

ELDERLY PATIENTS WITH SLOW-HEALING

LEG ULCERS -

An Embodied Suffering

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Groblad har PASS, Patient och Anhörigföreningen för Svårläkta Sår som symbol.

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ABSTRACT

The overall aim of this thesis was to investigate leg and foot ulcer patients, from the perspective of a population in a specific urban area, and to illuminate these individual patients' lived experience of living with slow-healing venous leg ulcers. Study (I) was a survey of chronic leg and foot ulcers and study (II) was a follow-up study of the wound healing rate and an intervention study. A structured questionnaire (I) was used, that included; prevalence, level of care, aetiology and wound treatment. In study (II) a questionnaire was distributed, 18 months after the survey. The questionnaire included; wound healing rate, recurrence, amputation and mortality. A further objective was an intervention study of wound healing, with the use of a triple-layer treatment. Descriptive statistics were used to analyse the collected data in these studies (I- II). Data in study (III) and (IV) was collected by interviews with 15 persons suffering from slow-healing venous leg ulcers. Data was analysed by means of the phenomenological-hermeneutic method (III- IV). In the survey (I) 294 patients with leg and foot ulcers were identified, this represents a prevalence of 0.12%. The majority of the patients (92%) were older than 65 years. More than half of the patients were treated in primary health care. Different local wound dressings were used (N=51). Pain was reported from 56% of patients with venous ulcers. After 18 months, 174 patients remained and in 61% of these cases, leg ulcers had healed (II). Twenty-one patients with a non-healed wound had venous insufficiency. The intervention study (II) indicated that slow-healing ulcers could be improved with modern technology and knowledge about the patients' specific risk factors. Risk factors that contributed to a delay in healing were identified as; impaired mobility, pain, pathological skin changes and the impact of arterial aetiology. The results from study III show that living with venous leg ulcers can be understood as a strain between, on the one hand, the feeling of being imprisoned in the body, the bandage and the home, and on the other hand, the hope of freedom from a burdensome body. The elderly people try to find ways to manage pain, uncomfortable bandages, and a disobedient body, but all of these factors influence their activities in everyday life and their social lives. They believe that the wound will heal, even those who suffer from a *slow-healing* wound. In study IV two main themes were identified: a dignified individual and a vulnerable individual under pressure. This study points to the importance of seeing the unique human being, not only a patient with a wound, requiring medical treatment. Care, based on solid evidence, should include assessments of the illness experience and actions to restore trust and confidence among persons involved in wound healing *before* the wound becomes manifest. The findings of this thesis show that more knowledge is necessary. Partly, in relation to the prevalence and treatment of leg ulcers and partly, by reaching an understanding about the embodied suffering among people with painful and slow-healing leg ulcers. Understanding the patients as human beings, in their everyday lives, in accordance with illness as a lived experience, provided the opportunity for care providers to perform skilful wound care, with mutual understanding, that is: an inter-subjective communion.

Key words: communion, dressing change, elderly care, embodiment, intervention, lived experiences, phenomenological-hermeneutic, prevalence, nursing care, slow-healing wound, suffering and venous leg ulcer.

ORIGINAL PAPERS

This PhD thesis is based on the following original papers, which are referred to in the text by their Roman numerals:

- I. Ebbeskog, B., Lindholm, C. & Öhman, S. (1996) Leg- and foot-ulcer patients. Epidemiology and nursing care in an urban population in Stockholm, Sweden. *Scandinavian Journal of Primary Health Care* **14**, 238-243.
- II. Ebbeskog, B., Lindholm, C., Grauers, M. & Öhman, S. (1999) A follow-up study of leg ulcer patients in South Stockholm. *Journal of Wound Care* **8**, (4), 170-174.
- III. Ebbeskog, B. & Ekman, S-L. (2001) Elderly persons' experiences of living with venous leg ulcer: living in a dialectal relationship between freedom and imprisonment. *Scandinavian Journal of Caring Sciences* **15**, 235-243.
- IV. Ebbeskog, B., Emami, A. & Ekman, S-L. More than just a venous leg ulcer: Elderly peoples' experiences of being in a dressing change situation. In manuscript.

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ABBREVIATIONS AND DEFINITIONS

ABPI Ankle Brachial Pressure Index

AN Auxiliary nurse, health care assistants

CVI Chronic venous insufficiency

DN District nurse

GP General practitioner

HCD Hydrocolloid dressing

NHS National Health System

RN Registered nurse

WBP Wound Bed Preparation

Staff The term staff refers to auxiliary nurse, enrolled nurse, registered nurse and district nurse. The term care provider and nursing staff is also used in the thesis. When reporting from other studies I will use the same words or terms that the authors uses.

FOREWORD

The background to this study involved knowledge from my own experience i.e. my pre-understanding as a registered nurse in surgical health care and my experience as a lecturer in nursing care. For many years, I was responsible for education in gerontological nursing, in public health, and in the supervision of nursing students in geriatric and elderly care practices. The nursing students frequently talked with deep affection, about variations in leg ulcer treatment. They stated that each caregiver had their own way of providing treatment and they did not seem to know the cause of the wound. From these valuable insights and reflections from nursing students, and my pre-understanding and knowledge according to the gap between theoretical knowledge and clinical practice, questions were raised for this study. One other reason for this study was my experience as a nurse and a specific encounter that took place during an assessment meeting, while caring for an eighty year-old woman suffering from leg ulcers. A question was raised concerning how it felt to live with a leg ulcer and undergo daily treatment.

During the 1980's, I was a project leader and was involved in initiating individual care planning. In connection with this project, plans were made to incorporate a leg ulcer outpatient clinic. During an assessment conversation with a woman, approximately 80 years old, the woman explained how she hoped that she could invite a childhood friend to lunch at a restaurant. However, she emphasised how embarrassing it was to have a leg ulcer and explained that this humiliation was aggravated when meeting friends. The woman was aware of the unpleasant odour coming from the ulcer and was concerned about what others might think during her visit to the restaurant. According to her lived experience, this idea was inconceivable to her. She was always conscious of the odour and explained how she covered the bandage up "*so it's not on view*". The nursing care situation appeared to be complex and it was difficult to achieve a balance, between treating the leg ulcer and the woman's personal experience of the unpleasant odour and the conspicuous bandage, which she felt attracted people's attention. It was also important, to consider the woman's longing to meet friends at a restaurant for lunch and her hesitation to do so because of the illness experience of everyday living with a leg ulcer.

According to the reflections of nursing students, education in public health and the nurses' pre-understanding, raised issues involving the prevalence, treatment and management of leg

ulcer disease, as well as the individual persons' lived experience. This is something, which I encountered when working in this field. During my work with the two first papers, there was an increasing awareness, that the nursing care situation stands out as problematic wound treatment, as reliable knowledge according to medical science, as well as dealing with patients' lived experiences of illness in everyday life. The process has slowly led to a cautious outlook and exploration, towards an understanding of how elderly persons experience leg ulceration and wound care treatment.

INTRODUCTION

The subject of this thesis, was to investigate the distribution of leg- and foot ulcers, the level of care regarding leg ulcers, wound care, and to illuminate the elderly patients lived experiences of everyday living with leg ulceration during the process of wound treatment. Leg ulcers have often been described as chronic, slow healing or difficult to heal, and the wound has largely been a concealed problem (Lindholm, 2002). Recently, health care systems have begun to acknowledge that this is an important unsolved health-care issue (Fagesjö et al., 1996). With an increased number of elderly people in Sweden, it is important that this problem is recognised. One common figure is that 1% of the population suffers from leg ulcers (Fowkes et al., 2001). Leg ulcers among the elderly, have been underestimated and there are about 50.000 persons with open leg ulcers in Sweden (Nelzén, 1997). During recent decades, studies show that the majority of patients with leg ulcers are elderly, that is, over 65 years old and that these wounds are most commonly associated with venous disease (Lindholm et al., 1992a; Nelzén, 1997; Bergqvist et al., 1999; Marklund et al., 2000; Öien et al., 2000). These leg ulcers can involve months or years of treatment and the recurrence rate is high. Therefore, there is a considerable drain on the resources in health services, as well as considerable suffering for the persons suffering from these ulcers (Nelzén, 1997; Harding et al., 2002). A common myth is that these persons deliberately delay the healing process, in order to maintain social contact (Bland, 1999).

Leg ulcers seem to have an impact on people's daily life. The view of wound treatment today, does not focus on issues, such as specific bandages or dressings, neither is it confined to healing specific ulcers. Instead it focuses on wound care treatment and on knowledge about a

person's uniqueness and their environment and it aims at maintaining this environment and preventing recurrence (Lindholm, 2002; Öien, 2002). This means that evidence-based leg ulcer care, requires a holistic multidisciplinary approach (cf. Eriksson et al., 1999). This requires knowledge about physiology in wound-healing, etiological diagnosis, identification of risk factors and the patients lived experiences of illness, such as leg ulcers. The caring sciences, need the advantages that can be gained, by paying attention to the patients' perspective, such as listening to the persons lived experience of their disease (Clarke, 1999). Caring research, according to Dahlberg et al. (2003) should be taken from the patients' own perspective regarding their health, illness, life-world, and nursing care. Nursing care according to Eriksson's (1997) concept, implies meeting the patient's needs systematically and it is based on illness and diagnosis. Benner (2001) argues, that nursing care, as a practice, requires both explanation and understanding, in connection with adequate treatment, from the patient's lived experience of everyday life.

Leg ulcers

Leg ulcers are a chronic problem, because they are difficult to heal, and there is a high recurrence rate (Lindholm, 2002). Having a chronic leg ulcer, means following a cycle of ulceration, healing and re-ulceration (Nelzén, 1997; Öien, 2002). A common definition of a chronic leg ulcer is: a wound below the knee, including the foot, which does not heal within six weeks (Bergqvist et al., 1999). Leg ulcers can also subdivided into foot ulcers and ulcers above the foot (Nelzén, 1997). A more accurate alternative to the definition is a *slow-healing wound* as most leg ulcers can be healed with modern wound treatment.

Leg ulcers are caused by a variety of underlying conditions and mostly caused by impaired circulation. The predominating causative factor is reported to be venous insufficiency (Nelzén, 1997). Studies in Sweden show that chronic venous insufficiency (CVI) was estimated in between 43 to 54% of all cases (Nelzén, 1997; Öien, 2002). Recent studies have pointed out that CVI was associated with reflux in superficial segments and is potentially for surgical correction (Magnusson et al., 2001; Ruckley et al., 2002). Even if leg ulcers are usually caused by CVI, other aetiological diagnosis, such as arterial diseases, diabetes and rheumatoid diseases have to be considered (Baker et al., 1992; Andersson et al., 1993; Nelzén et al., 1994). The aetiology outlook is more complicated, than one previously thought (Nelzén, 1997). Combined venous and arterial insufficiency is common (Nelzén et al., 1991a;

Baker et al., 1992; Öien et al., 2000), and up to 26% of venous leg ulcers, show a detectable arterial component (Nelzén et al., 1994). The aetiology, of chronic ulcers is multi-factorial (Ruckley, 1998) which means that several aetiological factors operate together (Callam, 1992). In a recent study, in the County of Blekinge, 25 % of ulcer cases consisted of multi-factorial aetiology (Öien, 2002). Though with increasing age leg ulcers often complicate the picture (Baker et al., 1992; Andersson et al., 1993; Nelzén et al., 1994). Ulcers due to hydrostatic pressure (Bjellerup, 1997), vasculitis ulcers, as rheumatoid vasculitis, pyoderma gangrenosum and carcinoma, should also be included into standard aetiologies (Öien et al., 2001). The underlying pathology of a leg ulcer, must be determined before an adequate therapy can be instituted and regularly followed up (Lindholm et al., 1992b; Nelzén et al., 1994).

The difficulties in classifying ulcers are pointed out, where the cause of the ulcers was missing or unknown (Lindholm et al., 1992b; Lindholm et al., 1999; Öien et al., 2000). A study performed from 1993 to 1998- shows that monitoring standards for ulcer aetiology, seems to have led to a decrease in the unknown aetiology from 22% to 6% (Öien et al., 2000) The determination of the underlying pathology lies within the field of medicine, but there has been a tendency that the care of leg ulcer patients has been delegated to nursing staff (Nelzén, 1994; Fagesjö et al., 1996; Husband, 1996; Öien et al., 2000).

Ultrasound Doppler (Doppler), an investigation of Ankle Brachial Pressure Index (ABPI), is seldom used. Although, it is known that making a diagnosis can be difficult, if it is based only on clinical judgement (Nelzén et al., 1994; Öien et al., 2000). In one study, a hand-held Doppler was used in 17.5% of the cases (Lindholm et al., 1999). Doppler is the minimum investigation for measuring blood flow, but Duplex ultrasonography (Duplex scanning) is the most effective non-invasive investigation, to the patient's pathology of the leg ulcer (Gibson, 1998; Ruckley, 1998; Norgren et al., 2000; Coleridge Smith, 2001).

Management of wound treatment

According to Falanga (2000) three components are involved in treating the wound; 1) treating the underlying cause of an ulcer, 2) providing an appropriate dressing to create the optimum local environment for healing and 3) addressing focus on patient-centred concerns. According to Falanga, definition of the changing paradigm concept in wound care - Wound Bed

Preparation (WBP), links treatment to the cause of an ulcer and focuses on three components in local wound care: 1) Debridement, 2) Wound-friendly moist interactive dressings and 3) Bacterial balance (Falanga, 2000; Sibbald et al., 2000).

