenomenological writers may structure their texts (van Manen, 1990), and this study report is structured around the existential lifeworld themes of temporality, spatiality, corporeality and relationality. These themes are described by van Manen (1990, pp. 101-106):

Lived body (corporeality) "refers to the phenomenological fact that we are always bodily in the world" (p. 109). This theme is demonstrated in Chapter Four, with the descriptions of what it means to live with a body that is out of control, and of the suffering that the ulcers engender. **Lived other** (relationality) is "the lived relation we maintain with others in the interpersonal space that we share with them" (p. 104). Chapter Five reveals the alterations in family relationships created by the presence of ulcers, and the need to also establish and maintain relationships with health professionals.

Lived time (temporality) and **lived space** (spatiality) are outlined in Chapter Six. Temporality - "subjective time as opposed to clock time or objective time" (p. 104), is of particular significance in the leg ulcer experience, with current ulcers being interpreted in the light of previous experiences of ulceration, and diminished hopes for a future free from leg ulcers.

Spatiality is "felt space ... we become the space we are in" (p. 102), and in Chapter Six the particular requirements for increased personal space when leg ulcers are present is discussed. Home can become a prison when leg ulcers, or their treatment, restrict social activity, but can also feel like a haven in a world full of potential hazards.

While for the purposes of presenting these study findings, these four themes have been differentiated from each other, in reality they cannot be separated. They form what van Manen (1990) describes as "an intricate unity which we call the lifeworld - our lived world" (p. 105). The following three chapters together reveal the lifeworld of these nine persons with chronic leg ulcers - lifeworlds that have been significantly altered by the impact of this condition. The important thematic statements arising from their experiences are highlighted in bold throughout these chapters.

CHAPTER FOUR

THE BODY AWARE OF ITSELF

In this chapter, the chronic leg ulcer experience is examined from the perspective of one of the fundamental existential themes - the **lived body**. This provides an understanding of the illness experienced by the body, in contrast to "the body known through the method of natural science or disinterested observation" (Madjar, 1991, p. 57).

Chronic leg ulcers are evidence of a breakdown in the normal "smooth functioning of the body" (Benner and Wrubel, 1988, p. 59). This breakdown impacts on the body in two ways - **the body being out of control**, and **treatment regimes altering embodiment** by restricting previously taken-for-granted habits and routines, and altering bodily sensations.

An inability to control the body is demonstrated by the pain, odour and ooze that characterise these chronic leg ulcers. For, despite the best efforts of participants to adhere strictly to the prescribed treatment regimes, these wounds appear to continue almost at will - wounds fail to heal; new ulcers begin; and wound infections recur with disappointing regularity.

Alterations to embodiment are also experienced when treatment regimes disrupt being-in-the-world. Having a shower may now require almost military planning to protect the wound; unsightly and uncomfortable bandages restrict footwear options; and the advice to rest the limb poses almost insurmountable problems in relation to carrying out the activities of daily living and maintaining a sense of wellbeing.

THE BODY OUT OF CONTROL

Pain is a universal feature of the leg ulcer experience, although the nature and intensity of the pain varies greatly. The level of pain experienced may range from general discomfort to pain so severe that even walking becomes impossible:

I was laid up for four months - I couldn't even get off the couch.

I had to crawl to the toilet - I had a really bad one [ulcer].

(Don, Int 1: p11)

Jim became *so sick and tired of the pain* (Int 1: p8) that he requested the amputation of his leg, while for Gary pain was a significant factor in his decision to finally proceed with amputation:

But those pills got immune in the end - pain started creeping through. ... I came in and said to them - "I can't stand the pain any longer - take it off".

(Gary, Int 1: p9)

As previously stated, no attempt was made in this study to establish the aetiology of the participants' ulcers. Cornwall (1985) outlines the differences between pain experienced with venous or arterial ulcers. Differences were clearly evident in the nature of the pain and discomfort experienced by study participants.

Ulcers originating from ischaemic disease result in pain when the limb is elevated. Only short periods of elevation, perhaps no more than twenty minutes, can be tolerated before significant pain is experienced. Painful legs interrupt sleep, and while hanging the leg over the side of the bed may help, remaining in bed is not always an option:

I get up, have a walk around. ... go upstairs and have a little teacup full of Milo™ [milk drink], and I would have a couple of Panadol™. I had the idea that the hot Milo™ would help it dissolve, help it work a bit quicker, and I would listen to the talkback show.

(Don, Int 2: p25)

Although there is some acknowledgement in the literature of pain associated with venous ulcers (particularly when the wound is infected), for participants with this type of ulcer discomfort was a constant feature. Typical were the symptoms arising from leg oedema:

I get a lot of pain in the veins, throbbing pains, right up the leg. They sort of feel like someone has stuck a knife into the veins, and you yelp.

(Edna, Int 1: p3)

But (sighs) just now and again they grip - the pain grips and throbs where the ulcers are, just now and again. The left leg goes, and then it tells the right leg to go.

(Hugh, Int 1: p4)

The leg may be comfortable as long as it is elevated, but can be very painful when put to the floor :

I keep it up like this (has leg on footstool) and then when I put it to the ground and try to walk on it the blood comes down, and it's agony sometimes, and I get so mad I could scream.

(Freda, Int.1: p3)

Routines have to be altered so that standing still for any length of time is avoided, such as when preparing the vegetables for a meal, or doing the ironing. Standing in one place can be difficult to avoid, as when out shopping and unexpectedly meeting friends:

... because people want to stand. I just say, "look, can we go over by the counter?", and just lean on the counter. I just say that to them, because I can't just stand without having something to lean on.

(Edna, Int 2: p22)

In addition to the pain that arises directly from the condition itself, pain may also be clinically inflicted during dressing changes, as the old dressings are removed; when wounds are cleaned roughly; if the wound is exposed to the air for any period of time; or as the new dressing is applied:

I'm always glad when it is finished. Because you see they put that thick thing on [hydrocolloid dressing], and then they sort of press it down with their hands - it hurts when they put pressure on it, but they have to do that to make the stuff stick on the skin.

(Hugh, Int 1: p5)

Although at times there may be some discomfort associated with the procedure, dressing changes are normally welcomed because wounds feel so much fresher when they have just been cleaned:

Oh it is, it is much more comfortable. It feels lovely once they have dressed it. ... Feels great, when they do it.

(Freda, Int 2: p15)

If an allergy develops to a dressing product the resulting irritation is not only disappointing but can become quite painful. Some dressing products can cause an unpleasant 'drawing' sensation:

They [paste bandages] used to draw your legs - the nearest thing I could get to was a bad toothache, not just a toothache - it was a horrible feeling.

(Connie, Int.1: p5)

Bandages are often uncomfortable, especially if the leg swells during the day:

Well, they are not too tight when they are put on, but they get too tight if your leg swells. ... But the nurse will come in the morning, and then your leg swells during the day, and after you go to bed, and they [bandages] slip down and begin to cut into your legs.

(Connie, Int 1: p6)

Diagnostic procedures and examinations may cause distress, ranging from the discomfort of having the tissues surrounding the wound palpated by a doctor, to the agony caused by several unsuccessful attempts to perform a venogram:

Yeah, because when I collapsed I had been in there for three hours, and they had been putting a needle in, trying to find a vein, and every time the vein just wouldn't come to the party. ... When they pumped the stuff in, it was like my leg was burning, my veins were all burning.

(Jim, Int 2: p21)

Pain was normally not well-controlled by analgesia. There appears to have been a lack of appreciation by health professionals of the pain engendered by these wounds:

(Do the doctors and nurses understand [the pain you have got]?)

I don't think they do. I think they think you might put it on.

(Freda, Int 2: p21)

Digesic™ and Panadol™ were the analgesics most commonly used, and were often used regularly when ulcers were particularly painful:

I went through about six hundred Digesics™. Every four hours I was having two. And then when it started not to give me so much trouble I cut it down to one every four hours. But I just lived on Digesic™. I would wake in the middle of the night, just about screaming with pain - well into the Digesics™ I went. And they take a while to take.

(Edna, Int 1: p4)

However, study participants were generally reluctant to take pain relief. This was partly because of the sedating effect, which may be welcomed at night, but was a nuisance during the day. There may also be a reluctance to take medication of any type:

I don't believe in it. If I can't sleep at night I won't take a pill to put me to sleep. I think probably the strongest thing I've ever taken is Aspro™, and that's years ago, and even my wife has a hard time now getting me to take my antibiotics, because I just ... it's just a thing I've got about it.

(Jim, Int 2: p20)

Analgesics were more commonly taken at night, when pain disrupted sleep. Distraction was often also needed then to cope with the pain until the analgesics started to work, and involved activities such as getting up to write some letters, or listening to the radio.

Study participants frequently had difficulty in articulating the pain they experienced. The nature, frequency, and intensity of the pain varied considerably for individuals over time, and participants were reluctant to dwell on this topic. Pain becomes something to get used to, something to learn to live with.

Something else to get used to are **wound infections**, which are common, despite strict attention to aseptic dressing techniques on the part of the nurses, and the care taken by the participants. Particular care is taken to keep the home clean, like vacuuming the room before dressings are changed. Animals are seen as a potential source of infection, and even much-loved pets may be barred from entering the home. Other family members are encouraged not to bring their pets when they visit:

We were told that as long as you have got an animal living in the house it would take longer to heal. ... When our son's dog was here on the section I kept getting ulcers more frequently over that time.

(Don, Int 1: p7)

Wound infections usually mean an increase in pain, and a delay in wound healing. One of the greatest drawbacks with a wound infection is the need for antibiotic therapy. Side effects from antibiotics, such as nausea and vomiting, are not infrequent:

And I started taking those (antibiotics) and I felt terribly sick - I felt the veins right across my stomach, and sick. ... But I felt that miserable, I didn't care what they did - I felt I wanted to die. ... Anyway, after that happened they gave me a white tablet, a little white tablet [anti-emetic], and I had to take that a half an hour before I took the antibiotic capsule, and then an hour after I took that I could have my meals. It was a bit of a nark, because I had to have the alarm clock for half-past seven to take my tablet so I could have my breakfast by nine.

(Hugh, Int 1: p3)

Antibiotics may be prescribed on a frequent basis, with one study participant being prescribed eighteen different courses of antibiotics over a two year period.

For another participant in this study, a severe reaction to antibiotics prescribed for him in the past has resulted in major health problems that makes living on his own very difficult. Fearful of further antibiotics exacerbating his condition to the point where he will require rest home admission, he is nevertheless regularly faced with the necessity for another course of antibiotics because of recurrent ulcer infections.

Wounds oozing out onto bandages, clothing, and even bedlinen was also a problem that had been experienced by all study participants at some time:

It looks so dirty, filthy when they [bandages] are looking all brown, and they get darker and darker. ... Well, it's not nice to look at really. Well, if someone's coming to take me out for a ride, I don't like to go out looking grubby, and I mean, it's not just a little mark, sometimes it's right round my leg.

(Connie, Int 1: p4)

Leaking wounds not only looked unsightly, but mean having to deal with the laundering of filthy, soiled bandages:

[The bandage] gets pretty messy. So I soak it for a while, and then I've got to stand at the tub and scrub it with a scrubbing brush to get it off - it's pretty painful then - so I just have to stand on one leg.

(Edna, Int 1: p4)

For those no longer able to do their own laundry, it may mean the shame of having to let others deal with this them:

I can't handle the sheets myself. ... And it is embarrassing, but fortunately I have a very understanding lady [home help].

(Connie, Int 2: p27)

Extensive precautions must be taken to protect the surrounding environment from being soiled. Wounds are frequently redressed just before retiring at night, or extra padding applied. But despite this, wounds leaking out onto bedlinen is still a great concern:

Well, it was getting on the bedclothes. I had dressings on, and even now, when I take the stocking off at night - I'll put a sock over it - that dressing, but it was coming through, and it was on to the bed, and on to the sheet, so I put plastic bags on, which wasn't very pleasant because they sweated.

(Jim, Int 2: p22)

Some participants reported that they had been "given permission" by the district nurses to completely redress the wounds when necessary, but others were only able to at best "mop up" the exudate by the application of extra layers of padding.

The location of the ulcer also determines whether dressings can be changed independently, especially as *feet get further away as you get older* (Connie, Int 2: p29). Having to look at the wound when changing dressings isn't always easy:

Yeah, it looked all yucky and horrible. I've got a touchy stomach at the best of times, with blood or anything, and I just about used to throw up.

(Edna, Int 2: p23)

Going away from home when wounds were leaking copiously is at the very least fraught with tension, and at worst even impossible. Not only do used dressings need to be disposed of, and soiled bandages laundered, but there is the ever-present fear that wounds will leak out onto somebody else's sheets. When wounds leak copiously, there is concern that this ooze could damage the surrounding skin, and may further harm the ulcer itself:

And I think, that oozy mess can't be good left on your leg, and it begins to smell.

(Connie, Int 1: p3)

Having a body that smells is difficult to ignore because of physical proximity to the wound. Particularly at times of wound infections, or copious wound exudate, the fear of offending others is very real, and compounds the unpleasantness for participants of being able to smell their own wounds:

Oh, I think, yeah, the worst part would be just occasionally when you get the smell, and you can't get home and you can't change, and...(voice trails off). I suppose people think you have got b.o. [body odour] or something. ...//.. You know, if it's starting to smell you have got that when you go to bed at night too, and then my wife has to put up with it too.

(Jim, Int 2: p25)

For Gary, the months prior to the amputation of his leg were filled with a constant awareness of the wound odour, and the impact it had on others:

The pain was getting awful. And it wasn't only that - it was an embarrassment. No matter where I went to, people - you could see them moving away - because of the smell. Now I know what the human body smells like when it is deteriorating.

(Gary, Int 1: p3)

Gary described the wound odour as *a putrid, sickly smell, a smell you could taste in your mouth* (Int 2: p27). He became so self-conscious about the smell that he would wait outside in the hospital corridor at clinic appointments rather than risk offending others in the waiting room.

Wound odour is minimised when occlusive dressing products are used, because the exudate is contained. When that dressing is removed, or the exudate leaks out, the odour suddenly becomes evident. Jim describes what happened to him the first time hydrocolloid dressings were used on his leg:

I lifted up the bedclothes and there was this mess all over the bedclothes. So anyway, he [specialist] came up and took it off. I said "hell, I think I'm dead". The smell was whoof!

(Jim, Int 1: p10)

Dressing can be an unpleasant experience when occlusive dressings are being used because of that sudden awareness of the wound smelling. And there is always the worry that wounds will leak out before the next scheduled dressing change, with others becoming aware of the smell.

THE IMPACT OF TREATMENT REGIMES

Having a bath or shower when leg ulcers are present can become a major drama. There are now a number of waterproof dressing products available, but the majority of the study participants had dressings on that needed to be kept dry. Elaborate precautions are needed to achieve this when showering:

I just put a plastic bag over the whole thing, tie it round my knee. I put a piece of sheeting right round there (indicates calf) to make sure I don't get it wet, and then I put a pair of the legs of the pantyhose, and I pull that up, and leave the tape sticking up above it, and then I tie the elastic with the bag. I've got to put my foot up on either a bucket or stool. ... I pull the shower curtains down. I've got pegs in them, so that they can peg together, and the shower curtain sits on top of my legs, up above the plastic bags.

(Connie, Int 1: pp8-9)

It takes Connie a long time to have a shower. She prefers to have one in the morning, but because she is worried about the possibility of holding the nurses up if she is not finished, she now has her shower at night.

For people without leg ulcers, keeping clean is usually a routine and taken-for-granted task. When ulcers are present, and need to be kept dry, having a bath or shower requires planning and care. Despite decades of having to protect his wounds when showering or bathing, Jim still found the restrictions difficult to get used to:

You get really fed up with it. With all these dressings that I've got on I've got to put a plastic bag on, and you get really fed up with that.

