

**The Development and Validation of a Self-Efficacy Tool for People over 60 with  
Venous Leg Ulceration**

**Annemarie Kathleen Brown**

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## **ABSTRACT**

Venous leg ulceration has a high recurrence rate. Patients with healed or frequently recurring venous ulceration are required to perform self-care behaviours to prevent recurrence or promote healing, but many find these difficult to perform. Bandura's self-efficacy theory is a widely used and robust behaviour change model and underpins many interventions designed to promote self-care in a variety of chronic conditions. By identifying areas where patients may experience difficulty in performing self-care, interventions can be developed to strengthen their self-efficacy beliefs in performing these activities successfully. There are currently a variety of self-efficacy scales available to measure self-efficacy in a variety of conditions; but not a disease-specific scale for use with venous ulcer patients. The aim of this study, therefore, was to develop a disease-specific, patient-focused self-efficacy scale for patients with healed venous leg ulceration.

Phase 1 consisted of a qualitative design and used focus group methodology to generate an item pool for potential inclusion into the scale from the patients' perspective. In phase 2, factor analysis using equamax orthogonal rotation methods was used to reduce the items from 60 to 30, resulting in 5 major domains: general self-care; daily self-care tasks; normal living; developing expertise and avoiding trauma.

Preliminary reliability studies indicated that the developed scale, VeLUSSET<sup>®</sup> has good internal consistency, with an overall Cronbach alpha of .929 and a strong test-re-test reliability. Furthermore, correlation with the General Self-Efficacy Scale demonstrated a strong positive relationship between the two scales.

These results indicate that the VeLUSSET<sup>®</sup>, although still in the early validation stages, is a reliable instrument to measure venous leg ulcer patients' self-efficacy in performing self-care tasks within clinical practice. The development of this disease-specific tool has now filled a gap in the research on managing patients with healed venous leg ulceration.

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## **1.0 Chapter One**

### **1.1 Background to the study**

A chronic venous leg ulcer (CVLU) is defined as a breakdown or loss of skin on the lower leg, above the ankle, which has not healed within six weeks (Nelson et al. 2008). CVLUs most often occur as a consequence of chronic venous insufficiency, caused by venous reflux and/or valve incompetence (Brem et al. 2004). Although precise prevalence data is difficult to obtain due to methodological anomalies, CVLUs have been estimated to affect between 0.6 to 3.6 % of the adult population of the United Kingdom (Briggs et al. 2003; Graham et al. 2003) and prevalence increases with age (Nelzen et al. 1994; Margolis et al. 2002; Moffatt et al. 2004).

Treating venous leg ulceration in the United Kingdom has been estimated at costing £300-£600 million per annum, representing 3% of the total National Health Service (NHS) budget (Simon et al. 2004; Posnett and Franks 2008) and involves the application of a graduated compression system (bandages or hosiery) to promote healing. Guest et al. (2012) have estimated the annual cost of treating one patient at £4400 per annum with nurse time accounting for up to 58% of the cost. In the absence of surgery, once healed, patients are encouraged to wear life-long compression hosiery which is currently recommended for the prevention of recurrence (Nelson et al. 2000). The high recurrence rates quoted above are indicative of the difficulties patients experience in maintaining their healed ulcer which may include patient non-adherence, application difficulties and multiple co-morbidities (Brown, 2010). Apart from the economic burden on the NHS, it has been reported that CVLUs have a negative impact on patients' quality of life (Persoon et al. 2004; Briggs et al. 2007; Herber et al. 2007; Moffatt et al. 2009; Renner et al. 2009). Patients report experiencing high levels of pain (Hoffman et al. 1997); mobility restrictions (Heinen et al. 2007a) sleep disturbances, negative emotions, reduced social interaction (Franks and Moffatt 2006) and the inability to maintain their personal hygiene (Brown, 2005).

Venous leg ulcers are, however, often recalcitrant to treatment, and healing is known to be a complex process involving many factors, including age (Gohel et al. 2005; Meaume et al. 2005), ulcer duration (Kjaer et al. 2003; Gohel et al. 2005; Meaume et al. 2005; van Gent et al. 2006; Moffatt et al. 2009), ulcer size (Margolis et al. 1999), poor ankle mobility (Franks et al. 1995; Barwell et al. 2001) and non-adherence with compression therapy (Dickey et al. 1991; Moffatt et al. 2008; Moffatt et al. 2009b; van

Hecke et al. 2011). Unfortunately, venous leg ulcers often recur and recurrence rates vary between 45 and 67% (Harrison et al. 2001; McDaniel et al. 2002; Abbade et al. 2005). More recently, recurrence rates of between 26% - 69% have been reported at 12 months (Kapp et al. 2008; Finlayson et al. 2009, 2011). Compression therapy is considered the gold standard for the treatment of CVLU and recurrence prevention (Eff. Health Care 1997; Nelson et al. 2000; Sackheim et al. 2006; O'Meara et al. 2009) and healing rates of between 37-46% at 12 weeks and 55-68% at 24 weeks have been reported with this therapy (Iglesias et al. 2004). Unfortunately, for a large percentage of patients, however, healing may never occur or they will go on to suffer multiple recurrences (Vowden and Vowden 2004; van Gent et al. 2006). This is supported by the data obtained during this study.

## **1.2 NHS Reforms**

The introduction of Payments by Results (PbR) (DH 2002, 2011) underpins the NHS systems reforms agenda and is a rules-based, transparent method of reimbursing health providers for care delivered (Pate, 2009). PbR has been introduced as a driver to achieve several key objectives of health service reform which include: improved efficiency, value for money through enhanced services, more choice for patients, plurality and contestability and the introduction of more innovative models of care and quality services (Pate, 2009).

The 2010 Government White Paper 'Equity and Excellence: Liberating the NHS' (DH 2010a) and supporting document 'Liberating the NHS: Greater choice and control' (DH 2010b) clearly signalled the intention to provide greater choice for patients in most sections of healthcare. As a result, any qualified provider (AQP) of health services can now become a provider of services if they can demonstrate that they can fulfil the conditions set within a service specification. Within the service specification are key performance indicators (KPIs) which are measurable targets, set by commissioning bodies, designed to demonstrate the quality of care provided. The current service specification for venous leg ulcer management lists the following KPI's:

- To heal 70% of venous leg-ulcers care pathway 1 within an 18 week period.  
(Care pathway 1 – simple ulcer)
- To heal 70% of venous leg- ulcers care pathway 2 within a 24 week period.(Care pathway 2 – complex ulcer)
- Assessment of concordance rate at 4 weeks

The service specification emphasises the importance of education and encouraging self-care for patients with healed venous leg ulcers but will only reimburse providers for a 1 hour follow up session and provision of compression hosiery posthealing (2011 pg.13). Furthermore, it recommends assessment of patient concordance at 4 weeks, but does not give guidance on how this should be assessed. According to the service specification, “if the patient is deemed non concordant with treatment, the service specification recommends that the patient be referred back to the original referrer”. This is nonsensical since a patient cannot be non concordant; it is the nurse/patient relationship which can be deemed nonconcordant and indicates an organisational misunderstanding of the concept of concordance. (See further in the chapter for a detailed discussion).

This lack of provision for recurrence prevention long-term will create “a revolving door” service, with some patients, once healed, frequently re-presenting with a recurrence within a relatively short timeframe. It could be argued, therefore, that ulcer recurrence will become financially advantageous for the service provider as the patient enters the reimburseable care pathway again. Furthermore, the KPIs reinforce the assumption that CVLU are an acute condition, where healing of the ulcer is the only acceptable reimbursable outcome (Brown, 2010). In addition, the anticipated healing times of 18 weeks and 24 weeks respectively could be considered somewhat optimistic, borne out by the data gathered in this study and evidenced more recently from another study (Guest et al. 2012).

### **1.3 Chronic conditions**

CVLU, with its periods of healing, alternating with open ulceration, has the characteristics of a chronic condition defined by Lubkin (1990) as “an irreversible disease/condition without prospect of complete recovery” since the underlying aetiology, chronic venous insufficiency, if not treated surgically, will persist. CVLU bears similarities with the disease trajectory of other chronic conditions, such as multiple sclerosis or rheumatoid arthritis. The focus of care provision for these conditions, however, is not on cure, but rather to enable the patient to learn to accept and adapt to living with their condition. An important element of this focus is on encouraging self-care or self-management.

The economic impact of chronic conditions on the NHS, together with an ever increasing ageing population, has led to the introduction of self-management

programmes, such as the Expert Patients programme (DH 2005a,b). These programmes have been developed to provide patients with chronic conditions with the tools, techniques and confidence to manage their condition better on a daily basis. They promote self-advocacy, and provide information about making informed choices and forming effective working partnerships with health professionals.

The theory underpinning these self-management programmes is self-efficacy theory (Bandura, 1977), a social-cognitive health behaviour change model. Self-efficacy refers to a person's sense of confidence in his or her ability to perform a particular behaviour in a variety of circumstances (Bandura, 1977, 1986) and is considered to be a robust predictor of health behaviour change, offering health educators a practical but research-based theoretical construct with which to develop interventions designed to reduce the economic, human and societal burden created by chronic disease (Marks et al. 2005).

In order to demonstrate objective outcome measures of these interventions, many scales have been developed to measure patients' self-efficacy levels pre- and post-intervention. An individual patient's self-efficacy level can be assessed at baseline and targeted interventions implemented to increase self-efficacy within a particular domain. An increased self-efficacy score, assessed post-intervention is indicative of a positive outcome. Self-efficacy, however, is disease-specific and these existing self-efficacy scales may not tap into the self-efficacy expectations and specific behaviours and performance accomplishments which are unique to patients with venous leg ulceration (Bandura, 1977).

It is recommended that health professionals in the future will consider implementing similar self-care programmes for patients with CVLU as a means to encourage self-care to prevent recurrence and/or adaptation to living with a chronic condition in response to the challenges set out within the recent NHS reforms (DH 2006). This study describes the development and validation of the VeLUSSET, a disease-specific scale to measure patients' perceived self-efficacy in undertaking activities which may help to prevent ulcer recurrence or, if this is not achievable, to accept and adapt to living with this chronic condition. This will provide commissioners and health professionals alike with an alternative objective outcome measure of clinical interventions when ulcer healing is not attainable within a specified timeframe.

## 1.4 Aim and Objectives of the study

The aim of this study was to develop and validate a self-efficacy scale for patients with healed or non-healing venous leg ulceration, using a combination of qualitative and quantitative methods.

The objectives were:-

- To establish, through review of the literature, whether self-efficacy is the most appropriate theoretical framework for achieving health behaviour change in patients with healed leg ulceration.
- To generate qualitative data from the users' perspective, eg. health professionals, patients and carers/relatives in order to generate self-efficacy statements to be included in the scale (Phase 1).
- To use quantitative methodology to reduce the data and test for internal/external reliability of the developed scale (Phase 2a and 2b).
- To test the developed scale against the Generalised Self Efficacy Scale in order to assess construct validity and specificity to leg ulcer patients over time (Phase 2c).

## 1.5 Venous ulcer recurrence – literature review

### Introduction

In order to establish the size of the ulcer recurrence rate and to determine what is known about recurrence, a literature search was conducted using the following databases: MEDLINE (1966 to 2012), CINAHL (1982 TO 2012), EMBASE (1980 to 2012), The Cochrane Group trials register (August 2012), the RCN ROM, Centre for Reviews and Dissemination at York and the Cochrane Controlled Trials Register (Central) 2012 and the National Research Register to locate ongoing research in the NHS using the following keywords:-

leg	venous	MeSH term
Ulcer	bandage	<i>bandages</i>
stocking	compression	<i>Randomized controlled trial</i>
recur*	prevention	<i>Recurrence (prevention &amp; control)</i>
		<i>Risk</i>
		<i>Varicose ulcer (prevention &amp; control)</i>

The Medical Subject Headings (MeSH) listed above were used in addition, as used alone, the terms 'ulcer', which refers to open wounds anywhere on the body surface or internally, and 'leg ulcer', which includes ulcers of both arterial and venous origin with their different aetiology, treatment and methods of prevention, were unspecific. Other combinations of the keywords such as 'venous leg ulcer' and 'prevent\*' failed to identify any additional articles. Boolean operators were used to combine searches. In addition, hand searches of conference proceedings, wound care journals and secondary references were undertaken.

A total of 42 studies were retrieved and these were further searched systematically for relevance for inclusion into the literature review. Exclusion criteria were: studies conducted prior to 1990, non- English language, surgical interventions and healed ulceration as an endpoint. Inclusion criteria were: studies from 1990, randomised controlled trials (RCTs), any other study methodologies, ulcer recurrence as an endpoint as opposed to healing, English language and the use of compression alone as an intervention. The remaining studies were obtained and the search was refined by abstract skimming for relevance for inclusion. From the initial literature retrieval, 26 RCTs were excluded as the intervention used was a surgical procedure and/or compression or a comparison of types of wound dressings or comparison between different types of compression therapy, for example, multilayer bandaging versus Unna's boot. As this system of applying inelastic compression is a rather outmoded method, still used in America but not in the United Kingdom, it was not felt to be appropriate for inclusion in the literature review. Four studies were excluded due to their age; two were excluded as the intervention consisted of oral medication and two studies used intermittent pneumatic compression as a comparator. (A list of the excluded studies is given in appendix 1).

A systematic review on ulcer recurrence (Nelson et al. 2000) was also retrieved which included only two RCTs which had met their inclusion criteria and these were reviewed. A further RCT which had not been completed at the time of Nelson's systematic review was also reviewed (Vandongen and Stacey 2000). In total, eight studies met the inclusion criteria and these were reviewed and scored for inclusion using the CONSORT framework for critiquing RCTs according to Sacketts' (1996) framework of the hierarchy and strength of evidence for research studies. The individual studies will not be discussed here in detail however an overview of the findings will be briefly presented. Table 1 gives a summary of the studies reviewed.

1.5.1 Table 1. Summary of studies reviewed

Author	Methodology	Sample Size	Intervention/ Control	Recurrence rate (Compliance)	Recurrence rate (non compl.)	Follow-up Period	Method of assessment
<b>Harper et al. 1999 UK</b>	R.C.T.	300	Hospital study. Patients randomised to receive Class II or Class III hosiery	39%	Not stated	5 yrs.	Patient self-report – interview weekly – 4 mths – 5 yrs.
Class II hosiery							
Class III hosiery							
<b>Franks et al. 1995 UK</b>	R.C.T.	188	Community study. Patients randomised to receive 2 different types of Class II hosiery	26%		1 year	Patient self – report – interview 3 mthly – 18 mths
Class II hosiery				21%	Not stated	18 months	
Class II hosiery				34%	Not stated	18 months	
<b>Vandongen and Stacey 2000 Australia</b>	R.C.T.	78	Randomised into receiving Class 3 compression hosiery (Int) or no hosiery (control)	72%	Not stated	2 yrs.	Patient self-report
<b>Samson and Showalter 1996 USA</b>	Prospective Observational cohort study	53	Convenience sample Treated with Class III hosiery	3%	97%	6 mths –69 mths (average 28 mths)	
<b>Nelzen et al. 1997 Sweden</b>	Prospective Cohort study	382	Patients studied to assess long-term prognosis – evaluations, questionnaires. Death rate statistics obtained from Govt. Dept.	9%	Not stated	20 months	
				21%	Not stated	54 months	
				10%	Not stated	5 yrs.	

<b>Barwell et al. 2000 UK</b>	Prospective observational study	486	Assessment of risk factors for healing/recurrence in leg ulcer clinic patient.  4 layer compression & weekly clinic follow-up Ulcers > 3cm pinch- skin grafted	38%	Not stated	3 yrs.	
<b>Fassiades et al. 2002 UK</b>	Prospective observational study – 3 groups	101	Hospital clinic Convenience sample Treated with compression – followed up every 3 mths.				
<i>Venous ulcer</i>		64		10%	Not stated	5 yrs.	
<i>Venous ulcer + 1 con.disease</i>		23		8%	Not stated	5 yrs.	
<i>Venous ulcer + 2 con. Disease</i>		13		1.3%	Not stated	5 yrs.	
<i>Non Ven. Ulcer</i>		19		1.9%	Not stated	5 yrs.	
<b>Gohel et al. 2005 UK</b>	Longitudinal observational study	1324	Leg Ulcer clinic Treated with 4 layer compression/hosiery Follow- up every 3 mths	17%	Not stated	1 year	

## 1.6 Summary of the literature

Review of the literature indicates that the likelihood of ulcer recurrence is significant, however, there is some evidence that the prophylactic wearing of compression hosiery post-healing may help to reduce recurrence rates (Nelson, 2001). Despite patients being prescribed compression hosiery routinely post-healing, recurrence rates, however still remain depressingly high, between 1.3% - 72% when patients are concordant with wearing compression hosiery (Vowden and Vowden 2006), rising to up to 97% in patients who are not (Moffatt and Franks 1995).

Many of the studies reviewed suffered from methodological weaknesses, for example, adherence was not assessed formally but patient-reported, and consequently, the results must be viewed with caution. Follow-up periods varied between studies and large numbers of subjects were lost to follow-up. The focus of many studies was on time to healing as an outcome measure as opposed to ulcer recurrence. In addition, many authors were investigating the efficacy of one system of compression over another and these studies were often commercially sponsored.

Secondary outcome measures included duration of episodes of re-ulceration, length of time patients remained ulcer free, patient compliance and comfort, cost of treatment and quality of life. The assumption underpinning these studies was that graduated compression hosiery is regarded as a pre-requisite for the prevention of venous leg ulceration recurrence (Edwards and Moffatt 1996). A systematic review by Nelson et al. (2000) concluded that, in the absence of well-designed RCTs comparing recurrence rates with and without compression usage as a single outcome measure, there is no robust evidence that compression prevents the recurrence of venous ulcers. The authors acknowledged however, that this may have been due to lack of evidence rather than evidence of lack of benefit. A Cochrane Review in 2000 conducted by the same authors in an attempt to give a more definitive answer concluded, however, that there was some circumstantial evidence that compression reduces ulcer recurrence and that high pressure compression (40mmHg) may reduce ulcer recurrence rates (Nelson et al. 2006). As a result of this, Best Practice consensus documents have been published which recommend compression therapy as the mainstay approach to reduce recurrence (WUWHS 2006, 2008). Nelzen (1999) however, quite rightly commented that compression alone does not hold the answer for prevention of venous ulcers since a venous leg ulcer is simply one of a number of manifestations of the underlying disease and

further comments that: “*Compression treatment has been used since the days of Hippocrates and has not as yet solved the problem of leg ulceration*” (pg. 123).