The standards of care for venous leg ulcers, involve compression therapy and moist wound healing (Rudolph, 2001). According to the international and national consensus document and other guidelines, the following recommendations on venous ulcer treatment should be based upon (Armstrong et al., 1998; Gibson, 1998; Risberg et al., 1998; Falanga, 1999; Norgren et al., 2000):

- Aetiological diagnosis of all patients
- Assessment of the patient by nurse and physician and re-evaluation every month, including continuous documentation
- Ankle Pressure Index by ultrasound for all patients or Ultrasound Doppler investigation
- Reduction of dressing changes, with as few types of dressings as possible
- Standardisation of local wound dressing

In Sweden, great variation in the management of wounds has been found, with regard to topical treatment and in one study, (Lindholm et al., 1999) 113 different types of dressings were reported. In recent years, graduated compression has come to be the most important conservative treatment of venous ulcers (Cullum & Roe, 1998). Compression, as a treatment for CVI was reported to be absent in 40% of all cases (Lindholm et al., 1999).

Epidemiology of leg ulcer patients

It is important for society to have knowledge about the prevalence and distribution of leg ulcers within health care services. Leg ulceration is not a new public health problem (Nelzén, 1994). One often referred to figure, is that approximately 1% of the population in the Western World will suffer from leg ulceration, open or healed, at some point in their lives (Callam, 1992; Fowkes et al., 2001). The prevalence of leg ulceration during the last decades seems to vary between and within countries. The size of the problem is different between populations throughout the world. This variation also depends on the different definition of leg ulcers. There are also different sampling methods, as well as variations in age groups among populations. (Nelzén, 1997).

In Sweden, the number of patients with leg ulcers is not decreasing (Nelzén, 1997). Prevalence in the county of Blekinge was reported as being 0.19% in 1998 (Öien et al., 2000). This was slightly higher compared to a study in Malmö, where prevalence was reported to be approximately 0.12% (Lindholm et al., 1992a). The prevalence of open leg and foot ulcers varies between 0.11% and 0.32% (Andersson et al., 1984; Nelzén et al., 1991a; Lindholm et al., 1992a; Nelzén et al., 1994; Fagesjö et al., 1996; Lindholm et al., 1999; Marklund et al., 2000; Öien et al., 2000). Nelzén (1997) concluded that the actual number of people suffering from open and healed leg ulcers, is likely to be at least twice as high as shown in studies and it has been estimated that about 2% of the population in Sweden, may have leg ulcers (open or healed) at any time. In Western countries, the general point prevalence for patients with leg ulcers, known to health care professionals, is estimated to range from between 0.1% to 0.3% (Andersson et al., 1984; Cornwall et al., 1986; Nelzén et al., 1991; Baker et al., 1992; Callam, 1992; Lees & Lambert, 1992; Lindholm et al., 1992a; Nelzén et al., 1994; Fagesjö et al., 1996; Lindholm et al., 1999; Marklund et al., 2000; Öien et al., 2000). The highest prevalence was found in Sweden, where the point prevalence of venous leg ulcers was 0.16% (Nelzén et al., 1994).

Age and sex distribution

The relationship between the elderly and leg ulcers is obvious. The prevalence of leg ulcers increases with age and there is a marked increase in the number of patients with leg ulcers. In Swedish studies, the peak prevalence was reported to be around the age of 80 (Andersson et al. 1984; Nelzén et al., 1991; Lindholm et al., 1992a; Nelzén et al., 1997; Lindholm et al., 1999; Öien et al., 2000). In Sweden, the total prevalence in an elderly rural population, involving open or healed leg ulcers, in persons aged 70 years or older, was 12.6 % (Marklund et al., 2000). Chronic lower limb ulcers are a growing problem in the Western World, due to the ageing population (Baker et al., 1992; Lees & Lambert, 1992). In the UK- the percentage of people aged over 75 years, will increase from the current figure of 16% to 20.5% by the year 2021 and this age group has the highest leg ulcer prevalence (Thorne, 2000). Although, in the US the prevalence of venous leg ulcers in those aged 65 years or older was 1.69% (Margolis et al., 2002). Leg ulceration is predominantly a problem, which affects the elderly, even though it has been reported by Nelzén et al., (1996) that persons taking care of their ulcers by themselves, were most commonly identified among the younger population.

Recent studies in Sweden show that females only slightly outnumbered men and according to Nelzén et al. (1996) the gender ratio was 1:1.6 (Male: Female). In the US- the overall incidence rate among people suffering from venous leg ulcers, among those older than 65 years, was 0.76 for men and 1.42 for women (Margolis et al., 2002). An Italian epidemiological study, reported that females outnumbered men, 35% and 17% respectively (Canonica et al., 1998). However, it has been shown that men feel more ashamed of leg ulcers, compared to women and they also feel more emotionally disturbed by leg ulcers than women (Phillips et al., 1994; Lindholm et al., 1995b).

Survival

An increase in mortality has been shown among dermatological outpatients and the rate was twice as high, for the same age group in the population (Hansson et al., 1987). A five- year follow-up study shows a figure of 52% survival rate for leg ulcer patients. Patients with non-venous ulcers had a higher mortality rate than expected (Nelzén et al., 1997). The higher mortality among people with non-venous ulcers is mainly caused by cardiovascular disease (Andersson et al., 1987; Nelzén et al., 1997) and probably also diabetes (Nelzén et al., 1997).

Wound healing rate and risk-factors

Healing of the leg ulcer can take months, years or even decades. Hansson et al., (1987) reported that 16% of cases had open ulcers, throughout a three-year period. In a long-term study lasting 54 months, 38% of all the cases, still had open ulcers. The prognosis for wound healing was the lowest among patients with venous ulcers, only 44% were healed throughout a four and half year period (Nelzén et al., 1997).

The healing rate can be documented in several ways. Ulcer size and duration have been used to predict time for healing (Margolis et al., 1999). Studies in the UK- show that wounds healed rapidly in a smaller initial ulcer, in ulcers involving a shorter duration, among those who were younger and among those with no deep vein involvement (Moffatt et al., 1992; Franks et al., 1995). In the UK it has been demonstrated that three-month healing rates could be improved from 22% at baseline to 80% after three years, with four-layer bandaging at community leg ulcer clinics (Moffatt & Dorman 1995). However, Harding et al., (2002) showed that many factors impair healing for example, pain and oedema. Local factors, such as foreign bodies, tissue maceration, ischemia and infection and also system factors, such as

malnutrition, diabetes and renal disease, are important risk factors in wound healing. In addition to this, a reduction in active growth factors, an imbalance between proteolytic enzymes and their inhibitors and senescent cells, all seem to influence the wound -healing rate.

The risk of recurrence is high and has been reported to occur in the majority of cases, with variation in time spans after healing (Moffatt et al., 1992; Franks et al., 1995; Ruckley, 1997). Regular follow-up is essential after healing. The prevention of recurrence is one important aspect, involved in the treatment of venous leg ulcers and recurrence could be avoided with the use of compression hosiery and regular elevation of the leg. However, a systematic review relating to prevention of recurrence in venous ulceration, shows weak evidence that using compression hosiery reduces the recurrence rate and there is also insufficient evidence that exercise or leg elevation helps (Nelson, 2001).

Franks et al., (1995) reported that risk factors such as age, social isolation, size and duration of ulcer, oedema, pain, recurrence and lack of continuity in the treatment, delayed wound healing. In the relationship between the healing of natural wounds and anxiety and depression, it has been reported that depression can delay the healing process (Cole-King & Harding, 2001). The researchers also noted that; indirect factors might delay healing among depressed individuals. These factors included; self-neglect, disturbed sleep and poor appetite. Tonge (1995) suggested that by taking into consideration the persons' perceptions' and lifestyles when planning wound care, improvements might be made. But further research is needed, to gain a deeper understanding of the experience and processes involved for persons with leg ulcers.

Economical aspects regarding wound management

The management of slow-healing wounds represents a major burden on healthcare resources (Harding et al., 2002). It has been estimated that the treatment of leg ulcer care in Sweden, costs about two billion Swedish crowns (SEK) (~£150 million) per annum, roughly 1.5% of the total health care budget (Fagesjö et al., 1996). In the County of Blekinge, an average of 7% of the nurses' time is spent on wound management in primary and community care with leg ulcer patients (Öien, 2000). The major expense for wound management, was shown to be the amount of time nurses spent on patients, while working in primary health care. Savings in

costs (SEK 22,000 per annum and patient) can be obtained, if the number of dressing changes can be reduced, with the use of modern, hydrocolloid dressings, instead of the saline gauze that is used in primary care (Ohlsson et al., 1994). Nelzén et al., (1994) stated that five million dressing changes take place every year in Sweden. It is estimated that this accounts for a high proportion of the costs of primary health care.

In the Western World, the management of chronic leg ulcers is a major and costly health problem in society (Thorne, 2000). In the UK alone, the treatment of chronic leg ulcers costs the National Health System (NHS) between £300 and £600 million per year, and a high proportion of this is related to the costs of the District Nurse service. With an increasing number of elderly persons, the NHS has estimated an annual cost of wound- treatment to be close to two billion pounds (Thorne, 2000). In the US (Chase *et al.*, 1997) treatment costs are estimated to be \$775 million to \$1 billion per year. The average, total, medical cost of treating venous ulcers was \$9685 (MD \$3036) (Olin *et al.*, 1999). Health economic analyses, are scarce within leg ulcer treatment (Nelzén, 2000). It is difficult to compare costs between different countries, because of variations in costs and variations in the health care system. A health economic analysis, based on a small number of estimates in the Western World, shows that approximately 1% of the total costs for health care, are most likely used for the management of chronic leg ulcers (Nelzén, 2000).

Care of leg ulcer patients

Few studies in Sweden describe wound management, in relation to the staff qualifications and knowledge about leg ulcers (Hjelm et al., 2000). Hjelm et al., (2000) claims, that this indicates a risk of delayed healing and a risk of inadequate treatment. Nurses and doctors are primarily concerned with healing the wound and little consideration is given to the person during the healing process. The ideal is to cure the slow healing wound, with a low frequency of dressing changes, in the shortest possible time (Lindholm, 2002).

In Sweden, an overwhelming majority, 70-80% of leg ulcer patients, are treated within the primary health-care system, as outpatients (Nelzén et al., 1991; Lindholm et al., 1992b; Fagesjö et al., 1996; Öien, 2000). The primary contact for leg ulcer patients, in most cases, is the district nurse. The wound treatment of leg ulceration, is essentially the function of the district nurse. The district nurses are dependent on regular contact with the general

practitioner (GP) and often with a dermatologist (Fagesjö et al., 1996). The main responsibility for investigation in wound care lies with the general practitioner, in primary health care (Öien, 2002). One study showed, that the home-based, nursing staff treatment, of leg ulceration has increased (Lindholm et al., 1999). One reason for this might be that there has been a reduction in health-care finances in primary care, while there has been an increase in health-care finances in community care for the elderly.

In Sweden, a growing number of units such as wound care clinics have been established within the area of medical health care. Wound care teams have developed recommendations for the assessment and the management of wound treatment. A few teams have formed an organisation, which enables district nurses or nursing staff to consult with a dermatology nurse, an RN who is specialised in the care of patients with wounds and wound treatment issues (Lindholm, 1995b). Several centres, with multi-disciplinary groups for ulcer management have been established in Sweden. Team-work consists of specialised physicians, such as dermatologists, vascular surgeons and plastic surgeons and nursing staff includes nurses with different areas of expertise e.g. dermatology nurses. The multi-disciplinary team acts as an intermediary between primary health care/community and hospital care (Andersson, 1999; Gottrup et al., 2001; Öien, 2002). Multi-disciplinary wound healing centres, provide a better use of investigative resources, enhance knowledge and increase the interest in leg ulcer diagnosis, leading to improved healing and treatment for patients in wound care (Gottrup et al., 2001; Ruckley, 2001; Öien, 2002).

In the UK the transfer of leg ulcer management, from the hospital to community settings, are common (Thorne, 2000). An increasing number of health authorities are developing districts with community leg ulcer services, to meet the needs of the local population. In the UK-the trend has been towards treating patients almost exclusively in the community and the treatment has been provided by trained community nurses e.g. tissue-viability nurses with assessment forms and handheld Doppler devices (Moffatt et al., 1992,). Studies show that improved healing rates, lower recurrence rates, and reduced costs, are achieved when community leg ulcer clinics are established. Leg ulcer patients' perceived a better quality of life after the treatment (Moffatt et al., 1992; Franks et al., 1995; Simon et al., 1996; Franks & Moffatt, 1998).

Everyday living with slow-healing leg ulcers as a chronic illness.

There is a growing awareness of the importance of understanding the person's own perspective, regarding chronic illness experiences for example, chronic leg ulcers. Dahlberg et al., (2003) emphasises that nursing care should be taken from the patients' own perspective, in relation to: their health, illness and life-world. A patient perspective means to: affirm a human beings life- world. The perspective of a person's life- world means that the human being is given attention, in everyday life and during the treatment of leg ulceration care. This implies seeing, understanding, describing and analysing the world, as the leg ulcer patients experience it.

The impact of living daily with a leg wound can be seen in different ways, but only the individual, genuinely understands the meaning of that experience (Price, 1998; Roe et al., 1998). More direct and explicit consideration should be given to the patient's life-world with leg ulceration, from the perspective of an insider, focusing on the experience of the lived illness with CVI (cf. Söderberg et al., 1999; cf. Ekman et al., 2000; cf. Paulsson, et al., 2002). Toombs (1992, p. 31) made a distinction between the lived experience of illness and the state of the disease. Suffering from illness, involves conscious sensations that one reflects upon. Disease represents an objective phenomenon and is identified as a patho-physiological fact. In this context, illness will be understood as suffering from symptoms and ill-being and therefore, well-being is the opposite of illness Living with a chronic illness means disruptions and alterations in one's life (Toombs, 1992, p. 90). CVI interrupts life, and therefore, illness means living with perceptual interruption (Frank, 1995, pp. 56-57).