(Jim, Int 1: p11)

Archie has a waterproof dressing on his wound, and doesn't need to protect the area when showering. But he is still limited to showering only on the two days a week that the district nurses visit, because he can't reapply the bandage himself. A daily shower or bath had been his lifetime practice, and the restriction to twice a week was keenly felt.

Edna had her shower with her leg encased in a plastic bag, and washed her foot separately later:

But I'd love to be able to put it [foot] under the shower, and say, "here shower - wash it". It feels as though, no matter how many times I've sponged it, it never feels clean. Because I get very embarrassed about foot odours.

(Edna, Int 1: p6)

Only one participant mentioned the district nurses washing the leg when changing the dressings. It was never a routine part of the dressing changes and, as some nurses would never offer to wash the leg, weeks could go by without it being done.

The combination of summer heat and toe-to-knee bandages or compression stockings is not always a happy one, particularly when the opportunity for showering is also limited. **Bandages** present difficulties in a number of ways.

The physical discomfort that accompanies the bandages makes compliance a problem:

Having the bandage on, on hot days, that's not comfortable. 'I think one has to keep it on to assist the healing process, but then again, some days I take it off - it becomes unbearable. You feel as though you want to be like a kid with a broken arm - get the steel, and rub it up underneath the bandage.

(Archie, Int 2: p20)

Study participants appeared to have a good understanding of the importance of bandages in wound management. Appreciating why bandages were necessary meant Edna was particularly conscientious about following advice from her general practitioner:

I'm alright when I'm lying on the bed, but as soon as I go to get up I have to put the bandage on. Because they said, everytime I go to walk, that's when you do the damage. So when I get up in the middle of the night to go to the toilet I have to put the bandage on, and when I go to get back into bed off comes the bandage again and I have to sit there and roll it all up into a roll so it's easy to put on the first thing in the morning.

(Edna, Int 1: p5)

Bandages may need to be changed daily, particularly when wounds are leaking through the dressings. The supply of bandages by the district nurses was a matter of concern for some participants:

These bandages here are very old ones, from when I had ulcers before. And they were absolutely sending me crazy [because they had lost their stretch, and slip down the leg after they have been applied]. I've used these I suppose a couple of years. But I find these days they don't renew your bandages like they used to.

(Connie, Int 1: p3)

When only a limited number of bandages are supplied, problems are sometimes experienced in laundering soiled bandages in time for when they are next needed. Although she wears two bandages at a time, Edna was supplied with only four bandages in total:

I change them [bandages] every day. I leave them to soak in lukewarm water with soapsuds in it, and then I wash them. This weather is fine, because you can get them dry fairly quick, but in winter I don't know what it is going to be like.

(Edna, Int 2: p22)

Having layers of bandages around the foot and lower leg may mean shoes no longer fit, or get stretched out of shape. Slippers may be the only footwear that fits, even in the summer heat. The bandages are also considered unsightly, and likely to attract the unwanted attention of others.

Compression stockings are now replacing bandages for venous leg ulcers, and result in fewer difficulties with footwear. But these stockings are not always easy to manage:

I haven't tried them on yet. No, they are still in the box. ... I'm waiting for the hot weather to go. I've been told they are very tight to pull on and off. ... My friend - they gave him some to put on, and oh gosh, poor soul - I would go up there and he would only have it on one part of his foot, and I would have to pull it up the rest of the way.

(Freda, Int 2: p18)

Bandaging the limb, and **resting** were two of the mainstays of ulcer treatment for participants in this study. All had been advised to rest, but sometimes little information was given on how this was to be achieved, or what period of time should be aimed for:

(What specific advice have you been given about resting?)

Oh, just 'rest it up'. I've read a few books I can tell you. But ... yes, just rest it up.

(Archie, Int 2: p24)

Other participants had been given more detailed instructions of how the limb was to be elevated:

[the nurse] ... told me to rest - she wrote me out a list of what I had to do. She said "you've got to rest twice a day, with your leg up, and your ankle has to be up level with your heart".

(Don, Int 1: p13)

The advice to 'rest' posed many difficulties. Life must go on, and household responsibilities continue:

It's alright for some people, because they might have someone live in the house who can do for them, and they can rest their legs - they can have their meals cooked for them and everything - but I have to do it myself, my own washing and everything.

(Hugh, Int 1: p6)

When a participant was the main breadwinner for the family, the need to continue in paid employment meant that rest was almost an impossibility:

When I first got it [the ulcer] they said that's the only way you are going to heal it - get your feet off the floor. But I was a manual worker and I couldn't do much about that (sighs deeply).

(Jim, Int 1: p5)

When a choice is necessary between living for today, or making changes that will pay off at some future time, it can be difficult to decide which should be paramount:

I think that's the downfall because whatever else we do we make it top priority instead of looking at ourselves and the damage that we are doing to ourselves. Everything else is top priority - I mean to say you put [sic] before everything else - even your leg. But you can only sit for a short time and then you are away again.

(Gary, Int 1: p8)

Even when priorities are adjusted so that resting is possible, the enforced inactivity may provide an unwelcome opportunity to reflect on the things that need doing:

I get very frustrated. I think, while I'm lying here, I could be doing this, I could be doing that. ... But I just get so wild. I think, all this nice weather, and I've got to be lying down and I can't get out and do anything.

(Edna, Int 2: p19).

Allen (1984) details the perils of prolonged bedrest for the elderly, including pressure sores, constipation, loss of morale, and demineralisation of bones. I interviewed Hugh two days after his arrival home following more than six weeks in hospital undergoing skin grafting to his ulcers. Hugh had been effectively on bedrest for that entire time:

I suppose for the past fortnight I was allowed to go to the toilet, but I had to keep my feet up. The only day I was up I just sat in a chair, the day before I came home, but they made sure I kept my feet up even then.

(Hugh, Int 2: p22)

Hugh was already in poor health before he went into hospital, and his fitness levels would have reduced even further during this extended period of bedrest. He lives alone, and when he was discharged from hospital (just before a weekend, when no support services, such as home help were available) he was totally exhausted after just making himself a cup of tea.

When leg ulcers are a chronic condition, accepting advice to keep the leg elevated could mean a drastic restriction to lifestyle. Most study participants appear to have reached a compromise - with normal activities being undertaken as much as the pain of the leg will allow, but also making a conscious effort to fit in a specific rest period sometime during the day.

SUMMARY AND REVIEW

This chapter has begun the process of elaborating the lifeworlds of these study participants with an examination of the lived body in this illness experience. **The body out of control** is evidenced by the physical suffering that accompanies chronic leg ulcers, while **embodiment is altered by treatment regimes** that disrupt normal ways of being-in-the world. The presence of chronic wounds has been demonstrated to impact not only on the individual, but on the way they are able to experience their world.

Having chronic wounds means being trapped in a body that is now imperfect. A part of the body has broken down, and stubbornly refuses to be repaired. In fact, the body may behave badly, and be a source of social embarrassment by smelling and leaking out in a relatively uncontrollable manner. The uncertainty of how the body will behave makes some social interaction difficult, and restricts the ability to plan ahead because of the unpredictability of what the body will be doing at that time.

Some aspects of the disease process itself are particularly unpleasant and difficult to adjust to, like the pain, or the vulnerability to wound infections. Pain may also limit social activities, limitations compounded by the instructions to 'rest the leg'. While a combination of distraction and medication may limit the impact of the pain to some extent, wound infections are ignored at one's peril. There is little choice but to take the antibiotics prescribed, even when they will create further problems for the body.

Treatment methods may also create additional distress to the body, such as the discomfort of bandages, and the difficulties inherent in keeping the body clean.

Having chronic wounds limits some of the social interactions that one may normally enjoy, but also opens up new social contacts because of the need for wounds to be treated. Chronic wounds may also impact on relationships with family. The impact of chronic leg ulcers on relationships is the focus of Chapter Five.

CHAPTER FIVE

THE IMPACT OF THE BODY ON RELATIONSHIPS WITH OTHERS

In this chapter, the breakdown of the body, as evidenced by the presence of chronic wounds, is examined from the perspective of a further existential theme - **lived other**. Van Manen (1990) describes lived other as "the lived relation we maintain with others in the interpersonal space that we share with them" (p. 104).

When there are problems with the body breaking down, such as the development of leg ulcers, **new relationships are formed**, and **existing relationships change**. The assistance of health professionals is required to help treat the wounds. Relationships with health professionals are complex, and to some extent necessitate the 'handing over' of control to others who are perceived as (or hoped to be) experts. Care must be taken not to offend those experts, and lifestyles are altered as far as possible to accommodate the rules the experts set.

Family members can be a source of comfort and support, but the patient may also feel that they need to be protected from the more unpleasant and distressing aspects of the wounds. Families share in the financial expense the ulcers can incur, and family social activities may be curtailed because of the chronic nature of the wounds.

RELATIONSHIPS WITH THE DISTRICT NURSES

Literature indicates the majority of leg ulcer patients overseas are managed in the community (Callam, Ruckley, Harper & Dale, 1985). Fundamental to this management in New Zealand is the input of the district nursing service, with

nurses visiting on a regular, sometimes daily basis, for what may be lengthy periods of time. Nurses were described by study participants as *struggling for years* to heal the ulcers, and were seen to be working with the client, general practitioners and other nurses to achieve the best possible wound management.

Wound healing is perceived by participants to be largely out of their control. It is the treatments applied by health professionals to the wound that generates results. It was not uncommon to hear specific nurses being credited with healing a particular wound. It is therefore very important that 'their nurse' has the expertise to heal wounds, and that confidence is reinforced when other health professionals acknowledge that expertise too:

she [district nurse] is the only one I've been able to understand, and she seems to know what she is talking about, and when I mentioned to the doctor that I had her, he said "oh, she's good".

(Edna, Int 2: p21)

While all the nurses were considered by the participants to have considerable experience and expertise in wound management, one nurse who specialised in wound care was singled out as being someone who knew *everything there was to know* about the management of ulcers. This nurse was seen as being not only genuinely interested in healing the wounds, but also concerned for the general wellbeing of her clients, and they felt confident they were receiving the best possible treatment available. This nurse always seemed to have *something else up her sleeve* to try when wounds failed to progress, and to provide hope that wounds would eventually heal.

The perception of the nurses as experts resulted in the reluctance of participants to express their own ideas about possible wound treatment, such as increasing the frequency of dressing changes, or the use of alternative treatments. While the nurses were seen as approachable, and open to new ideas, there was a sense amongst the participants of not wanting to tell the experts their job:

Well, I think - they know what they are doing and they are trained for that sort of thing, and here you are, just an ordinary person, trying to tell them how to treat a thing.

(Edna, Int 2: p25)

Being perceived as experts also carries with it significant responsibility, as demonstrated in the district nurses' involvement in Gary's decision to proceed with amputation:

Because I really love the district nurses. ... And they said, well if it was mine I would have it cut off ... If you are asking them, and they are telling you that - there's pretty much nothing they don't know about sickness.

(Gary, Int 2: p28)

Frequent contact over a lengthy period of time sometimes results in strong friendships being established, particularly when the nurses extend their concern to other family members, acknowledging the impact the ulcers have had on them as well.

While developing a close personal relationship with a particular nurse is valued, there can be problems when it is necessary for the client to be 'handed-over' to another district nursing team. As well as coping with the loss of that personal relationship, the new nurse(s) may not be perceived as having similar competence:

And I have a new crowd. And one of them came yesterday for the first time and she dressed it all the way round - where you are not supposed to, and taped it all the way round. ... [the previous nurse] was good. She just sort of daubs it, washes it, daubs it lightly, but the one yesterday - she was scratch, scratch, scrape like that, and it was quite sore when she had finished.

(Name withheld)

Not only may the dressing itself be done in a different way, but the nurse may not appear as focused on healing the wound:

But there is just that, oh, (sighs) how would you put it - yeah, uncertainty with others nurses who come in, and I'm talking about their feelings - they are just not, um... they are just not switched on.

(Jim, Int 2: p18)

It was not unusual for nurses to have different ideas about how the wounds should be managed:

Well, the nurses are all very good, but they all have their own ideas of what they should use, there is [sic] no two nurses that are the same. Even to the way they put bandages on.

(Connie, Int 1: p12)

Change is not always unwelcome. Several participants expressed the belief that regular changes to the type of dressing product being used was a good thing:

I think, my own feeling over the dressings, any one of them does a certain amount of good for a certain amount of time, but the ulcer then becomes resistant to that particular dressing, so okay, try another one and away things go.

(Betty, Int 1: p4)

Two of the study participants had managed their own ulcers for a number of years before being referred to the district nursing service, and were enthusiastic about the benefits of the district nurses' involvement, such as being made aware of new wound care products:

(Is it an advantage having the district nurse come?)

Yes, I think so, because I think sometimes if you are doing it yourself you tend to be a bit slap-happy - you don't do it properly.

I think this is good.

(Jim, Int 2: p23)

Participants were generally very positive about the services provided by the district nurses, and for the personal qualities of the nurses themselves:

Well, they've all been good. I mean, I can't say anything about any of them - they have all been marvellous.

(Freda, Int 2: p18)

However, not all the interactions with the district nurses were positive. Two study participants saw personality clashes as being almost inevitable. Comments were also made by some about their lack of choice over which district nurse they had, with one person talking about *dreading one or two particular nurses turning up*.

Nurses were felt to be sympathetic to the difficulties inherent in resting legs, but occasionally the nurses ignored the wishes of the client in relation to some aspects of wound management, such as continuing to apply a bandage that was uncomfortable, or taking a wound swab without consulting the study participant even when his refusal to take further antibiotics was well-documented.

Participants were conscious of the workload of the district nurses, and were anxious not to keep them waiting. The nurses normally adhered to reasonably regular and predictable visiting times, and made every attempt to reschedule visits to fit in with the social activities of clients. Only one participant had problems with irregular visiting times:

It would be easier, if they came more at the same time, but they don't. I suppose they can't help it. They have got other patients - I'm not the only one.

(Hugh, Int 1: p10)

RELATIONSHIPS WITH OTHER HEALTH PROFESSIONALS

Although many individuals are able to tend their own wounds, health professionals become involved when expert advice and the supply of large quantities of dressing products are required. While the majority of leg ulcer management is carried out by the district nurses, general practitioners, practice nurses and hospital specialists are also involved.

There were differing opinions among the study participants about the knowledge and expertise of general practitioners, with several commenting unfavourably on their dealings with their own general practitioner:

[the district nurses] they take an interest in it - quite honest [sic] not like the doctor. He just glances at it and says "that's it", but they take an interest.

(Archie, Int 2: p25)

Several participants had been told by their general practitioners that the district nurses had more expertise than they did in relation to leg ulcers, and all but one participant believed that district nurses had considerable influence in deciding how the wound was to be managed. General practitioners appeared to have little involvement in the day-to-day management of the wounds. Only Edna saw her doctor on a regular (fortnightly) basis, and seeing him so frequently was not always helpful:

And he says, "Oh, I don't know what we are going to put on that", and "I don't know what we are going to do with this" - and then she [practice nurse] is reading a chart on the wall what dressing to put on.

(Edna, Int 2: p21).

However, this doctor was sympathetic to the emotional distress Edna was experiencing, and made every effort to assist with the financial and emotional impact of the wounds.

When a hospital specialist was involved, general practitioners were reputed to be happy to leave all decisions to them. The authority of the specialist was respected by all the participants. Even although the specialist may prescribe unpopular remedies (such as skin-grafting), in the end there was no option but to comply as far as possible with instructions:

You do go along with it in the hope that he's got enough brains to know what he is doing. He should know what he is doing, and therefore you trust him.

(Betty, Int 2: p18)

There is a tacit understanding of the need to comply with suggested treatment regimes. An inability to comply with those regimes gives rise to a sense of guilt, but also the potential disapproval of those who set the rules:

It's very easy just to see the ulcer and make a judgement, because there is a lot involved with it - not only physical but spiritual also. It's almost impossible to rest.