This statement infers that there may be other factors that may help reduce ulcer recurrence such as performing self-care activities including limb elevation, ankle/foot exercises and increasing mobility levels which patients are asked to perform. The evidence to support these self-care strategies will be reviewed in Chapter 2.

### **1.7 Non-adherence with wearing compression hosiery**

Non-adherence with wearing compression hosiery has frequently been cited as a reason for ulcer recurrence within the literature (Franks et al. 1995; Edwards 2003; Jull et al. 2004; Brooks et al. 2004; Polignano et al. 2004). This may be circumstantial evidence rather than empirical since it would be considered unethical to conduct a study and allocate patients to a control group where no compression was worn in the light of research evidence to support its efficacy (Kappa and Sayers 2008; Moffatt et al. 2009a). Furthermore, these results were based on patient self-report, with only one study (Franks et al.1995) giving more details of how this information was obtained.

Moffatt et al (2009a) and Van Hecke et al. (2007) reviewed the literature to investigate the reasons attributed to patient non adherence with compression therapy and its effects on clinical outcomes. They commented on the differing definitions of concordance and non-concordance within the studies, making comparison difficult and which necessitated the inclusion of ‘adherence’, ‘compliance’, ‘non/poor concordance’ as keyword search terms for the literature search. Horne et al. (2005) conducted a scoping exercise on strategies to improve concordance with medication and concur with Moffatt et al, describing the lack of definition and interchangeability of the terms. Interestingly, the title of Van Hecke et al’s publication still refers to “patient compliance” as opposed to concordance or adherence (Van Hecke et al. 2007). This chapter will now continue with a more in-depth exploration of these terms including an overall definition in relation to healthcare generally and more specifically, how these terms can be applied to the behaviours of venous ulcer patients.

### **1.8 Defining compliance, adherence and concordance**

Compliance was defined by Sacket (1976) as “the extent to which a patient’s behaviour coincides with the clinical prescription provided by the health professional”. Patients who do not follow professional advice may be labelled non-compliant, and early nursing literature reinforced the medical viewpoint that ‘non-compliance is a

substantial problem with devastating consequences for society, specifically costly relapses and re-admission to hospital (Allen et al. 2011).

Fraser (2010) suggests that non-compliance is behaviour that challenges professionally-held beliefs, expectations and norms. Whilst on the surface, the focus of the literature on compliance appears to be concerned with improving health care, in reality, it appears to be influenced by issues relating to professional control and entrenched beliefs about nurse-patient relationships (Fraser 2010; De las Cuevas 2011). Non-compliance can, therefore, be seen as a label used by professionals to maintain power and control over patients: it is ascribed by health professionals *onto* patients in order to meet their objectives and agendas (Amro et al. 2012).

The concept of 'compliance' can be viewed as an expression of the paternalistic model of medical decision making, in which medical staff are considered to be in authority and they therefore decide what action is in the patient's best interests. The assumption is that the physician is a benevolent authority and that patients should acquiesce and willingly accept the doctor's word (De las Cuevas 2011). This medically oriented approach to compliance places the doctor-patient relationship as pivotal in ensuring patient adherence to treatment; however it has been suggested that this over-simplifies a complex construct and is based on the assertion that patients are rational human beings (Lawn 2011). Furthermore, Lawn asserts that people have ideas and attitudes about medicine which are shaped by their relationships with others and past and present lay beliefs and experiences.

Within the social model of health, where health and illness are features of the complex and interactive system of 'life' the model acknowledges the importance of social factors in shaping health behaviours and outcomes, including the behaviour, referred to as 'non-compliance' (Russell et al., 2003). The term *good holistic 'patient-centred'* nursing practice implies that nurses must recognize and acknowledge the social factors that constrain people's capacity to change. An example of this would be a young woman who wishes to wear dresses/skirts and consequently refuses to wear thick ugly compression hosiery. With this insight into the woman's world, the health professional should now seek to find a compromise with the patient, rather than merely label her 'non-compliant'.

Brown (2005) highlighted the need for health professionals to ascertain patients' expectations of their leg ulcer treatment, which may be dichotomous to their own. The health professional may see healing or recurrence prevention as the only

desired endpoint of treatment, whereas the patient may seek pain relief or odour control rather than complete healing and may therefore refuse compression therapy, viewing it as an unnecessary burden. This may be viewed by the health professionals as non-compliance, however it may be deemed as informed patient choice. The dilemma for health professionals directly involved is that, whilst they are aware of the outcomes when their treatment plan is not followed, they are also aware of the person's right to choose not to comply. The juxtaposition of these two concepts is at the heart of the issue; the health professionals' need to act to encourage treatment adherence whilst concurrently acknowledging individual responsibility for actions. This is explored in greater detail in chapter 8 in relation to the findings from the focus group which exposed this paradox.

### **1.8.1 Adherence/Non Adherence**

The term adherence has been adopted by many, particularly within the psychological and sociological literature. It is offered as an alternative term to compliance, in an attempt to emphasise that the patient is free to decide whether to follow the health professionals' recommendations and that failure to do so should not be a reason to blame the patient. Adherence develops the definition of compliance by emphasising the need for negotiation and agreement and may be defined as: 'the extent to which the patient's behaviour matches agreed recommendations from the health professional'(Horne et al 2005). This definition is very similar to that of compliance, the difference being the emphasis on "agreed".

Adherence, however, is not a static concept and can change over time and circumstances, particularly in the case of long-term treatment (Moffatt 2004). A case in point would be a patient who tolerates compression bandages to heal his ulcer but refuses compression hosiery as after care because he does not see the need to do so. Although associated with poorer clinical outcomes, the scale of non-adherence in leg ulcer patients is still unknown (Moffatt 2004). Cognitive models of adherence have proposed that there is a relationship between understanding the information given, remembering it and being satisfied with the consultation process (Mudge et al. 2006). However, although patients may appear to be offered a partnership in the treatment decision-making, they are reliant on the HP for information and may feel coerced into treatment strategies (Rich and McLachlan 2003). Furthermore, personal health beliefs and life experiences, together with those of friends and family have been shown to impact on adherence to treatment (Vermeire et al. 2001).

### **1.8.2 Concordance**

Concordance is now a preferred term to compliance, whereby greater emphasis is placed on factors, often not directly associated with the condition, but which may impact on the patient's choice to follow a particular treatment regime. Examples include patients' beliefs, previous treatment experiences, expectations of care, anxiety and coping strategies (Moffatt 2004). Concordance is often used in a way that seems to imply that attaining 'concordance' will improve adherence. Horne et al (2005) assert that this may well be the case, but this is an assumption that needs to be tested empirically. Moffatt (2004) describes the three essential elements that are required to achieve concordance:

- Patients have the knowledge to participate as partners in their care;
- The consultation involves the patient;
- Patients' decisions are respected and they are supported during treatment.

One unfortunate outcome of the concordance initiative however is that the term concordance is now often used as a synonym for compliance or adherence (eg, 'the intervention was designed to improve patient 'concordance'). This is not just a problem of semantics (Horne et al. 2005), since the terms 'adherence' and 'compliance' reflect different perspectives of the same phenomenon: the degree to which patients' behaviour matches the HP's advice. Furthermore, these terms describe the behaviour of one individual: the patient, however concordance is a much more complex and less clearly defined term relating to the process (eg, partnership) and outcomes (agreement or shared decision-making) of treatment. In terms of terminology, therefore, Horne et al. suggest that it is nonsensical to describe a patient as "non-concordant" when describing the behaviour of an individual since it is not the patient in isolation but rather the relationship and interaction with the HPs that is defined as concordant.

Concordance has now been incorporated into clinical practice language, however, for some nurses, it is seen merely as the latest in a series of terms used to describe compliance and, more recently, adherence (Weiss and Britten 2003). Anderson (2007) conducted a small study to determine health professionals' views of the concept of concordance in relation to venous leg ulceration. Seven non-specialist nurses were asked to define their understanding of concordance and the researcher found that there were contradictory views on compliance and concordance from most of the participants. It appeared that they were unclear of the definition and how this

fitted into their practice. Moreover, none of the participants could explain where the term concordance originated from and two felt it was only applicable to medication usage.

Concordance, however, may appear as a somewhat idealistic concept since inevitably this process may lead to “shared” decisions which are not what the health professional would advise on his/her own. It also requires the health professional to take into account the patient’s health beliefs, which may be at odds with the views of the health professional and if the two parties cannot agree a mutually acceptable treatment plan, the result is a non-concordant relationship (Weiss and Britten 2003). Kyngas et al. (2000) suggest that the change in terminology is signalling a real shift from the paternalistic concept of compliance to a more ‘patient-centred’ philosophy, however, Russell et al. (2003) disagree and suggest however, that health care professionals continue to view non-compliance from a reductionist, biomedical viewpoint rather than the social model of health in order to understand why the patient will not/or cannot follow medical advice. Concordance appears to be a concept that continues to challenge health professionals in day to day practice and this is discussed further in Chapter 8 in relation to the findings from the focus groups.

### **1.9 Non-adherence with wearing compression hosiery – literature review**

There may be many reasons for non-adherence with wearing compression hosiery. Franks et al. (1995) found that 30% of the patients interviewed were unable to tolerate compression hosiery due to friable skin or skin irritation, for example, redness, itching, rash or swelling. Travers et al. (1990) found that of 32 females studied, 17 patients would not wear their stockings at all, whilst 60% found their cosmetic appearance unacceptable. There is very little empirical evidence to support this finding, however, anecdotally, in clinical practice, many patients do verbalise this. Moffatt and Dorman (1995) found that of 166 patients in their trial, 25 patients (15%) could not put their stockings on themselves and 43 (26%) had great difficulty. Flanagan et al. (2001) described the practical difficulties patients experience such as discomfort caused by the stockings, application difficulties due to physical factors such as the patient’s inability to bend down, poor dexterity due to arthritic hands and wrists and skin problems. One participant in this qualitative study described her hosiery as “impossible to put on and ugly..... they’re either too tight or wrinkle... you can’t blame the patients for not wanting to wear them all the time” (Flanagan et al. 2001:pg. 156).

Flaherty (2005) reported similar findings in her qualitative study on the views of patients living with healed leg ulcers as did Vowden and Vowden (2004a) in their Bradford ulcer prevention study. Flanagan et al. (2001) suggest that it may be these physical factors that deter patients from wearing their hosiery rather than a deliberate desire to be non-adherent. A variety of aids have now been introduced to help overcome these problems, such as the Medi® Valet, to reduce bending and Acti-Glide™ (Activa Healthcare) however, although useful for some patients, problems with application are still encountered by a large proportion of patients (Kapp and Sayers 2008). In the past, patients received help with stocking application from their local district nursing service; however, this is viewed negatively by some health professionals as labour intensive and not efficient use of nursing skills and scarce staff resources (Flanagan et al. 2001). Flanagan et al. (2001) concluded that a strategy, aimed at supporting healing behaviours, particularly in the elderly, has the potential to reduce the recurrence of leg ulceration and improve quality of life.

Jull et al. (2004a) conducted a study to investigate the factors influencing patient compliance with wearing compression stockings after venous leg ulcer healing. 163 patients who had been discharged from a specialist leg ulcer service in New Zealand were approached to participate in a structured interview about their use of compression stockings in the first six months following ulcer healing. 52% reported wearing stockings every day for the first six months after healing, 16% stated they wore their stockings most days, 5% had worn them occasionally and 22% had not worn them at all. Two factors distinguished those who wore stockings from those who did not 75% of the time, firstly, the belief that wearing stockings was worthwhile. This may only be partly related to the belief that stockings prevent recurrence and the patients may have perceived other benefits, for example, a reduction in aching legs and the containment of oedema. The second factor was the belief that stockings were uncomfortable to wear and this was associated with a reduced likelihood that the patient would wear them. Interestingly, the authors claimed that the factors commonly cited in the literature for not wearing compression, i.e. age, sex, difficulty in application and cosmetic appearance (Kiev et al., 1990, Samson and Showalter 1996, Travers et al. 1999) were not significantly related to stocking use.

Van Hecke et al. (2008) conducted a systematic review of 31 papers in order to determine the reasons for non-adherent behaviour in terms of leg ulcer treatment from both the patient and health professional perspective. This paper discussed adherence to several components of leg ulcer care – compression, skin care, leg

elevation and exercises. Van Hecke et al. found that the reasons for non-adherence were diverse and included pain (Douglas, 2001), discomfort and unbearable on hot days (Flanagan et al. 2001, Bland, 1999, Chase et al. 1997, Ebbeskog and Ekman 2001, Brown, 2005, Raju et al. 2007), negative experiences with treatment (Bland, 1996, Douglas, 2001), lack of awareness of the efficacy of compression (Edwards 2003, Raju et al. 2007), difficulties in application (Raju et al. 2007) and informed non-adherence (Brown, 2005).

Van Hecke et al. (2007) also conducted a literature review on interventions, such as lifestyle advice or educational to enhance patient compliance with leg ulcer treatment. A total of 20 studies met the inclusion criteria, however, Van Hecke et al concluded that there was a lack of consistency in defining the standard and operationalisation of “compliance” or the method for assessing compliance and the majority of studies reviewed relied on patient self-report. Furthermore, some studies referred to the issue of compliance by evoking a simple duality between compliance and non-compliance. Two of the studies reviewed had methodological limitations and were weakly reported (Kane 1998; Brooks et al. 2004). Both these studies described single-focused interventions to improve knowledge however their relevance is questionable there are conflicting opinions concerning the relationship between knowledge and compliance (Cameron 1996) and whether knowledge alone can enhance compliance (Van Hecke et al. 2007).

Mudge et al. (2006) used focus methodology to explore patients’ understanding of adherence in terms of their own experiences of compression bandage systems. Six participants (four female, two male, aged 64-86 yrs) took part in the study. The dominant themes to emerge were: frustration with the healthcare system, functional limitations, emotional reactions and avoidance strategies. None of the participants could explain the cause of their ulcer. This is consistent with the findings of other studies, including the current one, which suggest that a large proportion of patients cannot recall information despite having had explanations by the health professionals caring for them (Cameron, 1996; Edwards et al. 2002). This could indicate, however, that the health professionals are communicating information to patients in a way that is not suitable for them as individuals, or the patients feel it is not of interest or relevance to them. Furthermore, it could be that as leg ulcer management tends to sit within nursing as opposed to the medical domain, it may be trivialised by patients who view it as an inconvenience rather than as a disease and is, therefore, not life-threatening. Furthermore, Mudge et al. (2006) found that patients view compliance as

“seeing the treatment through” implying that the treatment and therefore their willingness to comply is limited to healing of the ulcer only.

Van Hecke et al. (2007) suggest that compliance with leg ulcer treatment may be enhanced if patients receive information which is clear and unambiguous and delivered by staffs that are motivated and skilled in the use of cognitive and behavioural self-regulation strategies. In addition, they stress the importance of effective treatment relationships between patients and health care professionals, where alternative therapeutic means are explored, the regimen is negotiated, and compliance is discussed, taking into account the patient’s individual health beliefs, lifestyle and social networks.

### **1.10 Discussion**

Review of the leg ulcer recurrence literature revealed a lack of consistency in defining the standard and operationalization of compliance. Most studies which reported on compliance relied on patient self-report and merely distinguished between compliance and non-compliance (Van Hecke et al. 2007) which is misleading since people may comply with treatment regimens to a different degree in different situations over the course of long-term treatment (Moffatt, 2004a). A case in point would be a patient who tolerates compression to heal his ulcer but refuses compression hosiery as after-care because he does not see the need to do so.

The literature highlights the complexity surrounding our understanding of concordance which is influenced by many factors often not directly associated with the patient’s condition (Mofatt, 2004a). For example, a leg ulcer patient may have been advised not to stand for long periods, yet their occupation may require them to do exactly that. Faced with the prospect of redundancy or unemployment, the patient may decide to ignore the health professional’s advice, but is this simple non-adherence? Leg ulcer patients report pain, discomfort and inconsistent lifestyle advice by health professionals as primary reasons for non-adherence with treatment whereas health professionals tend to focus on patient-related factors such as poor motivation, lack of knowledge and external locus of control beliefs. Patient’s beliefs that compression was unnecessary, uncomfortable, or ineffective in preventing recurrence significantly impacted on adherence, which was defined by the health professional as a patient following the treatment ascribed within the medical model, i.e. where ulcer healing was the expected outcome; however, the high recurrence rates alluded to earlier, suggest that this is often not the case.

To conclude this section, HPs' need to reflect on their clinical practice, professional attitudes and relationships with venous leg ulcer patients and focus on patient-related factors in order to truly embrace and operationalise the concept of concordance. The responsibility of achieving a concordant relationship has now shifted from the patient to the HP, resulting in differing perspectives for the HP. On the one hand, the patient is seen as a partner in their care and must be offered a choice of whether or not to adhere to treatment (compression therapy). On the other hand, the HP is required to meet organisational targets, which are linked to financial reimbursements by demonstrating percentage of healed ulcers, which is largely achieved through adherence with compression therapy.

### **1.11 Redefining venous ulceration as a chronic condition**

Briggs and Flemming (2007) conducted a synthesis of qualitative research exploring patients' experiences of living with a leg ulcer. 12 studies were reviewed and five themes related to the experience of living with leg ulceration were identified: Physical effects of leg ulceration; Describing the leg ulcer journey; Patient-professional relationships; Cost of a leg ulcer and Psychological impact.