The characteristics of chronic illness or lingering disease, include uncertainties concerning prognosis and treatment. The course of the chronic illness is difficult to predict, and acute phases often alternate with resting phases. Chronic illness often means considerable disability, which causes, not only physical limitations but also worries and anxiety. A person's whole life-situation changes, because disease and treatment often require a marked change in a person's lifestyle (Curtin & Lubkin, 1995). Curtin and Lubkin (1995) have studied different definitions of chronicity, but did not find any, which were considered sufficiently comprehensive and therefore, they suggest the following flexible definition:

Chronic illness is irreversible presence accumulation, or latency of disease states or impairment that involve the total human environment for supportive care and self-care, maintenance of function, and prevention of further disability. (Curtin & Lubkin 1995, pp. 6, 8).

This description fits in nicely among persons with leg ulceration. Leg ulcers are a chronic problem, with individuals suffering from a cycle of ulceration, healing and re-ulceration (Nelzén et al., 1997). Research indicates that the individual's views on chronic leg ulceration are not necessarily static and may change over time (Price & Harding, 1996).

Studies reported a decreased quality of life among persons with leg ulcers, mainly due to pain, restriction of mobility, and social isolation (Lindholm et al., 1993; Launois et al., 1996; Franks & Moffatt, 1998). Social contact has received considerable attention and Phillips et al., (1994) reports that, in the case of a significant number of leg ulcer patients, there are financial, social and psychological implications. Contrary to the findings of a psychosocial study Flett et al., (1994) did not discover any significantly greater feelings of loneliness, or a greater lack of close and satisfying social relationships, among elderly people with leg ulceration, compared to a comparable control group. The authors argued, that one must be cautious about assuming that persons with leg ulceration are depressed, or have deficient social lives.

Studies that address the qualitative experiences of living with chronic leg ulcers, reported frequent pain, lifestyle consequences, strategies to overcome the isolation brought about by their frailty and impaired mobility and emotional distress (Walshe, 1995; Chase et al., 1997; Bland, 1999; Hyde et al., 1999). Leg ulcers were perceived as, a never-ending process by patients and they also referred to an altered body image. Profound themes, including; leakage, oozing, unpleasant odour and lack of sleep, were described in the participants' own words, in the text (Neil & Munjas, 2000; Douglas, 2001; Rich & McLachlan, 2003).

Leg ulcer patients experience of wound dressing changes

Research that deals with the patients' experiences of wound management practices, are scarce in caring research, apart from a limited number that focus on patient's lived experiences of leg ulcers. Despite some misgivings, the leg ulcer patients expressed general satisfaction with the nurses who provided their care (Walshe, 1995; Chase et al., 1997; Bland, 1999). The patients

had insufficient understanding, regarding the cause of their ulcers and they claimed that they had little knowledge of the wound treatment (Chase et al., 2000; Douglas, 2001).

An investigation showed that the patients' satisfaction with primary health care was significantly related to the technical quality of the care, to communication, and to the relationship between the patient and the district nurses (Törnqvist et al., 2000). Husband (2001) reported that because the patient adjusts to the treatment, this means that they deny their own individuality and they also have to adapt their lifestyles to their uncomfortable and unsightly dressings. Adopting and endurance were strategies that were used, in order to accommodate the treatment of leg ulcers.

To gain an understanding of the patient's experience during wound dressing changes, it is essential for the nurse to reflect on every move and every decision and relate these to the patient in the situation. In doing so, they will learn something from their performance (Carrington, 1999). A survey among tissue viability nurses, who were experts in wound care, showed that their perceptions of pain and tissue trauma during dressing changes, were not always the same as the patient's (Collier & Hollingworth, 2000). Studies showed (Collier & Hollingworth, 2000; Hansson, 2001; Kammerlander & Eberlein, 2002), that the main concern for nurses, during dressing changes, was to prevent trauma to the wound. The next most important concern was to reduce the patients' pain and to prevent damage to the surrounding skin. The findings showed a certain level of confusion, regarding products designed to prevent pain and tissue trauma, during dressing changes.

Frank (1995) pointed out, by telling a story about illness to someone else, that to describe our own experience, is to give voice to and face disease. By listening to the patient's stories about everyday living with leg ulcers, the patients can experience that their story is being shared. Through narratives, the caregivers can achieve access, to at least some part of the patients' perspective (Dahlberg et al., 2003). Caring research, on an ontological basis, together with an attempt to understand a person's life-world, means that the unique human being is taken into consideration, such as experiences during dressing change.

Rational for the study

With a growing number of elderly people, there will be an increase in the number of patients requiring care for leg ulcers, since the prevalence of leg ulcers seems to increase with age.

Figures estimate that prevalence is dependent on the study population (Nelzén, 1997). Although major developments in management, have been attained during recent decades and initiatives have been taken, regarding co-operation between the nurse and the general practitioner, the debate about how to treat leg ulcers still remains. There is still a great deal to be explained, before wound care can develop, so that the focus is on the lived illness experiences of those suffering from leg ulceration. Investigation from the individuals' perspective is important, as well as an understanding as to how care and medical treatments are performed, for elderly people with leg ulcers in the Health and Medical Services. It is of great importance to gain insight about the patients' perspective of lived illness experiences in everyday life and the level of wound care treatment. By listening to the explanations of illness from patients with leg ulcers, and trying to understand how it feels, to live with a slow-healing leg ulcer, health-care providers can create a caring context (Neil & Munjas, 2000).

Leg ulcers continue to be a problem for many elderly people during their lives. Therefore, during treatment, these persons need to be supported and protected in their quest for well-being and this subject should be of great importance for health care. Existing research concerning wound assessment, choice of dressing, and painful dressing-changes, is mainly based on quantitative research methods, which are related to the clinical practitioners' viewpoint (Lait & Smith 1998; Hollingworth & Collier, 2000; Hansson, 2001). The patient's perspective, in caring research, can be seen as an important field of research (Fagerström et al., 1999). Patient-focused caring research, concerning the patients' perspective of nursing care in wound management, will be a priority, in health-care assessments for the next ten years, according to Morison, Moffat, Bridel-Nixon and Bale (1998). Furthermore, caring research is required, in order to develop appropriate management of leg ulcer care for this group of clients (Thorne, 1998). Chase et al., (2000) emphasises the importance of anticipating the problems faced by leg ulcer patients and Flanagan et al., (2001) suggests, the need to gain insight into the individual patients' views on how health professionals carry out their practice in wound care.

Because a large majority of the population, may have an active ulcer sometime during their lives, interest of this group of patients with leg ulcers, raises important questions that need to be investigated. Nurses who care for patients with leg ulcers, also require knowledge about the individuals own perceptions of their lived illness experiences and their perceptions of being in a wound dressing change situation. In nursing care, knowledge is also needed in

relation to this subject. Results from the overviews of research in Sweden, indicate that an attempt must be made to reach the best possible care for these patients.

THE AIMS OF THE THESIS

The overall aim of this thesis was to investigate leg and foot ulcer patients, from the perspective of a population in a specific urban area, and to illuminate these individual patients' lived experiences of illness when suffering from slow-healing venous leg ulcers.

The specific aims of the studies (**I-IV**) were:

- I.** To survey foot and leg ulcer patients in a medical area in South Stockholm. With regard to prevalence, aetiology, characteristics of the ulcer, latest contact with the physician, pain and analgesics, dressing materials, compression procedure, and aspects concerning the financial burden to the patient.
- II.** To investigate the numbers of this patients, who had healed or unhealed ulcers and whether they had recurrent ulceration and also to establish how many patients had died during the 18 months following the first study. A further objective was to study a certain number of patients with non-healed venous leg ulcers, by means of a structured assessment instrument and to find out whether wound healing could be improved by use of the triple-layer treatment during a period of three months.
- III.** To illuminate the meaning of elderly people's experience of living with venous leg ulcers, in order to get a nuanced understanding of how it feels to live with this type of ulcer.
- IV.** To illuminate the meaning of being in a wound dressing change situation, during outpatient clinic treatment, as narrated by older people with venous leg ulcers.

METHOD

Design

This thesis is based upon data from four studies. Quantitative methods were used in the first two studies, including an intervention study, within the second study. In the third and fourth study, a qualitative method was used. An overview of the content and status of the papers included in the thesis is shown in Table 1.

Table I. Overview of the status of papers and studies.

Paper	Aim	Data collections	Analysis	Status
I	A survey of leg and foot ulcer patients in South Stockholm Medical Area, with regard to prevalence, aetiology, characteristics of the ulcer, latest contact with the physician, pain and analgesics, dressing materials, compression procedure, and aspects of financial burden to the patient.	Structured questionnaire	Epi info, multi-purpose program	Published
II	Investigation of the patients who had healed or unhealed ulcers and whether they had recurrent ulceration, and also to establish how many patients had died during the 18 months following the first study.	Structured questionnaire	Excel and StatView program	Published
II	To study a certain numbers of patients with non-healed venous leg ulcers by means of a structured assessment instrument and to find out whether wound healing could be improved by use of the triple-layer treatment for a period of three months.	Assessment of risk-factors ABPI planimetry photographed ulcer	Healing rate ABPI Ulcer area Riskfactors	
III	To illuminate the meaning of elderly people's experience of living with venous leg ulcer in order to get a nuanced understanding of what it is like to live with this type of ulcer	Research interview	Phenomenological hermeneutic	Published
IV	To illuminate the meaning of being in a wound dressing change situation, during outpatient clinic treatment, as narrated by older people with venous leg ulcers.	Research interview	Phenomenological hermeneutic	Manuscript

Knowledge gained from quantitative and qualitative approaches could be seen as different positions on each side of a continuum, involving different domains of knowledge. However, in this thesis, a broad population perspective was taken, which was then narrowed down to an individual perspective, in order to gain a deeper insight, that is, from a macro level to a micro level (cf. Polit et al., 2001).

The research question focused on investigating leg ulcer patients from a section of the population, in order to illuminate these individual patients' lived experiences. Therefore, a multi-method research approach has been used. The advantages of using a multi-method approach meant that, the limitations and weaknesses of each method could be avoided by using this design (cf. Polit et al., 2001).

Quantitative data from surveys (**I-II**) showed a significant number of patients with CVI. This data was combined with the individual patients narratives concerning their lived illness experiences, leading to a more substantial amount of data. (cf. Foss & Ellefson, 2002). The quantitative method involves a descriptive approach (cf. Polit et al., 2001) and a survey design was used to obtain information on leg ulcer patients' in a specific urban population, regarding prevalence, distribution and health care, such as wound management. Eighteen months later, a secondary survey was used to follow up rates of wound healing, recurrences, amputation and mortality within the same population. A further objective was an intervention study of patients with venous leg ulcers. During a three-month period, a triple-layer treatment (Bjellerup et al., 1993) method was used. An assessment instrument, which was formed in accordance with wound healing factors, was also used with CVI patients (Lindholm et al., 1995a). The intervention study, focused on evaluating the systematic wound treatment, which involved the promotion of wound healing, among patients with therapy-resistant venous leg ulcers. The qualitative approach was chosen, in order to obtain rich descriptions and find uniqueness among the individuals' everyday illness experiences of leg ulceration and wound dressing change situations.

Settings, study population and persons

In study **I** the investigation was carried out in an urban area in Sweden, with a population of 241.804 (Statistical Yearbook, 1996). An overview of the population in the studies is presented in Figure I.

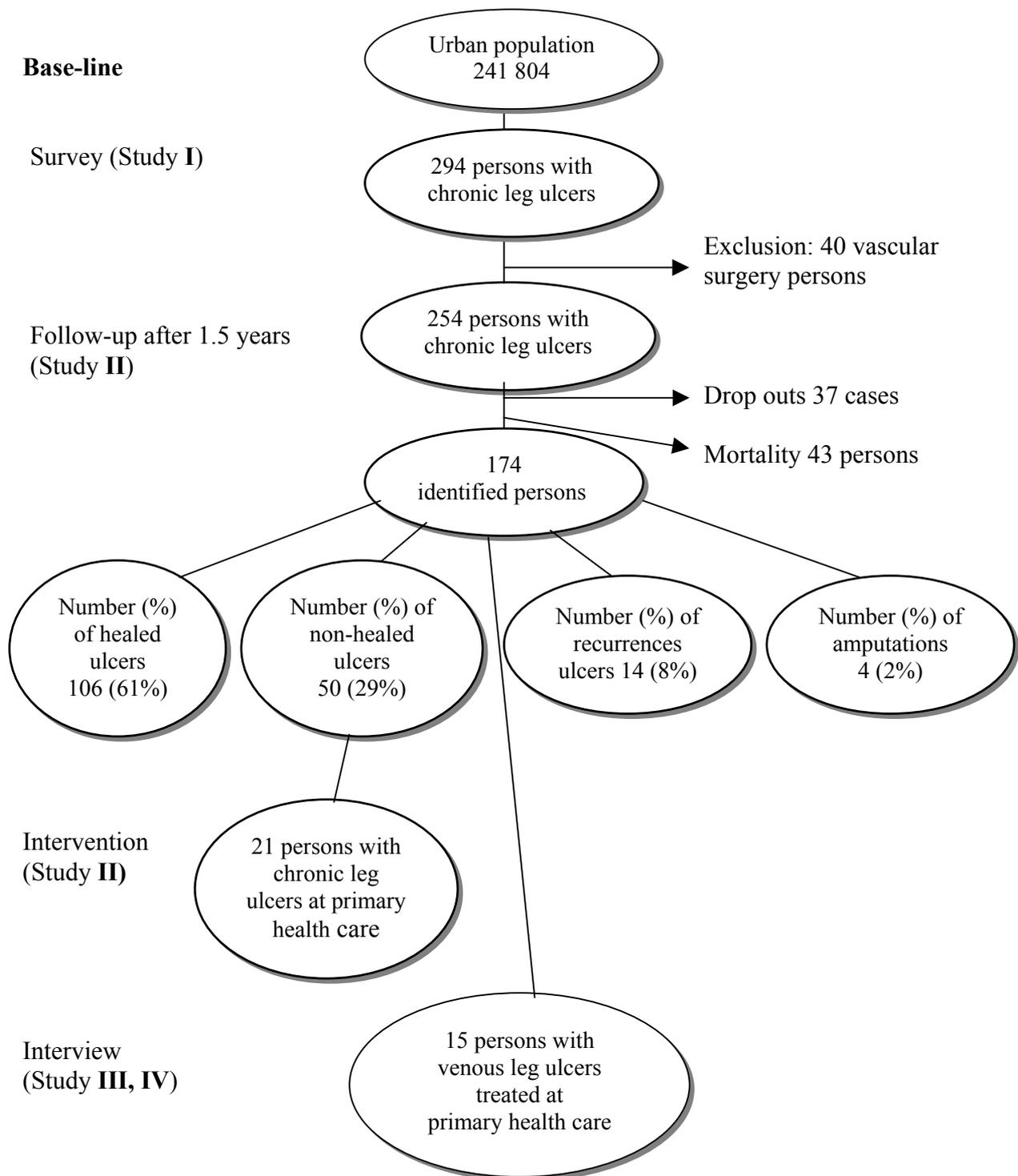


Figure 1. Flowchart of data collection, and results deriving from epidemiology and the follow-up study.