(Gary, Int 2: p32)

There is an unequal balance of power between the parties. Accepting the professionals as experts means there is an obligation to try to comply with the recommended treatments even though individuals may have accumulated

considerable knowledge and expertise about their wounds over the years. When health professionals are involved, individuals may effectively surrender control of the wound:

[the bandages] *slip and slide, and of course I'm not allowed to take them off or do anything. ... I'm not allowed to take the underneath one off.*

(Can you change your own dressings if you need to?)

They won't let me do that. They used to at one time, but not now.

(Name withheld)

Surrendering control means having to accept, or work within, the rules set by the health professionals. Sometimes a certain tension exists, when rules are acknowledged, but the body-aware-of-itself is making other demands:

Nobody knows my body like I do. If my body wants a good wash, a good shower - it gets it. I'll do everything in my power so that I can do that. No other person can tell me what I should do - because I feel like it, I want it, I'll have it.

(Archie, Int 1: p14)

A balancing act is required - acknowledging the requirements dictated by the body, but taking care not to antagonise health professionals. At times, participants may wonder if dressings should be changed more often, but are reluctant to suggest this - partly because of their awareness of how busy the nurses are, but also because the 'experts' should know what is best.

Health professionals, including the district nurses, were at times guilty of concentrating on wound management without acknowledging the participant as an individual:

You see, I'm lying on the bed, and I'm facing this way (indicates lying on side) - they are down at my legs, talking among themselves. I feel if there is anything to be said - say it to me.

(Betty, Int 2: p20)

One disadvantage when there are various health professionals involved is the potential for conflict to arise over wound management, with the client in the middle - struggling with divided loyalties, and wondering whose advice to follow:

[the nurse] this morning told me I'm better if I get up and do a bit of exercise, and yet the doctor told me to lie down all day with my legs elevated higher than my heart. And yet here is one this morning telling me I'm better if I get up and do a bit of walking.

(So how does that make you feel?)

As though I don't know which way to turn! I'm trying to please everybody and I don't seem to be getting anywhere!

(Edna, Int 2: p21).

FAMILY RELATIONSHIPS

The disruptions caused by leg ulcers extend to the wider family, particularly when they are living in the same house as the person with the ulcers. Family dynamics can be altered by the need to reluctantly surrender some independence and accept the assistance of a spouse in carrying out household tasks. Spouses may also be involved in the laundering of soiled linen and bandages, and may at times even have to assist with dressing changes.

Family members share the joy when an ulcer heals, and the disappointment when new ulcers develop. When the pain from his ulcers forces Don up at night, his wife's sleep is also disturbed:

Sometimes I would think I had better go back to bed because I knew she would be awake, worried if she heard a bang that I had hurt the leg.

(Don, Int 2: p36)

Gary, a single parent, found the pain he was experiencing made it almost impossible for him to cope effectively with his family responsibilities:

I messed up my life a bit with my children because I couldn't cope with the pain as well as cope with them because they were all teenagers.

(Gary, Int 1: p1)

Sleeping arrangements may need to be altered, with single beds protecting the spouse from close proximity to wound odour, exudate and potential infection, while at the same time protecting the wound from being accidentally kicked or knocked by the partner.

Ulcers may restrict the social activities previously enjoyed by the family because of the potential for accidental injury to the wound, or the pain experienced from activities such as dancing or walking. Don could never take his young family to the beach because of the concern about sand getting in his wound. Holidays are difficult when there are dressing changes required; used dressings to be disposed of; a fear of wounds leaking out; and a reluctance to draw attention to the presence of the ulcers. While staying with other family members or very close friends may be manageable, staying with casual acquaintances can be difficult:

And I just go and lock myself in the bedroom and go and do it [change the dressings], but a couple of times I've had to just leave the dressing on for two or three days until I get back home. Just 'cos you couldn't say to people "look I would like to go and do this".

(Jim, Int 1: p12)

Both participants and family members worked to protect each other from potential hazards or further damage. Don was particularly concerned about the possibility of cross infection when near his young grandchildren with open skin lesions from eczema. Some study participants also chose to protect family members from the potentially distressing sight of the wound, or to deliberately withhold from their family information about the ulcers:

Why worry them about it? They have got enough of their own worries, with family, and one thing and another. Why should old Nana put that on to them?

(Freda, Int 2: p21)

Family members were vigilant for potential hazards and anxious to prevent further damage:

She (eldest daughter) still says to the children, when they are running around near me, watch out for Poppa's legs . . .//.. I had a walking stick, I've always sort of put it down beside my leg - if anyone of them are going to rush around the walking stick is always there to protect it.

(Don, Int 2: p30)

OTHER RELATIONSHIPS

Having leg ulcers was in some ways like belonging to a secret society, whose membership is signalled by the presence of bandages. Participants seemed particularly alert in noticing others with their legs bandaged:

I've always felt sorry for people who have them on their leg. You see a woman with a bandage on her leg, and the first thing you think of is, oh, you must have an ulcer.

(Don, Int 2: p39)

Edna was embarrassed to go out in public with bandages on her legs:

Yes, I feel ... as though people are looking at me. ... Strangers have never said anything, but I always feel as if people are looking at the big thick bandages on it.

(Edna, Int 1: pp5-6)

Edna attended an important social event having to wear a slipper on one foot because she didn't have a shoe that would accommodate the bandages. She also had to use a walking stick, and her self-consciousness about the attention these created made the outing a misery.

Concealing the ulcers was easier when they were near or on the foot area, and the male participants had the advantage of being able to hide the ulcers by wearing socks and long trousers. Only one of the men was prepared to wear shorts in public during the summer, and admitted that initially he had worried about people being able to see his bandages. When others know about the ulcers, it can sometimes feel that the ulcer becomes the focus of attention:

Yes, a friend of mine walked in and said "hello, how's your leg?" (laughs). And I think, oh good - how is yours?

(Don, Int 3: p44)

Don worked for some years in the food industry, and was reluctant to let his workmates know about his ulcer:

They were very strict on personal hygiene, and having an ulcer on the leg I was, oh, conscious with it. I would wash my hands about ten times a day . . .//.. And I wouldn't like anyone working in the factory to think, oh yes, he's got an ulcer.

(Do you see the ulcer as something dirty?)

Oh yes, yes !

(Don, Int 3: p45)

Both Don and Jim worked for several decades with ulcers, trying to fit in visits to the doctor and dressing changes around work obligations, with Don actually losing one job because of the extensive sick leave necessitated by a particularly troublesome ulcer. Leg ulcers restrict employment options, such as the need to avoid jobs where standing is involved. Frequent or prolonged absences make job security a real concern :

Well, the irritation seems to heal and then it seems to break out again - and it's another month off. I'm frightened every time the phone rings that the boss is going to say that I've got no job. And where can I find another job at my age?

(Edna, Int 1: p6)

There can be considerable financial expense associated with having leg ulcers, such as the costs involved in obtaining antibiotics - paying both the doctor to write the prescription, and then the pharmacy charges. When participants had been tending their own ulcers prior to the involvement of the district nurses, dressing supplies and bandages also had to be purchased. Being off work for a lengthy period because of the ulcers proved financially disastrous for Don and his family many years ago, and is still remembered vividly even now by his partner:

That was when we really got into debt, into trouble, and it was only that his cousin stood as guarantor for us that we were able to borrow some money from the bank . . .//.. We still had the rent to pay, and with a new baby - oh...

(Don's wife, Int 1: p12)

REVIEW AND SUMMARY

This chapter has described the development of **complex relationships with health professionals** that are necessary when leg ulcers require treatment, and detailed how **relationships with family and others are altered** because of the ulcers.

The presence of chronic leg ulcers means that assistance is usually required with wound management. All participants in this study were receiving the majority of their wound care from the district nursing service, with some other health professionals involved to a lesser extent.

The relationship with the district nurses can be multifaceted. There is **gratitude** for their expert assistance, and their continued interest in the wound. When nurses (and the other health professionals) are perceived as **experts**, there is then little choice but to comply with the treatments they prescribe, no matter how unpalatable or inconvenient those treatments might be. **Accepting** the help of health professionals means 'playing by the rules' and having to surrender some control.

The chronic nature of the wounds, with treatment sometimes stretching over years, can mean the development of strong personal relationships with individual nurses, or a reliance on a nurse who is perceived as having particular expertise. These relationships can help make a difficult situation bearable, but do leave the client vulnerable should that nurse leave.

General practitioners were not always perceived by study participants as being especially interested in, or knowledgeable about, the wounds. As the number of health professionals involved increases so does the possibility of receiving differing advice - posing the dilemma for the client of how to keep **all** the health professionals happy.

Wounds endured over years impact on other family members. Some study participants were reluctant to involve their family in the care of these wounds, and went to some lengths to **protect them from having to be involved**. For other families, ulcers have been a significant part of all their lives, with family members displaying **vigilance, concern and support**. Families share in the restrictions to social activities that are needed to protect the body, and in particular the wound, from further injury.

The need to increase personal space to protect the body (spatiality) will be examined in the next chapter, together with the fourth lifeworld theme of temporality (lived time).

CHAPTER SIX

THE BODY IN TIME AND SPACE

The previous two chapters have outlined the ways in which having a body that is not functioning correctly impacts on the way in which that body is experienced, and on relationships with others. This chapter will continue the description of the leg ulcer experience by examining the final two existential lifeworlds of **temporality** and **spatiality**.

Benner and Wrubel (1989) contrast the Western notion of time as "a linear succession of moments" (p. 64) with the existential concept of temporality, which they define as "the way the person simultaneously lives in the present, is influenced by the past, and is projected in the future" (pp. 412-413). The **experience of ulcers in the past helps shape the way current ulcers are experienced**, and offers both hope and fear for the future.

The chronic nature of the leg ulcer experience can mean that even in the absence of current ulcers the potential for their development in the future is such that **ulcers are effectively always present**. At the same time, interpretations of chronological age are distorted by the physical impact of the ulcers, and a consciousness develops of the ageing process being a factor in delayed healing.

The concept of **lived space** (spatiality) will be demonstrated in a discussion of the way in which leg ulcers increase the need for personal space. Existing wounds have to be protected from further damage; the body must be positioned carefully to minimise pain; and care taken to guard against the possibility of an accidental injury causing new ulcers.

Alterations to lived space occur with the loss of privacy that results from having health professionals coming into the home on a regular basis. **Home can be a haven of safety in a world** where potential injuries abound. But it can also **feel like a prison** when waiting for a nurse who has been delayed; when holidays are out of the question because of the rigmarole associated with dressing changes; or when extended periods of rest are required because of the condition of the ulcer.

THE PAST, PRESENT AND FUTURE

As demonstrated by the literature, leg ulcers are a chronic condition, with more than 50% of participants in a Swedish study having ulcers for a duration of more than twelve months (Nelzen et al., 1994). Two of the participants in this study have lived with leg ulcers for the majority of the past four decades, and another three participants have had their lives disrupted by leg ulcers for more than five years.

Although chronic in duration, the wounds themselves are dynamic in nature, with constant cycles of deterioration, new ulcers forming, and wounds healing. Improvements may be slow and difficult to discern but regular measuring of wounds by the nurses gives some indication of progress. However, deterioration in wounds is usually much more dramatic - sometimes seeming to occur virtually overnight.

Particularly when new treatments are being used, there is a certain tension when dressings are changed - wondering what will be revealed this time, for **the body can no longer be trusted to behave:**

Well, it had dried up good. ... [district nurse tries new dressing product overnight]. Well, the next day she came, and it had all broken out again, all flamed up, sore and red.

(Edna, Int 2: p15)

Setbacks and disappointments are commonplace. In particular, skin-grafting raises hopes of a reasonably quick end to the ulcers - hopes that had been dashed for several of the participants in the past when grafts had failed to take.

Hugh spent six weeks in hospital, and during this period his ulcers were grafted twice. He was interviewed two days after returning home, and was asked how confident he felt that those second grafts would be successful.:

These ulcers are up and down (sighs heavily). I mean, they look as if they are coming right and then they take a turn for the worse. As I say, when I came home the girl [district nurse] just touched it, and it oozed, and it hadn't oozed for days. ... But I think by this time they should have [taken] - that worries me a little bit.

(Hugh, Int 2: pp28-29)

For those study participants who were already elderly, leg ulcers had the effect of **emphasizing physical deterioration**, described by Archie as *old age creeping up on me, from the legs up* (Int 1: p19). Physical fitness is harder to maintain as one ages, a situation that is not helped by the advice to rest for lengthy periods. When physical frailty means a daily battle to retain independence and continue living at home, there is a wariness of doing anything that might jeopardise that independence.

There was also an awareness that physical healing was likely to be slower as one aged:

And the one thing that I've got to take into consideration is that my body is deteriorating. ... It doesn't matter what I do, or anyone else does - it will. It's just a fact of life.

(Archie, Int 1: p17)

The older participants felt it had been easier to cope with the ulcers when they were younger, as life was usually busier, and there weren't the same opportunities to dwell on one's fate. On the other hand, when ulcers are present at a younger age, the physical impact of chronic wounds can alter perceptions of the ageing process on the body, and force a reappraisal of what the future may hold.

Edna had not yet reached retirement age, and had always been physically active. The presence of leg ulcers had led her to re-evaluate what she thought her life would be like when she was older:

I feel as though all my parts are starting to break down. ... But I always imagined myself as still being quite energetic at about 100. ... I keep thinking I'll have to buy one of those motorised things that old people get round on, because that's how I feel - as though I've finished my life.

(Edna, Int 1: p10)

When there have been leg ulcers in the past, comfort is obtained from the fact that previous ulcers eventually healed. But unpleasant experiences can also be recalled, and used to interpret current situations, such as the suspicion, or even dread, that the current delay in wound healing may indicate the presence of an infection:

Because I don't want an infection in them [donor sites on thighs] again - you can't bear to have them bathed, you can't bear to have dressings on. ... It's dreadful, really dreadful, very painful.

(Connie, Int 2: p28)

When procedures had previously been undergone that were either painful and/or unsuccessful, such as skin-grafting or venograms, there was apprehension that they would need to be repeated in the future. Conversely, a positive outcome in the past, either experienced personally or by someone else known to the participant, meant that proposed treatments might be regarded favourably:

(How do you feel about the idea of a skin- graft?)

Oh, I don't mind. If it goes the same way as [mentions name] went, it would be alright. I'd rather have that, because there's only just a weeny bit of pain for the time being, instead of probably going on day after day like they are now.

(Hugh, Int 1: p11)

Skin-grafts were regarded with caution by some participants however, because of the concern about creating another wound [donor site] that then itself may not heal. Freda was also concerned about the actual grafting process itself, being put off by *the idea of the skin coming off my body - however they do it* (Int 2: p22).

Past events and lifestyles are re-examined in order to try to find some explanation for the ulcers developing. In general, the causes were felt to be due to factors beyond their control, such as diabetes or accidental injury. Several current ulcers were believed to be caused by skin being damaged by the removal of adhesive tape from other dressings. Sometimes no explanation was obvious:

I have asked the Lord upstairs - what have I done to deserve this?

...//.. It surprises me, where do I get it from?

(Freda, Int 1: p4)

With first ulcers, the inability to predict what will happen means little or no progress is particularly difficult to deal with because of the uncertainty about whether the wound will ever heal, and the concern about why it won't heal:

Well, the doctor said he had a woman in with exactly the same thing that I had, and yet hers was cleared up in a month. Why was mine still going six months later? What did she do that I haven't done to get hers cleared up so quick? (laughs bitterly). I wish I had been given her phone number so I could ring her and ask her what she did to get hers cleared up.

(Edna, Int 2: p26)

Comparable levels of frustration were not evident in participants with long histories of leg ulcers, for whom ulcers had become a part of life. They frequently found it difficult to recall the duration of the past ulcers, and even details of the current ulcers were sometimes hazy. While ulcers may be acknowledged as a fact of life, they can still cause a certain sense of injustice:

As you age you have enough to put up with, without ulcers and things like that.