Briggs and Flemming found that the median ulcer duration is 6-9 months (range 4 weeks – 72 years) which is considerably longer than recognised healing rates in the literature (Nelson, 2000; Polignano et al. 2004) and which was also found in this study. They assert that whilst healing rates can be improved through standardised management guidelines (RCN 2000), it has been estimated that over 40% of patients will have open ulceration for over a year (Nelzen et al. 1994) and even if healing is achieved, 26-69% recur within 12 months (Nelson, 2000). Venous ulceration, therefore, must be seen as a chronic, lifelong condition. The question must be, therefore, is it appropriate to continue to treat venous ulcer patients within the medical model, and where healing within a given timeframe is the only acceptable, yet often unachievable outcome? Currently, practitioners are required to promote this route because KPIs linked to payments are calculated by “number of ulcers healed” , “time to healing” and “numbers of recurrent ulcers (PRODIGY Guidance 2004, DH 2011) Furthermore, the assumption is that the factors that diminish a patient's quality of life will disappear once healing has occurred. Briggs and Flemming assert that this is an appropriate goal of care if an ulcer is likely to heal, however, for some patients, this may be an improbability.

Failure to heal an ulcer within the prescribed timeframe may lead to despondency in the health professional, who may resort to blaming the patient for the lack of progress or accusing them of being non-adherent with treatment and a “spiralling sense of hopelessness” for the patient (Morgan and Moffatt 2008). Furthermore, this approach denies the patient the opportunity to learn to live with their chronic condition (Briggs and Flemming 2007). Briggs and Flemming conclude that, in practice, KPIs and professional targets need to be re-framed from viewing venous ulceration as an acute event, to that of a chronic condition, such as multiple sclerosis or rheumatoid arthritis since its disease trajectory bears strong similarities with these conditions.

In recent years, in response to the growing numbers of patients suffering from chronic conditions, self-management programmes have been introduced for conditions such as diabetes or multiple sclerosis (DH 2001b). The emphasis is on empowering the patients to take control of their condition, whilst teaching them self-management strategies in order to manage and adapt their lives to living with a chronic condition.

### **1.12 Conclusion of Chapter One**

This chapter has reviewed the literature on concordance, with particular reference to venous leg ulcer patients. An argument has been developed that venous ulceration should be classified as a chronic condition and that treatment within the medical model may be inappropriate for many patients since healing may not be realistic.

The following chapter will present an overview of the literature on chronic conditions self-management programmes together with an exploration of the outcomes of such programmes. The definitions of the terms “self-care” and “self-management” which are used interchangeably within the literature will be discussed in relation to the activities venous leg ulcer patients are asked to undertake to prevent recurrence. The current evidence base on these self-care activities will be critiqued in order to establish how effective these activities may be in the prevention of ulcer recurrence.

## **2.0 Chapter 2 Self-care or self-management?**

Within this chapter, the literature on self-care/self-management will be reviewed in order to achieve clarity around the muddled concepts of self-care versus self-management. The literature on self-care activities recommended to leg ulcer patients to reduce recurrence will be reviewed in order to determine whether this is evidence-based. A literature review on any existing self-care interventions for venous leg ulcer patients will be presented together with a brief overview of the outcomes of self-management programmes for chronic conditions. An argument will be developed that self-care programmes, underpinned by self-efficacy, may be an alternative approach for helping patients, whose ulcers recur frequently, perform self-care.

### **2.1 Self-care versus self-management – definition of terms**

Self-care or self-management is considered to be a hallmark of the management of all chronic illnesses (Department of Health, 2001b) and requires the patient to acquire and develop new knowledge and skills (Watt, 2000; Wilson, 2007). Much of the literature focuses on self-management programmes designed to enhance these. The majority of studies relating to self-management of chronic conditions, such as diabetes and asthma, focus on interventions designed to promote patient compliance with treatment and the outcome measures tend to be empirical, such as a reduction in HbA1C in the case of Type 1 diabetes or a reduction in the use of NSAIDs (non-steroidal anti-inflammatory drugs) in arthritis. In addition, these self-management programmes are generally designed from the health professionals' perspective, with the assumption that, following attendance, the patient will be able to make therapeutic, behavioural, and environmental adjustments in line with professional advice. Interestingly, even though the Expert Patient Programme (EPP, DoH 2001a) was designed to promote patient participation and empowerment, sessions are delivered by lay persons who teach from a manual which has been developed from the health professional perspective and from which they are not permitted to deviate (Wilson, 2001; 2007).

Berman and Iris (1998) contend that self-care is a value-laden concept and those self-care behaviours and strategies promoted in health promotion are often grounded in the value systems of the professionals designing the programmes, although Dean (1989) suggests that it is known that the bulk of all care in illness is self-care. She suggests that, whilst little researched, available data suggests that illness related self-care is generally appropriate and effective, although it is "softer" and low-tech

compared to professional care, often involving social approaches or responses to promoting health or treating illness.

Paraphrasing Wilson (2007), review of the literature revealed various perspectives through which self-care and self-management are defined. From an individual's perspective, self-care is a psychosocial response, which has been shaped by interpretation and response to conditions affecting health (Dill et al. 1995; Berman and Iris 1998). Berman and Iris's study into self-care approaches found that older people may interpret chronic conditions associated with ageing in biomedical terms but may also frame explanations of symptoms and coping responses within broader beliefs about the ageing experience (Berman and Iris 1998). This was certainly confirmed in the qualitative findings of this study where many participants felt that their ulcer was an inevitable consequence of old age. Researchers have repeatedly identified attitudes toward personal control, self-efficacy, or taking responsibility for health as important factors influencing self-care behaviours and coping responses (Dean, 1986; Segall and Chappell 1991; Nicholas, 1993; Lorig, 1996). Beliefs about one's ability to control the experiences associated with ageing, such as disability, undoubtedly also determine approaches to self-care (Hennessy, 1989). Dill et al. (1995) agree and suggest that self-care can be viewed more broadly as the promotion of overall well-being of the self and that self-care behaviours are not simply responses to concrete health conditions during a specific point or period in time but involve decisions that develop over time and reflect changing perceptions of self-identity. As a consequence, health beliefs and approaches to self-care are dynamic, formed and reconstructed throughout the person's life and may shift with the persons' changing images of their ageing self. In addition the continuity of self-care practices over a long period of one's adult life course implies that individuals may develop a personal history of "things that work" and "things that don't". In all likelihood, these personal successes and failures with various self-care strategies are embedded in a context of the experiences of other persons in the social network.

Berman and Iris contend that older adults have accumulated a lifetime of self-care experiences and will be more responsive to self-care interventions if their beliefs are recognized in the professional health care setting and they are offered the means to build on what they already know. However, whilst self-care and self-management are often defined as independence from health professionals, Wilson (2007) suggests that the literature indicates a paradoxical but concurrent idea of self-care being the performance of professionally set behaviours.

## **2.2 Summary**

As alluded to earlier, there appears to be considerable blurring around the definitions of self-care versus self-management. Definitions of self-management appear to be more specific and focus more on the patient performing tasks that the health professional would normally do, for example, monitoring of blood sugars and taking appropriate action if the levels deviate from the norm.

Self-care, on the hand, relates more to the everyday activities that patients may undertake in order to care for their condition. The prevention of recurrent venous ulceration would be an example, where patients are required to undertake certain health behaviours at home daily, for example, wearing compression hosiery, elevating their limbs and performing ankle exercises, independent of professional intervention. It would appear; therefore, that self-care as opposed to self-management is more germane to the activities leg ulcer patients are requested to perform in order to prevent recurrence.

## **2.3 Self-care strategies for venous leg ulcer prevention – review of the literature**

A search of the literature was conducted in order to determine the strength of evidence to support the recommendations made by health professionals in terms of elevation of limbs, exercises and mobility levels. The evidence supporting the use of compression hosiery posthealing was not reviewed here as it has been reviewed earlier in the thesis.

## **2.4 Physical activity, mobility, walking and exercises –the rationale**

Anatomically, there are three elements of the lower limb which work together to optimise venous return; the calf muscle pump, the foot pump and the respiratory pump (Yang et al. 1999; Abadi et al. 2007). During walking, the calf muscle pump contracts and empties the veins of the lower limbs, which aids venous return and maintains a low ambulatory venous pressure (Blomberry & MCGrath 2000) Distention of the foot veins, and extension and relaxation of the Achilles tendon form the foot pump, which works together with the calf muscle to maintain low ambulatory pressures. The third mechanism to aid venous return is the respiratory pump. During inhalation, the abdominal pressure increases and compresses the abdominal veins. The combination of changes in pressures and venous valves enables blood to flow back to the heart (Yang et al. 1999; Abadi et al. 2007; Blomberry & McGrath

2000). In patients with venous ulceration, the function of the calf muscle pump has been found to be weakened, although it is not known whether venous ulceration is a consequence of a weakened calf muscle or if ulceration leads to poor ankle mobility, resulting in reduced muscle function (Abadi et al. 2007). Researchers have found that severe venous disease is linked to a reduced range of ankle movements, particularly in dorsiflexion (McRorie et al. 1998). Logically, therefore, if patients are encouraged to perform exercises to enhance calf muscle pump, foot pump function and ankle mobility, this may help reduce ulceration or recurrence.

## **2.5 Limb elevation – the rationale**

Elevating the limb above heart level aids venous return (Abadi et al. 2007). The rationale behind elevation of the leg is that the oedema will be reduced as the blood flows back to the heart with the force of gravity, thus aiding venous return. An overview of the studies reviewed on the influence of physical activity, mobility, exercises and leg elevation on ulcer recurrence and the findings have been presented in presented in Table 2.

## **2.6 Search Strategy for studies relating to self-care activities - VLU**

The databases Medline, CINAHL, Psychinfo and Cochrane were searched for literature relevant to the topic. Since there was a paucity of relevant literature, any papers dating from 1990 were included. Reference lists, journal articles and grey literature were also hand searched. Search terms used were: leg ulcer OR venous ulcer or varicose ulcer, varicose\*, in the title and Boolean operators were used in combination with the following terms: recurr\*, exercise\* leg exercise\*, ankle exercise\*, activity\*, leg elevation\*, limb elevation\*, stockings\*, self-care, self-manage\*. Papers that discussed any of the above self-care activities considered to be beneficial in preventing leg ulcer recurrence were included and a total of 20 papers were retrieved. The following table (Table 2) gives details of the studies reviewed.

Subject	Author (s)	Study Design	Study aims	Method	Findings
Physical activity	Berard et al. (2002)	Prospective, matched case-control	<b>Primary</b> – to study association between heredity and physical activity as risk factors for development of VLU <b>Secondary</b> – association with obesity, multiple pregnancies, lifestyle and leg trauma	Patients presenting with VLU between Jan – Dec 1997 served as cases (n=102). Control group with chronic conditions (n=200). Mean age – 61yrs. Data collected on family history, physical activity levels, education level. VURFQ questionnaire and Godin's LTEQC.	Possible predictors of first time ulcer are family history of maternal CVI, history of DVT, female, multiple pregnancies and history of strenuous activity such as running, tennis hockey as opposed to moderate exercise. No explanation given for this
Physical activity	Barwell et al. (2000)	Prospective study	To identify independent risk factors associated with delayed healing and recurrence	587 participants included if ABPI > 0.85; ulcer in gaiter area, duration of > 1 month. Mobility was assessed. Seen weekly at leg ulcer clinics and Class 2 hosiery given when healed. Reassessed at 1,3,6,9 months and 1,2 & 3 years posthealing	Risk factors identified: age was risk factor for ulcer development but not recurrence. Also ulcer chronicity, popliteal vein reflux but no evidence that mobility levels predicted healing/recurrence. Authors acknowledge crude scoring system was not definitive enough as patients can be mobile but may not exercise their foot/calf muscle pump.
Physical activity	Roaldsen et al. (2006)	Physiotherapy study Prospective study with 34 women aged 60-85 years matched with 27 age-matched controls	To describe and quantify disease consequence in elderly females with Venous LU compared to age-matched group	Inclusion criteria: ABPI > 0.7 with open/headed ulcer and confirmed diagnosis of CVI. Data collected on pain (VAS	Leg ulcers patients with current ulcer had reduced ankle plantar and dorsiflexion, slower walking speeds and

			without LU.	scale), ankle movement range using goniometry and self-report, walking speeds with stop watch, walking endurance. Borg scale to measure exertion, Barthel ADL Index, Grimsby Scale and Life Satisfaction scale (LiSa), self-rated global health.	lower walking endurance and higher perceived exertion that control. Had lower values in functional status and lower levels of activity. Authors conclude pain can result in reduced mobility, compounded by oedema and limitation on ankle movements due to compression bandages.
<b>Physical activity</b>	<b>Roaldsen et al. (2009)</b>	Physiotherapy study – postal questionnaires	To examine the level of fear-avoidance beliefs associated with physical activity in patients with venous leg ulceration	98 patients aged 60-85 yrs completed questionnaire. Fear avoidance (f.a) was defined as: an avoidance of p.a. based on the fear of movement or (re)injury with an assumption that pain experienced would delay healing. Used scale to assess f.a. beliefs, Melzack pain scale and Barthel ADL, Rivermead mobility index to assess mobility across 15 items.	83% (n=81) expressed f.a. beliefs and 41% (n=40) expressed this even after ulcer had healed. Authors emphasised importance of pain management and recommended individually tailored physiotherapy programmes to demonstrate physical activities/exercises.
<b>Physical activity</b>	<b>Roaldsen et al. (2011)</b>	Physiotherapy-led Phenomenological study	To identify and describe how physical activity is perceived and understood by patients with open/healed venous leg ulcers	22 patients aged 60-85 years with CVI were interviewed using guide. Interviews were transcribed verbatim	<b>4 categories:</b> <i>Self-management; instructions and support; fear of injury; a wish to stay normal.</i> Patients had difficulty in

					performing physical activities due to far of injury, restricted bandages, and oedema. Participants displayed poor understanding of the benefits of exercise and felt HPs gave conflicting advice.
<b>Physical activity and leg exercises</b>	<b>Heinen et al. (2007a)</b>	Quantitative cross-sectional study using structured/open-ended questionnaires	To identify the determinants of physical activity in venous/mixed aetiology leg ulcer patients to develop behavioural interventions	Random sample of 25 patients from 2 clinics. Mean age 75 yrs. 3 parts of questionnaire: general health; physical activity and patients' beliefs on beneficial effects of p.a. Pain and adherence to compression therapy was also assessed.	Only 36% (n=9) met the norm of 30mins daily moderate PA for 5 days. Most of the activities described lacked intensity or duration required. 15 participants performed leg exercises but the remainder were unaware of the need to do this. Authors report low self-efficacy for PA but higher levels for exercises although they do not indicate how SE was assessed. 15 patients experienced high pain levels; 11 in the low exercise group and 4 in the sufficient exercise group.
<b>Exercise and mobility</b>	<b>Heinen et al. (2007b)</b>	Descriptive cross-sectional study	<b>Primary aim:</b> To assess levels of walking and exercise in patients with venous leg ulcers. <b>Secondary aim</b> – to	150 leg ulcer patients (mean age 67yrs) who were having treatment at outpatient Dermatology clinics in the	Included mixed aetiology ulcers. 56% of patients did less than 2.5hrs of physical activity per week. Only 13% had

			<p>assess with therapy</p> <p>concordance compression</p>	<p>Netherlands were interviewed. Asked to wear accelerometer for 1 week prior to interview. Data on ulcer recorded, duration etc. and patients were asked about leg exercises, frequency, type etc. Footwear was observed and heel height was noted. Also asked about adherence to compression therapy.</p>	<p>walked for more than 30mins on at least 5 days per week. Only 35% performed leg exercises; 20% flexed and stretched their feet and only 7% performed tip-toe exercises.</p>
<p><b>Physical activity and exercise</b></p>	<p><b>Heinen et al. (2012)</b></p>	<p>Multi-centre RCT</p>	<p><b>Primary outcomes:</b> To investigate whether a physical activity programme (Lively Legs) promotes adherence with compression and effects on recurrence</p> <p><b>Secondary outcomes:</b> Wound characteristics, aetiology, co-morbidities. Time to next recurrence</p>	<p>184 patients (mean age 66 yrs, 60% female) from 11 dermatology outpatients departments, randomisation was stratified by centre, age, sex and aetiology. Intervention group received usual care, lifestyle 2-6 counselling sessions according to LL programme; control group received usual care only. 4 year study. Randomisation not blinded. Intervention group (n=92) were assessed at baseline, 6, 12 &amp; 18. Lifestyle, adherence to compression (self-</p>	<p>Randomisation not blinded. Only 124(69% Inter group and 66% Cont) had active ulcer; only 148 were wearing compression. No information on leg exercises, assessed via self-report.</p> <p><b>IG</b> – 38% venous aetiology; chronic ulcers mean ulcer duration &lt;4 mths – 55%; 4-12 mths – 26%; &gt; 12 mths 16%.</p> <p><b>CG</b> 42% venous aetiology; chronic ulcers mean ulcer duration &lt; 4 mths – 63%; 4-12 months 20%; &gt; 12 months -17%. Findings indicated 25%</p>

				<p>report), physical activity levels, wound status was assessed at baseline (1 interviewer). Physical activity was assessed by self-report and IPAQ and PAR. Patients were counselled by nurse counsellors and given health advice tailored to patients' health beliefs, had demonstration of leg exercises and asked to walk 30 mins daily for min 5 days per week and perform exercises. Used accelerometer during and 7 days prior to intervention. Control group (n=92) received usual care with no health advice. Intervention based on motivational interviewing and elements of SE theory – goal setting etc. Data analysis – ITT, generalised linear mixed model, proportional hazard regression</p>	<p>patients in IG –remained ulcer free for 13 mths (95% CI), vs. CG – 5mths (95% CI) after 18 mths – 56% CG vs 46% IG. 10% less wound days for IG (p = 0.01%). Authors report higher adherence to compression in the IG than the CG however this was only significant at 6 months, and reduced at 12 &amp; 18 mths. May have been due to Hawthorn effect High drop out rate Self-report on physical activity/exercises. No details on exercises, no pain assessment. Mobile patients. No assessment of calf function/foot mobility Wound healing is multi-factorial – difficult to assess influence of this intervention alone</p>
<b>Physical activity (walking)</b>	<b>Van Uden et al. (2005)</b>	Case control observational study	To gain insight into the gait and calf muscle endurance in patients with severe CVI	15 patients with CVI (healed or open ulcers – Group 1) and 19 controls. (Control Group).	Young patients and only 1 with open ulcer. Findings were that patients with CVI exhibited a significantly