During the time period of the study, the health-care area was divided into seven primary health-care districts for outpatient care, including community home care services for the elderly. Within this area, there was one regional hospital and one minor private hospital, three geriatric hospitals and eight nursing homes. The hospitals had outpatient clinics, specialising in different areas of expertise. There were also private practitioners in the area. The survey included 193 units and during a defined period of six weeks, the objective was to identify all patients with chronic leg and foot ulcers, visiting these units (definition p. 3).

In study **II** the healing rate of patients from the first study, was followed up 18 months later. Patients who had been treated in hospital and had been subjected to vascular surgery, were excluded (N = 40). The next step was inclusion to the intervention study, of patients with non-healed venous leg ulcers. The intervention study included a structured assessment form relating to wound healing factors (Lindholm, 1995a) and a standardised form of triple-layer treatment for patients with CVI (Bjellerup et al., 1993). The inclusion criteria included, patients with venous leg ulcers with an Ankle-Brachial Pressure Index (ABPI) of more than 0.8 that were treated in primary or community care. Twenty-two patients were identified and were offered the triple-layer treatment. All were considered mentally and physically able to participate in the study. One person declined to take part in the study. A total of twenty-one patients took part in the study.

The selection method was a purposeful sampling strategy (cf. Polit et al. 2001) in study **III** and **IV**, and participants with venous leg ulcers were chosen because of their ability to provide rich data. They were recruited from primary health care, in the same area as studies **I-II** (Figure 1). Persons who were considered to be capable of engaging in a dialogue with the researcher were sought, through consultations with the district nurses. Criteria for inclusion was that; the persons were 65years or older, lived at home and that they had been given a verified diagnosis of venous insufficiency, an ABPI > 0.8 and had an ulcer duration of more than two months. The participants fulfilling the inclusion criteria consisted of twelve women and three men. The sample size was judged as sufficient for this study, together with the depth of the participants' narrated lived experiences (Sandelowski, 1995). An overview of the interviews with people suffering from leg ulcers is shown in Table 2.

Data collection

Data were collected with the use of different methods and tools, and are shown in Table 1.

Table II. Demographic data, ulcer history and level of care of the interviewed persons with venous leg ulcers (N=15).

Gender	Age	Living arrangement	Aetiology and ulcer medical history	Duration of current ulcer	Recurrent ulcer	Previous health care service	Dressing change	Members of staff
Female	74	Living alone	Venous insufficiency Wound infection, two times	4 months	More than three times	Dermatological clinic	Once weekly	DN
Female	75	Living alone	Venous insufficiency Venous surgery	9 months	More than three times	General practitioner Out patient clinic	Once weekly	DN AN
Female	82	Living with husband and son	Venous insufficiency Diabetes	24 months	More than three times	Dermatological clinic Geriatric hospital	Three times weekly	DN GP
Female	78	Living with daughter and two grandchildren	Venous insufficiency Wound infection, three times	4 months	More than three times	Duplex Doppler at medical clinic	Two times weekly	DN RN
Female	79	Living alone	Venous insufficiency Wound infection two times	7 months	First occurrence	Out patient clinic	Two times weekly	DN RN GP
Female	75	Living alone	Venous insufficiency Wound infection, three times Venous surgery Pinch crafting	24 months	More than three times	Out patient clinic	Two times weekly	DN RN GP
Male	86	Living alone	Venous insufficiency Eczema Wound infection, three times	29 months	First occurrence	Dermatological clinic An other primary health care	Three times weekly	DN RN GP

Gender	Age	Living arrangement	Aetiology and ulcer medical history	Ulcer duration	Recurrent ulcer	Previous health care service	Dressing change	Members of staff
Female	74	Living alone	Venous insufficiency Venous surgery	7 months	Second times	Duplex Doppler Surgery clinic	Twice monthly	RN AN
Female	83	Living alone	Venous insufficiency Venous surgery Inflammation at leg	4 months	First occurrence		Once weekly	DN GP
Female	74	Living alone	Venous insufficiency Venous surgery Wound infection	4 months	First occurrence		At first daily Three times weekly	DN AN
Male	80	Living alone	Venous insufficiency Arterial component	12 months	More than three times	Dermatological clinic	Once weekly	RN AN
Female	89	Living alone	Venous insufficiency Venous surgery Wound infection	12 months	Second times	Out patient clinic Geriatric hospital Duplex Doppler Medical clinic	Once weekly	DN AN GP
Female	88	Living alone	Venous insufficiency	9 months	Second times	Geriatric hospital	Three times weekly	DN AN
Female	78	Living alone	Venous insufficiency Venous surgery Wound infection	4 months	Many times	Dermatological clinic	Two times weekly	DN AN GP
Male	76	Living alone	Venous insufficiency	9 months	Third times	Dermatological clinic	Two times weekly	DN AN GP

Questionnaires

In study **I** a structured questionnaire with twenty items, was used to collect information about each patient with a leg and/or foot ulcer. The questionnaire, was designed to be filled in by physicians and/or nurses and it had previously been used and proved to present relevant data (Lindholm et al., 1992a, 1992b). It included question areas, such as demographic data, aetiology according to staff, characteristics of the ulcers, latest contact with the physician, level of care, wound management, use of compression, and perception of patients' pain and the use of analgesics.

In study **II** a questionnaire was also used, to collect information about each patient's healing progress. Eighteen months after the survey in study **I**, a questionnaire attached to the completed response-chart of each patient (that had been identified in the first study) was distributed to all health-care personnel who had responded to the first study. The questionnaire included parameters, such as: healed or non-healed ulcers, recurrences, amputations and patient mortality.

Assessment form at the intervention study

Two nurses (RN) within the area of dermatology, who were specialised in the care of patients with wounds, assessed twenty-one-identified patients. The patients were examined either at the Dermatology Clinic or in their homes. The structured assessment form was produced from wound healing factors and encompassed a holistic view of wound care design, according to Lindholm (1995a). The assessment instrument, took account of *factors related to the patient*, - such as their psychosocial situation, nutrition, sleep, pain and mobility, *factors related to the leg and foot*, -such as oedema, skin changes and local pain and finally *factors related to the ulcer*, -such as duration, size, recurrence, necroses, exudation, odour, pain, cellulite and wound edges. The assessment form is shown in appendix 1. ABPI was recorded in all patients and ulcers were planimetrically measured and photographed. Assessment of aetiology was mainly clinical and based on the patient's record. In cases where information on aetiology was uncertain (e.g. *ulcus cruris*) the physicians were contacted for a more accurate diagnosis. Risk factors, which were liable to delay wound healing, were marked as risk squares on the assessment form. The risk factors were summarised and the collected material was discussed with the project team, dermatology nurses and dermatologist. An individualised care plan was worked out for each patient, according to the assessment form (Appendix 1).

For a period of three months, the patients' venous leg ulcers (N=21) were treated once a week, with the triple-layer treatment (Bjellerup et al., 1993). According to Bjellerup et al., (1993) the treatment has shown indications of improvement in healing on therapy-resistant venous leg ulcers. A-hydrocolloid dressing (DuoDerm[®]) was used as a local wound dressing. A zinc-oxide-impregnated stocking (Salvstrumpa[®]) was applied from toe-base to knee. With the leg in an elevated position, a short-stretch compression bandage (Comprilan[®]) was firmly applied, by bandaging from toe-base to knee. As recommended by the health care service, the wounds were cleansed with lukewarm tap water. During the three-month period, district nurses and/or health care assistants performed dressing changes, during their ordinary practices in primary health care, or nursing homes.

After three months, all patients were reviewed and their healing progress was assessed by a dermatologist and two dermatology nurses. All patients with non-healed ulcers were re-assessed by the same two nurses and dermatologist that performed the initial assessment, with the aid of the risk factor instrument (Appendix 1). The patients' ulcers were measured, photographed and ABPI was recorded again in all patients.

Qualitative research interviews

Data were collected by means of qualitative research interviews (cf. Kvale, 1996) in order to come into contact with the knowledge, embedded in the patients' narratives (III, IV) concerning their experience of living with venous leg ulcers and dressing change situations. The patients were encouraged to tell their stories. In order to inspire them to narrate in their own words, they were interrupted as little as possible (cf. Kvale, 1996). Interviews were in the form of a dialogue, in relation to aspects of lived experiences, connected with the leg ulceration and wound management during dressing changes. The interview began with what amounted to an open question, "Please tell me about what's it like living with a leg ulcer" and later on "Please tell me about what's it like, during the dressing change of your leg ulcer." The persons were guided to speak as freely as possibly and to narrate their lived experiences by giving concrete examples from everyday life and dressing change situations. Following the individual responses, subsequent questions were asked, in order to obtain a clarification of statements, for example, "Please give me a concrete example." The interviews lasted from 45 to 120 minutes and were carried out by the author. All interviews were audio-taped and transcribed verbatim by the author. This gave an overview and enabled a first understanding of the data.

Analysis

Statistical analysis

The questionnaire in study **I** was computerised and processed with the help of Epi Info. Epi Info is a multi-purpose computer program, designed for epidemiological research and public health personnel. In study **II** data were analysed by using the Excel and StatView[®] programs.

The statistics in studies **I** and **II** were descriptive statistics and bivariate descriptive statistics (Polit et al., 2001). Descriptive statistics were used to summarise, evaluate and interpret the frequency distributions. Values are given as mean, median or percentages. In study **II** relations between variables, were expressed in product moment correlation, with continuous variables and dummy variables, and only significant results at the 1% or 5% risk level, were used. The same significant risk level was also used in study **I**. In study **II** mortality rate was calculated by comparing the expected mortality rate in an age-matched population (Hansson et al., 1987). In the intervention study (**III**) values were only given as numerical information, the numbers in this study being too small for a significant analysis.

Phenomenological hermeneutic analysis

A phenomenological hermeneutic method was chosen, because this method provided the opportunity to understand lived experiences. The phenomenological hermeneutical approach of interpretation, inspired by Ricoeur's philosophy (1976) was chosen to analyse the text. This method has been developed by Lindseth and Norberg, at the Department of Nursing and Health Science, at the University of Tromsø, Norway, and at the Department of Nursing at Umeå University, Sweden (Lindseth et al. 1994). The method is under constant development and has previously been used, for example, by Nilsson et al., 2000, Sundin et al., 2001 and Strandberg et al., 2003.

The overall aim in the phenomenological-hermeneutical interpretation, was to illuminate the world that opened up in the front of the text in studies **III-IV** and to show interpretations of the meaning of illness experience, as narrated by patients with venous leg ulcers. Ricoeur was influenced by phenomenology and Ricoeur departs from these thoughts and combines them with a hermeneutic philosophy of interpretation (cf. Kristensson Uggla, 1994).

Phenomenological-hermeneutics is based on the idea that the meaning of lived experience can be grasped through the interpretation of people's narratives (cf. Ricoeur, 1976, pp. 14-19).

Ricoeur states (1976, pp. 1-16) that an event or experience, as lived, cannot pass directly from one person to another, however, the meaning of the event or experience can be transferred. According to Ricoeur (1976) people reveal themselves when talking about their lived experience, in a certain context. Meanings can be unveiled by studying the discourse. Ricoeur's (1976, pp. 71-80) interpretation of the text, integrates explanation and understanding, in a constructive dialectic movement that is rooted in the properties of the text. Understanding and explaining, details of the text brought an understanding of the whole text (cf. Ricoeur, 1976). The aim, of the narrative research interviews, was to gather descriptions of the life world of the participants lived experiences, so it could be used to interpret and achieve a deep understanding and to describe the phenomenon. The hermeneutic part of the phenomenological-hermeneutic method is needed, in order to achieve understanding through interpretation.

The method involved an interrelated circular process, during analysis of the data. This involved movement between the parts and the whole of the text, between the actual situations, and the background to them, as described by the participants. All of these movements were essential phases in the interpretative process. Ricoeur explains that the interpretation of a text is a process (Ricoeur, 1976, p. 74). This process involves, first of all, movement from a preliminary understanding by means of explanation (which is carried out in several steps) until a comprehensive understanding, of the patients' illness experiences of leg ulceration and dressing change situation is achieved. Interpretation of the text involves three various phases, *i.e.* the naive reading, the structural analysis and the comprehensive understanding (Ricoeur, 1976, pp.73-75). The naive reading aims to capture a preliminary understanding of the whole text. The structural analysis aimed at explaining what the text says. The final phase in the interpretation, aims to achieve a comprehensive understanding of the whole text. This was based on the authors' pre-understanding, the naive reading, the structural analysis and knowledge on this topic. All of these were brought together to form a deeper understanding. This phase aimed to achieve an understanding of what the text indicated, *i.e.* the world that was opened up in front of the text (Ricoeur 1976 p 86-89). The interpreted whole embraces the whole material and the aim is to articulate something new, from something already given.