(Connie, Int 1: p12)

Developing a degree of acceptance about the ulcers doesn't mean that hope of permanently healing the wounds is abandoned, and all participants remained open to trying new dressing products. Study participants had all heard about alternative treatments that have been used successfully on someone else's ulcer. But the vulnerability of wounds makes experimentation dangerous:

And it is in such a raw state that I wouldn't like to experiment with it. ...//.. If it was a wee bit closer to getting better, I may be tempted to experiment, but I thought to myself - the district nurses have got the old tried methods - not saying they are perfect.

(Archie, Int 2: p17)

The use of alternative treatments at some future time was not discounted, but new or different orthodox treatments suggested by the district nurses were definitely welcomed:

Everything is worth trying, and you do have a certain hope that it will be the answer, but after two or three days you find it's not. But the only thing is to keep trying, keep plugging.

(Archie, Int 2: p27)

This belief in the existence of the 'miracle cure' helped retain hope in difficult situations. Jim was faced with no longer being able to tolerate what had previously been for him a particularly acceptable and successful dressing product over a number of years:

Well, I think when one door closes another will open - there will be something. Like this Sorbsan™ - I think it is incredible for what it is.

(Jim, Int 2: p23)

Some participants were realistic enough to acknowledge that their ulcers may never heal, and indeed may deteriorate to the extent that amputation of the limb would be required:

But I did quite often think that if I was going to have these all the time, could it turn into gangrene or something? Yes, I have thought about that. And I have thought about it with this one.

(Don, Int 2: p26)

I kept checking my foot and everything to see if it looked black. But I checked my foot, and oh yeah, it's only the veins that are black, not the foot, not gangrene!

(Edna, Int 2: p23)

The possibility of amputation is obviously a very distressing prospect, and ethical concerns limited how deeply this topic could be pursued during the study. Amputation was only discussed with participants when it was evident from their comments that they had already considered this eventuality themselves.

Avoidance of the word "amputation" was obvious, with the term "gangrene" being used by participants instead, which suggests that the issue is almost too awful to contemplate.

The possibility of amputation wasn't obvious to Gary, and he failed to heed medical advice about changing his lifestyle:

*Yeah, I was warned, but as I said - I've got painted-on ears. ...
I've come to understand that if I had listened in the first place and
did all I was supposed to do I wouldn't have had it [amputation].*

(Gary, Int 1: p3)

Amputation hasn't meant an end to Gary's problems, but instead produced new difficulties to be overcome. He is now keenly aware of his dependence on the remaining limb (which is also ulcerated), and the challenges he now faces to retain it.

An inability to control what state the ulcers will be in at some future date makes planning difficult. Two study participants had booked overseas holidays for some months in the future, hoping that by the time the travel was imminent the current ulcers would be healed.

When an ulcer does finally heal, the possibility of further ulcers developing means that vigilance is always required. Care must still be taken to protect the limbs, and the legs are constantly monitored for any signs that a new ulcer may be forming. **The ulcers never go away**, for victory over the wounds is only temporary - with the next ulcer is just waiting round the corner. A future without ulcers is difficult to imagine.

ALTERATIONS IN SPATIALITY

Van Manen (1989) describes home as "where we can *be what we are*" (original emphasis, p. 102). While the input of the district nurses may be welcomed, their regular visits still invade the privacy of the home:

They come so often they get to know the house, they just roam around as if... . They are quite at home - I just let them go.

(Connie, Int 1: p13)

Opening your home to the district nurses can feel as if the home, and everyone in it, is being laid open to the scrutiny and potential judgement of others:

She [district nurse] asked to use the toilet here one day, and we thought - oh yes, we had the same thought about it - she must have thought we were clean people.

(Don, Int 3: p46)

Sometimes participants made an effort to maintain privacy by restricting the nurses to just one or two rooms:

Yes, I've had quite a few different ones [nurses] come through, but they only come into this room. Sometimes they will go out to use the phone, but that's about all.

(Edna, Int 1: p2)

In an attempt to encourage patients to rest more, district nurses may offer temporary home help services. But for some, accepting home help would feel like a further erosion of privacy.

While the home may be considered a relatively safe haven in a world full of potential hazards for the ulcers, it may also start to feel like a prison. A number of factors may affect the ability to get out and about - such as the pain of the wound restricting the distance able to be comfortably walked, having to comply

with the advice to rest the leg, or being concerned about the uncontrollable nature of the wound:

I had some people at Christmas wanting to take me back north with them, but I wouldn't go on account of my legs. I mean I go out for dinner or things, but not to stay. You would mess up the ... [voice trails off].

(Connie, Int 1: p5)

Hugh had some problems with not knowing when the district nurses were going to visit, and had to stay at home until they arrived:

I couldn't go out anywhere or anything - I had to wait for them to come. ... But I had to stay home, because I had to have the dressings done.

(Hugh, Int 1: p6)

Venturing outside the home means exposure to potential injury. Busy shopping days have to be avoided because of the challenge posed by wayward supermarket trolleys:

(Do you worry about people knocking it [the ulcer]?)

Oh yes. That's why I always have a trolley, and I'm behind that trolley. Those kids with those little things [special child-sized trolleys] - they are a menace they are. But some of the grownups are pretty rough too with the trolleys.

(Freda, Int 1: p8)

Activities previously enjoyed may have to be abandoned because personal safety cannot be guaranteed:

I've paid my subs for bowls the last two years, and haven't played a bowl. ... I'm frightened that if you are playing bowls anyone could play a bowl that might whip up and hit your leg, or you could hit it on the boards around the thing. I haven't been, and I miss bowling very much.

(Freda, Int 1: p13)

Wounds can be very painful if knocked, and much energy is expended in trying to protect the area.

First of all I have to guard my legs against being knocked. I have to watch where I put my feet, watch when I walk round obstacles. ... And lying in bed at night - I might lie on my left side, and get it hooked against a wee bit of a wrinkle in the sheets - it always seems to hit the sore spot.

(Archie, Int 2: p20)

The pressure of bedclothes at night is frequently a problem, and a variety of solutions were used to overcome this, like placing rolled-up towels at the foot of the bed, or constructing bedcradles out of cardboard boxes. Connie had a more novel solution:

I've had all sorts of things to try to keep the blankets off. At the moment I've got a packet of eight toilet rolls. ... It doesn't fall over because of the double layer - it keeps it in place.

(Connie, Int 1: p3)

During the day the body can be monitored, and precautions taken, but this control is more difficult at night. Care is taken to 'arrange' the body in bed to avoid accidentally knocking the area or causing further pain:

When I go to sleep at night, and it gets a bit sore, I put one foot like this (demonstrates how he arranges feet), and I put the other one like that - so that the heel is on top of the other foot, and the weight is off the ankle.

(Don, Int 2: p28)

Sleep is disturbed not only because of the pain, but by the need to try to monitor what the body is up to:

And I'm awake two or three times, because every time I turn I wake so that I make sure I get the leg settled properly before I go back to sleep again.

(Edna, Int 2: p17)

When sharing a double bed there is always the potential for the partner to accidentally kick the wound. After years of taking care that his legs didn't get knocked, Don and his wife found it easier to resort to single beds. The need for increased personal space around the body requires **constant vigilance of both the self and others.**

REVIEW AND SUMMARY

This chapter has described how leg ulcers alter requirements for personal space around the body, and the role of previous experiences with leg ulcers in the understanding of present ulcers and hopes for the future.

Benner and Wrubel (1988) state that "temporality is not experienced in the abstract. It is specific and formed by what has gone on before and by what is anticipated" (p. 67). With chronic wounds, **the progress or setbacks from past ulcers provides a framework in which to interpret present events.**

Having had wounds heal in the past helps sustain the hope that this ulcer will also heal. But this hope is tempered by the knowledge that previous healing has been both difficult and temporary, and there is a certain wariness of what the future may hold.

While past experiences allowed some of the study participants to retain a sense of perspective and hope, those experiencing their first leg ulcers were not afforded similar comfort. They found it **increasingly difficult to predict what might happen with the wound**, and whether it would ever heal. The absorption with the current ulcer was such that the possibility of further ulcers at some future time was beyond comprehension.

When there has been a history of leg ulcers the possibility of certain procedures and treatments needing to be repeated can cause concern and even dread. Patients were aware of just how easy it was to accidentally injure the existing ulcer or start a new ulcer, and of the need to protect the body by **increasing personal space**. Routines were altered, and some social activities abandoned so that situations of potential danger - such as busy supermarkets - were avoided.

Even in the relative safety of home, the body is still not safe. Particular care must still be taken to position the body in such a way as to avoid pressure on the wound, especially at night. The environment must also be protected from a body that struggles against containment - with special precautions needed to ensure bedlinen isn't soiled with wound exudate.

When outings are curtailed by the need to rest the leg, or because of the pain experienced when mobilising, the potential exists for the home to become a kind of prison - with a sofa becoming the centre of a very restricted universe. Health professionals are usually welcomed, but their visits also open the home (and its inhabitants) to scrutiny and potential judgement.

Chapters Four, Five and Six have provided a detailed insight into the world of chronic leg ulcers. Reading these accounts of the lives of the study participants, it would be easy to focus on the affronts to personal dignity, and the physical and emotional suffering that has been experienced. But this would not be an accurate portrayal of the participants - for the majority of them have been able to **minimise the suffering, and develop a sense of normality**, whereby the differences created by the leg ulcers become part of the taken-for-granted way of being in the world. The work that is involved in minimising the impact of the ulcers, and restoring a sense of normality to life, is the focus of Chapter Seven.

CHAPTER SEVEN

CONTINUING ON WITH LIFE

Reflecting on the experiences outlined in the previous three chapters, chronic leg ulcers could easily be regarded as involving never-ending misery and distress. This would not be an accurate portrayal of the lives of all but one of these study participants. Life has continued on for them, despite the interruptions the ulcers have caused. **The ulcers have not been allowed to take over.**

I experienced some initial difficulty in obtaining participants for this study - not because those I approached were unwilling to take part, but because they felt they had *nothing to tell me*. Leg ulcers had become such a taken-for-granted part of normal living that the differences the ulcers caused were no longer immediately obvious, and were only revealed to them during the reflection of the interview process. It was common for participants to remark at the end of an interview how surprised they had been about how much was involved with their ulcers.

It was also not uncommon for participants to be quite hazy about specific details relating to the duration of the ulcers, and to be unable to recall just how many periods of ulceration had been experienced. Frequently, ulcers were recalled only in relation to specific family events, such as the birth of a child, or a very special holiday when ulcers had meant not being able to go swimming.

For lives had continued despite the ulcers. Although Jim and Don had active ulcers for much of their adult lives, they continued to work full-time in blue-collar jobs, except for several periods when hospitalisation or complete bedrest at home was forced upon them.

The acceptance of ulcers as 'normal' was also evident when participants were asked if they thought they were healthy. Other health problems are alluded to, but not the ulcers:

(Do you consider yourself healthy?)

Well, I am, apart from my high blood pressure. I would say so. Touch wood, I don't get colds or anything like that - I've never been a chesty person or anything.

(So having the leg ulcers doesn't make you unhealthy?)

No. No. I don't think so. It's just one of those things.

(Freda, Int 2: p20)

Benner and Wrubel (1988) 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" (p. 136).

One study participant, Edna, was experiencing considerable difficulty in coming to terms with her first experience of leg ulceration, and the significant impact it was having on her life. The remaining study participants had lived with ulcers as a fact of life for periods ranging from twelve months to forty-seven years, and had been able to reshape their lives by minimising the impact of their ulcers, so that **the differences the ulcer created had become part of the normal way of being-in-the-world.**

This chapter will examine the work involved in achieving this sense of normality. New routines must be established and old regimes modified; the ulcers must be accepted as a fact of life, while retaining hope; relationships of trust and confidence developed and maintained with health professionals; efforts made to retain independence despite the difficulties involved in controlling the situation; and a sense of humour maintained to help keep the ulcers in perspective.

This chapter will conclude with a discussion of Edna's difficulties in accepting her leg ulcer, and examine why her experiences differed so much from those of the other study participants.

MINIMISING THE IMPACT OF THE ULCERS

Accepting the leg ulcers as a fact of life

The majority of the study participants were remarkably philosophical in their acceptance of their ulcer(s), for ulcers were a fact of life, and could not be ignored. The situation may not be satisfactory, but there is no choice but to accept it:

(Do you find the loss of privacy...)

Oh, I find that maddening. But I can't do anything about it. You have just got to accept it.

(Betty, Int 1: p12)

Having a philosophical attitude to life certainly helped Archie accept his ulcer:

Oh, you adapt to life. If you don't life can be very miserable. You take things as they come, you don't worry about things. Worrying doesn't cure anything - it doesn't get you anywhere. In life you take things as they come.

(Archie, Int 1: p17)

Connie had no option but to work out some way of being able to have a shower, as she realised from her past experiences that the ulcers would be with her for some time:

Well, it's been a case of having to. It hasn't been a week or two, it's been a year or two. You've had to do it, and it's not the first lot of ulcers.

(Connie, Int 1: p9)

When the ulcers are a fact of life, treatment regimes, including hospitalisation, have to be accepted if ulcers are to heal:

(How did you feel about coming back into hospital?)

Oh well, I didn't feel that flash [happy about it], but I thought if I have to go, I have to go. ... If I want the legs to get better I have to have some help.

(Hugh, Int 1: p2)

Retaining hope

Accepting the ulcers as a fact of life doesn't necessarily mean being resigned to having ulcers permanently:

I wish to hang they [leg ulcers] would go away, and not come back again.

(Freda, Int 1: p13)

It has surprised me to have had it for so long. It's part of my life now. If I can wipe it out - well, good-oh. If I can't, then I've got to live with it.

(Archie, Int 1: p18)

Hope of a permanent cure was common among most study participants, even though they acknowledged the chances of this happening were slight:

Oh, I hope they will [heal up] but I know they will take a long time. But I'm hoping all the time they will heal up, and if I have this skin graft well That's all you can do, is to hope they will get better I suppose. A bit of a nark [nuisance] while you have got them.

(Hugh, Int 1: p11)

After a period when her ulcers had been particularly troublesome, Connie needed to be able to hope for better things in the future:

You just keep hoping that something will work. But they can get very sore, especially when you get tired. ... I would hate to have these for the rest of my life.

(Connie, Int 1: p11)

Connie was able to take comfort from having ulcers heal in the past:

(Do you expect that your legs will heal completely?)

Well, I hope so, I hope so. I mean in the past I've had ulcers and they've healed up completely. I think it is just a matter of when I get all the infection out.

(Connie, Int 2: p28)

Archie's hope was reinforced when progress in wound healing became obvious:

This morning it [red rim around ulcer] was clear. Hope it keeps like that.

(So it has given you new hope?)

Oh yes, yes. I have hope all the time.

(Archie, Int 2: p26)

Developing confidence in health professionals

The chronic nature of the leg ulcer experiences means that the assistance of health professionals may be required for periods of months or even years. Having faith and confidence in those who are helping you is very comforting:

because she [district nurse] is marvellous - what she doesn't know isn't worth knowing - she is a lovely person.

(Freda, Int 1: p5)

The friendship of the District Nurses was also valued, especially when their concern was extended to other family members:

She was becoming, well, a friend, to both of us - we were looking forward to her coming.

(Don, Int 2: p24)

It also feels good for study participants when the health professionals acknowledge the expertise they have themselves developed:

The last time I was in hospital there, and the nurse came along to bandage my leg, and he [hospital specialist] looked at it, and said "I think you had better let him do it himself" (laughing).

(Jim, Int 1: p14)

Gary was able to accept the loss of privacy that accompanied his need for twice daily dressings at home because of the concern demonstrated by the nurses:

I mean, people are only there for a reason. The people that come into my home are always concerned - I've never met one yet who isn't concerned.

(Gary, Int 1: p13)

Establishing new routines and modifying old regimes

Benner and Wrubel (1988) discuss how practical knowledge about living with a chronic illness is built up over time, by "develop(ing) a set of habits, practices and expectations" (p. 25).