				<p>Group 1 9 females; 6 male, mean age 59.9yrs; 1 open ulcer)  Control Group - 10 females; 9 male, mean age 51.4yrs  Tested in Gait laboratory using GAITRite system. Subjects were asked to perform heel-rises until exhausted – barefoot with one leg with foot in dorsiflexion of 10°. A metronome set at 1 Hz was used. Each subject was instructed to walk a distance of 10m at a comfortable speed. No compression was worn.</p>	<p>lower preferred walking speed than healthy controls and required a wider base of support. Authors conclude that the walking speed in patients with CVI walk too slowly to enhance venous blood flow. Healthy controls could perform 25 heel rises and CVI patients mean of 24 however the pace of performing these was too fast for the majority of CVI patients.</p>
<b>Exercises</b>	<b>Davies et al. 2006</b>	Single arm pilot study	To assess the efficacy of a 24 week home-based exercise programme to increase ankle range of motion and strength of calf muscle.	<p>11 patients with long standing ulcers undertook a 3 x weekly 5-10 minute exercise programme using elastic resistance bands and stretches for 24 weeks.</p>	<p>Conducted with bandaging removed. Patients screened for normal toe to heel gait Stat. Significant improvements in ankle range of motion were achieved at weeks 12(<math>p= 0.006</math>) &amp; 24(<math>p= 0.011</math>) compared to baseline. Median pain scores decreased from 5.2 to 2 during the study.</p>

<p><b>Physical activity</b> <b>Walking</b></p>	<p><b>Meagher et al. (2012)</b></p>	<p>RCT</p>	<p>To determine relationship between levels of walking and ulcer healing</p>	<p>40 patients with newly diagnosed VLU randomised into control or intervention group. Patients in exercise group encouraged to increase daily steps to 10 000; control were not asked. All patients received compression therapy. Wounds were measured at initial assessment and at 4 weekly intervals until healed for 12 weeks. All patients used an ActivPal activity monitor for 1 week to determine base levels. Exercise group wore pedometer for duration of study. All patients wore ActivPal again at 4 weeks.</p>	<p>5 patients withdrew due to non-adherence with compression following recruitment. Sample of 35 analysed. Only 33% of the exercise patients could achieve 10 000 steps daily. Ulcer healing occurred faster in the patients who took more steps, however the results failed to reach statistical significance due to small sample size. Authors recommend further studies to confirm findings and more research into optimum levels of steps to improve healing. Due to study design, blinding was not possible.</p>
<p><b>Exercises</b></p>	<p><b>Yang et al. (1999)</b></p>	<p>Single-armed experimental pilot study</p>	<p>To assess improvement on venous system following a 6 week exercise programme</p>	<p>20 patients with recently healed venous ulceration were enrolled on an individually developed 6 week exercise programme</p>	<p>Exercises were performed at home and monitored by research staff. Prior to study, Patients were assessed to calculate tolerance of heelraises and were asked to perform these on alternate days for 6 weeks. Calf muscle</p>

					function was assessed before and after using APG. After 6 weeks improvement was seen in terms of ejection fraction and decreased residual volume but no change in venous volume or venous refilling time. Authors conclude that poor calf muscle function can be improved by targeting specific exercises. Subjects did not wear compression during exercises.
<b>Exercises</b>	<b>Kan and Delis (2001)</b>	Prospective experimental matched controlled study	To evaluate the effects of short-term calf muscle exercises on calf muscle pump function and venous haemodynamics in venous leg ulcer patients	10 patients with v.l.u. matched for age/sex with control group of 11. Experimental group undertook 7 days of supervised exercises (3 sets of 6 minutes daily). Control group received standard care.	Ejected volume, residual volume fraction and calf muscle endurance increased by 135% from a median of 153 plantar and flexions at baseline to 360 by day 7. Authors do not state whether compression was worn during the exercise routines.
<b>Exercises</b>	<b>Jull et al. (2009)</b>	Community-based pilot RCT	To establish the feasibility of delivering a 12 week nurse-led home-based resistance exercise programme to improve calf function in community patients with	40 participants (mean age 54.6yrs randomised into 2 groups. Outcomes were; <ul style="list-style-type: none"> <li>• Changes in calf muscle function</li> <li>• Change in ulcer</li> </ul>	At 12 weeks, all calf muscle functions (except venous filling time) had improved in IG ( $p < 0.05$ ) Adherence with exercises was 81%, no significant difference in

			VLU	<p>area/healing</p> <ul style="list-style-type: none"> <li>• Time to healing</li> </ul> <p>IG (n = 21) received instruction on heel raises. Individual tolerance assessed at baseline and increased to 3 sets of repetitions at 80% of maximum at b/l, 3, 6 &amp; 9 wks. Performed on alternate days. Patients chose whether to wear comp.APG to measure venous vol., ejection vol, ejection fraction, residual vol/fraction and venous filling index.</p> <p>CG (n= 19) received usual care. Ulcer duration (CG mean 28 wks), (IG mean 23 weeks). High levels of mobility across both groups (85.7% and 84.2%). Followed up at 12 weeks. All participants usually wore compression bandages/hosiery.</p>	<p>ulcer healing parameters.</p> <p>Very small and relatively fit and young sample size – does not state how many participants wore compression during exercising.</p>
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<b>Elevation</b>	<b>Wipke-Tevis et al. (2001)</b>	Experimental study	To investigate the effects of leg elevation on $T_cPO_2$ in patients with venous leg ulcers	20 patients were rested for 30 minutes and $T_cPO_2$ was measured in 4 positions with and without inspired $O_2$ , with leg elevation, sitting, standing and lying supine	Lower extremity $T_cPO_2$ was lower in patients with VLU than normal subjects. Compression therapy when standing had a positive effect on $T_cPO_2$ but without compression, lying down achieved better $T_cPO_2$ levels than limb elevation, standing or sitting with additional inspired $O_2$ . Authors concluded that leg elevation, sitting/ standing decrease wound perfusion and may not be beneficial in patients with VLU or CVI.
<b>Elevation</b>	<b>Johnson (1994)</b>	Descriptive correlational design	To determine healing determinants in 156 older people with leg ulceration	Descriptive – 1 month follow-up.	Increased time spent with limbs horizontal (but not elevated) to the torso in combination with compression was a factor associated with poorer healing rates. The authors suggest that compression bandages with high working pressures and low resting pressures are beneficial for ulcer healing. This study was conducted prior to the widespread use of shortstretch bandages.
<b>Elevation</b>	<b>Barnes et al. (1992)</b>	Prospective study	To study effects of elevation on limb	13 patients with VLU. Following 24 hours	Authors report a significant change in laser Doppler

			volumes in patients with chronic venous leg ulcers	lying supine with legs elevated horizontally at 10°, T <sub>c</sub> PO <sub>2</sub> levels and laser Doppler flow were measured	flow levels after 24 hours and decrease in limb volume/circumference but no effect on T <sub>c</sub> PO <sub>2</sub> levels
<b>Elevation</b>	<b>Dix et al. (2005)</b>	Observational case control study	To investigate the efficacy of a device to measure leg elevation, assess how long venous ulcer patients elevate their limbs and the effect of elevation on ulcer healing and popliteal vein pressure	24 subjects, mean age 71yrs with venous leg ulcer < 6 week duration (mean size 2.8cm <sup>2</sup> ). Exclusion criteria included vasculitis, renal, liver, haematological disease or corticosteroids. All patients wore compression and were instructed to elevate their limbs 15° and elevate foot of bed as much as possible in 24 hour period over 6 weeks. 12 patients wore a VLU datalogger under their compression (IG) and 12 patients wore the VLU device and kept a diary (CG). They were asked to elevate their legs for 3 sets of 20 minutes every 24 hours.	Of the IG – median elevation times were 53 minutes/24hrs. Of the CG – median elevation times was 671 minutes/24 hours. The authors comment that in all VLU patients, limb elevation occluded the foot vein beyond 5°. They also suggest that in venous leg ulcer patients, elevation is poor but improved with the use of a diary; intermittent elevation when wearing 4 LB does not improve ulcer healing or femoral vein velocity, but changing from sitting to the supine position does.

<b>Elevation</b>	<b>Finlayson et al. (2009)</b>	Survey and chart review	To identify the relationship between preventative activities, psychosocial factors and ulcer recurrence	122 community based patients with healed ulceration between 12 and 36 mths prior to study commencement were followed up for 12-40 mths. Data were collected on demographics, medical history, previous ulcer history, treatment, self-report questionnaires on physical activity, nutrition, psychosocial measures, self-care activities.	Authors reported 68% (n = 83) had recurred since healing, 36% (n = 44) in the first 3 MThs and 20% (n = 22) within 12 MThs of healing. Patients who did not recur elevated their legs on average for 33 minutes/day compared to 14 min/day for those who recurred (p < 0.001). The authors do not state whether patients elevated their limbs whilst wearing compression.
<b>General mobility</b>	<b>Clarke-Moloney et al. 2007</b>	Matched controls pilot study	To compare mobility in patients with VLUs to matched controls and determine influence of mobility, age and ulcer size on healing	25 (VLU) patients matched with 25 controls. Used ActivPAL™ device to monitor no. of steps, time spent walking, standing, sitting or lying for 1 week. Median age 70.5 (range 30-89)	No difference in time spent standing, walking and resting between groups. Significant reduction in no. of steps taken by VLU group. Smaller ulcers or recent onset ulcers were most likely to heal within 12 weeks. The percentage of time spent mobilising and resting did not influence ulcer healing. Researchers conclude mobility patterns of VLU patients are not significantly different from matched controls.

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## **2.8 Discussion**

Review of the literature indicated that increased mobility and moderate physical activity may be beneficial for ulcer healing and may help prevent recurrence; however patients may need reassurance that these activities will not adversely affect their ulcer. If pain has been identified as a barrier, effective pain management is a key factor in ensuring that patients are able to follow this advice.

The evidence to support the assumption that elevation when wearing compression bandages will enhance ulcer healing is inconclusive. Elevation, however, has been shown to reduce oedema, thus promoting healing and making the application of compression hosiery easier and less painful to apply. It is not clear whether elevation combined with the wearing of compression is beneficial or not and more research is required to clarify this. If it is proven to be detrimental, it could have a significant impact on clinical practice since compression bandages are designed to give sustained compression over a number of days and it could have major resource implications if they needed to be reapplied daily. Furthermore, the frequency, degree of elevation and length of time needed for elevation to be beneficial is currently not clear and further research is needed to ensure clarity.

Exercises, such as heel rises, flexion, extension, and rotation of the ankles, have been shown to increase venous return (Padberg et al. 2004; Jull et al. 2004; Roaldsen et al. 2006). Health professionals should consider involving members from the multidisciplinary team, such as physiotherapists in producing information leaflets or organising exercise programmes to ensure patients are shown specific, targeted foot exercises which may achieve the potential benefits associated with this activity. Studies, however, have confirmed that patients often receive conflicting information from health professionals about performing self-care activities (Bland, 1996; Douglas, 2001; Flanagan et al. 2001; Edwards, 2003). An argument will now be developed that implementing disease-specific self-care programmes which incorporate SE enhancing techniques, may be an alternative approach to encouraging self-care in patients to prevent ulcer recurrence.

## 2.9 Self-care programmes for venous leg ulcer patients – literature review

In order to establish whether self-care interventions for leg ulcer patients have already been developed, the literature was searched and seven relevant papers were retrieved.

Seppanen (2007) studied the self-care deficits of venous leg ulcer patients, using the WAS-VOB<sup>®</sup> tool developed by Panfil et al. (2004). This tool consists of a catalogue containing propositions for self-care activities for venous leg ulcer patients in 8 sections: general compression, wearing compression bandages, wearing compression hosiery, mobility, maintaining correct body temperature, overloading of the venous system, prevention of skin damage and wound healing. Originally developed and validated within a German population using the conceptual frameworks of Orem's Self-Care Deficit theory (Orem, 2001) and self-efficacy theory (Bandura, 1971), the tool was translated into Finnish and culturally modified for the study by Seppanen (2007).

The study used convenience sampling (n=88, aged 65 yrs +) and data were collected via structured interviews, formal wound assessment of patients' ulcers by nurses and completion of the WAS-VOB<sup>®</sup> (appendix 2 is a full translation of the original German article). The findings of Seppanen's study indicated that only 72% of the participants applied compression (in the case of an open ulcer) and only 35.4% continued to implement compression therapy to prevent recurrence and these figures reflect those published in other studies (Margolis et al., 2002; Leach, 2004). The best implemented self-care activities reported were: avoiding overloading the venous system, skin care and the avoidance of very high temperatures. Interestingly, these activities would appear to be related to patients' perspectives on self-care as opposed to those of the health professionals.

This study highlights the difficulties patients face in their everyday lives in implementing ulcer preventative strategies, however, the WAS-VOB<sup>®</sup> appears to be more germane to self-care activities for patients with active, open leg ulceration. In addition, Panfil and colleagues claim that the tool is based on both Self-Care Deficit Theory and self-efficacy; however it does not measure patients' confidence in their ability to perform the self-care activities. In addition, the self-care propositions appear to be professionally determined and may not reflect patients' views of self-care. Finally, it is doubtful whether the cultural and health care differences between the U.K. and Finland make it a valid instrument for use with an English population at

present. For example, patients apply their own compression bandages in Finland and care for their ulcer largely independent of health professionals, which is not the norm for British leg ulcer patients. In addition, Seppanen added a sub-section on sauna usage in her modified tool, which would not be applicable to the British population generally. Whilst providing a meaningful insight into the difficulties patients face in their daily lives in caring for their ulcer, the tool does not measure or predict patients' levels of self-efficacy in performing these tasks successfully.

This intervention was designed using traditional patient education techniques, as opposed to self-management education and the results support Kralik et al's (2004) comments that education and information alone are not sufficient to bring about the required behaviour change. Its focus appeared to be on self-management rather than self-care and it does not appear that the intervention was underpinned by a theoretical health behaviour change model, such as self-efficacy or locus of control which may have encouraged self-care activities such as the wearing of compression hosiery. In addition, it is strange that the design of the study, which aimed to improve patient compliance, did not allow the authors to investigate the reasons for non-compliance in more detail. Nevertheless, this study is useful in highlighting the need for alternative methods of preventing leg ulcer recurrence, as opposed to 'usual' care which is largely ineffective in the main.

Heinen et al. (2006) describe the development of the Lively Legs programme within a Dermatology clinic in the Netherlands. The purpose was to develop a lifestyle programme for leg ulcer patients, using Social Cognitive Theory (Bandura 1991) and Goal Setting Theory as the underpinning framework. The authors used an intervention-mapping (IM) framework and needs assessment to develop theory and evidence based health promotion. The intervention, delivered weekly over 6 weeks, used motivational interviewing, guided practice, active learning, reinforcement, both written and verbal, modelling and consciousness raising as strategies for changing health behaviours. Outcome measures included generic quality of life, leg ulcer recurrence, time to healing, leg ulcer free months, and behavioural outcomes for patients in terms of weight management, nutrition, physical exercise, smoking cessation, leg/foot care and compliance with compression hosiery. The authors acknowledge the lack of good quality evidence to support the premise that these factors may influence leg ulcer healing/recurrence (Heinen et al. 2006) but suggest that although the evidence currently is circumstantial, these factors, nevertheless, may be important in leg ulcer healing/recurrence.

A further study led by Heinen et al. (2012) evaluated the effect of the Lively Legs programme on increased physical activity and ulcer recurrence with 184 patients recruited from dermatology clinics in the Netherlands (see previous chapter for more indepth description of this study). The results indicated that the group receiving the intervention performed significantly better for leg exercises ( $p < 0.01$ ), 10 minute walks on 5 days per week ( $p < 0.01$ ) and had a reduced time to recurrence ( $p < 0.01$ ) than the control group which did not receive the intervention. There was no significant difference between the groups in adherence to compression hosiery.

Freeman, Gibbins et al. (2007) describe the development of an innovative support group “Look After Your Legs” (LAYL) to promote self-care messages to patients with healed leg ulceration. Using a similar model to the Expert Patient Initiative (DoH 2001b), the education element encompasses – Skin care, wearing hosiery, leg exercises, leg elevation, safe, well-fitting shoes, toe nail care, healthy eating and weight control delivered by leg ulcer nurses and the multidisciplinary team. The support group runs alongside the leg ulcer clinic and patients with healed leg ulceration are encouraged to participate in the support group. Patients with healed ulcers are encouraged to become “Patient Ambassadors” to befriend patients and to reinforce self-care messages from the community nursing team. The outcomes of the support group have been evaluated using a qualitative approach from the patients’ perspective, focusing on empowerment and support received by attendance at the support group, which was very positive (personal communication, 2008). Although not stated, it would appear that the theoretical framework underpinning this intervention bears similarities with self-efficacy theory (role modelling, vicarious experiences, cognitive interventions) and this may be a good model for self-care programmes for venous leg ulcer patients in the future. Interestingly, in order to address the difficulties in conveying self-care information to patients, the nurses leading this initiative have developed a CD promoting health behaviour messages using “rap” which has been translated into various languages in order to include all ethnic groups.