Ethical considerations

The project, was approved by, the Ethics Committee at Karolinska Institutet (Dnr 41/96, Dnr 255/99). Ethical considerations in studies (I –II) relate to individual confidentiality, informed

consent, the risk of causing emotional injury, in relation to the questionnaires and the intervention study. According to the interviews in studies (III- IV) the participants were informed about the nature of the study and were guaranteed confidentiality. All participants gave their informed consent to participation in the study.

Permission to carry out the survey (I) and follow-up (II) was given by the directors at the hospital, directors in primary health care, and the nursing directors at the nursing home. Anonymity was guaranteed in relation to the questionnaire, this was achieved by means of a coding system, which made it impossible to identify the people involved. The patients received information concerning the questionnaire form and the tape recording. The collected data was stored in a strongbox at Huddinge University Hospital (Hermerén, 1996).

In the intervention study (II) the patients were informed about the study both orally and by letter and were told that they could withdraw at any point, both before and during the treatment period. All twenty-one patients freely provided their informed consent, before enrolment in this study.

In study III and IV the persons with venous leg ulcers were informed by the district nurse both orally and by letter. The investigator then telephoned the subjects, in order to make an appointment. Informed consent was obtained from the subjects, before the study was initiated. The elderly persons were also given the option of choosing the time and the place for the interviews. Most of the group wished for the interviews to take place in their private homes, and only four persons chose to be interviewed at the primary health care department. The freedom to choose a place for the interviews, was considered to be an indicator that the participants might feel less dependent on the health care system and might feel more free when narrating their lived experiences. All of the participants permitted the interviews to be tape-recorded and they were also assured that the data would not be listened to and guaranteed confidentiality concerning personal matters (cf. Hermerén, 1996). All interviews ended by asking the participants to contact the researcher, if they felt that something was unclear or incomplete. Moreover, the participants agreed to use quotations from the collected transcribed text. Translation into another language, and grammatical revision would subsequently be further protected from identification (cf. Kvale, 1996). When issues of a medical or a social nature arose, patients were referred to the district nurse, who could provide them with the appropriate nursing care.

RESULTS

Study I

This survey identified 294 patients with leg and foot ulcers in an urban area. The prevalence was 0.12%, with a population of 241,804 (Statistical Yearbook, 1996). The results show that chronic wounds are a major cause of morbidity, with a peak among the elderly at approximately 80 years of age. In the age group higher than 70 years old, women outnumbered men ($p < 0.01$), whereas men predominated in the younger age groups. The most common cause of leg ulceration was venous insufficiency (42%), but in 6% of the cases the aetiology was either unknown, or no diagnosis was given. Arterial disease was significantly more common in men than women ($p < 0.01$). Seven per cent of the patients had never had their ulcers examined by a physician.

The majority (61%) of the patients with leg and foot ulcers were treated within the primary health care system. Patients treated within primary health care and nursing home services, were older than those treated at dermatology departments ($p < 0.01$). Health care assistants usually carried out dressing changes (54%) while nurses performed dressing changes to a lesser extent (RN) (18%). In the primary health care system, 57% of the patients were treated at home. At home, dressings were changed much more frequently by health care assistants and by the persons themselves ($p < 0.01$).

The main findings of the study, involved the different methods used in relation to local wound dressings and bandage management. The total number of different types of local wound dressings was 51. However, compression treatment of venous ulceration was commonly used (85%). Wound cleansing was usually performed with a saline solution. At the Department of Dermatology, 100% of the patients with CVI were treated with compression ($p < 0.01$), and 46% of the cases used a double-layer bandage. The cost of dressing materials was usually paid through the health-care system. In the primary health care system, the patient paid all costs of dressing materials (14%).

Pain afflicted almost half of patients with venous ulceration (47%), but no analgesics were given to 29% of these patients. The pain occurred on and off, during a 24 hr period and also during dressing changes. Members of staff treating persons with ulcers at home and in nursing homes, were frequently aware that pain relief was not achieved. In nursing homes, it was quite common for staff not to note the patients' pain during the night.

Study II

Follow-up study

In the follow-up study, 217 persons with leg ulcers were identified and 139 were identified in primary health care, including the institutions, which are run by the municipalities and 35 were identified at the Department of Dermatology. The healing rate was 61%, and 29% had non-healed ulcers during the eighteen-month period. Only 8 % had recurrences, and 2% included leg amputation (Figure 1). In the cases of those with wounds that had healed, 40% had CVI, while 40% of the ulcers included in the cases of unknown aetiology, had not healed. Recurrence was more common in the case of CVI. The mortality (N=43) rate was five times higher, than that for the age-matched population in the area. Arterial disease was more common (56%) compared to patients with CVI (30%) with reference to poor health.

Significantly more leg ulcers with an area of less than 10 cm² had healed, compared to those with an area larger than 10 cm² (p<0.01). Over half (55%) of the ulcers that had been present for a period of less than six months had healed. This is a significantly higher number, compared to ulcers that had been present for a period of more than six months (p<0.01). Fifty-eight per cent (58%) of small ulcers that had been present for more than six months, healed within 18 months. Leg ulcers greater than 10 cm², which had been present for more than six months, had a healing rate of 32%.

Intervention study

During a period of three months, 21 patients with CVI were treated with a triple-layer bandage (Bjellerup et al., 1993). The results show that during the three-months period, two ulcers had healed, nine ulcers had improved and were healing well, two ulcers had not changed and two had deteriorated when treated with a triple-layer bandage. Of the remaining six patients, two had died, two had become severely ill owing to other conditions, and two other patients had dropped out from the study.

The area of the leg ulcer was reduced within three months, from a range of 42.25-0.9 cm² to a range of 24-0.25 cm². Fourteen cases had distinct oedema of the leg. The impact of pain among the majority (N=14) of the cases, might have contributed to the therapy-resistance of many leg ulcers. The use of triple-layer treatment with an inner layer of Hydrocolloid dressing (HCD) and outer layers of paste stocking and compression, demonstrated that slow-healing

venous leg ulcers were healing. Wound healing occurred in approximately half of the patients and significant reduction in the size of the ulcer was obtained for nine of the 21 patients with CVI.

Risk factors identified as contributing to a delayed healing in the following-up study and intervention study were: impaired mobility, pain, insufficient nutritional, pathological skin changes, ulcer duration, ulcer area that was greater than 10 cm² and the impact of arterial aetiology. The impact of other causes, such as malnutrition and the patients' age might also influence the reduction in wound healing.

Study III

A preliminary understanding of the elderly people's life with venous leg ulcers, involves awareness of their sense of hopelessness due to the lengthiness of the healing process, wound pain, awareness of changes in one's body image and changes in one's social life.

In the structural analysis, four themes were identified as essential in relation to the elderly persons' experiences of living with venous leg ulcers. These themes were: emotional consequences of an altered body image, living a restricted daily life, achievement of well-being and management of emotions, in connection with a painful wound and bandage discomfort, and a struggle between hope and despair regarding the lengthy healing process.

The text reveals that the overall meaning for the participants showed that, physical realities include pain and the uncomfortable bandage; led to mobility limitation, sleep disturbances and fatigue. Pain had a major impact on their daily living. They struggle to find relief, to find ways, to first and foremost, alleviate the pain and achieve well-being. Pain undoubtedly caused breakdowns in the persons' lives. Their social lives changed because the persons decided to avoid certain contact. They did not want to subject the persons close to them, to the running ulcer, the bandage and the dressing. The narratives demonstrated that there were difficulties in finding suitable shoes. The persons with venous leg ulcers explained that their usual shoes did not fit them, because of the bulky bandage and this limited activities such as daily walks. The persons with venous ulceration also experience that they have a disobedient body. The body being is experienced as disintegrated and alienated from the self. It becomes apparent that one *has a* body, instead of *being a* body. A painful, aesthetically unpleasant leg ulcer, discomfort and an appliance attached to the body, become symbols for vulnerability, of being imprisoned in the body and the bandage.

The comprehensive understanding reveals that elderly persons with venous leg ulcers are greatly influenced by the experience of illness. Living with chronic leg ulcers, as described by the elderly, can be understood as an ongoing process between two opposite poles. On the one hand, there is a sense of an altered body image, of being imprisoned in one's body, a disruption of the body, which leads to changes in one's social life. On the other hand, there is the hope of being cured and achieving freedom from a burdensome and disobedient body, from managing the experience of a painful wound and the disability which restricts everyday living. The elderly people's experiences of living with venous leg ulcers, indicated that the meaning of living with venous leg ulcers, can be understood as living with the strain of the experience of imprisonment in the body, the bandage and the home, yet at the same time living with the hope of achieving freedom from a disobedient body.

Study IV

The preliminary understanding of the narratives shows that nurses fulfilled the leg ulcer patients' needs in everyday life, with respect to their discomfort and illness experience. They described nurses as: familiar, skilful, competent and committed and stated that care was given in pleasant surroundings. In contrast to this, they described encounters with members of staff who exposed them to pain and discomfort, during the wound dressing change. The persons felt that they had been mistreated and ignored and explained that they felt depersonalised and objectified on these occasions.

Throughout the structural analysis, two main themes appeared: a dignified individual and a vulnerable individual under pressure. The interpretations reveal that while having the wound redressed the persons experienced a great deal of tension. Sometimes, the dressing change was satisfactory with mutual understanding from both parties. At other times, the patients felt that they were treated more as an object than a person, and felt that they had been subjected to unpleasant and unsatisfactory dressing changes. This study points to a crucial objective in caring- *not* to see the patient's ailment *only as* an isolated entity for wound treatment. The experiences of the patients who were treated for venous leg ulcers, was expressed with the words: 'reduced as human beings', and 'being treated as undignified individuals'.

The participants' experiences of being redressed with dignity, is fulfilled through; *seeing the individuals* as well as their embodied experiences, for example, the vulnerability, the pressure and the ignorance that they were exposed to. This study shows that the patients

suffer and feel belittled during the wound dressing change, because they feel that they are treated more as an object than a person. A confident and skilful management of the wound dressing change allows them to feel secure, whereas procedures carried out without engagement, only lead to a lack of confidence in the nursing staffs' knowledge concerning the treatment. The experiences of negative wound care, were illuminated as a vulnerable individual under pressure (uncaring encounters).

According to the findings of this study, when the procedure of changing the bandage was carried out merely as a routine procedure, the leg ulceration patients felt that they were treated as an object. When patients feel that they are objectified, they tend to objectify the staff too. In the narratives, members of staff are referred to as *them* and they are not perceived as individuals, that patients can relate to and share experiences with. This study also shows that elderly people with venous leg ulcers have intrinsic or inherent knowledge, about their own body. A theme that runs through these findings, involved the lived experiences of patients with leg ulceration and how they felt that they had been neglected by nursing staff. The text also reveals that patients defended the caregivers' behaviour, so that they could feel worthy of receiving care.

The meaning of lived experiences in positive wound care was illuminated in the theme, *a dignified individual*. The patients with leg ulcers stated that it was important that they met with the same nurse (RN) or general practitioner, so that they would not have to repeat their medical history each time they went for treatment. The text showed that when care providers see the individuals' embodied experiences, in their present daily living, they were experienced as "an individual" for example "*she*". When patients were treated in a friendly and personal way, in an open relaxed atmosphere, this led to a feeling of affinity with the caregivers. Leg ulcer patients, that had a trusting relationship with the nursing staff, were able to develop faith in them and communicate with them about their own reactions to the treatment and the way it affected their daily lives. One of the themes demonstrated that the patients felt that they were *seen* in their present life situation. This means that they felt that the district nurse had an understanding for their situation and that when treating the wound she also took the patients views into consideration. Elderly patients with leg ulceration strongly emphasised that they can see in the nurse's facial expression that she *sees*.

The comprehensive understanding of this study can also be seen as a description of good nursing care. A skilful nurse can reduce the patients suffering during the dressing change.

Nurses ought to have competence in choosing an appropriate choice of dressing for the wound-healing process and the individuals physical experience of the leg ulcer. The nurses also have to be able to touch and clean the wound without causing pain, when this was achieved she/he was described as having good nursing qualities. In caring for leg ulcer patients, the nurse should not only have the competence to carry out technical and medical procedures. Older patients, who are treated for leg ulcers, have a strong desire that the person who changes the bandage treats them in an atmosphere of trust and confidence. According to the theme of the text, patients suffering from venous leg ulcers, wish to be seen as dignified individuals. They want to feel worthy of treatment and wish to encounter skilful, confident and above all gentle nurses, during the dressing change, in a sharing atmosphere i.e. mutual understanding (communion) and an ability to share the patients “world”. A skilful nurse can see the patients’ intrinsic value, can show respect to the patient, and is capable of seeing the patients’ vulnerability.

METHODOLOGICAL CONSIDERATIONS

The overall aim of this thesis was to investigate leg and foot ulcer patients, from the perspective of a population in an urban health area and to illuminate the individual patient’s lived illness experiences and wound care treatment. Within this study, an intervention study was also carried out with patients with CVI in primary care settings. The research questions gave direction to the design of the study and gave both methods equal importance (Foss & Ellefssen, 2002). Qualitative and quantitative methods seemed suitable for illuminating the different perspectives (cf. Polit et al., 2001). This study was also initiated, since wound care is scarce in caring research. A common statement is that, chronic leg ulcers represent a major burden on health care and a drain on resources. A prerequisite was to obtain knowledge concerning the distribution of leg ulcers within a population group, as well as knowledge on human suffering (Nelzén, 1997; Harding, et al., 2002).

Quantitative data

Prevalence study

Since the aim of studies **I** and **II** was to obtain descriptions of the care of leg ulcer patients in an urban area, a prevalence study was judged to be an efficient design. The validity in quantitative studies, concerns confidence in the credibility, that findings are ‘true’ for the

participants who are studied in the actual context. In an epidemiological approach, prevalence seemed to be useful in receiving knowledge about factors, such as health care resources, facilities and the spread of the illness, within a population (Beaglehole, 1993). Differences in figures, concerning prevalence, seem to vary between studies and within countries. The observed differences result from variations in methodology when: identifying patients, in definitions of leg ulcers, i.e. whether or not foot ulcers are included, age and gender distribution in the patients' registration lists, in sample size and in sample representatives. Prevalence is influenced by the demographic constitutions of the population, as well as by the study design. Considerable variation in methodology, and differences in the population under study, can also be expected to lead to differences in prevalence. Therefore, comparisons must be made with care. In this prevalence study (I), only persons suffering from leg ulcers that are known to health care professionals have been considered. People, who take care of their ulcers by themselves, are not included in this study.