The requirement to keep the wound, or sometimes the whole of the lower leg, dry meant that participants had to work out ways of being able to continue with showering or having a bath, or miss out altogether. For some of the participants this wasn't an issue - Betty's dressings were removed and her legs left uncovered

prior to showering, while Hugh had decided it was easier to "make do" with a good wash at the basin.

Although none of the other study participants had to undertake preparations to the extent required by Connie (p. 54), extra care was still required, with having a bath being described by Freda as *a work of art* (Int 1: p12). Don worked out his own ways of coping:

The shower - well, I used to hang a stocking, or a towel or something, across the two taps - hook my leg up on that ..//.. or a board across the bath. It was a bit awkward really, couldn't have a lot of water, in case you went under. Because I've been known to go to sleep in the bath. (laughing).

(Don, Int 1: p11)

Modifications are also required to many other routines, such as avoiding standing still at the bench for too long when preparing meals, while the possibility of slipping means an end to polished floors and mats.

Along with modifying existing routines, strategies must be developed for new happenings. Freda is always organised for the visit of the district nurse:

I always have a plastic bag and everything sitting on the table there - ready for them, and have the newspaper and a towel over there to put my foot on.

(Freda, Int 1: p11)

Some system must also be developed for disposing of the used dressing materials, particularly in the summer heat:

But the dressings - I supply plastic bags, and we put them in those, and I spray them with flyspray, and wrap them in newspaper, and put them in the rubbish bag. It piles up.

(Connie, Int 1: p5)

Complying with the advice to rest has become part of Jim's routine:

Once I've had lunch I put my feet up here (indicates sofa) - every day of the week - I think it's habit now. ... I generally do put my feet up for one and a half, two hours every afternoon.

(Jim, Int 1: p5-6)

Retaining control of the situation

Control of the ulcers themselves may be difficult to achieve, but study participants made strenuous efforts to exert some control over the situation they found themselves in, and to retain independence.

When study participants were able to do their own dressings, considerable independence was able to be achieved. When Jim was unhappy with the way his ulcers had been dressed by a nurse who was not familiar with his wound management, the solution was obvious:

Leave it until tomorrow, and then I'll take it off. ... Yeah, if I find it's uncomfortable, any discomfort - I'll just take it off.

(Jim, Int 2: p18)

Bandaging regimes were another area where considerable independence could be exerted, even if the dressings themselves weren't touched. Archie had his reasons for removing his bandage:

In the hot weather they [bandages] get too itchy, but I've got the cure for that - take it off. Because it's no good having anything that's irritating you all the time.

(Archie, Int 1: p12)

When study participants do take control of some aspects of the management of their ulcers, they become vulnerable to accusations by health professionals that they don't want their ulcers to heal. In actual fact, control is exerted not in an attempt to prevent healing, but **in response to the body aware of itself.**

Archie fully understood the need for compression therapy, but considered that the bandages were doing more harm than good by making his leg sweat and itch unbearably. Jim had extensive experience with the wound care product used by the nurse that morning, and knew that the way it had been applied would later cause considerable discomfort once he was up and about on the leg.

Jim has refused to let the ulcers control him. He is reluctant to take pain relief, even when the ulcers are particularly painful:

(What do you do at night, if it [the ulcer] is painful, and you are not going to take anything [pain relief] ?)

I just lie there. Just lie there. ... There is no way [I would get out of bed] - I'm in bed and that's it. No, I just won't do it. I know sometimes it gets a bit (sigh) really sore, but I still won't get out of bed.

(Jim, Int 2: p20)

Jim has been able to control what has happened to him by being confident in, and independent with, the management of his ulcers. Some of his ulcers have been managed without any input from health professionals. His ability to retain his independence has been assisted by the position of his ulcer, which makes dressing changes easy for him to do himself.

Several study participants spoke of deliberately delaying or postponing surgical interventions, or not being prepared to submit to complex diagnostic procedures, because of concern as to whether it was in their best interests at that time.

Connie experienced considerable distress when undergoing skin grafting without a general anaesthetic, and acted to control the situation when further skin grafts were proposed:

Oh, it was horrible. I dreaded the next Well, I refused to have the same thing. I said they could put me to sleep, or anything they liked, but I said I wasn't having that the second time.

(Connie, Int 2: p16)

Connie took charge again when there was confusion about her allocation of compression stockings on discharge from hospital, refusing to accept that they didn't need changing every day, as *you don't wear your stockings two days running* (Int 2: p18).

One of the participants had made the decision previously to refuse further antibiotics after receiving eighteen courses in a two year period. When he eventually succumbed to pressure to accept another antibiotic course, he was distressed at having surrendered control.

These antibiotics arrived. I sent it back actually. But it came back again to me, and I am taking it. ... I have always said I would not take antibiotics again. Against my better judgement I'm taking the things, and having started taking them, well - unless I finish the course it is stupid, so I will finish them, but never again. ... I don't know what made me foolish enough to start taking them and I have been foolish.

(Name withheld)

Keeping the ulcers in their place

Study participants used a variety of coping mechanisms to help minimise the impact of their ulcers. Keeping a sense of perspective, and being able to see

the humour in an otherwise distressing situation, was common. Don normally drove the family car, but at one time his ulcers were too painful for him to drive:

One time when I had an ulcer, it was quite bad then. So [wife] drove us up there in the car - she was doing about seventy miles an hour across the Takapau Plains, and my son was in the back, and he looked at me ... (laughing).

(Don, Int 1: p10)

Don made a concerted effort to see the funny side of life:

As far as misery is concerned, I've always tried not to make that a part of life. When I have been working if I couldn't get a laugh out of somebody during the day, I would have had a hell of a bad day.

(Don, Int 2: p36)

Study participants were also conscious of the need to keep themselves occupied, so that they didn't have time to reflect on the impact of the ulcers. And yet it is difficult to keep busy when the pain of the wounds restricts physical activity:

I just hate sitting here, thinking about things. I like to be knitting, or sewing or something, or reading.

(Freda, Int 1: p9)

Jim also tried to ignore his ulcers at a time when he had his own business, and ended up spending four months in hospital:

[I was] doing extremely long hours, and I was dressing it [ulcer] myself. Ended up with the doctor saying "if you don't go to hospital I'll come and close your business down" (laughing). It was just about gangrene!

(Jim, Int 1: p2)

Keeping the ulcers in perspective

During the course of these interviews, study participants described many distressing experiences that had arisen because of the leg ulcers. But almost all the participants had positive experiences to relate, or were able to keep the ulcers in perspective by realising that others were worse off than they.

Both Jim and Don realised that the position of their ulcers had made it easier for them to cope:

I've always had them on my ankle, so they have been more or less hidden.

(Don, Int 2: p39)

Don's ulcers had been at their worst when his family were young, and many social activities had been curtailed because of the ulcers. Don's wife was able to look on the positive side of this:

I think it's made our family very close, because we spent more time together than going out, sort of living it up.

(Don's wife, Int 2: p36)

Jim agreed that developing an ulcer at a very young age had a significant impact on his life, but the advice he received at that time to get regular exercise led him into an activity that became a major part of the lives of both he and his wife for a number of decades. Jim has also been able to keep active around the house, despite the ulcers:

We've only had this place five years, and I've redecorated the whole inside, put all the gardens out the side, and I'm working on the back to get that done.

(Jim, Int 1: p10)

A poor sleeper all her life, Freda was quick to acknowledge the benefits of the pain relief she took at night:

Yes, it [pain relief] usually makes you sleepy. And they make me sleepy and then I can settle down and go to sleep. In fact I slept in this morning.

(Freda, Int 1: p3)

Both Hugh and Betty had other major health problems that far outweighed the problems their leg ulcers caused. Healing the ulcers would not mean the end of their health problems, and this helped keep the ulcers in perspective:

I've been like this [in poor health] three and a half years so I'm getting used to it now. And I know it is not going to get any better, but if I could get my legs better that would be a help. It would be one less worry.

(Hugh, Int 1: p14)

COMING TO TERMS WITH THE INITIAL ULCER

While the majority of the study participants have been able to adjust to the suffering caused by the leg ulcers, Edna has found this experience almost unbearable.

The uncertainty that accompanies an illness trajectory is discussed by Benner and Wrubel (1989), who state "until an illness is identified, the patient is in limbo - his or her life is put on hold. Once the diagnosis is determined, there still remains uncertainty about the nature, degree and projected outcome of the illness" (p. 133). Although Edna's ulcers had been present for eight months, and diagnosed for six months, her life remains on hold, dominated by the uncertainty of what lies ahead of her. Edna is the sole breadwinner of the family, and the financial implications from her being off work are considerable:

I'm only surviving on ACC [Accident compensation payment] at present, and it's hard. I'm behind with the rent, and everything, and that's worrying me - trying to pay back that and feed everyone with the little bit of ACC you get.

(Int 1: pp5-6)

There seems to be little Edna can control in this situation. Despite her strenuous efforts to comply with prescribed treatment regimes, the ulcer stubbornly refuses to go away. Even her attempts to try to prevent wound infections by the liberal use of antiseptics around the house are unsuccessful:

I've just about lived on them [antibiotics]. I go 'no bugs' for about a week, and then I just catch them again.

(Int 1: p7)

Her mother died when Edna was young, and she has been used to fending for herself. Being dependent on others doesn't come easily to her.

And [Doctor] wanted to send home help in, but I didn't want a stranger around my home - because I have always been able to do for myself. I don't like people waiting on me.

(Int 2: p19)

Edna has a lot of faith in the specialist wound care nurse who has been treating her, but this nurse now admits to having tried everything available, and the ulcer still remains. In these circumstances, it is difficult to retain hope because there seems to be no solution in sight:

I feel as though I have [lost hope], because it doesn't seem to be wanting to heal - it just seems to be going on and on and on. Goodness, six months have gone already, and he's put me off for another ten weeks ,that's eight months. I'll be just about out of work for a year.

(Int 1: p12)

A referral to a hospital Specialist produced further problems, with the suggestion that vascular surgery may be required:

But since he told me that my brother-in-law rang up and said his wife had the same thing - she had her veins stripped, and she had more trouble once her veins were stripped than they were before. And I've heard from two or three others who have had veins stripped and they have had more problems since they were stripped than what they did before. (laughs nervously). I'm frightened to have it done.

(Int.2: p15)

With no previous experience of leg ulcers to shape her expectations, Edna is unable to imagine a future when the present leg ulcer is not present. She finds her day-to-day existence extraordinarily distressing, but there is no end in sight to her suffering. It is the uncertainty surrounding her future that is the most difficult aspect of the leg ulcer experience to accept:

(What has been the worst thing about this ulcer?)

(pauses, then sighs). *Well, the worst thing is to be told it would be cleared up in a month, then find I am still off work seven months later, and it could take up to a year to clear up. That's how I feel - as if I'm told a month one minute, next time I'm told it would be a year.*

(Int 2: p26)

Benner and Wrubel (1988) describe the historical basis of stress and coping, "meaning that one's stressful experiences and coping options are constituted by the way one is involved in the situation, the skills and concerns, the meanings, and the particular history, including the way one anticipates or projects oneself into the future" (p. xiv).

Archie was also experiencing his first leg ulcer, but the impact on his life was minor compared to the upheaval experienced by Edna. Each individual differed in what they considered to be the most stressful aspect of the leg ulcer experience, although pain and wound odour featured prominently.

Some of the study participants have experienced significant disruption to their lives because of the leg ulcers, while for others the impact of the ulcers has been considered to be not much more than just a nuisance, albeit a nuisance that may continue for years. The uniqueness of each individual's situation, and the impact of the ulcer(s) on their life, has resulted in a range of coping options being available. Over time, the majority of these study participants have been able to utilise various coping options to allow a degree of normality to develop, despite the ulcers.

Some control must be exerted over life, even if the ulcers themselves refuse to be controlled. The body can never be trusted, but life can't be dominated by its unreliability. Long-established patterns of living may need to be modified and new coping strategies developed, but over a period of time the management of the ulcer(s) is integrated into the normal fabric of daily life.

OVERVIEW AND SUMMARY

Chapters Four, Five and Six have detailed the suffering that is part of the chronic leg ulcer experience.

Chapter Four examined the impact of having a body that is out of control - with pain generated from the ulcerated limb, and also clinically inflicted during dressing changes and diagnostic procedures; of the difficulty of containing wound ooze; and of smelly wounds being not only unpleasant for the individual concerned, but raising fears of offending others.

Wound infections are a common occurrence with leg ulcers. Although the resultant antibiotic therapy may be associated with unpleasant side-effects, infections are ignored at one's peril, for gangrene is a distant, but ever-present, threat.

Treatment regimes present additional challenges - such as the inconvenience of keeping wounds dry when showering; the discomfort of wearing bandages, and the problematic nature of complying with the instructions to 'rest the limb'.

In **Chapter Five**, attention was drawn to the complex nature of the relationship between the study participants and health professionals in general, and district nurses in particular. Clients have no choice over which nurse will be involved with their care, which may mean having to tolerate a nurse who for some reason isn't entirely satisfactory, or being vulnerable to losing a 'favourite' or 'expert' nurse, on whom one has come to depend.

When specific health professionals are regarded as having expertise in wound management, and are felt to be genuinely interested in healing the wound, there is little option but to try to comply with the treatment regimes they prescribe. Ignoring the advice of the experts may risk incurring their displeasure, as well as jeopardise the likelihood of the wounds healing.

The impact of ulcers, such as the associated financial costs and the social restrictions, extends to other family members. Family members may provide support when new ulcers develop, or existing ulcers deteriorate, and may share

in the triumphs when ulcers heal. Sometimes family members may be considered to need protection from the sight and smell of the ulcers. Some family members may take an active part in helping protect existing ulcers from further damage, and in the work required to prevent new ulcers from developing.

When there have been repeated episodes of ulceration, past experiences influence the understanding of current ulcers, and help shape expectations for the future. This concept of temporality was demonstrated in **Chapter Six**, with comfort being obtained from the knowledge that previous ulcers have healed, along with unwelcome memories of past discomforts and failed interventions. Hope remains that the ulcers will heal permanently, although the chances of this happening are acknowledged as being slight.

Perceptions of chronological age may be distorted by the impact of the ulcers and associated treatment regimes, while the ageing process can be considered a factor in delayed wound healing.

Chapter Six also outlined the alterations to lived space that ulcers can cause. Experiences with repeated episodes of ulceration, and fears for the future, mean that ulcers are effectively always present, even when there are no current ulcers. A single moment of carelessness may be all that is required to start another ulcer, so the body must be constantly protected and monitored, and personal space carefully guarded.

The home may be a haven of safety in a world where personal space is difficult to control. Equally, when social activity is restricted by the instructions to rest, or the discomfort of the wound, the home can feel more like a prison. Even the normal being-in-the-world existence in one's own home is altered by the visits of the district nurses, with the loss of privacy a concern for some, despite their appreciation of the assistance provided by those nurses.

Suffering is a feature of the leg ulcer experience, but it is not the total experience. **Chapter Seven** described how the majority of the study participants had been able to accommodate the ulcers in their lives, rather than being overwhelmed by the misery the ulcers may cause. The ulcers, and the differences they create in life, were accepted as a fact, although hope was never lost of a permanent cure. New routines were established, or existing practices modified, to accommodate the ulcers, while health professionals were valued for their friendship, their expertise and their interest.

Experiencing leg ulcers means living with uncertainty, with no clear indication of when current ulcers may heal, or further ulcers will develop. In these circumstances, being able to take control of some aspects of the experience helped individuals to cope, such as the modification of treatment regimes so that a more normal life could be led, or giving priority to a body aware-of-itself.

Identifying coping strategies that allow life to go on, despite the ulcers, is a process that develops over time. A first ulcer may plunge life into disarray, as was the case with Edna, and coping options are not immediately available. With experience, those coping strategies are identified and utilised, and a more philosophical attitude to the ulcers develops. While life will never be the same again, a sense of normality is established.