Herber et al. (2008) developed a nurse-led education programme in Germany to enhance self-care in venous leg patients. The intervention was based on Orem’s Self-Care model (Orem, 2001), using only the health-deviation self-care requisites for this intervention. A self-care activity catalogue was developed from the literature, consisting of 132 self-care measures, classified into 14 subcategories of which 8 were compulsory and 6 optional. The compulsory category was based on the WAS-

VOB (Panfil et al. 2004), designed to measure the level of ulcer-related self-care agency.

This intervention was embedded into an open, multi-site clinical trial comparing healing rates, wound size and health-related quality of life, conducted over a 12 month period from December 2005 to December 2006. Patients were randomised into a control group (usual care performed by physicians) and the intervention group who received the nurse-led programme for 1 year or until wound healing had occurred. Patients in the intervention group were visited every 2 weeks for the first 2 months and thereafter once a month where their self-care activities were measured and additional education was given as necessary.

Unfortunately, the results of this study were never published (Herber, 2012, personal e-mail communication) and so it would be difficult to assess its efficacy. In addition, the focus of the intervention remained on achieving concordance with the professionally defined self-care activities since the patients continued to be treated within the medical model – ie the desired outcome was complete ulcer healing. Furthermore, the intervention used the WAS-VOB© tool to formulate the required self-care activities and, as discussed previously, this may not be appropriate for patients within the British healthcare system.

Van Hecke et al. (2010) developed a nursing intervention to enhance adherence in leg ulcer patients following an extensive literature review on why patients do not adhere to lifestyle advice and treatment. A qualitative evaluation approach and pre-post-test design was used to examine changes in adherence following the intervention. 26 community patients were enrolled into the study and data on the frequency of wearing compression hosiery, exercises, elevation, activity levels, pain and ulcer size were collected before and after the intervention. The intervention consisted of individual home visits by specially trained TVNs (Tissue viability nurses) and three to five sessions were delivered over 3 months. Median age of the participants was 79 years and 15 were female. Participant observation was used to ensure the intervention was implemented correctly. The sessions focused on enabling the patient to explain their ulcer story to the TVN, encouraging patients to perform self-care activities, using educational, cognitive and behavioural strategies. Goal setting and positive reinforcement strategies, drawn from self-efficacy theory were also used.

The results indicated that more patients performed leg exercises post-intervention ( $p < 0.001$ ) and at follow up ( $p < 0.003$ ) compared to baseline. Frequency of exercising also improved following the intervention ( $p < 0.001$ ) and at follow up ( $p < 0.003$ ). Walking and elevation did not reach statistical significance and a small improvement in elevation decreased 3 months post-intervention.

This study demonstrates how individually tailored patient education may lead to better adherence to lifestyle changes, however, introducing a similar intervention would be difficult due to the ever-increasing workloads of community nurses in the British NHS. In addition, the outcomes of this study still tend to focus on wound healing as an outcome endpoint.

Brooks et al. (2004) evaluated a structured nurse-led education programme aimed at enhancing patient adherence with strategies to prevent ulcer recurrence. The study was quasi-experimental and 49 patients (mean age 80 years) with 97 legs (72 of which were venous aetiology) were divided into 2 groups; control and experimental. The control group received "usual care" and the experimental group were visited weekly by a District Nurse who had received instructions and training on the delivery of the intervention. The contents of the intervention which was aimed at both staff and patients were: aetiology of venous ulcer and recurrence; types of hosiery and application techniques, nutrition, exercise and skin care. Data were collected on elevation to heart level (patient self-report); mobility and ankle flexion (mobility was patient self-report), ankle movement was measured using a goniometer and measurements were performed every 12 weeks. The primary outcome measure for both groups was ulcer recurrence (defined as a breach in the skin lasting for more than 6 weeks). Secondary outcome measures were: evidence in a change of adherence with strategies such as time having legs elevated, length of time wearing hosiery and difference in recurrence rates between groups. Results indicated that patients in the experimental group experienced significantly less recurrence over the year (log rank test=8.28;  $p=0.004$ ). To control for differences in mobility and ankle movement in the two groups as baseline, simultaneous logistic regression analysis was undertaken. This was a significant advantage for patients in the experimental group ( $p=0.035$ ; OR=4.45, 95% CI=1.11–17.74), who spent more time with their legs elevated each day. This difference was sustained throughout the 52 weeks ( $f=2.88$ ,  $p=0.015$ ). Those who had both full ankle movement (>60 degrees) and full mobility (without aid) had significantly less recurrence ( $p=0.042$ ). Education had no significant effect on the amount of time patients wore compression hosiery ( $f=2.1$ ). Recurrence rate in the experimental group was 4% which is considerably less than reported in

other studies. Of concern was that only 55-66% of patients suitable for Class 2 compression hosiery wore it. The authors comment that this is surprising given the evidence to support compression hosiery in the prevention of ulcer recurrence (Nelson et al 2000; 2006). The findings of this study are encouraging, however it is interesting that a study designed to enhance patient concordance with compression hosiery as an outcome measure did not appear to collect data on the reasons why patients did not wear their hosiery.

## **2.10 Discussion**

Although the evidence base on the efficacy of interventions in enhancing adherence with self-care strategies for patients with venous leg ulcers is small, it is now finally being acknowledged that this may be a useful approach as indicated by the growing number of studies in the literature. However, of the studies reviewed, many have an underlying assumption that education itself will achieve the desired change in behaviour (Kralik et al. 2004). This is not always the case as Lorig (1999) comments that *“whilst information is necessary it is not sufficient. If all people needed was information, nobody would be overweight or smoke”*. (1999, pg. 103). The literature on self-management programmes for chronic conditions will now be reviewed to determine whether this may be an alternative approach for patients with healed or frequently recurring leg ulcers.

## **2.11 Background to the development of self-management programmes for chronic conditions**

Momentum has been growing over recent years to develop policies and services that are responsive to the needs of patients with long-term conditions (Plews, 2005). The *National Service Framework for Long-Term Conditions* (NSF, DoH 2005a) published in 2005 set out 11 quality requirements to increase people's ability to cope and adapt to their chronic condition and enable patients to live as independently as possible. Although the NSF focuses on people with long-term neurological conditions, the guidance is intended to improve services and care for anyone living with a long-term condition (DoH 2005b). In ensuring the development of a person-centred service, one of the crucial aspects is that patients (and their carers) should be given opportunities for education and support which will enable them to manage their condition themselves (Plew, 2005). As a result, many self-management programmes have been developed for chronic conditions such as arthritis, diabetes and multiple sclerosis.

Formal self-management programmes for chronic diseases have been developed by Lorig et al. (1993). These programmes encompass a range of interventions which are designed to influence the knowledge and attitudes of participants, and are principally based on a social learning and behavioural theory, Social Cognitive Theory (Bandura, 1977). SCT suggests that behaviour is a result of interactions between both personal and environmental variables and is shaped through learning by environmental conditions. Behaviour is not only determined through direct experience, but also through observational or vicarious learning (Holloway and Watson 2002). Perceived self-efficacy is viewed as the judgement of an individual regarding their confidence in their capability to perform specific tasks successfully. A person's persistence and efforts to master a particular task will be dependent on their level of perceived self-efficacy and levels of self-efficacy can be enhanced by the use of specific strategies. A large body of empirical literature supports the link between self-efficacy and predictions of health behaviours and many self-management programmes for chronic conditions are underpinned by this health behaviour theory using specific interventions to enhance self-efficacy in participants.

A rapid and unsystematic search of the literature on self-management programmes developed for long term conditions had revealed 1129 hits which focused mainly on osteo/rheumatoid arthritis and diabetes and various health behaviour change models as a theoretical framework were used. In view of the paucity of studies relating to self-care interventions for venous leg patients specifically, and the huge number of studies retrieved on chronic conditions in general, it was decided to narrow the focus of the second literature search and review the literature on osteo/rheumatoid arthritis and diabetes. The rationale for this was to capture the literature pertaining to arthritis since the disease trajectory of arthritis is, in many ways, similar to recurrent ulceration, involving periods of remission from symptoms, alternating with periods of acute 'flare-ups' (i.e. recurrence of leg ulcer), resulting in debilitating symptoms which would require patient self-care skills. The diabetes literature was also reviewed since it is also a long-term condition and the focus of interventions is to enable patients to self-manage their condition by carrying out self-care activities, independent of health professionals. It was assumed that the results of these studies may be relevant, in some respects, to the development of self-care programmes for leg ulcer patients. The rationale for including papers published after 1993 was to capture any studies evaluating the self-management programmes (incorporating self-efficacy as an outcome measure) developed by Lorig et al. in the early 1990s.

## 2.12 Outcomes of Self-management programmes for arthritis /diabetes– literature search

A literature search on BIOMED, BIDS (Social Sciences and Science database), CINAHL, MEDLINE, PSYCLIT, Cochrane Library (York, UK), EMBASE, the RCN ROM and the National Research Register (1995 to date) in order to locate on-going research was conducted using the following key words:-

Support*	Psychosocial	Self-efficacy
Self-care	Self-management	Long-term conditions
Osteoarthritis/rheumatoid	Peer support	Self-help
Arthritis	Empowerment	Education
Support group	Social cognitive theory	Self-help (+ groups)
Locus of control	Health behaviour change	Health behaviour
Diabetes*	Type 1/Type 2	Social intervention

The keywords were combined in several combinations using Boolean operators and/or (1# and 2#) and in light of the huge amount of literature retrieved, the following criteria were applied:-

Inclusion	Exclusion
Self-efficacy (as an outcome measure)	Cost-effectiveness studies
Health behaviour change models	
Randomised Controlled Trials	Non RCT methodologies
English speaking	Self-management programmes delivered by mail/telephone/email
Target age > 60 yrs.	Target age < 60 yrs
Studies after 1993	Studies prior to 1993.
Arthritis (Osteo/Rheumatoid) diabetes	All other chronic conditions

The second search retrieved 66 papers on self-management of arthritis and diabetes. The abstracts were skim read and the methodological quality was assessed using the CONSORT checklist for evaluating R.C.Ts and the Critical Appraisal Skills Programme (CASP, 2002) framework for assessing the methodological quality of systematic reviews and meta-analyses. This left a final total of 16 papers which met the inclusion criteria. A summary of the studies reviewed and their outcomes is given in Table 3.

2.13 Table 3. Summary of studies relating to self-care/management programmes underpinned by Social Learning Models

Author	Type of study	Sample size	Intervention	Control	Outcomes	Method of assessment
<p><b>Green et al. (2006)</b> <i>Australia</i></p> <p>1. <b>Fu et al. (2003)</b> <i>China</i></p> <p>2. <b>Lorig et al (1999)</b> <i>U.S.A.</i></p>	Systematic Review	<p>8 (out of 30 RCTs) assessed SE as outcome -2,780 participants</p> <p>1. 430 (Intervent) 349(Control)</p> <p>2. 561 (Intervent) 391 (control)</p>	Participation in self-management programme based on ASMP	<p>1. Usual care by G.P.</p> <p>2. Waiting list</p>	<p>Only 2 studies demonstrated increased in SE after 4 months (MD – 1.14 [CI-1.68, -0.60]) and 6 months (MD – 0.63 [CI -1.04-0.22]) compared to control</p>	<p>1. ASES* - Baseline and at 6 mths.</p> <p>2. ASES at baseline and 6 mths.</p>
<p><b>Niedermann et al. (2004)</b> <i>Netherlands</i></p> <p>1. <b>Hammond et al. (1999)</b> <i>U.K.</i></p> <p>2. <b>Taal et al. (1993a)</b> <i>Netherlands</i></p> <p>3. <b>Parker et al. (1995)</b> <i>U.K.</i></p>	Systematic Review	<p>11 studies – 3 (RCTs) targeted self-efficacy</p> <p>1. 65 (intervention) 62 (control)</p> <p>2. 38 (intervention) 37 (control)</p> <p>3. 47 (intervention) 49 (control)</p>	<p>1. Psycho-educational joint protection programme (4 weeks @ 2 hrly sessions)</p> <p>2. Group education programme (5 weeks @ 2 hrly sessions)</p> <p>3. Stress management (10 weeks @ 1.5 sessions / 15 mth. maintenance)</p>	<p>1. Waiting list/crossover trial</p> <p>2. Physiotherapy.</p> <p>3. No intervention</p>	<p>Reviewers conclude that group education only beneficial for people with existing high levels of SE.</p> <p>2. SE score 0.57 (0.55) at f/up. Results were not statistically significant. Small sample sizes</p>	<p>1. ASES* at baseline and 12 and 24 weeks</p> <p>2. ASES* at baseline, 4 mths and 14 mths.</p>

Author	Study Design	Sample size	Intervention	Control	Underpinning Theory	Outcomes and measurements	Study duration	Results
<b>Sturt et al. 2006(a) U.K.</b>	Phase I – pre clinical study convenience	8 patients 2 practice nurses	Consultation (20 mins) x 4	N/A	Self-efficacy	HbA1c, DES*, DTSQ*, DMSES*, interviews* pre and post interventions	4 mths.	Mean HbA1c ↓ pre/post intervention ↓ decline in treatment satisfaction in 3 subjects. Time-consuming for P/Ns
<b>Chlebowy and Garvin (2006) U.S.A</b>	2 group comparative, descriptive convenience	N= 91 (19-83 yrs)	<b>A</b> -4 days session – MDT <b>B</b> – Outpatient clinic visits <b>C</b> - Educ.outpatient sessions	N/A	Relationship between social support, self-efficacy	HbA1c,SSQ,* SEQ,* OEQ,* TDAQ* Questionnaires, pre and post interventions	Not stated	SEQ, OEQ modified but not revalidated. Soc. support not related to self-care, no relationship between SE and self-care. OE score positively related to self-care.
<b>Trento et al.(2006) Italy</b>	Follow up RCT	N= 56 N= N=56 (int.) N= 51 (control)	T2DM GroupCare	Traditional education	Locus of control LoC Theory	DLoC MHLC PHLC CHLC	5-7 yrs 5-7 yrs Post-intervent	Int. group displayed reduced fatalistic attitudes to diabetes. Increased Int. control without modifying beliefs in health care professionals. Int. LOC Associated with ↓ Insulin resistance

<b>Gleeson-Kreig (2006) U.S.A.</b>	2 group intervention study	N=58 (40-65yrs)	Subjects kept daily activity records for 6 wks –posted to researcher 2wkly – post meeting	No records Kept post meeting	Self-efficacy (Exercise)	Daily records, HPAI*, SEE*, PFC*, interviews	6 wks	No difference in activity levels between groups Measurement tools adapted – not validated.
<b>Montague et al. (2005) U.S.A</b>	Descriptive pilot study	n=75 (25 – 84yrs)	Interviews	N/A	Relationship of Hb1Ac to demographic & SE, Locus of Control, Diabetes Self-efficacy	HbA1c, , DSEQ*, DLCS*, SF-36* questionnaires	Once	High SE scores and internal LoC in subjects but not related to good HbA1c control
<b>Kirk et al. (2001) U.K.</b>	R.C.T.	n=13 (Int) n=13 (con)	1 to 1 Exercise consultation + leaflet	Exercise leaflet only	Transtheoretical model to change exercise behaviour	Accelerometer, SPAQ*,WBQ* SF-36*	8 wks	↑ Physical activity in Int. group compared to control Improved SF-36 scores in int. group at 5 wks.
<b>Plotnikoff et al. (2000) U.S.A</b>	Longitudinal survey (part of larger study)	n=46	Telephone Questionnaire administered by interviewers	N/A	Transtheoretical model to change exercise behaviour	Non validated tool incorporating self-efficacy, cognitive processes and psychosocial variables	6 mths	↑ SE and ↑behaviour processes scores in action/pre-action groups. SE strongest predictor of behaviour change

<b>Agurs-Collins et al. (1997)</b> U.S.A	R.C.T	n= 32 (Int) n= 32 (control)	Programme + materials, individual diet plan, exercises, 12 wkly group sessions	One class only 3 wks post-enrolment. Nutrition mailings x 2. HbA1c results	Use of Social Action Theory in order to moderate exercise behaviour, weight loss, dietary knowledge, reduction in HbA1c levels	Demographics, HbA1c, blood pressure, SE scale (Crabtree), BMI, PASE*, FFQ*	Baseline 3 mths, 6 mths.	Improved HbA1c at 3 mths (Int) not linked to behavioural change. ↑ Diabetes knowledge/behavioral change increased at 3 mths but not sustained (Int) at 6 mths. Weight loss in int. group but not sustained over time. SE only measured at baseline.
<b>Anderson et al. (1995)</b> U.S.A	Quasi R.C.T Between groups data analysis)	n=22 (Int) n=23 (con)	6 x 2h weekly Empowerment programme sessions, worksheets	6 weeks on waiting list then cross over	Self-efficacy, problem solving, attitude to diabetes, reduction in HbA1c	Demographics, DAS*, DCP*, SE Scale (? One), HbA1c	Baseline And 6 wks post int.	↑SE scores in int. grp. (Inconsistent Cronbach α's) Reduction in HbA1c and negative attitude to diabetes.
<b>Steed et al. (2005)</b> U.K.	R.C.T	n=65 (Int) n= 59 (con)	UCL-DSMP group based. 5 x 2.5hrs + 1 session (2.5hrs) after 3 mths	No intervention – just completion of assessments	Self-efficacy – goal setting, topics focused on needs of patients – predetermined by focus groups	RSSCDAM* ADDQOL* UK SF-36* HADS* PANAS* MDRTC* MDS* BDS* SSCSA*	Baseline post intervention (6 wks) and 3 mths f/up – both groups.	High attrition rate in both groups at follow-up. Improved sense of control, improved SE for exercise/blood monitoring in int. group at 3 mths.