The 'true' prevalence depends on the number of patients, who take care of their ulcers by themselves, and this may be even higher than point prevalence (Nelzén et al., 1997). Bergqvist et al., (1999) found that younger people, quite clearly, seek professional help less often. Geographical differences can be expected, because of age distribution and differences between regions and countries. The results of survey (I) suggest a possible estimation regarding the prevalence of chronic leg ulcers. Although we cannot be absolutely sure that all care professionals have registered every single leg ulcer, during the study period. The questionnaires have been used several times and seemed to contain reliability data. However, a combination of questionnaires to the health care system and medical examination of a representative sample seemed to obtain an optimal estimate (Bergqvist et al., 1999). These estimates, despite the fact that a medical examination was not performed, show the approximate size of the leg ulcer problem, within this specific urban population. The follow-up study (II) was performed according to the same criterion as study I.

Intervention study

In study (II) two tools were used for managing the intervention. This instrument was chosen because it was preferred at assessments of patients with wounds (Lindholm, 1995a) and gave optimal treatment for patients with CVI (Bjellerup et al., 1993). The assessment form has been tested and gave valid information regarding the identification of risk factors, which were seen as potentially important for outcomes of wound care. This assessment form has a three-

step approach, including the patient, the leg, and the ulcer (Appendix 1). The factors were identified from a review of the literature that reported significant delays in wound healing (Lindholm, 1995a). The assessment form was deemed most suitable at this time, for obtaining risk factors concerning delays in wound healing for the intervention study. Other available wound care diaries, mostly focused on the local wound care.

The choice of triple-layer treatment in the intervention study (II) was based on a development of patients with therapy-resistant CVI and it was the most suitable alternative at this time (Bjellerup et al., 1993). This study (II) was a nonrandomized and uncontrolled investigation; however, it seemed unethical to leave patients untreated with their therapy-resistant ulcers and not to use available knowledge. The study was nonblinded; the ulcer size was objectively assessed by tracing it on Clingfilm and by photographs. This improved the outcome of reduced ulcer size.

Intervention is a dynamic process and setting up comparable groups for longer periods is difficult (Fogg & Gross, 2000). Creating identical groups in intervention studies would cause considerable bias. Fogg and Gross, (2000) described the impossibility of controlling human beings. The intervention study was dependent on and based on, the outcome of patients with non-healing venous ulcers. Within the non-healing group of 50 patients, 22 patients had CVI, and their ulcers had not healed within 18 months. This figure is used in the intervention study.

The loss of participants during the follow-up and intervention (II) were most likely systematic (cf. Kazdin, 1998), since those who accounted for internal dropouts in particular, were participants who became severely ill because of other diseases, i.e. cardiovascular disease. In addition to this, the age of the participants was high and so was the mortality rate. This affected factors within the whole study.

Qualitative data

Trustworthiness in data collection

The nature of validity and reliability, in qualitative research should not be judged with the same criteria used for quantitative research. Qualitative data has to be reflected upon, using criteria that are required for the qualitative paradigm. A qualitative study truth-value, ought to be judged by its credibility, that the results give credible depictions of the participants lived experiences. Trustworthiness concerns, therefore, the issue of validity in describing the truth

of qualitative data (Sandelowski, 1993; Sandelowski, 2000). In order to guarantee trustworthiness, in the data collection process, some issues have to be scrutinised.

Persons with venous leg ulcers were chosen by means of purposive sampling. Polit et al. (2001) argued that purposive sampling could be used, to handpick subjects who are particularly knowledgeable concerning the issue. The problem with this kind of sampling is that the subjects might be atypical, but on the other hand, the researcher might select the widest possible variety of persons. Small, random selected samples require persons with specific and unique knowledge (Sandelowski, 2000). The district nurses selected the persons and this might involve a “bias” because these persons might have more severe problems than other people. On the other hand, they were persons who had knowledge about living with venous ulcers. One of the qualitative principles is appropriateness, which means selecting persons who are best able to meet the informational needs of the study (Sandelowski, 1995).

The importance of attaining good informants is often emphasised in instructions for qualitative studies, i.e. patients who are able to and willing to describe their experiences (Morse & Field, 1995). The leg ulcer patients in the studies (III-IV) appreciated that research had been taken in leg ulcer management. The participants also explained that no one had taken the time to listen to their stories. It was stated that members of staff were always in a hurry, and this might be an indicator of confidence during the interviews, strengthening credibility. The author in this thesis was not involved in the patients’ wound care. The patients’ willingness to contribute to the research, in combination with the relaxed atmosphere during the interview, meets the criterion of a trusting and confidential relationship, between the researcher and the respondent.

Trustworthiness at interpretation

The interpretation process has to be validated and validation is an argumentative process. A text has a surplus of meaning and according to Ricouer (1976); the argumentation for the interpreted meaning is the means to achieve trustworthiness. Good qualitative data reductions capture the essence of the phenomena according to Sandelowski, (1993). The naive reading, originated from coming into contact with the voice in the text, and aimed at a preliminary understanding. The preliminary understanding from the text has to be validated through the structural analysis. It has to be explained by means of the objective structure of the text. The structural analysis was the objective part of the interpretation, with focus on the meaning of experience expressed in the text, explaining what the text actually said. The method for

validation, relating to guesses and the understanding, involves subjective and objective ways in the hermeneutic circles way of approaching the text (cf. Ricouer, 1976). To search for truth means to express something that appears in the background. Interpretations of meaning and understanding, of the results from the structural analysis were discussed until coherence had been reached. The phenomenological hermeneutic study presents an interpretation that is only one of several possibilities (cf. Ricouer 1976). The analysis was to conduct a line of argument, in the one of many examples, which were seen to be more probable than the others. The presented results represent the most appropriate understanding, of the meaning of these elderly patients' experiences of dressing changes and their everyday illness experiences.

All phases in the analyses involved communication between the co-authors. Interpretation of meanings and an understanding of the results, derived from the structural analysis, were discussed until consensus had been reached in the structural analysis. To validate the research process, I have tried to make the structural analysis visible, from the context to a written rapport. The structural analysis and papers, have been discussed at the seminars with doctoral candidates that have used interpretation methods (Sandelowski, 1998). At the seminars, my co-authors and doctoral students have ensured my trustworthiness by following my thoughts and helping me to open up my mind as much as possible, they also gave alternative interpretations of the texts and made sure that my descriptions and interpretations were grounded in the text (Ricouer, 1996, pp. 75-78).

The trustworthiness in the interpretations of meanings has also been obtained during presentations at a patient association, involved in leg ulcer care. This group represented experience from the actor's point of view, which is in agreement with the findings (Sandelowski, 1993). Presentations of the results, to a patient association, involved with wound and leg ulcers (from the studies **III-IV**) confirmed the patients' lived experiences and this might also contribute to trustworthiness.

Quotations in this thesis were chosen as representatives for the older patients' experiences. This was done in order to show grounds for, and to provide support for the interpretations. Quotations were also used, in order to make it possible to judge the interpretations and to show the credibility of the research findings. In qualitative studies, there has been discussion as to whether quotations should be preservative or standardised (Sandelowski, 1994). Because the quotations in studies **III-IV** were chosen with the aim of allowing the reader to judge interpretations, the preservative mode was chosen.

Transferability

The purpose of qualitative research was not to produce generalisations, but to understand and obtain knowledge of the illness and the lived experiences of everyday life with leg ulcers. Even though this is usually accompanied by a criterion of transferability of the results (cf. Polit et al., 2001). When language has been transcribed (from the narratives concerning the experience of everyday living with leg ulceration), the discourse was decontextualised and recontextualised to form a new context (Ricoeur, 1976, p. 298). It seems possible to transfer the results of studies (III-IV) to other situations in wound care, involving patients suffering from slow-healing wounds. The results cannot be generalised, but reveal the possibility of understanding the meanings behind experience, and they also provide a basis for reflection, about the complex phenomenon of everyday living with a slow-healing wound. However, further investigation is needed regarding the results from studies III-IV concerning how these results could be transferred and applied to other wound care contexts.

REFLECTIONS ON THE RESULTS

The results are focused on the individual patient and to the patient in the health care system. The reflections are, on the one hand, from a nursing care perspective of clinical practice, i.e. everyday lived illness experiences of being in a dressing change situation, and on the other hand, from the perspective of the caring organisations and consequences for leg ulcer patients in the health care system.

Wound care and treatment

The results of these studies (I-IV) represent significant life changes for this group of elderly people with leg ulcers. The therapies involved in treating these wounds are often painful (I-IV) and the elderly persons felt objectified during the removal of the dressing. Dressing changes were also performed with repetition and a lack of continuity (IV). The treatment of patients with venous leg ulcers that are difficult to heal, requires that nursing staff are capable of understanding the person's individual needs and are able to respond to these needs. Understanding the patient, in their everyday lives, provides nurses with the opportunity of performing skilful wound care. It is considered a challenge for the nurses to reach a level of expertise in clinical practice, where they can create an atmosphere of harmony throughout the

dressing change, especially regarding the patients' bodily experience of venous leg ulcers. This means seeing a person, in relation to their everyday lives and understanding how people live with a disabling illness and a leg wound. The text in study **IV** reveals that the district nurse follows up and sees what needs to be done and discusses and explains the dressing change process with the patient. As a result of this, the patients became confident in the district nurse treating their wound. The patient's longed to be treated in a skilful and gentle dressing change, in a confident atmosphere (**IV**). Nurses ought to be aware that any slight touch can cause pain and therefore, it is crucial that wounds are handled gently (Collier & Hollingworth, 2000; Briggs & Torra, 2002). The debridement process was extremely painful, according to patients with chronic wounds (Neil & Munjas, 2000). Briggs and Toro (2002) suggested methods of reducing pain during dressing removals, by: identifying the triggers of pain, involving the patients as much as they wanted to be involved, encouraging rhythmic breathing and by adjusting the pace of the treatment to the patients' own preferences.

The caregivers used 51 different types of local wound treatment in the study area (**I**). There were great variations in routine, regarding topical wound treatment within the health care system, and consistent routines were only found in the Dermatology Department. This is in line with finding in another study (Douglas, 2001) which shows that there appears to be confusion about dressing properties. Thus, it is important for nurses to maintain an up-to-date and reliable knowledge of local dressings and bandages (Collier & Hollingworth, 2000; Bently, 2001). A lack of continuity and a lack of competence, were emphasized by patients with CVI (**IV**). Nurses that deal with patients with chronic wounds should be able to offer continuous and consistent wound treatment (Collier & Hollingworth, 2000; Neil & Munjas, 2000).

The findings from the intervention study (**II**) indicate that even ulcers that are slow-healing, can be healed or improved, with the aid of research-based knowledge. Assessments, with the use of a structured instrument, based on a review of literature relating to risk factors, (Lindholm et al., 1995a) indicates that many factors might influence the healing process, in the case of people with venous leg ulcers. The high incidence of impaired mobility, both generally and in the ankle joint, might be one of many other contributory factors, such as nutrition. General mobility of the foot and ankle seems to be a factor that requires more careful treatment. Research within the same area, found that mobility was important in relation to wound healing (Nelzén et al., 1997; Wissing et al., 1997). Wissing et al., (1999) reported that the risk of malnutrition was common among elderly persons with leg and foot

ulcers. The researcher recommended nutritional assessments and preventive action, in order to restore the person's nutritional status before malnutrition became obvious. The practitioner must consider that good nutrition is necessary, so that the growth of granulation tissue is encouraged (Sibbald et al., 2000).

Another piece of information in study **III** showed that the persons' usual shoes did not fit them, because the bandage was quite bulky and this affected activities such as daily walks. Persons with venous ulcers described their difficulties in finding suitable shoes. Stotts and Deitrich (1997) emphasise that the nurse must take the initiative, in ensuring that footwear is safe and that footwear facilitates daily walks. It is highly important to carefully question and emphasise that people should continue with their daily walks.

Wound healing

The follow-up study (**II**) of persons with chronic ulcers shows that the ulcer area and duration of the ulcer, were significant factors in delaying wound healing. The size and duration of the ulcer, predict the healing time (Margolis et al., 1999). The study shows that ulcers that had been present for a period of more than six months, take significantly longer time to heal and that an ulcer with an area greater than 10 cm² also heals more slowly than a smaller ulcer. This corresponds well with previous findings (Moffatt et al., 1992; Franks et al., 1995). Ulcer duration was found to have particular importance, as a factor that influences the healing process. The healing process had an emotional impact on the persons with venous ulcers and the persons stated (**III**) their longings that the ulcer would heal. The person's life is lived with the hope of a future without a wound. They hope for a healed ulcer, even those suffering from a slow-healing ulcer, and longed for freedom from leg ulceration. To be treated for a period of 18 months and sometimes even longer, has been shown to have an emotional effect on persons with leg ulcers. One study, noted that people who are depressed, have a delayed healing process (Cole-King & Harding, 2001) and that indirect factors might delay healing. These factors included self-neglect, disturbed sleep and poor appetite among depressed individuals. Neil and Munjas, (2000) demonstrated that patients lived their lives, despite their wounds, but they were severely affected by the leg ulcers. The patients had made significant changes in their lives, because of pain, oozing, unpleasant odour, sleep loss, and immobility.

Chase et al., (1997) found that persons with venous leg ulcers, experience different dimensions of healing, compared to persons with a surgical wound. The current venous ulcer might heal, but the underlying condition remains present. The persons experience this healing

as never ending (III). Bland (1999) asserts that they desperately want their ulcers to heal and argues that caregivers have to challenge the myth, that these persons deliberately delay the healing process, in order to ensure continued contact with the nurses, which I supported.