CHAPTER EIGHT

DISCUSSION

The previous four chapters have detailed the experiences of nine people whose lives have been significantly altered by chronic leg ulcers. My interest in this topic results from the many contacts I have had with people with leg ulcers since commencing work as a district nurse. Over a period of time I gradually became aware of the impact these wounds had on their lives, and how little health professionals understood of what those lives were like.

This study utilised Heideggerian hermeneutic phenomenological research methods to make visible the realities of living with chronic leg ulcers. Semi-structured interviews allowed the participants to reveal the chronic suffering that accompanies leg ulcers, and talk about their interactions with health professionals. Their stories were more than just detailed accounts of distress from the pain, wound ooze and odour, and the interruptions to daily living that accompany leg ulcers. The ulcers have become incorporated into new worlds of meaning, and life has continued on, despite the ulcers.

Phenomenology allows "participants to describe their everyday concerns and practical knowledge, thereby giving access to practical worlds" (Benner, 1994, p. 112). This study has revealed the everyday worlds that leg ulcers create, allowing the patients' perspectives of the leg ulcer experience, including the care they receive, to be identified. These are the worlds that should be the focus of health professionals, for this study has demonstrated that a leg ulcer is not just a wound that fails to heal, but becomes part of a whole new way of life.

In this chapter, the study findings will be related to the literature in a discussion of wound management practices and compliance with treatment regimes. A particular emphasis will be placed on the importance for health professionals of understanding the comprehensive and chronic nature of the leg ulcer experience, instead of merely focusing on wound management. The implications of the study findings for nursing practice and nursing education will be discussed, and areas for further research identified. A case will also be presented for the need for further consideration to be given to definitions of chronic illness, as the experiences of the study participants do not appear to be congruent with existing definitions and frameworks.

THE MANAGEMENT OF LEG ULCERS

Some of the difficulties experienced by the participants in this study have received little acknowledgement in existing literature, but an understanding of their significance in the total leg ulcer experience is crucial to the provision of appropriate nursing care. As outlined in Chapter Two of this thesis, although there has been a considerable amount of literature published on the subject of leg ulcers much of the nursing literature has concerned itself with general wound management and compression bandaging principles, and with trials of new wound care products.

All study participants experienced pain associated with their leg ulcers, with the intensity of pain ranging from general discomfort through to an almost unbearable degree of suffering. Frequently that pain appeared to be poorly-controlled, with participants expressing their belief that health professionals had little idea of the extent of the pain they were experiencing. A review by Thomas (1989) identified the paucity of literature relating to the control of pain from leg ulcers.

Although the occasional writer states that there is little or no pain associated with venous ulcers (Young, 1994), it appears generally accepted in the literature that pain is a feature of the leg ulcer experience, and particularly significant in ischaemic ulcers. Pain in venous ulceration may be assumed to be related mainly to the presence of infection (Chapple, 1994), with Morris (1993) suggesting that the pain of venous ulcers "can usually be alleviated by an appropriate **systemic** antibacterial drug" (original emphasis, p. 61). Frequently, the only references to pain are the potential use of pain as a diagnostic tool in identifying the aetiology of an ulcer or the presence of a wound infection, rather than as a problem requiring nursing action.

Further research is required to determine New Zealand practices, although it is clear that for the participants in this study, pain management was not satisfactory. In the 1994 study by Hamer et al., 37% of respondents identified pain as being the worst thing about their leg ulcer (p. 100), with the authors expressing concern that this pain receives little acknowledgement from health care workers or researchers. The study by Roe et al. of English community nurses' management of leg ulcers identified that only 55% of nurses surveyed assessed the patients' experience of pain (1993, p.304). A crude extrapolation of the findings of these two studies would mean that more than one-third of patients considered pain the worst thing about their ulcer, yet only half of their nurses even assess pain.

The inconvenience of dressings was of concern to all the study participants, with the restrictions to showering or having a bath proving particularly tiresome when dressings need to be kept dry. The use of compression hosiery that patients are unable to remove without assistance, or the growing use of bandaging regimes designed to be left untouched for up to a week, further compromises personal hygiene practices. The New Zealand literature provides conflicting advice about the advisability of allowing the affected limb(s) to get wet. Morris (1993) states that showering or bathing the limb will cause deterioration of the wound, Watt (1993) stresses the importance of maintaining limb hygiene, while Chapple

(1994) suggests "it is also useful and humane to allow full showering to be integrated with changes of dressings" (p. 68). Limb hygiene is an area that receives curiously little attention in the nursing literature, but is of considerable significance to patients.

When the limb cannot be washed daily because of the presence of bandages, the possibility of foot odour compounds existing concerns about wound odour generally. Problems with wound odour and exudate were frequently mentioned by study participants. Hamer et al. (1994) cite exudate as being one of the worst aspects of having a leg ulcer, but as they provide no explanation of what the term 'exudate' means it is unclear whether it also encompasses wound odour. Wound odour also receives little attention in the leg ulcer literature, but is discussed in some of the literature pertaining to the management of fungating wounds, such as the article by Grocott (1993). Van Toller (1994, p. 105) draws our attention to the "complete lack of studies relating to social interaction in patients suffering from body malodour" and to the social isolation and reduced quality of life for these patients.

For the participants in this study, the difficulties in complying with the instructions to rest, or the precautions needed to have a shower or bath, or the discomfort associated with bandages, all strongly impacted on their quality of life. However, the undesirable consequences of treatment regimes are seldom, if ever, addressed in the nursing literature. While diminished quality of life is acknowledged as part of the leg ulcer experience, the role that treatment regimes play in this diminution is seldom recognised. For some participants the impact of treatment regimes was as significant as the symptoms generated by the wound itself. People with leg ulcers must not only learn to live with the disease process, but also with the effects of the treatment of their wounds, treatment that may well continue for months or even years.

COMPLIANCE WITH TREATMENT REGIMES

Other problems arising from treatment regimes, such as the reluctance to take yet another course of antibiotics because of the diarrhoea they cause, often only feature in the literature in discussions about the alleged non-compliance of a patient, rather than from the perspective of suggesting strategies that may make those treatments more tolerable.

To date, I have discussed my emerging findings with groups of nursing colleagues, nursing students, nursing tutors, and district nurses. Invariably someone present has argued strongly that these patients 'need' their ulcers, and that the ulcers would heal if they really wanted them to, citing evidence of some alleged non-compliance with treatment regimes. As discussed by Cullum (1994), despite the lack of supporting evidence it has not been uncommon for health professionals to express their belief that these patients do not want their ulcers to heal.

Frequent examples of such unsubstantiated beliefs can be found in the nursing literature. Pottle (1987), reporting on the trial of a particular wound care product, draws conclusions about the psychological state of a patient:

This patient had been reluctant to accept a new treatment which might improve her condition, so it was not surprising that once the treatment looked like being successful she reverted to her former mental state, and has to have daily dressings as part of her mental management (p. 54).

Some of the participants in my study described how, at times, they felt unable to fully comply with the treatment regimes prescribed for them because previous experience led them to believe that the treatment was not in their best interest. Examples were the reluctance to consent to skin-grafting again when previous grafts had failed, or repeating a trial of a dressing product that had been used previously with disastrous consequences. From the patient's perspective, the possible harm from such an intervention is likely to outweigh the potential

benefits.

At times the demands of everyday living made compliance with treatment regimes unachievable. In particular, rest was not a practical option when household responsibilities remained, or there were work commitments. Alleged non-compliance is a major issue in relation to leg ulcer management. Hunt, Jordan, Irwin and Browner (1989) state that "compliance is usually defined as the extent to which patients' behaviour coincides with medical advice" (p. 315). Roberson (1992) draws attention to the assumption(s) underlying this definition that such advice is in the patient's best interests, and therefore any rational patient would follow such medical advice precisely.

Such assumptions are simplistic, failing to consider how suggested treatment regimes may compromise the ability of patients to keep on with their lives. Bryant (1992) states "the long-term nature of the disease, slow treatment progress, and dependency on others are situations that must be borne day after day" (p. 191). Study participants had **chronic** wounds, and there was no guarantee that the prescribed treatment regimes would result in the ulcers healing. Temporary inconvenience, when success is virtually guaranteed by treatment regimes, is a very different matter from compliance on a long-term basis, with no similar guarantees of success.

The use of compression therapy for venous ulcers is an example of a treatment which may be considered perfectly acceptable, and indeed eminently desirable, from the health professional's perspective, but which the patient finds difficult to tolerate. Not only did study participants consider the bandages or stockings to look unsightly, but assistance was frequently required with their application and/or removal. The bandages/stockings were also found to be uncomfortable, particularly in warmer weather. Much attention is given in the literature to the use of compression bandaging, but little mention is made of patient acceptability, except to acknowledge that compliance can be a problem.

Toombs (1992) discusses the different perspectives of physician and patient, stating "the physician and patient apprehend illness from within the context of separate worlds, each world providing its own horizon of meaning" (p. 10). Comments by study participants suggest that Toombs' remarks may well be applicable also to the nurse/patient relationship. Toombs continues by describing how a doctor is trained to focus on the physical signs and symptoms of an illness, while the patient experiences it "essentially in terms of its effects upon everyday life" (p. 11). When the focus of the health professional is on wound management, and the focus of the patient is on minimising the impact of what appears to be a permanent condition so he or she can get on with life, compliance can become problematic for the patient. In their study of compliance from the patient's perspective, Hunt et al. (1989) found that

real patients are not passive recipients of recommendations, but are reflective actors who review information about health and illness, and make decisions based on what makes sense given their experience of bodily changes, the framework of their prior knowledge, and the everyday life situation in which the illness is lived and the treatment used (p. 325).

They continue: "to be of any real value the treatment for an illness must be usable. It must be capable of addressing illness as it occurs in the context of everyday life" (p. 331). Kane (1990) advises that compliance with leg ulcer treatment can only be achieved when the patient's expectations, perceptions and constraints on daily living are considered. Roberson (1992) describes how patients develop "systems of self-management which are suited to their life-styles, belief patterns, and personal priorities" (p. 7). She suggests there needs to be less emphasis on the issue of noncompliance, and more attention paid to assisting individuals to live well with their chronic illness and accompanying treatment regimes. Compromises may be needed, particularly when treatment regimes are likely to be long-term, for despite the best efforts of all involved, these ulcers do recur (Baker et al., 1991; Moffatt et al., 1992).

Hugh was able to describe the inconvenience of his antibiotic treatment as *a bit of a nark* [nuisance] (Int 1. p3). When I mentioned his comment to several other participants I got a quite different response, with one person becoming quite angry, detailing the way leg ulcers had disrupted her life, and saying to me *I can tell you it's a lot more than just a bit of a nark* (Fieldnotes, Mar. 26). The excerpts that have appeared in the data chapters of this thesis are just a very small part of the stories that participants shared with me. I will be the only person who will ever read all the interview transcripts. I believe that anyone who had the opportunity to read those transcripts could not fail to be moved by the impact the ulcers have had on the lives of these people, and realise how hard they have tried to comply with treatment, and just how much they want those ulcers to heal permanently. And yet, as a client group, people with ulcers seem very vulnerable to criticism, particularly in relation to the issue of whether their need to continue contact with the district nurses is the reason why their ulcers fail to heal.

Given the chronic nature of these wounds, and the likelihood of visits over an extended period of time, it is not unreasonable to expect that friendships may develop between patient and nurse. Don's comments about a particular nurse becoming a friend to both him and his wife are a glowing testimony to a nurse who was able to see the individuals in this situation, but run the risk of being cited as proving that he doesn't want his ulcer to heal, when in the story he related to me it is clear nothing could be further from the truth.

During my years as a district nurse I have become very fond of some of the patients with leg ulcers with whom I have had regular contact, and would regard them as friends. Yet it has never been suggested to me that I am deliberately delaying the healing of those particular leg ulcers to avoid losing the regular contact with those patients.

Why is it that only **patients** are considered likely to value these friendships? Is the nurse/patient relationship one of two equals, or are these patients in some way inferior? Chapple (1994) draws our attention to the special problems associated with chronic discharging wounds, and how "we simply need to constantly remind ourselves to imagine how it is for them as we deal with their dressings, and try to include them in the human race" (p. 68).

Study participants were leading full and meaningful lives, despite their leg ulcers. Some aspects of their lives were different because of the ulcers, but nevertheless they had been able to minimise the impact, displaying considerable courage and tenacity by getting on with life.

These ulcers are not just a temporary phenomenon - for several of the study participants most of their adult years have been shared with leg ulcers. A focus on healing the wounds can easily distract health professionals from the chronic nature of the interruptions caused by both the wounds and the treatment regimes.

The optimum treatment regime, the one most likely to heal the current ulcer, may well be unmanageable in the context of an ongoing life. The challenge is for health professionals, and particularly nurses, to understand the realities of life with chronic ulcers, and to work with the patient to determine the most realistic treatment that will allow life to continue, while still facilitating wound healing.

LIMITATIONS OF THE STUDY

This study is an examination of the experiences of nine particular individuals with leg ulcers, who happen to be clients of one particular district nursing service, and is a first step in furthering the understanding of this illness experience. The study findings relate specifically to the experience of those individuals, and are not necessarily generalisable to leg ulcer patients in other parts of New Zealand.

Time and resource constraints have limited the size of this study. However, while the number of participants in this study is small it is in keeping with accepted practice for phenomenological studies, which aim to focus on in-depth analysis of the lived experience. The decision to stop at nine participants was made arbitrarily by myself, after discussion with my thesis supervisor. Those participants had already provided me with a wealth of detail about their lives with leg ulcers, and there was a depth to the variety of their experiences. I became concerned that I would not be able to do justice to the stories that had already been shared with me if the number of participants was increased further.

All the study participants were existing clients of a district nursing service. While they were assured of anonymity and confidentiality, some participants may have felt concerned in that by sharing information they could possibly jeopardise their continuing treatment. All the study participants were also aware of my own status as a district nurse in another area, which may have had some influence on what they were prepared to discuss with me. Their obvious personal fondness for many of the nurses they dealt with may also have restricted their willingness to criticise some aspects of the service they were receiving.

The phenomenological method requires the validation of study findings with participants. All participants had the opportunity to validate and clarify with the researcher the transcripts of their own interviews. I am concerned about whether participants are really in a position to validate the intellectual processes which result from reflection on the combination of all the essential structures of each individual's experiences, without having access to every interview transcript.

Ethical concerns limited some of the questions which could be asked of participants, as I did not wish to distress participants by asking them to reflect on issues that they were uncomfortable discussing. For instance, I did not always feel that it was appropriate to ask for much detail about previous ulcers or

whether they believed their ulcers would heal permanently. The possibility of amputation was only raised with those participants who had already given me some indication that this was an area they had already considered themselves.

At times I experienced conflict in my roles as researcher and clinician, finding it extremely difficult, and sometimes impossible, not to intervene in situations where I felt I could be of some assistance to the study participant.

When the emerging study findings were presented to some of the district nurses who cared for the study participants, and my own district nurse colleagues, several nurses challenged some of those findings. In particular, agreement was not reached as to whether leg ulcer patients really want their ulcers to heal. These nurses did not have access to the study data, and their opinions were based on their own previous experiences and assumptions.

When I originally designed this study I was unaware of the impact the ulcers had on other family members. Several of the study participants had a spouse present at the time of their interviews, and the input of those partners was invaluable. It is to be regretted that the family members of the other study participants did not also have the opportunity to contribute to the study.

This study has examined the chronic leg ulcer experience from the perspective of the patients. They have reflected on many aspects of their experiences, including their interactions with many health professionals, particularly district nurses. Those health professionals have not had the opportunity to contribute to this examination of the illness experience. For this reason, I do not wish to suggest specific changes that need to be made to nursing practice, but rather to identify some areas where reflection on practice is required, and areas where research and further education are indicated.