<b>Miller et al. (2002) U.S.A.</b>	Randomized pretest-posttest control design	n= 48 (exp) n= 50 (con)	10 weekly group sessions with dietician	No intervention - completed mailed assessment tools	Social Cognitive Theory, Theory of Meaningful Learning, Information Processing Model	Instruments were developed to assess outcome expectations, nutrition self-efficacy, diabetes related knowledge – not validated	Baseline and 10 weeks	↑ SE scores for diabetes management and barriers to self-management in exp. Grp. ↑ in knowledge scores exp. group.
<b>Sadur et al. (1999) U.S.A</b>	R.C.T	n= 97 (Int) n=88 (con)	Intervention delivered by MD care team – mthly – 2 hrs for 6 mths	Usual care with physician	Self-efficacy	Baseline questionnaire, HbA1c, demographics self-efficacy (? which one), Diabetes satisfaction questionnaire (not stated)	Baseline Questionnaire, 6 mths, 12 mths but not followed up	Funded by Kaiser Permanente – real outcome was reduction in health care costs, very small ↑ in SE scores in int. group not stat. significant.
<b>Barlow et al. (2000) UK</b>	Pragmatic RCT	n=311 (Int) n=233(con)	6 x weekly sessions (ASMP) 2 hrs delivered by lay leaders using guide.	Control group attended session after baseline assessment and at 4 mths.	Self-efficacy	Baseline questionnaire. Assessed using 2 subscales of ASE, HAQ health assessment, pain and fatigue VAS, PANAS., EuroQol	4 mth and 12 mth follow up.	IG less depressed, decrease in anxiety ↑ SE scores for symptoms, cognitive symptom management; communication with HPs. Improved scores for pain; anxiety, depression and positive affect.
<b>Lorig et al. 2001 USA</b>	Multi-centre before and after cohort study	n= 613	7 week (CDSMP) intervention taught by lay instructors	No controls	Self-efficacy	Baseline assessment for self-rated health; HAQ, health distress MOS, pain VAS, health behaviour measures	Reassessed at baseline and 12 mths	20% drop out rate. Small improvements in SE, health status; less use of ED

**Table 4 Key to tools used in reviewed studies to measure outcomes of self-management programmes**

<b>Abbreviation</b>	<b>Full Name of tool</b>	<b>Author</b>
<b>DAS</b>	Diabetes Attitude Scale	Anderson, Donnelly & Dedrick 1990
<b>RSSCDAM</b>	Revised Summary of Self-Care Diabetes Activities Measure	Toobert, Hampson & Glasgow 2000
<b>ADDQOL</b>	Audit of Diabetes Dependent Quality of Life Measure	Bradley et al. 1999
<b>UK SF-36</b>	Short Form Medical Outcomes Survey	Jenkinson, Layte, Wright & Coulter 1996
<b>HADS</b>	Hospital Anxiety and Depression Scale	Zigmond & Snaith 1983
<b>PANAS</b>	Positive and Negative Affect Scale	Watson, Clark & Tellegen 1988
<b>MDRTC</b>	Michigan Diabetes Research and Training Center Questionnaire	Fitzgerald et al. 1998
<b>MDS</b>	Multidimensional Diabetes Scale	Talbot, Nouwen, Gingras, et al 1997
<b>DCP</b>	Diabetes Care Profile	Davis, Hess et al. 1987
<b>SSCSA</b>	Self-report of self-care behaviours	Toobert, Hampson & Glasgow 2000
<b>PASE</b>	Physical Activity Scale for the Elderly questionnaire	Washburn et al.1993
<b>FFQ</b>	Food Frequency questionnaire	Eck et al. 1991
<b>Accelerometer</b>	Objective Measurement of dynamic physical activity	Melanson & Freedman 1995
<b>WBQ</b>	Well-Being Questionnaire	Bradely 1994
<b>SPAQ</b>	Scottish Physical Activity Questionnaire (7 day recall)	Loughlan & Mutrie 1999
<b>DSEQ</b>	Diabetes Self-Efficacy Outcomes Expectancies Questionnaire	Developed by Crabtree in collaboration with Bandura 1991
<b>HPAI</b>	The Habitual Physical Activity Index	Baeke & Froman 1982
<b>SEE</b>	Self-efficacy for Exercise Scale	Resnick et al. 2000
<b>PFC</b>	Perceived Feasibility Checklist	Created specifically for study (Gleeson-King 2006)
<b>DES</b>	Diabetes Empowerment Scale	Anderson et al.2000
<b>DTSQ</b>	Diabetes Treatment Satisfaction Questionnaire	Bradley 1994

<b>BDS</b>	Beliefs about Diabetes Scale	Hampson et al. 2000
<b>SSQ</b>	Social Support Questionnaire	Sarason et al.1983
<b>SEQ</b>	Self-Efficacy Questionnaire	Glasgow et al. 1989
<b>OEQ</b>	Outcome Expectancy Questionnaire	Glasgow et al.1989
<b>MHLC</b>	Multidimensional Health Locus of Control Questionnaire	Wallston & Wallston 1976
<b>DLOC</b>	Diabetes Specific Locus of Control Questionnaire	Peyrot & Rubin 1994

## **2.14 Discussion and conclusion of Chapter 2**

The purpose of this chapter was to establish whether self-care or self-management is the most appropriate term to describe the activities leg ulcer patients perform in order to reduce recurrence. The evidence to support health professionals' self-care recommendations was also reviewed, and whilst the efficacy of some activities remains inconclusive, there is some evidence that ankle exercises and elevation may be beneficial in this client group. The literature around self-management programmes for chronic conditions was reviewed in order to determine outcome measures and demonstrated that, when compared to no intervention (i.e. standard care), the self-management programme approach, particularly when underpinned by the theoretical construct self-efficacy may provide benefits for participants, specifically in terms of knowledge acquisition, performance of self-management behaviours, self-efficacy and aspects of health status (Barlow et al. 2000).

Richardson et al. (2005) suggest, however, that a major limitation of the findings of the R.C.Ts conducted to evaluate the efficacy of self-management programmes is that the follow-up period of 1 year or less is too short to demonstrate long-term effectiveness, particularly for long-term conditions. They also suggest that interventions to support patient self-care are very diverse and take place in many different settings, so drawing firm conclusions about the cost-effectiveness of such interventions is problematic.

Some of the studies reviewed had methodological flaws, such as lack of an intervention, small sample sizes and large standard deviations that were reported indicated insufficient power to reject the null hypothesis. Within the diabetes research, the variability in terms of interventions, diabetes-specific self-efficacy measures and lack of standard behavioural or health-outcome measures limits the ability to generalise the findings or replicate the studies (Brown, 1990). In addition, the Hawthorne effects may have been present since patients cannot be blinded to their allocation or offered a placebo (Richardson et al. 2005).

Despite the limitations of the various methods used however, the findings of the studies reviewed at least indicate a positive trend. Self-efficacy was associated with behaviour change, whether it was analysed as a single behaviour efficacy belief score or multiple efficacy beliefs were combined as a composite score (Chlebowy & Garvin 2006; Montague et al. 2005; Plotnikoff et al. 2000; Miller et al. 2002; Sadur et al 1999; Anderson et al. 1995).

The following chapter will discuss the origins of health behaviour change models, with a particular focus on the social cognitive perspective and the major social cognitive models. The operationalization of each model will be discussed, together with its strengths and weaknesses. An argument will be developed that interventions underpinned by a robust social cognitive model such as self-efficacy may be of some benefit to venous leg ulcer patients if the development of these interventions considers the fit between the proposed intervention and the patient's existing social, work and domestic context of everyday life and their beliefs and practices already operating in relation to their leg ulceration (Chapple and Rogers 1999).

### **3.0 Chapter 3 Health Behaviour Change Models**

A brief overview of the Health Belief Model (Becker, 1974), Protection Motivation Theory (Rogers, 1983), the Theory of Planned Behaviour/Theory of Reasoned Action (Ajzen 1985; Fishbein and Ajzen 1975) the Health Locus of Control (Wallston, 1991) and Self-efficacy theory (Bandura, 1977) will now be presented. In addition, the differences and similarities of each model will be discussed, together with a review of the research evidence on their efficacy in achieving health behaviour change. The chapter concludes with an argument that self-efficacy theory may be the most appropriate framework to underpin the developing scale, the purpose of which is to achieve behaviour change or modification in order to encourage patients to perform self-care behaviours to prevent ulcer recurrence.

#### **3.1 Background to the study of health behaviours**

The systematic study of health-related behaviour began in the early 1970s (Blackwell 1989; Haynes, 1987) and was based on two assumptions. Firstly, in industrialized countries, a substantial proportion of the mortality from the leading causes of death was due to particular behaviour patterns (Conner and Norman 1999) and secondly, that these behaviour patterns were modifiable (Stroebe and Stroebe 1995).

Early studies of health-related behaviour however focused on the demographic and social characteristics of patients or biomedical factors that might influence behaviour: disease complexity, duration, and adverse treatments. The results indicated that these factors were poor predictors, and were not generally amenable to change, so that the findings would not aid clinical practice or intervention (Harvey and Lawson 2009). It became recognized that subjective psychological processes involved in health protective behaviour and illness-related behaviour were more likely to be of major importance (Leventhal and Cameron 1987) in changing behaviours. Since then, over 30 different psychological theories of behaviour change have been developed, making it difficult to choose the most appropriate one when designing interventions to promote long-term adherence to treatment (Munro et al. 2007). Various interventions, underpinned by behaviour change models, have been designed to improve treatment adherence, in particular in the field of adherence to long-term medications (Mitchie et al. 2005) however few theories describe specifically the processes involved. These theories can be divided broadly into two categories; stage models and social cognition models. The term 'social cognition models' is used to refer to a group of similar theories, each of which specifies a small

number of cognitive and affective factors (beliefs and attitudes) as the proximal determinants of behaviour (Mitchie and Abraham 2004). These models do not deny that behaviour is influenced by many other factors (e.g. social structural, cultural, and personality factors), but they assume that the effects of such distal factors are largely or completely mediated by the proximal factors specified by the model (Harvey and Lawson 2009).

### **3.2 The Biomedical Perspective**

As discussed previously, a variety of health belief theories have been proposed and the validity of such models, meaning the ability of measured beliefs to predict measured behaviour successfully, have been tested in psychometric studies (Harvey and Lawson 2009). Early studies of health-related behaviour focused on biomedical factors, demographic and social characteristics of patients that might influence behaviour: disease complexity, duration and adverse effects of treatment (Harvey and Lawson 2009). Patients were assumed passive recipients of doctor's instructions (Ross and Deverell 2004) and health or disease was traced back to biomedical causes, such as bacteria and viruses, and treatment, therefore was focused on the patient's body in isolation (Munro et al. 2007). The results indicated that these factors were poor predictors and they were generally not amenable to change, so that findings would not aid clinical practice or intervention (Harvey and Lawson 2009). The assumption underpinning many of the early health behaviour change models was that once the patient has been given education and information about their condition, they would change or moderate their behaviour accordingly. Lack of knowledge seemed to be the most easily remediable reason for failure to achieve successful behaviour change and it has been suggested that the provision of education may alter the patient's attitude to treatment and improve their satisfaction with it (Barlow et al. 2000). However, a meta-analysis of 30 studies of patient education in chronic disease found that improving patient knowledge alone is rarely sufficient to improve adherence to a treatment regime (Mazucca, 1982). An example of this can be found within the literature on venous leg ulceration where it is reported that patients are given information on the importance of wearing compression hosiery to prevent recurrence but still do not appear to do so (Brooks et al. 2004).

A fundamental limitation of this perspective is that ignores factors other than patient characteristics that may impact on health behaviours – for example, patients' perspectives of their own illness (WHO 2003), psycho-social influences (Blackwell, 1992), patients' own health beliefs (lay beliefs) (Wilkinson, 1999) and the impacts of the socio-economic environment. Furthermore, it assumes that human beings act in

a rational manner and value their health status. Latterly, it was recognised that subjective psychological processes involved in health protective behaviour and illness-related behaviour were likely to be of major importance (Leventhal and Cameron 1987) and models, known collectively as social cognition models incorporating cognitive and affective factors (beliefs and attitudes) were developed. A brief overview of the most frequently used social cognition models used to design interventions to change health behaviour will now be discussed.

### **3.3 The Social Cognitive Models**

#### **3.3.1 The Health Belief Model (Becker 1974)**

The health belief model (HBM) was developed in the 1950's by a group of social psychologists working in the field of public health who were seeking to explain why some people do not use health services, such as immunisation and screening (Harvey and Lawson 2009). The model is still in common use and consists of four core constructs: the first two refer to a particular disease whereas the second two refer to a possible course of action that may reduce the risk or severity of that disease. The HBM identified five basic dimensions as a basis for behaviour: perceived severity of the condition, perceived susceptibility or vulnerability to the disease process, perceived benefits (belief in efficacy), costs/barriers, and cues to action, which may be internal (symptoms) or external (health education, illness of family or friend). Perceived susceptibility (or perceived vulnerability) is the individual's perceived risk of contracting the disease if he/she were to continue with the current course of action (Conner and Norman 1995). Perceived severity refers to the seriousness of the disease and its consequences as perceived by the individual. Perceived benefits refer to the perceived advantages of the alternative course of action, including the extent to which it reduces the risk of the disease or the severity of its consequences. Perceived barriers (or perceived costs) refers to the perceived disadvantages of adopting the recommended action as well as perceived obstacles that may hinder or prevent its successful behaviour (Munro et al. 2007). The HBM views health behaviour change as a rational appraisal of the balance between the barriers to and benefits of action (Blackwell, 1992), that is, individuals' representations of health and health behaviour and threat perception will lead to behavioural evaluation and subsequent behaviour modification (Sheeran and Abraham 1995). Thus, high susceptibility, high severity, high benefits and low barriers are assumed to lead to a high probability of adopting the recommended action (Munro et al. 2007). Perceived threat is influenced by cues to action, which can be internal (e.g. symptom perception) or external (e.g. health communication) (Rosenstock, 1990).

The HBM has provided a useful framework for investigating health behaviours continues to be widely used and has met with moderate success in predicting a range of health behaviours (Conner and Norman 1996). According to Conner and Norman, its strength lies in the fact that it was developed by researchers directly working with health behaviours and so many of the concepts possess face-validity to those working in this area. However, compared to other social cognitive models, the HBM suffers from a number of weaknesses.

The HBM has been criticised for its assumption that people are rational beings, value their health and will therefore make the right decision to change their behaviour once the facts were given (Stone 1979; Robertson and Minkler 1994). However, theoretically, the HBM is not able to explain intention to perform the behaviour in question (Schwarzer, 1992b), nor how to change habitual behaviour patterns or spontaneous behaviours (Salazar, 1991).

Munro et al. (2007) conducted a review of health behaviour theories in relation to developing interventions to promote long-term medication adherence for TB and HIV/AIDS. On reviewing the HBM, they concluded that the model had major limitations as a theory to predict behaviour change as the relationship between the individual variables (high-perceived threat, low barriers, high perceived benefits to action) have not been explicitly spelt out. Furthermore, they assert that no definitions have been constructed for the individual components or clear rules of combination formulated (Armitage and Conner 2000). Generally, all of the model's components are seen as independent predictors of health behaviour and it is assumed that the variables are not moderated by each other and have an additive effect (Armitage and Conner 2000). Several cognitive variables found to be highly predictive of behaviour in other models are not incorporated in the HBM (Conner and Norman 1996). For example, intentions to perform a behaviour and social pressure are key components of the theory of reasoned action/planned behaviour (Fishbein and Ajzen 1980; Ajzen and Fishbein 1980) which do not appear in the HBM. Furthermore, perceptions over control over the performance of the behaviours (self-efficacy beliefs) which have been found to be powerful predictors of behaviour change in models based upon self-efficacy theory (Bandura, 1977) were not initially included within the HBM. Bandura (1997) however noted that 'perceived threats' – especially 'perceived severity' have a weak correlation with health action and might even result in avoidance of protective action. He concluded that perceived severity may not be as important as perceived susceptibility and as a result, more recently, self-efficacy

was added into the theory (Rosenstock et al. 1988), thereby incorporating the need to feel competent before effecting long-term behaviour change (Munro et al. 2007).

Munro et al. (2007) further criticise the model for the exclusion of important determinants of behaviour, such as the positive effects of negative behaviours and social influences (Stroebe and Stroebe 1995). Furthermore, some behaviours, such as smoking are based on habit rather than decisions and while the theory may predict adherence in some situations, it has not been found to do so for “risk reduction behaviours that are more linked to socially determined or unconscious motivations” (Blackwell 1992, pg. 165).

Meta-analysis of studies using the HBM to affect health behaviour change have drawn inconclusive findings on the predictive validity of the model, mainly due to poor methodology of the included studies (Becker 1974; Wallston and Wallston 1984;; Harrison et al. 1992; Tanner-Smith and Brown 2010). Only one review by Janz and Becker (1984) has drawn direct conclusions as to the HBM predictive validity and they concluded that “given the numerous survey-research findings on the HBM now available, it is unlikely that additional work of this type will yield important information” (1984, pg. 44).

### **3.3.2 Protection Motivation Theory**

Protection motivation theory (PMT) (Rogers, 1983) was originally developed to explain how people respond to ‘fear-arousing health threat communications’ or ‘fear appeals’ and can be regarded as an adaptation of the HBM (Munro et al. 2007). The main difference between the HBM and the PMT is the way in which the two are organised (Prentice-Dunn and Rogers 1986). The HBM is organised as a catalogue of variables contributing to behaviour. The PMT is organised along two processes that attempt to match the cognitive processes that people use in evaluating threats (the threat-appraisal process) and in selecting among coping alternatives (the coping-appraisal process).

In PMT, protection motivation refers to the motivation to protect oneself against a health threat; it is usually defined operationally as the intention to adopt the recommended action. Of the determinants of intention specified by the model, the four that have received the most empirical attention are vulnerability and severity (equivalent to perceived susceptibility and severity in the HBM), response efficacy (the belief that the recommended action is effective in reducing the threat), and perceived self-efficacy (the belief that one can successfully perform the

recommended action). Thus, a person will be more motivated to protect himself/herself (i.e. have a stronger intention to adopt the recommended action) if he/she believes that the threat is likely if the current course of action is continued. In addition, the person must believe that the consequences will be serious if the threat occurs, and that the recommended action will be effective in reducing the likelihood or the severity of the threat, and that he/she is able to carry out the recommended action.