The intervention study (II) showed that knowledge about specific risk factors and consistent treatment with a triple-layer bandage, led to improved and healed legs at therapy resistant CVI. Minimising the number of dressings and adopting a consistent routine, as recommended, would contribute to more effective wound care and less suffering for persons with ulcers. Leg ulcer care, should be based on scientific knowledge of the factors that support healing (II) (Collier & Hollingworth; 2000; Bently, 2001). Recent advances relating to chronic wound biology, have led to the development of several new treatments (Harding et al., 2000). The clinical nurse needs have an open mind in relation to these new opportunities for patients with slow-healing ulcers (Falanga, 1999).

The results from the intervention study (II) indicate that even slow-healing ulcers can be healed or improved with modern technology, and knowledge about the person's specific risk factors. Risk factors which were identified as being particularly important, with regard to delayed healing were: impaired mobility, pain, pathological skin changes and the impact of arterial aetiology.

Recurrence

People with venous leg ulcers live with uncertainty regarding the recurrence of the ulcer. (III). The recurrence rate was low in study II. One explanation might be that more persons are wearing compression hosiery (85%), as was found in study I. To continue using compression, even after the leg ulcer is healed, is the most effective preventive measure. Ruckley (1997) argues, that the least one can expect, is complete permanent healing and he suggests that we must start thinking about long-term patient care. There is evidence that shows that compression therapy is vitally important, in the case of venous insufficiency (Falanga, 1999; Harding et al., 2002). Follow-up plays an essential part in preventing recurrence and has been shown to be effective (Bently, 2001). In order to prevent recurrence, adequate compression is extremely important (Lindholm et al., 1997; Nelzen et al., 1997; Norgren et al., 2000).

Pain

The high frequency of pain among patients with venous leg ulcers, as reported by staff in study **I**, must be considered, since it is obvious that pain slows down the wound healing process (Borglund, 1988). In many cases, the persons with venous ulcers did not achieve pain relief with the use of analgesics. The intervention study (**II**) showed that the impact of pain for most of the individuals with venous disease, together with the pathological skin changes recorded, might also have contributed to the slow healing process. The effect of pain relief on the wound-healing rate requires more detailed study but assessments should begin by talking to the patient about their pain, together with the use of validated intensity rating scales (Briggs & Torra 2002; Moffatt, 2002). Nursing research, in relation to wound care, challenges certain assumptions about venous ulcer pain. Findings in one study show that the severe pain experienced by persons with venous ulcers, is inadequately controlled. (Hofman et al., 1997; Krasner, 1998). The assessment of pain is an important, but often neglected part of the management of venous ulceration. More effective strategies are needed to achieve pain relief for these patients.

Living with a venous leg ulcer

Suffering from pain

In study (**III**) persons with venous leg ulceration, had the overall impression that physical reality included pain and an uncomfortable bandage; this led to limitations in mobility, sleep disturbances and fatigue. Pain has a major impact on their daily living. It was also shown (**I**) that persons with venous ulcers had pain both during the day and at night. The persons (**III**) gradually began to analyse symptoms and struggled to achieve relief from the physical experience of wound pain. They struggled to find relief and most importantly, to find ways of alleviating the pain and achieving well-being. Several recent studies have indicated that pain often accompanies venous ulcers (Lindholm et al., 1993; Hofman et al., 1997; Krasner, 1998). Krasner (1998) asserts that caregivers must recognise and manage the individuals' pain and suffering, as well as optimising local wound care. Studies **I-IV** showed that pain undoubtedly caused a breakdown in the persons' sense of self. It is important to accept the person's word that they are in pain and their descriptions of pain. The person's perception of pain must be assessed and development in the management of pain is required. There is no doubt that patients with CVI suffer from pain and that those suffering from chronic wounds feel pain during the dressing change. Moffatt (2002) stated, according to current literature, that there is

still a lack of clear understanding regarding pain, among patients with wounds. However, in studies with patients suffering from chronic wounds, pain has been identified as a major issue that has an impact on the patients everyday lives (III). Patients are often subjected to painful dressing changes (IV). Pain might even have an important effect on the wound healing process (Moffatt, 2002).

Embodied suffering

In study III the persons with venous ulceration felt that they had a disobedient body. Awareness of the body, can be described in terms of an altered body image, in relation to changes in body reality, body ideal and body aesthetics (Price, 1990). The persons have to live with a disabled body and with a different relationship to their body. This included an experience of being imprisoned within one's own body. Söderberg et al., (1999) made the same findings in the case of women with fibromyalgia: stating that the lived body asserts its presence. It becomes apparent that one *has a* body, instead of *being a* body (Merleau-Ponty, 1962). A persons' bodily being, is experienced as disintegrated and alienated from the self. A painful, aesthetically unpleasant leg ulcer, discomfort, and an appliance attached to the body, become symbols of vulnerability, of being imprisoned within one's body and the bandage. Walshe (1995) also reports these bodily experiences, in a phenomenological study. The findings in study (III) indicate that body image is fundamentally relevant and should be included within caring, since it is obvious that body image has an impact on the well-being of persons with venous leg ulcers. Toombs (1992, p. 28) emphasised the importance of listening, in order to try to understand the illness as lived by the persons and to help prevent unnecessary disruption in their everyday lives. This task involves advanced care, because it entails taking cognisance of the unique language of someone's lived body, as well as observing and interpreting the signs and symptoms of the disease (Benner & Wrubel, 1989).

Having goals to fulfil, impels a person to go on living and to actively use available resources to achieve well being .In illness, the body speaks a particular language, which the individual learns to interpret and respond to (Gadow, 1980). The individuals develop body awareness and skills in self-management. According to Benzein (1999) hope is always a lived activity, we do not *have* hope but we *live in* hope and hope conquers despair. Persons with venous leg ulcers are involved in a tension between the hope that they will become free of the wound and worry about the backlash and imprisonment in a burdensome body. The experience of

belonging to two worlds, a body *with* and a body *without* a wound, involves disunion and frustration (Ricoeur, 1976).

Impact on everyday living

Social contact was limited for persons with venous leg ulcers, as they appeared to avoid contact with friends, because they did not want to show their dressings and leaky bandages. Finding in qualitative research, reported lifestyle consequences caused by problems connected to the bandage (Neil & Munjas, 2000; Douglas 2001; Rich & Mc Lachlan, 2003). In study **III** patients suffering from a depressed mood, had less energy for social life, which gave them a sense of being imprisoned in their homes. Having a leg ulcer meant a loss of freedom for these persons. This is in agreement with Söderberg et al., (1999), who found that a person's everyday life is influenced by illness and the loss of freedom. The persons in study **III** experienced that leg ulcers limited their social relationships. Leg ulcer disease was a cause of restricted mobility and less social activity. The patients felt exhausted and suffered from fatigue, which had a considerable impact on their daily lives. For the afflicted person, these bodily changes and this socially restricted life, lead to feelings of hopelessness and uncertainty regarding wound healing within the foreseeable future.

In study **I**, 70% of the patients lived alone, but during the interview no participants (**III**) mentioned loneliness. Only two persons with unhealed ulcers reported a depressed mood in the intervention study (**II**). Findings from research, on the impact of psychosocial factors on wound healing are contradictory. On the one hand, they show that chronic disease often results in immobility and fewer social activities. However, on the other hand, Corbin and Strauss (1988) draw attention to the complex nature of chronic disease and suggest that the ulcer might, in some cases, be associated with positive social contacts with health care staff. The persons in this study emphasized that they longed for the wound to heal and hoped to become free from the leg ulcer.

Suffering from venous leg ulcers

The following comprehensive understanding is based mainly on the two studies (**III-IV**) that represent a part of the thesis. The studies reflect upon Katie Eriksson's theory of suffering (Eriksson, 1994; Eriksson, 1997). Eriksson (1997) describes three forms of suffering: suffering that relates to existence itself, suffering caused by illness and its treatment, and suffering caused by nursing.

Suffering from illness and its treatment

Prominent findings in the data showed that patients thought that other people perceived their bodies as disgusting, with an unpleasant odour and leakage on their visible bandage. They also had feelings that people stared at them (III). The feeling of being stared at, subsequently, led to a need to hide the ulcer from people. They hid it from strangers and people they did not know very well and sometimes even from those closest to them. Their personal, physical experience can be explained as an altered body image, an altered self, and an altered relationship to others. This can lead to a desire to hide their bodies from the people around them.

Patients felt that they were alone with their ailments. Goffman (1968) addressed the place of the body in everyday life, in the context of being stigmatised. Stigmatised individuals felt disqualified from social acceptance, they also felt that their social identity was ruined and they tended to look down on themselves. They were ashamed of being different and were embarrassed when people stared at their bandage. The body no longer supported them in its social function, and this may lead to social isolation. The patient with CVI suffering, which relates to suffering caused by illness and its treatment, might influence a person actual existence, as a result of not being able to pursue social relationships (cf. Eriksson, 1994). The suffering persons relate to life, and to being a human being among other human beings. They have been disturbed and restricted in their social lives, which means that they are involved in a struggle with their own lives.

The analyses of the themes, describe the elderly peoples' experiences of being isolated from others and living a restricted life (III). When no-one appears to listen to the suffering leg ulcer patients, for example, the non-listening staff (IV) and they are not acknowledged as a suffering embodied person, stigmatisation is then actualised (Goffman, 1968). The patients' described themselves as a 'visible body' with a wound, and they also expressed how vulnerable they were socially. They also explained how they were denied the opportunity of being a 'living human being' and were even denied an 'I-Thou' relation (Buber, 1990). A caring relationship, can be understood in the context of suffering that relates to suffering caused by illness, which has some effect on existence itself (cf. Eriksson, 1994; Eriksson, 1997). The stigmatised person is not only trying to avoid embarrassment to her/himself by hiding the leg ulcer, she/he is also trying to avoid embarrassing friends (cf. Goffman, 1968).

Suffering by nursing

The interpretation reveals, that wound care such as dressing changes, have a major impact on the patients' experience, in terms of body perception and of being a vulnerable individual under pressure (IV). The theme demonstrated 'a lack of skilful touch' in relation to débridement wounds, dressing changes and bandaging, and this created a negative response from the patients. Pain, during dressing changes (IV) and discomfort during the bandaging process, was expressed by the patient, as something that they had to deal with (III). When the suffering became unbearable, they felt that they obtained no response from the caregivers and also felt that they were objectified (IV). The wound treatment, relates to suffering caused by nursing (cf. Eriksson, 1994). The patients confront this treatment in different ways, either by resigning themselves to this unpleasant situation with non-listening strangers, or by merely enduring the situation (IV). Movements toward a life, which does not involve caring encounters and being denied by others, can lead to regression and unbearable suffering. The results shows that patients suffer from health care relationships, that are not caring in the true sense of the word (Dahlberg, 2002). Instead of receiving care, which is beneficial to their health, they are objectified and neglected by the care providers (IV). The leg ulcer patients subjected themselves to a range of different regimes and they had to endure this suffering.

Understanding the persons' suffering, meant being able to see the leg ulcer patients vulnerability and being able to provide them with an opportunity to express this suffering. (IV). Care suffering, which arises from experiences with non-listening and non-present caregivers, meant that the patients are not only denied, they are denied as a suffering person (cf. Dahlberg, 2002). This is in line with Halldórsdóttir findings concerning uncaring and caring encounters within nursing and health care, from other contexts (Halldórsdóttir & Hamrin, 1997).

In a description of the drama of suffering, Eriksson (1994) emphasises, that the first act of the drama means to see and confirm human suffering. The study shows that when the nurse "sees" (IV) (Martinsen, 2000) this provided the patient with an opportunity to express bodily discomfort and gave them the courage to open up and confront this suffering. In act two, the patient was given time to 'suffer out' and was given a response to his/her embodied knowledge and involved in the treatment (cf. Eriksson, 1994).

In study IV the text reveals that the leg ulcer patients felt that they were encountered as dignified individuals, in a confidential atmosphere, which resulted in a caring communion.

According to Eriksson (1994) the third act in the suffering drama, is to give patients the opportunity of recovering health. In study **III** the text reveals that the patients, in their everyday lives, strive to perform meaningful activities, in order to achieve well being. Patients also expressed their longing for the wound to heal.

The studies demonstrated (**III-IV**) a tension between sufferings from wound care, or achieving care communion, in the suffering drama. A part of the suffering drama, meant that patients with CVI were seen and respected and given time to express their unique character of embodied suffering (cf. Eriksson, 1994). Care of the skin associated with dressings wounds, requires keeping track of how patients respond and adjust to the products that are available and also to the changing needs of the patient with CVI (cf. Benner et al., 1999). Providing good pain management means to scrub and debride each different area of the wound, while simultaneously informing patients about what kind of sensations could be expected (cf. Benner et al., 1999). Care suffering does not belong to wound care and it is an unconscious action, which might be caused by a lack of knowledge and a lack of reflection. These shortcomings need to be rectified, by all members of staff involved in health care (cf. Dahlberg, 2002).

The studies show that the meaning of living with leg ulcers of the CVI type, and undergoing unpleasant treatment during dressing changes and bandaging, involves being vulnerable during unpleasant wound dressing changes. There is a struggle for freedom from a disobedient body, together with a striving for well-being and a healed ulcer. The struggle with suffering is a struggle for life (cf. Eriksson 1994). The comprehensive understanding of the studies resulted in an understanding, which states that the elderly with CVI, struggle *with* life. This struggle with suffering, can be understood as an effort to be seen with one's embodied suffering as a vulnerable individual and it includes the right to be encountered as a dignified individual in a caring communion. The inter-subjective relationship between the nursing staff and the patients in study (**IV**) includes sharing the patient's experiences and feelings, of being seen in their everyday lives, leading to a caring communion (cf. Sundin et al., 2001).