AREAS FOR FURTHER EDUCATION AND RESEARCH

There is very little published New Zealand information relating to leg ulcers. There are no published epidemiological studies; and while local statistics may be available, no national information exists relating to the provision of treatment and the associated financial costs. As resources are now located on the basis of demonstrated need there is an urgent requirement for information to be collected that will provide an overall picture of the extent of the incidence of leg ulcers in New Zealand; the present resources being expended on their care, and the identification of the initiatives that would improve the management of these wounds within the New Zealand context.

English surveys by Roe et al. (1993) and Ertl (1992) investigated the management of leg ulcers by community nurses, and identified areas for further research, and educational needs. Many of the findings of Roe et al. (1993) would appear to have application for the district nurses caring for the participants in this study, such as the failure by more than half of the nurses to assess pain levels. They describe (p. 305) how few nurses realised that leg elevation was contraindicated when arterial disease was present, with 41% of the nurses advising their patients with arterial ulcers to elevate their legs. While for the purposes of this study I made no attempt to formally establish the aetiology of the study participant's ulcers, it would appear from the symptoms they were experiencing (such as pain on elevation of the limb) that several participants had ulcers with an arterial component, but they were still being advised to elevate their leg(s).

Over the past two decades, leg ulcer management has changed dramatically, and there is now an extensive range of treatment options for nurses to select from (Flanagan, 1994). Walsh and Ford (1989) describes how the wound management practices of many nurses "leaves much to be desired. It is outdated, ritualistic, and lacking foundation in fact or research" (p. 33).

Williams (1984) suggests that "so much of what passes for knowledge among health care professionals ... contains unexamined assumptions elevated to the status of knowledge through the power of established professional convention" (p. 94). To date, there have been no published New Zealand surveys of the management practices of nurses in relation to leg ulcers. There is presently no national training course available for nurses to update their knowledge base relating to leg ulcer management, and educational needs are unknown.

The effective management of leg ulcers is a complex task, particularly with the burgeoning number of wound care products available, and in light of the identified difficulties of keeping up to date with wound care developments. A multi-disciplinary approach to wound management is needed, and it is likely that considerable resources will be necessary to establish, staff and maintain such an approach.

It is unlikely that appropriate resources will be allocated in New Zealand in the immediate future because of the paucity of information presently available to justify such expenditure. Research is required to examine current practices, identifying strengths and weaknesses. Consideration can then be given to establishing comprehensive assessment and treatment protocols. Also required are wound education courses, such as those developed in the United Kingdom, and described by Flanagan (1994) and Moffatt and Oldroyd (1994). An English leg ulcer management course, detailed by Moffatt and Karn (1994), was devised to meet the specific needs of district nurses, and includes education on research-based leg ulcer management, together with broader professional issues pertaining to autonomous practice.

Further research is also required to determine and enhance the accuracy of nurses' perceptions of patients' needs so that nursing practice can be more appropriately tailored to meet those needs. Farrell (1991) studied the accuracy of perceptions of general and psychiatric nurses in an English hospital, and found that nurses may be basing their assessments on stereotypes, rather than on an individual basis. Health professionals have been slow to identify the specific needs of leg ulcer patients, and this study is one of but a few studies to date that have sought to examine patients' perspectives of the leg ulcer experience. Grocott (1993), in a case-study of a patient with an ulcerating and fungating breast wound, found nurses had underestimated the patient's perception of problems such as discomfort associated with the dressings, wound odour and exudate. Similar comments made by some of the participants in this study suggest that some needs had not been identified by their nurses.

Also required is further research into ways to construct shared worlds of meaning between the nurse and patient (Toombs, 1992), to enable the illness experience to be more fully understood by nurses. This would facilitate the provision of treatment regimes better tailored to individual patient need because the impact of the illness, rather than wound management, would become the focus of care.

The majority of study participants had been able to gradually adjust to the presence of their chronic wounds, and develop strategies whereby life could continue. Currently little is known about how this sense of 'normality' develops, and what can be done to assist these patients maintain their quality of life. Further research is needed to help nurses identify the critical factors that facilitate adaptation to chronic leg ulcers, and how to utilise and enhance the coping resources of these patients (Flett et al., 1994).

Finally, strategies must be developed that will allow district nursing clients some choice over which nurse provides their care. In her study of patients' perceptions of district nursing care, Young (1989) identified how "nursing care is often organized to suit nurses and little credence has been given to client's [sic] wishes in that respect" (p. 134). Young described how important continuity of nurses was to her study participants, which was also a finding of this study. When close relationships had developed over a period of time, a sense of loss was experienced when they were allocated a new nurse, particularly when that nurse appeared unfamiliar with their wound management.

In this study there were also, infrequently, times when the nurse-patient relationship was problematic. It would be very difficult for patients to express their dissatisfaction with a particular nurse without feeling that they may jeopardise their future treatment in some way. It is also difficult to see just how the present system could be reorganised to allow the patients some degree of control over which nurse visits them, but it is an issue that was consistently raised by study participants, and is obviously of importance to them.

In Chapter Two I outlined the confusion that currently exists about what actually constitutes a chronic illness and how various categorisations were used interchangeably. Benner and Wrubel (1989) discuss the role of symptoms in chronic illness, and how "through careful management, a chronically ill person can achieve an adaptation to his or her illness that in some ways resembles the smooth running bodily experience of the healthy person" (p. 208). This has indeed been the case for most of the study participants, who have been able to manage their illness to the extent that they consider themselves healthy, despite the existence of a chronic condition.

If illness, as defined by Benner and Wrubel (1989) is "the human experience of loss or dysfunction" (p.xii) the question now is - do these study participants indeed have a chronic illness? Obviously the chronic disease state still exists, but they may no longer be experiencing loss or dysfunction. There does not appear to be an appropriate illness/disease category which could be used to describe this particular health state. Existing categories need further refining so that standardisation of application is established, and research undertaken to determine if any of those present categories accurately reflect the realities of the lived experience of the study participants. If terminologies are applied consistently, the results of such studies can then be compared for commonalities and differences, and together contribute to a greater understanding of the experience of chronic illness. Such contributions are unlikely while purported studies of chronic illness are in fact studies of chronic disease.

CONCLUDING STATEMENT

There is a paucity of literature on chronic illness experience, which is only just beginning to receive attention from nurse researchers. Much of the considerable literature on leg ulcers has focused on wound management, failing to acknowledge the disruption to the embodied self that chronic illness creates.

A case has been presented for New Zealand research on the incidence and management of leg ulcers, so that resources can be made available to provide a more comprehensive approach to leg ulcer management, and identify the educational needs of health professionals involved in this complex area.

This study has exposed this particular illness to phenomenological scrutiny to reveal the previously invisible essential structures that comprise the experience. A picture has emerged of chronic suffering, and of the work required to allow a relatively normal life to continue. Leg ulcers have been shown to affect virtually every aspect of daily life, with treatment regimes adding to this disruption. The lives of both the study participants, and their families, have been reshaped by the demands of the ulcers.

A failure by health professionals to see this chronic illness experience from the perspective of those undergoing it has led to many significant issues, such as pain management, being neglected. In discussions in the literature, the failure of wounds to heal has not been attributed to any shortcomings by health professionals, but apportioned to the patient, who must 'need' the ulcer to continue, and will not always comply fully with the treatments prescribed for them. As this study has demonstrated, compliance is not a clear-cut issue for the patient, who must balance the possible benefits of treatment regimes against the disruptions such regimes may bring.

Health professionals must guard against focusing on wound management to the detriment of seeing the whole person in context, thereby being able to appreciate more fully the impact of the ulcers and their treatments.

"Nursing practice is essentially and fundamentally about people's experiences of embodied existence, particularly at those times when the body fails to function normally" (Lawler 1991, p. v-vii). This study has provided an insight into what it actually means to live with chronic leg ulceration. It challenges the current myths, and provides direction for the provision of nursing care which will more appropriately focus on the person in the situation, not just on the wound.

REFERENCES

- Allen, M., Hourston, R., Shorey, B., Ward, J. & Thomas, D.J.B. (1993). Two year audit of a nurse supervised leg ulcer clinic in a district general hospital, *Journal of Wound Care*, 2 (5); 289-292.
- Allen, S. (1985). Leg ulcers and their management, *Nursing Times*, 81 (25); 49-56.
- Allen, S. (1988). Ulcers: Treating the cause, *Nursing Times*, 84 (51); 62-63.
- Anderson, R. & Bury, M. (1988). Introduction in R. Anderson & M. Bury (Eds), *Living with chronic illness: The experience of patients and their families*, London, Unwin Hyman; 1-13.
- Antrobus, M. (1982). Care study - venous ulcers: A lot of care, *Community Outlook*, 8 (2); 346-353.
- Baker, S.R. & Stacey, M.C. (1994). Epidemiology of chronic leg ulcers in Australia, *Australian and New Zealand Journal of Surgery*, 64; 258-261.
- Baker, S.R., Stacey, M.C., Jopp-McKay, A.G., Hoskin, S.E. & Thompson, P.J. (1991). Epidemiology of chronic venous ulcers, *British Journal of Surgery*, 78; 864-867.
- Beck, C.T. (1992). The lived experience of postpartum depression: A phenomenological study, *Nursing Research*, 41 (3); 166-170.
- Benner, P. (1984). *From novice to expert: Excellence and power in clinical nursing practice*, Menlo Park, Ca., Addison-Wesley.

- Benner, P. (1985). Quality of life: A phenomenological perspective on explanation, prediction, and understanding in nursing science, *Advances in Nursing Science*, 8 (1); 1-14.
- Benner, P. (1994). The tradition and skill of interpretive phenomenology in studying health, illness, and caring practices, in P. Benner, (Ed.), *Interpretive phenomenology*, Thousand Oaks, Ca., Sage; 99-125.
- Benner, P. & Wrubel, J. (1989). *The primacy of caring: Stress and coping in health and illness*, Menlo Park, Ca., Addison-Wesley.
- Bergum, V. (1991). Being a phenomenological researcher in J.M. Morse (Ed) *Qualitative nursing research: A contemporary dialogue (revised edition)*, Newbury Park, Ca., Sage Publications; 55-71.
- Bosanquet, N. (1992). Costs of venous ulcers: From maintenance therapy to investment programmes, *The Venous Forum of the Royal Society of Medicine and Societas Phlebologica Scandinavica*, Phlebology Supplement (1) ; 44-46.
- Brody, H. (1987). *Stories of sickness*, New Haven, Yale University Press.
- Bury, M. (1988). Meanings at risk: The experience of arthritis, in R. Anderson, and M. Bury, (Eds), *Living with chronic illness: The experience of patients and their families*, London, Unwin Hyman; 89-116.
- Bryant, R.A. (1992). *Acute and chronic wounds: Nursing management*, St. Louis, Mosby-Year Book Inc.

- Callam, M.J., Harper, D.R., Dale, J.J. & Ruckley, C.V. (1987). Arterial disease in chronic leg ulceration: an underestimated hazard? Lothian and Forth Valley leg ulcer study, *British Medical Journal*, 294; 929-931.
- Callam, M.J., Harper, D.R., Dale, J.J. & Ruckley, C.V. (1988). Chronic leg ulceration: socio-economic aspects, *Scottish Medical Journal*, 33; 358-360.
- Callam, M.J.; Ruckley, C.V.; Harper, D.R. & Dale, J.J. (1985). Chronic ulceration of the leg: extent of the problem and provision of care, *British Medical Journal*, 290; 1855-1856.
- Callam, M.J.; Ruckley, C.V.; Dale, J.J. & Harper, D.R. (1987). Hazards of compression treatment of the leg: an estimate from Scottish surgeons, *British Medical Journal*, 295; 1382.
- Cameron, J. (1991). Using Doppler to diagnose leg ulcers, *Nursing Standard*, 40 (5); 25-27.
- Chapple, J. (1994). Assisting wound healing, *New Zealand Practice Nurse*, (March); 65-68.
- Conrad, P. (1990). Qualitative research on chronic illness: A commentary on method and conceptual development, *Social Science and Medicine*, 30 (11); 1257-1263.
- Cornwall, J. (1985). Diagnosis of leg ulcers, *Journal of District Nursing*, 4 (3); 4-11.
- Cornwall, J.V., Doré, C.J. & Lewis, J.D. (1986). Leg ulcers: epidemiology and aetiology, *British Journal of Surgery*, 73; 693-696.

- Coulehan, J.L. (1992). Pearls, pith and provocation: Teaching the patient's story, *Qualitative Health Research*, 2 (3); 358-366.
- Cullum, N. (1994). *The nursing management of leg ulcers in the community: A critical review of research*. Report produced for the Department of Health by Department of Nursing, University of Liverpool, England.
- Cuzzell, J.Z. and Stotts, N.A. (1990). Trial and error yields to knowledge, *American Journal of Nursing*, (October); 53-60.
- Diamond, M. & Jones, S.L. (1983). *Chronic illness across the lifespan*, Norwalk, Conn., Appleton-Century-Crofts.
- Ertl, P. (1992). How do you make your treatment decision?, *Professional Nurse*, 7 (8); 543-552.
- Ertl, P. (1993a). Planning a route to treatment: a framework for leg ulcer assessment, *Professional Nurse*, 8 (10); 675-679.
- Ertl, P. (1993b). The multiple benefits of accurate assessment: Effective management of leg ulcers, *Professional Nurse*, 9 (2); 139-144.
- Farrell, G.A. (1991). How accurately do nurses perceive patients' needs? A comparison of general and psychiatric settings, *Journal of Advanced Nursing*, 16; 1062-1070.
- Flanagan, M. (1994). Assessment criteria: Education, wound assessment, *Nursing Times*, 90 (35); 76-88.

- Flett, R., Harcourt, B. & Alpass, F. (1994). Psychosocial aspects of chronic lower leg ulceration in the elderly, *Western Journal of Nursing Research*, 16 (2); 183-192.
- Gadow, S. (1985). Nurse and patient: The caring relationship in A.H.Bishop and J.R.Scudder, (Eds), *Caring, curing, coping: Nurse, physician, patient relationships*, The University of Alabama Press; 31-43.
- Garro, L.C. (1994). Narrative representations of chronic illness experience: Cultural models of illness, mind, and body in stories concerning the temporomandibular joint (TMJ), *Social Science and Medicine*, 38 (6); 775-788.
- Gerhardt, U. (1990). Qualitative research on chronic illness: The issue and the story, *Social Science and Medicine*, 30 (11); 1149-1159.
- Grocott, P. (1993). Practical changes, *Nursing Times*, 89 (7); 64-70.
- Hamer, C., Cullum, N.A. & Roe, B.M. (1994). Patients' perceptions of chronic leg ulcers, *Journal of Wound Care*, 3 (2); 99-101.
- Higgins, C.S. (1983). Caring for the elderly at home, *The New Zealand Nursing Journal*, 76 (10); 14-15.
- Hunt, L.M., Jordan, B., Irwin, S. & Browner, C.H. (1989). Compliance and the patient's perspective: Controlling symptoms in everyday life, *Culture, Medicine and Psychiatry*, 13; 315-334.
- Hutchinson, S.A., Wilson, M.E. & Skodol Wilson, H. (1994). Benefits of participating in research interviews, *IMAGE: Journal of Nursing Scholarship*, 26 (2); 161-164.