PMT was based on expectancy-value theory (Rogers, 1975) and was later revised to include reward and self-efficacy components (Maddux and Rogers 1983; Rogers, 1983). Inputs to the model include environmental sources of information (e.g. verbal persuasion and observational learning) and intrapersonal sources (e.g. personality aspects and feedback from prior experiences). Prior experiences include feedback from personal experiences associated with the targeted maladaptive and adaptive responses. As mentioned earlier, PMT is organised along two cognitive mediating processes: the threat-appraisal process and the coping-appraisal process. Assessments of threat and coping factors combine to form the intervening variable protection motivation. Protection motivation is similar to other types of motivation in that it arouses, sustains and directs activity. The threat-appraisal process is addressed first, since a threat must be perceived or identified before there can be an evaluation of the coping options.

Threat appraisal evaluates the maladaptive behaviour. Factors comprising the threat-appraisal process are maladaptive response rewards (intrinsic and extrinsic) and the perception of threat (severity and vulnerability). Rewards will increase the probability of selecting the maladaptive response (not to protect the self or others) whereas threat will decrease the probability of selecting the maladaptive response. Factors that influence the coping-appraisal process are efficacy variables (both response and self-efficacy) and response costs. Response efficacy is the belief that the adaptive response will work, that taking the protective action will be effective in protecting one's self or others. Self-efficacy is the perceived ability of the person to carry out the adaptive response. Response costs are any costs associated with taking the adaptive coping response, (for example, monetary, personal, time and effort). Response efficacy and self-efficacy will increase the probability of the person selecting the adaptive response, whereas response costs will decrease the probability of selecting the adaptive behaviour. Munro et al. (2007) suggest that this is the only theory within the broader cognitive perspective that explicitly uses the

costs and benefits of existing and recommended behaviour to predict the likelihood of change.

The output of these appraisal-mediating processes is the decision (or intention) to initiate, continue or inhibit the applicable adaptive responses. Thus, the typical dependent variable in research on PMT is a measure of behavioural intentions (Rogers and Prentice-Dunn 1997). The purpose of PMT research is usually to persuade people to follow the communicator's recommendations; so intentions indicate the effectiveness of the attempted persuasion.

Sutton (1982) conducted a meta-analysis on 65 studies of fear-arousing communications published between 1953 and 1980 which showed that increases in the perceived level of fear consistently resulted in only moderate effects on behaviour. The PMT has been applied to many areas of interest, not necessarily within the healthcare arena, for example, to injury prevention, political issues and environmental concerns (Sutton, 1982).

Munro et al. (2007) point out that an important limitation of this theory is that not all environmental and cognitive variables that could impact on attitude change (such as the pressure to conform to social norms) are identified. The most recent version of the theory assumes that the motivation to protect oneself from danger is a positive linear function of beliefs, i.e. that the threat is severe; one is personally vulnerable; one can perform the coping response (self-efficacy) and the coping response is effective (response efficacy). Beliefs that health-impairing behaviour is rewarding but that giving it up is costly are assumed to have a negative effect (Stroebe and Stroebe 1995). However, the sub-division of perceived efficacy into categories of response and self-efficacy is perhaps inappropriate since people would not consider themselves capable of performing an action without the means to do so (Bandura, 1997).

Boer and Seydel (1995) point out that the results of research into the effects of health education using PMT as a framework are rather ambiguous. They argue that the theory has some strengths but also some weaknesses. Firstly, it can be seen as a hybrid theory since three major components (vulnerability, severity and response efficacy) originate from the HBM (Becker, 1974). A fourth component, self-efficacy originates from Bandura's social learning theory. Secondly, they conclude that PMT may be useful to *understand* and *predict* intentions to engage in preventative health behaviours but does not necessarily bring about successful behaviour change.

Health professionals often adopt 'fear appeal' approaches when trying to persuade patients to change unhealthy behaviours. An example of this would be a health professional telling a patient that her leg may need amputation if she does not adhere to wearing compression bandaging to achieve ulcer healing. PMT recognises that high levels of fear may lead to avoidance/denial, but proposed that low to moderate fear levels may motivate patients to comply. Leventhal and Cameron (1987) however suggest that individuals respond to avoid danger but also avoid experiencing the emotion of fear. This may well be why the model has not been well supported by research findings (Beck and Frankel 1981).

### **3.3.3 Theory of Planned Behaviour and the Theory of Reasoned Action**

The Theory of Planned Behaviour (TPB; Ajzen 1985, 1988, 1991) is an extension of the earlier Theory of Reasoned Action (TRA) (Fishbein and Ajzen 1975; Ajzen and Fishbein 1980) that continues to attract a great deal of attention in the field of psychology (Conner and Sparks 1995). The TRA itself has its origins in Fishbein's early work on the psychological processes by which attitudes may influence behaviour. The model assumes that most behaviours of social relevance (including health behaviours) are under volitional control, and that a person's intention to perform behaviour is both the immediate determinant and the single best predictor of that behaviour. According to the Theory of Reasoned Action (TRA)/ Theory of Planned Behaviour (TPB), behavioural intention is a function of:

- (i) the individual's attitude to the behaviour and evaluation of performing it. This attitude refers to expectations and evaluation of outcome.
- (ii) the individual's perception of social pressure to perform the action (the subjective norm) and whether he/she is motivated to comply with this pressure (wanting the approval of significant others: spouse, family, doctor).

Fishbein and Ajzen (1980)

According to the TRA, "attitude" is held to reflect the person's salient behavioural beliefs concerning the possible personal consequences of the action. For example, a person who believes that performing a given behaviour will lead to mostly positive personal consequences will hold a favourable attitude towards the behaviour (Munro et al 2007). For operationalization purposes, attitude and subjective norms are expressed as complex mathematical equations (Conner and Norman 1995). Specifically, "attitude" is held to be a function of the sum of the person's salient behavioural beliefs concerning the outcome of the action each weighted by their evaluation of that outcome (Harvey and Lawson 2009). An indirect, belief-based

measure of attitude can be created by multiplying each behavioural belief by its corresponding outcome evaluation and then dividing it by the sum of outcomes (Harvey and Lawson 2009). In a similar way, “subjective norm” is a function of the person’s belief that specific individuals or groups think he/she should or should not perform the behaviour. A person who believes that most significant others think he/she should perform the behaviour will perceive social pressure to do so. Specifically, subjective norm is held to be a function of the person’s salient normative beliefs with respect to each referent, each weighted by their motivation to comply with that referent. An indirect measure of subjective norm can be created by multiplying each normative belief by its corresponding motivation to comply and dividing over referents.

In summary, the assumptions of the TRA model suggest that generally speaking, people will have strong intentions to perform a given action if they evaluate it positively and if they believe that important others think they should perform it, thus the TRA places the individual within their social context. The relative importance of the two factors, however, may vary across behaviours and populations. However, intention does not always result in action, which may be influenced by other factors (Harvey and Lawson 2009). Many behaviours cannot simply be performed at will; they require skills, opportunities, resources and cooperation for their successful execution. The TPB (Ajzen, 1991) was an attempt to extend the TRA to include behaviours that are not entirely under volitional control, for example, giving up smoking or using a condom. To accommodate such behaviours, Ajzen added a variable called “perceived behavioural control” to the TRA (Munro et al. 2007). This refers to the perceived ease or difficulty of performing the behaviour, and is assumed to reflect past experiences as well as anticipated obstacles. Conceptually, this is very similar to self-efficacy (Stroebe and Stroebe 1995) and includes knowledge of relevant skills, experience, emotions, past track record and external circumstances. Behavioural control is assumed to have a direct influence on intention (Sutton, 1997) and meta-analyses examining the TPB have found varied results regarding the effectiveness of the theory’s components (Hardeman et al. 2002; Godin and Kok 1996, Armitage and Conner 2000). Although not conclusive, the results of the analyses are promising.

Sutton (1997) however, suggests that the TRA and TPB require more conceptualisation, definition and additional explanatory factors. Attitudes and intentions can also be influenced by a variety of factors that are not outlined in the above theories. Specifically, these theories are largely dependent on assumed

rationality (Mullen et al. 1987) and do not allow explicitly for the impacts of emotion or religious beliefs on behaviour, which may be relevant for diseases which are stigmatised within society.

The rationale for using this model by health researchers is often the identification of beliefs and values that influence attitudes in the hope that these may be addressed in communication strategies to promote behavioural change (Conner and Sparks 1995). However, research assessing this possibility is surprisingly thin on the ground (Brubaker and Fowler 1990; van den Putte 1993). For example, a recent review of applications of the TPB to behaviour change found a diverse literature with few studies that were explicit about how the theory had been applied. Hardeman et al. (2002) found that of the 12 identified studies that used the TPB to develop a behaviour change intervention, four were found to change behaviour and none investigated where behaviour change was mediated by the psychological changes proposed by the theory. Thus, although numerous studies have demonstrated that the TPB can predict health behaviours (Godin and Kok 1996), the theory has not been systematically evaluated as an explanation of behaviour change (Mitchie and Abraham 2004).

#### **3.3.4 Health Locus of Control**

Psychologists have long been interested in the beliefs that underlie people's health behaviour, with particular attention being focused on perceptions of control over health. It is assumed that people who believe they have control over their health will be more likely to perform a range of health promoting behaviours (Strickland 1978; Wallston and Wallston 1981), and as a result, have better health status (Seeman and Seeman 1983; Marshall 1991). This assumption has been used in many health promotion interventions, ranging from "internality training" (Wallston and Wallston 1978) to programmes developed to overcome the barriers to control. Moreover, it is an explicit feature of the *Ottawa Charter for Health Promotion*, which defines health promotion as the "process for enabling people to increase control over, and to improve, their health" (World Health Organisation 1986). As a result, practitioners in primary care, for example, general practitioners, are now under obligation to give patients advice on the impact poor lifestyle choices, such as alcohol and smoking, have on their health. Against this background, it is not surprising that health locus of control (HLOC) is one of the most widely researched constructs in relation to the prediction of health behaviour (Wallston 1992).

The origins of the HLOC construct can be traced back to Rotter's (1954) social learning theory. The main tenet of social learning theory is that the likelihood of a behaviour occurring in a given situation is a function of (a) the individual's expectancy that behaviour will lead to a particular reinforcement and (b) the extent to which the reinforcement is valued (Norman and Bennett 1995). Rotter (1954) proposed that the theory could operate on a general as well as a specific level, so in addition to having expectancy beliefs for particular situations, individuals are also believed to have generalised expectancies that cut across all situations (Norman and Bennett 1995). It was from this perspective that the notion of locus of control was introduced, as a generalised expectancy relating to the perceived relationship between one's actions and experienced outcomes. In particular, Rotter made the distinction between internal and external locus of control: 'internals' are seen to believe that events are a consequence of their own actions and thereby under personal control. 'Externals' are seen to believe that powerful others, fate or chance primarily determine events and see little impact of their own efforts on events and outcomes (Gruber-Baldini et al. 2009).

Locus of control, as a generalised expectancy that one's actions are instrumental to goal attainment, was first measured in Rotter's (1966) internal-external scale which has since become one of the most widely instruments used to predict health behaviour. Reviews of early work with this scale (Phares, 1976; Strickland, 1978) reported that, compared with externals, internals were more likely to exert efforts to control their environment, to take responsibility for their actions, to seek out and process relevant information, to exhibit better learning and show more autonomous decision-making. In applying such findings to the question of health behaviour, it was predicted that internals would take a more active responsibility for their health, and, as a result, would be more likely to engage in health-promoting activities.

Early work applying the internal-external scale to the prediction of health behaviour met with some success (Strickland 1978; Wallston and Wallston 1978). Furthermore, in terms of coping and adjustment to chronic conditions, it has been suggested that LOC can be a mediator in adaptation (Meiher et al. 2002). Research suggests that an internal LOC seems to be predictive for illness-related adjustment (Jacobson et al. 1990; Miles, Sawyer and Kennedy 1995) and that internals are better adjusted than persons with an external LOC (Benson and Deeter 1992, Steinhausen et al. 1983), however the use of the scale has met with two criticisms (Norman and Bennett 1996).

Firstly, the amount of variance in health behaviour explained by the internal-external scale was typically low, and this led to a call for, and development of, situation or domain-specific locus of control measures (Norman and Bennett 1996). This is in line with Rotter's (1975) view that when an individual has some prior experience in a given situation, situation-specific expectancy beliefs will be more predictive of behaviour. Secondly, the scale was criticised by a number of researchers for conceptualising locus of control as a uni-dimensional construct (Gurin et al. 1969; Mirels, 1970; Collins, 1974; Levenson, 1974). In response to these criticisms, Wallston and colleagues developed the multidimensional health locus of control (MHLC) scale, with the sub-categories 'doctors', 'God' and 'other people' in the group 'powerful others'. The HLC scale that is currently used assesses five dimensions: 'internal' HLC, 'powerful others' HLC, 'chance' HLC, 'other people' HLC and 'doctors' and can be expected to undergo further changes as the beliefs and values of society evolve (Przybylski, 2010).

Studies on the relationship between HLOC and adherence or non-adherence to health behaviours have been extensive; however results have been mixed (O'Hea et al. 2005). While some researchers (Balch and Ross 1975; Kincey 1981; Tobias and MacDonald 1977) have found HLOC to play a role in determining if a patient follows his/her doctor's recommendations, others have not (O'Hea et al. 2005; Gruber-Baldini et al. 2009; Seeman and Evans 1962; O'Hea et al. 2005, Kincey, 1981).

It is important to note that Wallston (1976; 1991) evaluated subjects' values towards health. In theory, if a subject does not place a high value on his/her own health, then a high HLC will make no difference with regard to positive health behaviours (Przybylski, 2010). Much of the current research does not assess health values, which may be one of the reasons why the research in this field remains inconsistent (Reynaert et al. 1995; AbuSabha and Achterberg 1997; O'Hea et al. 2005).

In terms of health value, this may be problematic with patients suffering from venous leg ulceration. Studies have indicated that because many patients within this client group have, by the nature of their age, many existing co-morbidities, and therefore, the presence of a small ulcer may not concern them sufficiently to affect behaviour change/modifications (Brown, 2003, 2005, 2010). In addition, operationalization of the HLOC model may be difficult in this client group, since venous ulceration is a condition where periods of healed ulceration alternate with periods of open ulceration. This would necessitate the use of several HLOC scales at different stages of interventions in order to assess patients' internal and external LOC. For

example, during periods of active treatment, the patient would have little control since the application of compression bandaging is a skilled nursing intervention. On the other hand, when healing has been achieved, a further LOC scale would need to be administered in order to ascertain whether the patient is internally or externally situated in terms of performing self-care behaviours to prevent future recurrence.

### **3.4 Summary of social cognitive models**

Despite a substantial volume of research using the main social cognition models to predict a range of health behaviours, Norman and Conner (1996) suggest that there has been little empirical work comparing the predictive power of the different models. As Weinstein (1993) notes, the lack of comparison studies means that there is little consensus on whether some variables are more influential than others and whether some models of health behaviour are more predictive than others.

A number of authors have commented on the similarities between the various models at a conceptual level. Cummings et al. (1980) have noted that there is considerable overlap between the various constructs contained within the models and where differences do appear, they may represent differences in labelling rather than differences in the underlying constructs (Munro et al. 2007), for example, 'perceived susceptibility' or 'perceived vulnerability' occur in both the HBM and PMT. Other constructs appear to be very similar, for example, perceived behavioural control and self-efficacy (Sutton, 2002). Schwarzer (1992) has argued that perceived behavioural control should simply be re-labelled as self-efficacy and considered as such. Self-efficacy (Bandura, 1997) is a well-established and well-researched construct that is firmly embedded with social cognitive theory and can be contrasted with the still exploratory nature of the perceived behavioural control construct. Norman and Conner (1995) conclude that whilst most social cognition models provide an important framework for considering the social psychological determinants of health behaviour, it is clear that they only account for a small amount of variance in health behaviour.

Over the years, the notion of self-efficacy has become so appealing to health psychologists that it has been adopted as part of most health behaviour theories (Schwarzer and Fuchs 1995). Examples include the Health Belief Model (Becker and Rosenstock 1987), the Theory of Planned Behaviour (Ajzen, 1988, 1991) and Protection Motivation Theory (Maddux, 1993). Thus, this key construct, originally developed within Bandura's social cognitive theory has proven to be an essential component of any health behaviour model (Schwarzer and Fuchs 1995).

Perceived self-efficacy is the belief in one's competence to tackle difficult or novel tasks and to cope with adversity in specific demanding situations (Luszczynska and Schwarzer 2005). Self-efficacy makes a difference in how people think, feel and act (Bandura, 1997) and people with high self-efficacy will choose to perform more challenging tasks, and when setbacks occur, they will invest more effort, recover more quickly and remain committed to the goals set to them (Luszczynska and Schwarzer 2005). Thus, self-efficacy represents a belief in one's competence in dealing with all kinds of demands, implying an internal-stable attribution of successful action and a prospective view. According to Lawrance and McLeroy (1986) the fundamental underlying principle of self-efficacy can be summed up simplistically as *"If you think you can – you might. If you think you can't – you're right!"*

The evidence for self-efficacy theory as an explanatory framework for health behaviours and outcomes is extensive. It includes application in anxiety disorders, depression, smoking cessation, weight loss, pain management, cardiac rehabilitation and adherence to both simple and complex self-care regimens (Bandura, 1991; Schwarzer and Fuchs 1995). Self-efficacy theory has demonstrated its explanatory and predictive power in a variety of areas of life (Rapley and Fruin 1999), including chronic illness, for example self-efficacy research has demonstrated a significant effect with diabetes and arthritis-related health behaviours (Lorig et al. 1989). Within self-efficacy theory, the two key determinants of behaviour are perceived self-efficacy and outcome expectancies, with perceived self-efficacy characterised mainly as being competence-based, prospective and action-related (Luszczynska and Schwarzer 2005).