According to Eriksson (1992) the meaning of inter-subjectivity and a caring communion, involves understanding that this is a creative act, which involves presence and togetherness. The atmosphere, during dressing changes in this study, was narrated by the patients as: an encounter involving presence, where they are seen and listened to, in a mutual relationship (cf. Ekman, 1993). The patient was 'present' for the nursing staff, not as an object; on the contrary, the nurse listened to them and acknowledged them. The relationship between an 'I

and a Thou', mediates an understanding of the patient's embodied message to the nurse and vice versa: that is, an inter-subjective communion.

The organisation and management of leg ulcer care

Summing up, the epidemiological and wound management results, show that chronic leg ulceration within the elderly population, has been a problem in the past and continues to be a problem (I-II). The prevalence, 0.12% in study I, shows that leg ulcers are a common problem, especially among the elderly in urban areas. In the county of Uppsala (Lindholm et al., 1999) the prevalence figures were 0.14% and divisions in age had not changed. The differences between recent studies might be attributable to either the design of the research, or to the increasing number of elderly people in society. The prevalence of leg ulcers might be underestimated, because people who work, often take care of the ulcers themselves (Nelzén et al., 1996). This study shows that leg ulcers clearly remain a problem and also shows that health care services need to be improved, for persons with leg ulcers.

In study I- more than the half (63%) of the subjects were treated within the primary health care system and health care assistants carried out dressing changes in 54% of the cases. Health care assistants, have a great deal of responsibility for dressing changes, yet the actual responsibility for leg ulcer care, should rest with nurses (RN). Within home care services for people over 70 years of age, health care assistants performed significantly more dressing changes. Most of the risk factors and underlying symptoms of the disease, occur more frequently among elderly people. Persons with venous insufficiency, combined with arterial impact, were more common in this study (I). In the intervention study (II) it was shown that the status of people with leg ulcers was greatly influenced by non-ulcer related risk factors and arterial disease, for example, diabetes sometimes occurred during the course of the treatment. In the follow-up study (III), the mortality rate for persons with leg ulceration was five times higher than that for the age-matched population. In the sub-group analysis (III) slightly more than half (56%) of the subjects were found to have arterial disease. The trend in this study (I) was that less qualified members of staff were involved with the treatment of more complex wounds. This was also seen in Hjelm et al., (2000). In research-based practice, the responsibility for wound management should be shared between physician and nurse (RN), together with health care assistants (SOSFS 1993:17). Further research is needed regarding the health care assistants' skills and knowledge, based on scientific research on the management of leg ulcers. It should be considered as an urgent challenge, for health-care

providers to make changes in practice, education, and research, leading to improvements for persons with leg ulceration. Standardisation of local treatment, using fewer dressings, might bring substantial savings, in terms of both human suffering and financial costs. Frequent examinations by physicians, would probably also contribute to a more specific etiological diagnosis.

In 6% of the cases, (study I) the diagnosis was not reported by the staff and in 7% of the cases; a general practitioner had not examined the patients. According to the results of study I, the diagnosis was more commonly reported and the general practitioner had carried out recent examinations. Similar findings have been reported in other studies (Lindholm et al., 1992a; Nelzen et al., 1994) and one study showed that the diagnosis was still absent in a small number of cases (Lindholm et al., 1999). The National consensus document has shown the importance of aetiological diagnosis and ABPI of all persons with leg ulcers and emphasised the importance of performing adequate wound treatment. It is extremely important that nurses become aware of the cause and the underlying pathology, before making any decision regarding treatment.

Provision of effective health care services for patients with leg ulcers and wound problems, requires skills in many specialities. The staff in charge of such patients must be interested in the subject and have access to a wide range of knowledge, based on multidisciplinary strategies and guidelines for wound treatment (Gottrup et al., 2001; Harding et al., 2002).

CONCLUSIONS

Elderly people with venous leg ulcers, struggle with the illness and exist with the strain of being imprisoned in the body, the bandage and the home. However, they also exist with the hope of becoming free from a burdensome body. The relationship between experiences of the lived body and the environment has changed. The elderly people try to find ways of managing pain, uncomfortable bandages, and a disobedient body. These are all obstacles in the pursuit of everyday activities and relationships with others, in a persons' social life. The people with leg ulcers live with the hope that the leg ulcer will heal. Hope is a possible source of relief in their altered situation.

The challenge for caregivers is to shift from focusing on wound management, to focusing on understanding the specific needs of each individual, within the context of their daily lives. This should be balanced with the ongoing disruptions, which impair their ability to live a reasonable life. By understanding the nature of the individuals' personal experience of venous leg ulcers, nurses can anticipate problems and provide more sensitive care. The findings of this study illustrate the need for further research, in order to discover the needs of persons receiving treatment for active ulceration and in particular, their needs regarding care of the painful venous ulcers. Strategies should be developed, in order to enable persons with leg ulcers to actively participate in their own care.

In the findings, it has been shown that patients expect care to be performed in a skilful and gentle way and they also expected the dressing changes to be carried out in a confident atmosphere. These reflections led to practical wisdom, which affected caregivers' ability to meet the sufferings persons and allowed them to act wisely, and this was considered to be extremely important. Practical wisdom has to be practised in real life, to gain skilfulness in encountering and performing wound care in a competent and skilful way, by co-operating with the suffering patient with leg ulcers. The caregivers need to learn to listen actively to the patients' experience and develop a clinical understanding of the patients' situation. Gaining this practical knowledge, requires an embodied way of knowing, that cannot be fully learned, except through experience (cf. Benner et al., 1999). In human practice, this can be achieved by receiving the wisdom and insight that the suffering person can give and narrate about, during the dressing change situation and in other situations concerning everyday illness experience with CVI.

Comprehensive nursing care, based on solid evidence, should include assessment of the lived illness experience and preventive actions. This is an important starting point in the treatment of leg ulcers and wound healing, in maintaining hope and confidence among these people before the wound becomes too difficult to heal. According to Eriksson et al., (1999), Willman (1998) and Ruckley (1997), evidence-based care, requires a multidimensional approach, because such care, involves not only dressings and bandages but also the persons experience of illness. Further research is needed, to gain a deeper understanding of the nursing staffs' qualifications and knowledge relating to wound management, and this should come from the perspective of the persons suffering from leg ulcers.

The challenge is to create an organisational and wound care unit that can accommodate both the science and the human aspects. Treatment should be associated with confronting human realities (lived illness experiences) and embodied suffering, and should aim at offering skilful treatment with mutual respect. By listening to the patient, in mutual understanding, the aim should be to achieve, a caring communion during wound care and treatment. Organisations that value patient-focused care ought to be designed with a range of diversity. Such diversity requires healthcare providers that possess knowledge and resourcefulness, when encountering leg ulcer patients in their embodied suffering. An active assessment of patients with chronic leg ulcers, including medical diagnosis, prognostic factors for healing and an individualised care programme, could probably change the outcome of care. In the long term, following these measures will lead to less suffering for the persons and a more cost effective care for society.

Collaboration between theory and practice, could promote knowledge and skills for leg ulcer management. Research has demonstrated, that leg ulcer clinics (cf. Gottrup et al., 2001), such as multidisciplinary wound healing centres, can deliver cost-effective care to patients with wounds. They can also, provide a centre for nurses and educators, to develop skills in leg ulcer management and also increase good practice, based on nursing care research (Harding et al., 2002). A real challenge for the future is to select appropriate interventions for each patient. Developing appropriate clinical services and clinical research are some suggestions in this important and neglected subject.

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POPULÄRVETENSKAPLIG SAMMANFATTNING

Äldre patienter med långsamt läkande bensår - ett kroppsligt lidande.

Personer med bensår vårdas ofta under lång tid inom sjukvården. Alltför hög acceptans sker av icke-läkande bensår. Betydande brister på samordning i vårdkedjan har framkommit vilket utgör ett hinder för god vård och omvårdnad. En mängd olika preparat används för lokal bensårsbehandling för patienten. Undersökningar visar att personal som ansvarar för bensårsbehandling inte känner till den bakomliggande orsaken till bensåret. Ett fåtal studier beskriver den komplexa bilden av patientens egen upplevelse av sitt bensår och dess behandling.

Syftet med studien i den här avhandlingen var att kartlägga förekomsten av kroniska bensår, behandling och vårdnivå inom ett sjukvårdsområde i Stockholm samt efter 18 månader en uppföljning av sårhelingsfrekvens. Ett ytterligare syfte var att dels beskriva äldre patienters upplevelse av leva med ett venöst bensår och dels, dessa patienters upplevelse av såromläggning under pågående behandling vid venöst bensår.

Metoden vid studie **I** och **II** var en kartläggnings- och uppföljningsstudie av kroniska ben- och fotsår inom ett sjukvårdsområde. En enkätundersökning med fasta svars alternativ har använts i studie **I**. Frågeformuläret omfattande demografiska data, data om såret/såren samt omvårdnadsrutiner och behandling. I studie **II** utsändes en enkät 18 månader efter kartläggningsstudien. Enkäten innehöll frågor om bensåret läkt/icke läkt respektive recidiverat, samt eventuell amputation. Vårdpersonal inom primärvården, kommunal hemsjukvård, geriatriska avdelningar, somatiska avdelningar samt sjukhem inom undersökningens geografiska område ombads fylla i enkätformulären i studie **I** och **II**. Bearbetning av insamlade data i studierna har utförts deskriptivt.

Data i studie **III** och **IV** samlades in genom intervjuer med 15 patienter med venösa bensår. Personerna som ingick i studien har efter medgivande intervjuats i sin hemmiljö. Intervjuerna har spelats in på band samt skrivits ut ordagrant. Intervjuerna inleddes med en bred öppen fråga som möjliggjorde för den intervjuade att berätta om sin upplevelse utifrån syftet av att leva med venöst bensår och såromläggningssituationen. I studie **III** har data analyserats utifrån en fenomenologisk-hermeneutisk ansats som utgår från den individuella människans berättade erfarenheter. Metoden innebär att man i det första steget gör en naiv läsning, för att bilda en spontan uppfattning om materialet en s.k. ytlig tolkning. Sedan görs en strukturanalys

för att förklara innebörden i texten. Slutligen görs en helhetstolkning av hela materialet. Även i studie **IV** har en tolkande ansats använts. I metoden ingår tre samordnande tolkande strategier; helhets förståelse, tematisk analys och identifiering av patientfall som illustration av teman. Dataanalysen för arbeten **III** och **IV** innefattar en integrerad, cirkulär process mellan delar och helhet av texten, mellan förgrund och bakgrund av situationer som beskrivs av deltagarna.

Resultatet vid kartlägningsstudien (**I**) identifierades 294 bensårspatienter, det motsvarar en prevalens på 0,12%. Majoriteten av patienterna var äldre än 65 år. Inom primärvården var 63% av patienterna äldre än 80 år. Den vanligaste orsaken till bensår var venös insufficiens. Mer än hälften av ben- och fotsår behandlades inom primärvården. Kompressionsbehandling användes i 85% av fallen med venösa bensår. Många olika lokala förband användes (N=51). Smärta rapporterades i 47% av alla patienter med venösa bensår. I 29% av patienter med ben- och fotsår gavs ingen smärtstillande behandling.

Uppföljningsstudien (**II**) efter 18 månader visade att 61% av patienternas bensår var läkta och 29% hade fortfarande ett öppet bensår. Patienter med icke-läkande bensår hade i högre grad nedsatt rörlighet och ett arteriellt inslag än personer med läkta bensår.

Vid dataanalys utifrån patientintervjuerna av studie **III** identifierades fyra teman; förändrad kroppsbild, begränsning och anpassning till dagliga aktiviteter, emotioner vid smärtsamt sår och bandage, samt ambivalent förhoppning om ett läkt sår. Den tolkade helheten kan förstås utifrån att personer med venösa bensår lever i dialektiken mellan att vara instängd i den egna kroppen, hopp om befrielse från såret. Bensåret ger en känsla av skam och de vidtar handlingar med avsikt att undvika att visa den defekta kroppen. Detta leder till ett socialt tillbakadragande.

Utifrån dataanalys vid studie **IV** framkom följande tema; att bli behandlad med skickligt handlag och engagemang eller som en rutinuppgift, att bli sedd inte endast som en bensårspatient utan som en person i sitt sammanhang (livsvärld), och att bli sedd antingen som en besvärlig patient eller välinformerad, erfaren person. Studien visar på betydelsen av att beakta patientens perspektiv vilket innebär att patientens dagliga tillvaro uppmärksammas. Genom förståelse utifrån den unika patientens liv och unika sätt att relatera sig till hälsa och sjukdom kan sjuksköterskan utföra en sensitiv och evidensbaserad sårbehandling.

Studierna visar att ett strukturerat omhändertagande av personer med bensår kommer att leda till betydande besparingar både i mänskligt lidande och i kostnader för sjukvården. Det finns behov av att förbättra vården för patienter med bensår. Förutsättning för detta är att patientens diagnos verifieras och att patienten bedöms utifrån sin upplevda livssituation samt möjligheter till aktiv egen medverkan vid pågående behandling. Det framkommer i studien att långsamt läkande sår läker snabbare med standardisering av lokal behandling genom att använda färre material och kunskap om specifika sårläkningshämmande faktorer. Bedömning av patientens bensårssmärta är också betydelsefull och resultatet pekar på att patienter med bensår är ofta underbehandlade. Det krävs regelbunden uppföljning av patientens bensårssmärta. Vid omvårdnad av patienter med bensår bör även deras kroppsliga upplevelse av bensåret innefattas med avsikt att införskaffa specifika kunskaper om personens individuella behov. Utmaningen för sjuksköterskan är att skifta fokus från sårbehandlingen till att förstå varje individs specifika behov utifrån deras dagliga liv. Genom att balansera mellan ett vårdlidande som bensårbehandlingen förorsakar den äldre patienten och genom förståelse av patientens upplevelse av sitt sjukdomstillstånd kan sjuksköterskan utföra en sensitiv och adekvat behandling.

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APPENDIX