- Hyland, M.E., Ley, A. & Thomson, B. (1994). Quality of life of leg ulcer patients: Questionnaire and preliminary findings, *Journal of Wound Care*, 3 (6); 294-298.
- Jasper, M.A. (1994). Issues in phenomenology for researchers of nursing, *Journal of Advanced Nursing*, 19; 309-314.
- Kane, K. (1990). Prompt action on leg ulcers, *Community Outlook*, (November); 25-28.
- Larkin, J. (1987). Factors influencing one's ability to adapt to chronic illness, *Nursing Clinics of North America*, 22 (3); 535-541.
- Lawler, J. (1991). *Behind the screens: Nursing, somology, and the problem of the body*, Melbourne, Churchill Livingstone.
- Leonard, V.W. (1994). A Heideggerian phenomenological perspective on the concept of person, in P. Benner (Ed.), *Interpretive phenomenology*, Thousand Oaks, Ca., Sage; 43-63.
- Lindholm, C., Bjellerup, M., Christensen, O.B. & Zederfeldt, B. (1992). Leg and foot ulcers: Nursing care in Malmö, Sweden, *Acta Dermato Venerologica (Stockholm)*, 72; 224-226.
- Lindholm, C., Bjellerup, M., Christensen, O.B. & Zederfeldt, B. (1993). Quality of life in chronic leg ulcer patients: An assessment according to the Nottingham Health Profile, *Acta Dermato Venerologica (Stockholm)*, 73; 440-443.
- Lubkin, I.M. (1990). *Chronic illness: Impact and interventions* (2nd Ed.), Boston, Jones and Bartlett Publishers.

- Madjar, I. (1991). Pain as embodied experience: A phenomenological study of clinically inflicted pain in adult patients, Unpublished PhD dissertation, Department of Nursing Studies, Massey University, Palmerston North, New Zealand.
- Mechanic, D. (1978). *Medical sociology*, New York, Macmillan Publishing Co.
- Moffatt, C.J., Franks, P.J., Oldroyd, M., Bosanquet, N., Brown, P., Greenhalgh, R.M. & McCollum, C.N. (1992). Community clinics for leg ulcers and impact on healing, *British Medical Journal*, 305; 1389-92.
- Moffat, C.J. & Karn, E.A. (1994). Answering the call for more education: Development of an ENB course in leg ulcer management, *Professional Nurse*, 9 (10); 708-712.
- Moffatt, C.J. & Oldroyd, M.I. (1994). A pioneering service to the community: The Riverside community leg ulcer project, *Professional Nurse*, 9 (7); 486-494.
- Morgan, D. (1991). Practice in nursing homes, *Nursing Times*, 87 (49); 58-60.
- Morris, W.T. (1984). Management of leg ulcers, *Patient Management*, (May); 79-88.
- Morris, W.T. (1993). Management of leg ulcers, *New Zealand Practice Nurse*, (September); 56-61.

- Morse, J.M. (1991). Strategies for sampling in J.M. Morse (Ed), *Qualitative nursing research: A contemporary dialogue* (revised edition), Newbury Park, Ca., Sage Publications; 127-145.
- Morse, J.M. & Johnson, J.L. (1991). Toward a theory of illness: The illness-constellation model in J.M. Morse and J.L. Johnson (Eds) *The illness experience: Dimensions of suffering*, Newbury Park, Ca., Sage Publications; 315-341.
- Munhall, P.L. & Oiler, C.J. (1986). Epistemology in nursing in P.L. Munhall & C.J. Oiler (Eds), *Nursing research: A qualitative perspective*, Norwalk, Conn., Appleton-Century-Crofts; 27-46.
- Negus, D. (1991). *Leg ulcers: a practical approach to management*, Oxford, Butterworth-Heinemann Ltd.
- Nelzen, O., Bergqvist, D. & Lindhagen, A. (1994). Venous and non-venous leg ulcers: Clinical history and appearance in a population study, *British Journal of Surgery*, 81; 182-187.
- Packard, N.J., Haberman, M.R., Woods, N.F. & Yates, B.C. (1991). Demands of illness among chronically ill women, *Western Journal of Nursing Research*, 13(4); 434-457.
- Paterson, B. (1986). The experience of acute illness: Whose experience?, *Nursing Praxis in New Zealand*, 1(4); 3-8.
- Pottle, B. (1987). Trial of a dressing for non-healing ulcers, *Nursing Times*, 83 (12); 54-58.

- Register, C. (1987). *Living with chronic illness: Days of patience and passion*, New York, The Free Press.
- Riordan, C.A. (1991). The management of venous ulcers of the legs, *Australasian Journal of Dermatology*, 32; 111-116.
- Roberson, M.H.B. (1992). The meaning of compliance: Patient perspectives, *Qualitative Health Research*, 2 (1); 7-26.
- Robinson, I. (1990). Personal narratives, social careers and medical courses: Analysing life trajectories in autobiographies of people with multiple sclerosis, *Social Science and Medicine*, 30 (11); 1173-1186.
- Roe, B.H., Luker, K.A., Cullum, N.A., Griffiths, J.M. & Kenrick, M. (1993) Assessment, prevention and monitoring of chronic leg ulcers in the community: Report of a survey, *Journal of Clinical Nursing*, 2; 299-306.
- Rudolph, R. (1983). Natural wound healing processes in R. Rudolph and J.M. Noe (Eds) *Chronic problem wounds*, Boston, Little Brown and Co.;1-7.
- Rummel, L. (1993). The proving ground: The lived world of nursing students in their pre-registration clinical experience, unpublished M.A. thesis, Department of Nursing Studies and Midwifery, Massey University, Palmerston North, New Zealand.
- Ryan, T.J. (1987). *The management of leg ulcers* (2nd ed), Oxford, Oxford University Press.
- Sandelowski, M. (1986). The problem of rigor in qualitative research, *Advances in Nursing Science*, 8 (3); 27-37.

- Sandelowski, M. (1993). Rigor or rigor mortis: The problem of rigor in qualitative research revisited, *Advances in Nursing Science*, 16 (2); 1-8.
- Shami, S.K., Shields, D.A. , Scurr, J.H. & Coleridge Smith, P.D. (1992). Leg ulceration in venous disease, *Postgraduate Medical Journal*, 68; 779-785.
- Smeltzer, S.C. (1991). Use of the trajectory model of nursing in Multiple Sclerosis, *Scholarly Inquiry for Nursing Practice: An International Journal*, 5 (3); 219-233.
- Stotts, N.A. (1986). Impaired wound healing, in V.K. Carrieri; A.M. Lindsey and C.M. West (Eds) *Pathophysiological phenomena in nursing human responses to illness*, Philadelphia, W.B. Saunders; 343-366.
- Strauss, A.L. (1975). *Chronic illness and the quality of life*, St. Louis, C.V. Mosby.
- Strauss, A.L. (1987). Health policy and chronic illness, *Society*, Nov/Dec; 33-39.
- Swanson-Kauffman, K. & Schonwald, E. (1988). Phenomenology in B. Sarter (Ed) *Paths to knowledge: Innovative research methods for nursing*, New York, National League for Nursing; 97-105.
- Taylor, S. & Hoile, A. (1986). Treating chronic venous ulcers, *Nursing Times*, 82 (22); 33-37.
- Thomas, S. (1989). Pain and wound management, *Community Outlook*, (July); 11-15.

- Thompson, J.L. (1990). Hermeneutic inquiry in L.E. Moody (Ed), *Advancing nursing science through research, Vol. 2.*, Newbury Park, Ca., Sage publications; 223-286.
- Toombs, S.K. (1992). *The meaning of illness: a phenomenological account of the different perspectives of physician and patient*, The Netherlands, Kluwer Academic Publishers.
- Van Manen, M. (1990). *Researching lived experience*, London, Ontario, The Althouse Press.
- Van Toller, S. (1994). Invisible wounds: the effects of skin ulcer malodours, *Journal of Wound Care*, 3 (2); 103-105.
- Venn, G. & Fox, A. (1987). Leg ulcers: Pointers to management, *Nursing Times*, 83 (12); 49-52.
- Wallace, G. (1993). The systematic approach to selecting the appropriate dressing, *New Zealand Practice Nurse*, (December); 50-56.
- Walsh, M. & Ford, P. (1989). *Nursing rituals, research and rational actions*, Oxford, Heinemann Nursing.
- Watt, S. (1993). Managing venous ulcers, *Nursing New Zealand*, 1 (5); 12-16.
- Williams, R.S. (1984). Ability, dis-ability and rehabilitation: A phenomenological description, *The Journal of Medicine and Philosophy*, 9; 93-112.
- Wise, G. (1986a). The social ulcer, *Nursing Times*, 82 (21); 47-49.

- Wise, G. (1986b). Overcoming loneliness, *Nursing Times*, 82 (22); 37-42.
- Young, T. (1994). Treatment of mixed aetiology leg ulcers, *British Journal of Nursing*, 3 (12); 598-601.
- Young, A.W. (1989). District nursing clients: Perceptions of participation in nursing care, Unpublished M.A. thesis, Department of Nursing Studies, Massey University, Palmerston North, New Zealand.

APPENDIX A: Technical Glossary

Alginate dressings	Sterile non-woven primary dressing, made from seaweed (Sorbsan™ and Kaltostat™). Wound exudate is drawn into the fibres which then swell to form a gel. Highly absorbent. Secondary dressing required.
Anti-emetic	Medication to prevent nausea and vomiting.
Aspro™	Asprin. Antipyretic/analgesic. Available without a doctor's prescription.
Digesic™	Dextropropoxyphene napsylate and paracetamol. Non-narcotic antipyretic/analgesic. Prescription item.
District nurse	Registered, comprehensive or enrolled nurse who undertakes domiciliary nursing care. Normally employed by Crown Health Enterprises (formerly Area Health Boards), although there are now some private district nursing services.
Doppler ultrasound	Used for the objective assessment of the arterial and venous circulation. A probe (transducer) is used to externally scan the area above the artery or vein to be assessed.
Enrolled nurse	A nurse who has undergone an eighteen-month (previously twelve months) education programme in a hospital school of nursing.
Film membrane	Thin, semi-permeable, hypoallergenic, adhesive coated film dressing (Tegaderm™, Op-site™) Can be either a primary or secondary dressing.
Hydrocolloid dressings	Self-adhesive, waterproof dressing (Comfeel™ and Duoderm™) which interacts with wound exudate. Secondary dressing not required.
Hydrogel	Sterile gel (e.g. Intra-site Gel™, Duoderm Gel™) which absorbs excess exudate and produces a moist wound environment .

Ischaemic disease	Disease arising from insufficient blood supply to a specific area.
Panadol™	Paracetamol. Antipyretic/analgesic. Available without a doctor's prescription.
Practice nurse	Registered nurse who works with a general medical practitioner. The majority of their work is undertaken at a health centre/clinic/surgery, but occasional home visits are made.
Registered nurse	A nurse who has undergone a three-year education programme in a hospital school of nursing. This education has now moved to Polytechnic Schools of Nursing, and the graduates of this educational programme are known as comprehensive nurses.
Secondary intention	Wound edges are not approximated, and healing occurs by the wound granulating up from its depths.
Venogram	Radiographic examination of the venous system using the injection of a contrast medium.

References:

- Flanagan, M. (1993). Notes from workshop on wound management, Palmerston North, New Zealand.
- Greaney, M. (Ed) (1990). *New Ethicals Catalogue*, Auckland, Adis International, 27 (2).
- Keachie, J. (1992). Making sense of: Doppler ultrasound, *Nursing Times*, 88 (10); 54-56.
- Moidel, H.C., Giblin, E.C. & Wagner, B.M. (1976). *Nursing care of the patient with medical-surgical disorders* (2nd Ed), New York, Blakiston, McGraw-Hill.
- Roper, N. (1966). *Livingstone's Dictionary for Nurses, (12th Ed)*, Edinburgh, R & S Livingstone Ltd.

APPENDIX B: Information Sheet for District Nurses**“LIVING WITH CHRONIC LEG ULCERS” - A STUDY**

Although there have been many studies looking at different treatments for chronic leg ulcers, there is little information available about what it is like to live with those ulcers.

As part of my Master’s Degree (Nursing), I am carrying out research in to the experiences of living with chronic leg ulcers.

The district nurses are being asked to distribute information about my study to possible participants, and to supply me with the names and phone numbers of anyone who is prepared to discuss the study in more detail with me. I wish to stress that no pressure should be brought to bear in asking your patients to take part.

This study has been approved by the Ethics Committee of Massey University and [name of Ethics Committee for the Crown Health Enterprise], and I have also been given approval for access to district nurse clients from [names of managers of district nursing service].

I will be talking to participants about the ways that leg ulcers have impacted on their lives, and it is likely that some participants will make comments about their experiences with the district nurses. All information that is given to me will remain confidential, and only my supervisor and myself will have access to it.

2.

At the conclusion of my study I am required to supply a report to the [name of Crown Health Enterprise] Ethics Committee. I want to assure you that at no time will it be possible to identify any details of either participants or district nursing staff in the study findings or any reports that will be made.

It is my intention to give a seminar on my findings for the district nurses at the conclusion of my study, and to share with you any information that could result in improved nursing care for these patients.

If you have any other questions about this study I can be contacted in the evenings at phone 32 353 13.

Thank you for your help with this study.

Marian Bland

APPENDIX C: Introductory letter to potential participants

January 1994

My name is Marian Bland, and I am a nurse who is studying for an M.A. (Nursing) degree at Massey University. I am carrying out research into the experiences of people with leg ulcers, and the district nurses have agreed to help me make contact with people who could help me with my study.

I have attached an Information Sheet, and would be pleased if you could consider participating in this study - the experiences of anyone who has leg ulcers are of great interest to me.

If you are prepared to discuss this further with me, the district nurses will give me your name and phone number. I will then contact you by phone, and arrange a time to visit you and explain the study in more detail so you are able to make a decision about whether to participate or not.

Thank you for taking the time to read this letter and the Information Sheet.

Yours sincerely

Marian Bland

APPENDIX D: Information Sheet for Study Participants

STUDY - THE EXPERIENCE OF CHRONIC LEG ULCERS

There are many people in New Zealand who have leg ulcers that take a very long time to heal. Little is known about what it is like living with these ulcers, and the aim of this study is to learn more about this.

If you agree to participate in this study, I would like to talk to you about your experiences with leg ulcers. I expect that this would involve two or three interviews, a total of about four hours altogether. The time and place of the interviews will be arranged to suit your convenience.

It is not expected that there will be any risk or discomfort to you if you take part in this study. Should you feel uncomfortable at any time during the interview, the interview will stop, and you will be offered the opportunity of help to deal with those feelings.

Although there will be no direct benefit to you by taking part in this study, there should be long-term benefits to all patients as nursing knowledge of this subject is increased.

All details about yourself, and any information you give me, will be strictly confidential. There will be no identifying details used in the completed study findings, or any published articles that may arise from the study. The district nurses will not have access to any information you give me.

2.

You are welcome to take time to consider whether you should take part in this study, and to discuss it with other people, such as your family, before you decide whether to participate. I am happy to answer any further questions you have about the study at any time. I can be contacted at Ph. 3235313 (after 5.30 pm or at weekends).

Participation in this study is voluntary. If you do agree to participate, you may resign from the study at any time. You may also refuse to answer any particular questions that you are not happy with.

If you do agree to participate you will be given a summary of the study findings when it is completed, which will identify the contribution you have made to the nursing knowledge on this subject. If you are interested, you will be given a copy of your own interviews. All interview tapes will be erased when the study is completed.

Thank you for taking time to read this Information Sheet, and considering whether to take part in this study.

Marian Bland

**Study Supervisor: Jo-Ann Walton, Department of Nursing Studies and
Midwifery, Massey University. Ph. 356 9099**

APPENDIX E: Consent Form for Study ParticipantsThe Experience of Chronic Leg UlcersConsent Form

Principal Investigator:

Marian Bland

Participant's Name:

Marian Bland has explained to me the reasons for this study and the procedures involved in it.

I have read the study Information Sheet, and my questions have been answered to my satisfaction. I understand that I am able to ask further questions at any time during the study.

I understand that I am free to withdraw from the study at any time, and that such withdrawal will not adversely affect my further care.

I have been assured that my information will remain confidential, and that my identify will not be revealed in any written or verbal reports about the study.

I understand that the study will be discontinued if it appears that it could cause me any risk or discomfort.

2.

I agree / do not agree to take part in this study.

Signed: (participant)/.. date

..... (witness)/.. date

Witness Name (please print)

Statement by Investigator:

I have discussed with the aims and procedures
involved in this study.

Signed: (investigator)

..... (print name)

..... (date)