As a pragmatic researcher and clinician, the apparent operational simplicity of self-efficacy theory, using a robust framework of interventions designed to enhance and build self-efficacy greatly appealed to me. It appeared to be the ideal health behaviour change model to underpin my developing, practice-based scale, particularly in light of the positive research findings in its application to self-management programmes for chronic conditions. This chapter now continues with an overview of self-efficacy theory.

### **3.5 Self-efficacy Theory**

Self-efficacy refers to a person's sense of confidence in his or her ability to perform a particular behaviour in a variety of circumstances (Bandura, 1977; 1986). Bandura proposed that an individual's persistence and efforts toward specific behaviour is

closely related to his or her level of self-efficacy (Lee et al. 2008). The personal perception of efficacy may further determine the type of activities chosen, the effort to be expended, and the degree of persistence in the effort (Lee et al. 2008).

Self-efficacy has demonstrated the potential to explain the adoption of new health-related behaviours (McAuley et al. 1993; Schwarzer & Fuchs 1995; Stretcher et al., 1986; Taylor et al. 1985) and the avoidance of risky lifestyle behaviours, including habitual behaviours, such as smoking (DiClemente et al. 1991; Shannon et al., 1990; Lawrance & McLeroy 1986). Furthermore, self-efficacy theory has proven its place in the maintenance of behaviours associated with chronic illness in general (Lorig 1996, Ruggiero & Prochaska, 1993).

A key part of self-efficacy theory is that the stronger the individual's belief in his or her ability to perform a set of actions, the more likely they will be to initiate and persist in the given activity. In contrast, those who have a lower level of self-efficacy may dedicate less effort, and therefore have a greater tendency to abandon their attempts in carrying out the required behaviour (Bandura and Cervone 1983).

Bandura (1986) based his concept of behaviour change on two central theories: self-efficacy and outcome expectancies. The underlying assumption of social cognitive theory suggests that behavioural change and the maintenance of that behaviour are a function of the expectations about one's ability to perform a certain behaviour (self-efficacy) and the expectations about the outcome resulting from performing that behaviour (outcome expectations). According to Bandura (1991), both self-efficacy and outcome expectancies play a role in the adoption of health behaviours, the modification of unhealthy habits and the maintenance of change.

Self-efficacy theory, whilst one of the social cognitive theories, differs by virtue of its specificity, and its recognition of the dual cognitive mechanisms that influence behaviour, outcome expectations and personal efficacy belief in the ability to carry out the required task (Bandura, 1986). Although outcome expectations and efficacy beliefs are viewed as differing mechanisms, their influence on behaviour change is considered to be synergistic (Bandura, 1977; Bandura, 1982; Rapley, 2001). Bandura (1986) saw a distinction between the person's perception of the expected outcome of behaviour (outcome expectation) and the person's perception of their ability to complete the behaviour successfully (efficacy belief). Both these outcome expectations (the belief that the behaviour will have the desired effect) and efficacy belief (confidence in ability) are required for any given outcome. The latter belief

controls the thought processes and emotional reactions, thereby affecting the person's choice of behaviour, degree of effort and persistence (Bandura, 1989). The greater the efficacy belief, the more the person will choose to make an effort to change their behaviour or persist with the behaviour when problems are encountered.

### **3.5.1 Efficacy beliefs/expectations**

Judgements about the particular task are built on past experiences and will vary according to the level (or magnitude) of efficacy belief, strength of belief and generality of the belief (Bandura, 1997, Bandura 1986). There is empirical evidence to support the assertion that efficacy beliefs about ability are independent of actual ability (Liebert & Spiegler 1994).

Initial performance of a new skill is affected by immediately preceding relevant experiences (sources of information) that contribute to efficacy beliefs about ability to carry out a specific behaviour. As one of the most important sources of information, past accomplishments may be the main influence on strength and level of efficacy beliefs for a new task. When a new task has not yet been mastered, perceptions of performance may be a personally biased interpretation based upon the person's physical, social, or self-evaluative outcome expectations for similar events (Rapley, 2001).

Specifically, the efficacy belief derived from a similar prior challenge and experience influences the individual's level of efficacy expectation. Similar prior challenges and experiences also influence the generalisation of the earlier belief to the new but similar task. In this way, the person determines if the task is to be attempted (worth the effort) and the extent of their persistence in the face of difficulties or an unresponsive environment (Bandura 1982; Shannon et al. 1990).

Belief in one's ability to undertake behaviour is an important link between knowing what to do and actually doing it (Grebowski et al. 1993; Bandura, 1982). It reflects the confidence and motivation that help in making decisions about a course of action. In particular, lifestyle behavioural changes are likely to be reliant on efficacy belief to overcome perceived barriers to adopting the new behaviour (Shannon et al. 1990; Schultz & Schultz, 1998; Rosenstock et al., 1988). Efficacy expectation influences the three categories of action or personal change: the adoption of new behaviours, generalised use under different conditions, and maintenance of the behaviour over time (Schwarzer & Fuchs, 1995; Bandura 1986).

High efficacy belief does not, however, imply that the behaviour will be performed without anxiety (Feist, 1994). Bandura (1991) referred to several studies that confirmed efficacy belief as able to mediate the relationship between stress or anxiety and a sense of controllability of an adverse situation. Life, in general, is a continuum of adversities, setbacks and failures, both large and small. When perceived coping ability does not match an unresponsive environment, a perception of threat may exist. To counteract the threat, an optimistic sense of personal efficacy is needed (Bandura, 1986). Setbacks and difficulties, however, serve to strengthen efficacy belief if the person perseveres and, subsequently, succeeds. In the face of difficulty, individuals who possess high self-efficacy belief have fewer self-doubts and will recover quickly (Bandura, 1986).

Individuals with stronger efficacy belief may still feel anxious but are more likely to attend to what was familiar in a new task or situation, rather than focus on the unknown (Bandura, 1997; Jerusalem & Mittag 1995). In relation to health, individuals with a strong efficacy belief were not as likely to perceive themselves as sick and less likely to be depressed, compared to people with a low self-efficacy belief (Bandura, 1997; Gecas, 1989).

Additionally, individuals with a low efficacy belief are more likely to worry about negative events in the past and may be unable to cope with uncertainty (Rapley, 2001). In this situation, individuals may believe that a potential threat is beyond their control, may visualise failure and become distressed with the resultant impaired level of performance. The interactions of poor performance, low efficacy belief and stress symptoms become iterative. The less resilient person will stop trying to reach the goal (Jerusalem & Mittag 1995; Bandura, 1986).

### **3.5.2 Outcome Expectations**

While personal efficacy expectation is a judgement about ability in relation to a particular behaviour or task, outcome expectation is a judgement about the result of enacting the behaviour (task) in question – a judgement as to whether the recommended behaviour will have the desired effect. Outcome expectation has been classified as a positive or negative expectation of a physical, social or self-evaluative nature (Bandura, 1989).

Outcome expectation was found to be important at the intention stage of behaviour change and less so for the maintenance of the behaviour change (Schwarzer &

Fuchs 1995). Schwarzer (1992 pg. 234) suggests that, in particular, without prior experience of a behaviour, “outcome expectations may have a stronger direct predictive influence”. For example, Maddux et al (1982) used 95 introductory psychology students to test the theory that efficacy and outcome expectancies were independent. The study has three levels (high, low, and no information) for cognitive expectancies. Information in brochures about a simple interpersonal skill of minimal risk was varied to reflect three levels of difficulty in using the technique (efficacy expectation) and effectiveness of the technique (outcome expectancy). Maddux et al. found outcome expectancy to be independent of efficacy belief in relation to intention to perform the behaviour change. Specifically, intention to perform a behaviour was significantly associated with higher levels of outcome expectancy whereas intention was not significantly associated with efficacy belief.

Outcome expectations have not been measured in many studies, and mixed results were found for those that did (Shannon et al. 1990). Outcome expectation and efficacy belief were found to be good predictors of intention to undertake breast self-examination behaviour (Seydel et al. 1990). Conversely, in relation to a less serious health outcome, outcome expectation was not predictive of intention to floss teeth (Beck & Lund 1981), lose weight (Shannon et al. 1990) or use pain coping strategies (Jensen et al 1991) when efficacy beliefs were controlled in respective regression analyses. It may be that “the greater the risk of aversive consequences, the greater the salience of self-efficacy expectation” (Maddux et al. 1982, p. 211).

### **3.5.3 Behaviour**

Behaviour is as important to the aetiology of many chronic conditions as it is to the self-care regimen. Although the interaction of efficacy beliefs and action-outcome expectations generally determine behaviour, optimal performance usually required both efficacy and outcome expectation to be high (Lent et al. 1991; Gecas, 1989, Stretcher et al. 1986). The likelihood that a recommended behaviour will be adopted depends on three aspects of people’s understanding: their perception of the degree of risk, followed by an expectation that the behaviour will reduce the risk and their expectation that they are capable of making the behaviour change. Together, the three perceptions influence behaviour intention (Bandura, 1997). Good intentions alone are not sufficient for people to adopt health practices, cease risky behaviours or change the habits of a lifetime (Grembowski et al. 1993). In low risk situations, outcome expectation was found to be more important to the formation of intention to change or adopt behaviour (Maddux et al. 1982). Efficacy expectation about ability,

however, influenced behaviour from initiation through to long-term maintenance (Schwarzer & Fuchs 1995; Bandura, 1986).

Optimal performance requires a reasonable degree of association between action and outcome. Without it, individuals develop a sense of hopelessness or learned helplessness (Sullivan, 1993; Buckelew & Parker, 1989). In particular, when the match between efficacy belief and the particular behaviour cannot predict outcome in a reliable way, the efficacy belief becomes more important in explaining behaviour change (Bandura, 1982). Bandura suggested that people give up trying because they either doubt their level of performance (efficacy-based futility) or they believed that they could not influence the outcome, regardless of their ability (outcome-based futility). This lack of coherence between action and outcome is particularly relevant to some health-related behaviours (Blackwell, 1992; Wallston, 1991; Lorig et al. 1989b). This unpredictable course and the varying disease activity of rheumatoid arthritis (RA), for example, caused patients to view their disease as uncontrollable (Long & Sangster, 1993), leading to lower efficacy beliefs in relation to self-care behaviours (Bradley et al. 1984; Taal et al. 1993a). Similarly, the uncertainty and ambiguity associated with future diabetic complications (Carey et al. 1991), regardless of how “well controlled” the diabetes may have been in the past, increase fear and guilt (Hunt et al. 1998; Armstrong, 1997). This may be particularly pertinent in the case of patients with healed venous leg ulceration, who, despite wearing compression hosiery as instructed and successfully adapt more healthy lifestyles, nevertheless continue to develop ulcer recurrence. A patient with high efficacy beliefs will continue to persevere with his/her self-care activities, whereas a patient with low levels of self-efficacy may well give up.

#### **3.5.4 Development of self-efficacy**

The information and feedback that an individual obtains from the performance of a task are referred to as sources of self-efficacy (Bandura 1977, 1986). According to self-efficacy theory, there are four major information sources of one’s self-efficacy: performance accomplishments, vicarious learning, verbal encouragement, and physiological and affective states. These sources may come in several forms (Lee et al. 2008; Bandura, 1982) and the individual uses this information to make judgements about personal efficacy. Hence, each source has the potential to enhance or decrease efficacy belief. Bandura recommended that strategies to build self-efficacy use all four sources of information.

### **3.5.5 Performance Accomplishments**

Performance accomplishment is the experience perceived from an individual's performance of a specific activity (Bandura, 1997). It is assumed that a sense of self-efficacy is enhanced by successful experiences, but weakened by negative experiences (Lee et al. 2008). This is why performance accomplishments are believed to be the most influential source among the four information sources of self-efficacy beliefs, because they are based on personal experience, and therefore have greater authenticity for the individual (Bandura, 1986; 1997). However, there is a lack of evidence to suggest that performance accomplishment alone can generate the expected behavioural changes among older people (Lee et al. 2008).

According to Lee et al. (2008), people's experiences of success may improve their self-efficacy; however, disappointments at an early stage may reduce it. Van de Laar and van der Bijl (2001) suggest that breaking the task or behaviour down into small but achievable pieces may be useful in order to build confidence. This is the reason why greater support is necessary in the initial stage of the behaviour or task to enhance confidence and minimise any frustrations that may adversely affect self-efficacy (Bandura, 1995). Goal setting within interventions tailored to the individual's needs and capacities, allowing for gradual progress has been found to be effective, particularly with older adults (Bandura, 1986; Blair, 1995; Lachman et al. 1997; Shilts et al. 2004).

### **3.5.6 Vicarious experiences**

Seeing others' achievements or learning from other's related behaviours, especially for individuals who are uncertain of their ability to perform a specific behaviour may help an observer believe that he/she can possess the capabilities to perform equivalent activities (Bandura, 1997). A trial of vicarious experience provided through visits to patients about to undergo cardiac surgery by those who had recovered from a similar procedure showed this intervention to be effective in helping patients cope with surgical anxiety (Parent and Fortin 2000). Several investigations have also tested the use of videos to enhance self-efficacy (Gortner and Jenkins 1995; Gross et al. 1995).

However, Lee et al. (2008) caution that the characteristics of the sources of vicarious experience need to be taken into account as they are likely to be highly influential in the success of bringing about the desired behaviour change. They suggest that people with a comparable lifestyle, such as friends or colleagues, or those with similar characteristics in age, sex, and socio-economic status may serve as models

for a specific behaviour and necessary skills. Bandura (1995) concurs with this view, stating that the relative success of vicarious experience is likely to be contingent on the comparability of the role models. In particular, role models who succeed despite difficulties, such as slow progression or trial and error, are often in a better position than those who achieve quick success without problems (Gonzalez et al. 1990). When designing interventions based on vicarious experience, it is therefore imperative to choose appropriate role models, taking into account their comparability with the subjects.

### **3.5.7 Verbal encouragement**

Realistic positive feedback from significant others or professionals has been proposed as an important reward to induce individuals to carry out and maintain a specific behaviour (Bandura, 1991). People may interpret their successes negatively or simply ignore or underestimate their achievements. It is important, therefore, that verbal encouragement is directed in such a way in that it helps people to interpret the experience as a success (Bandura 1982; Maddux and Lewis 1995). When others, specifically significant others or health professionals, have confidence in one's abilities to succeed, this may generate greater self-confidence for some individuals (Booth et al 1997; Oetker-Black et al. 1997; Lee et al. 2007). Although verbal encouragement alone may be limited in terms of promoting self-efficacy, it can serve to reinforce self-change if the positive appraisal is positive (Bandura, 2004). On the other hand, if unrealistic beliefs about personal capabilities are encouraged, this may, in contrast, lead to a loss of credibility of the provider and further weaken the recipients' confidence in their own capabilities (Lee et al. 2007).

### **3.5.8 Perceiving physiological and affective responses**

A person's perception of physiological and affective responses in relation to a specific activity is counted as an additional source in relation to self-efficacy because these personal perceptions may affect judgements about one's efficacy beliefs (Bandura 1986; 1991). High levels of anxiety serve as negative feedback that can erode self-confidence and performance, especially for complex tasks (Bandura, 1995). That is, in threatening situations, personal self-efficacy belief affects emotional reactions as well as behaviour. Perceived low efficacy in coping with unfavourable events has been shown to have a negative effect on heart rate, on blood pressure and on serum levels of catecholamines (Bandura, 1982; O'Leary, 1985).

Within the diabetes literature, physiological cues are considered critical for diabetic patients who need to learn to recognise the differing symptoms associated with hypo- and hyperglycaemia in order to take remedial action. However, while symptoms are a useful indicator of blood glucose levels, they can also be interpreted by the person as a sign that they have failed to 'control' their condition, or have done something 'wrong' (O'Leary, 1985). Similarly, arthritis sufferers need to recognise the presence of pain need not indicate further joint damage; that pain and fatigue may be the normal effect of exercise undertaken as part of the self-care routine (Holman and Lorig 1994; Taal et al. 1996). Patients with recurrent venous leg ulcers may view a new open ulcer as a sign that they have failed in their self-care activities. This may not be the case since the condition is characterised by periods of healing alternating with open ulcers and highly efficacious people will persist with their self-care strategies despite this initial setback. Furthermore, individuals are more likely to be optimistic about their situation when they are not feeling anxious or tense, although moderate levels of anxiety have been shown to improve efficacy belief and quality of behavioural effort (Feist, 1994).

### **3.6 Self-efficacy and chronic conditions**

Self-efficacy theory has demonstrated its explanatory and predictive power in a variety of areas of life (Bandura 1991, 1997), in particular with chronic conditions, for example, diabetes-related behaviour and with arthritis-related behaviour (Rapley and Fruin 1999). Following Bandura's usage, most researchers have treated self-efficacy, or at least the efficacy expectation component, as a task-specific or behaviour-specific construct (Bandura 1977; 1982). However, when applied to the self-management of complex chronic illness healthcare regimens, self-efficacy theory must account for initial and ongoing phases of a multi-task self-management regimen. For example, research outcomes that have one task (task specific) or behaviour change as a focus cannot warrant generalisation to the complex regimen situation, since this may involve multiple tasks, each with its own efficacy belief and expectation. It may be, therefore, that in the case of a complex regimen of care, a more general sense of self-efficacy is important at the start, while task-specific efficacy is of more importance later (Rapley and Fruin 1999). Bandura (1977) indicated that efficacy expectations would change over time; perhaps this change represents the movement of efficacy beliefs on a continuum from general to specific (Sherer 1990) or an interaction between the two, general and specific. This may explain why it has been found that, in terms of perceived efficacy (general, domain or specific), following all aspects of a recommended self-care regimen will not necessarily result in metabolic control for type 1 diabetics (Dunn 1986; Glasgow et al.

1987), weight loss for the type 2 diabetic (Becker and Janz 1985) or pain control for the arthritic patient (Lorig and Laurin 1985). There is, however, sufficient empirical evidence in the literature to support the notion that self-efficacy is central to the person's view of self and, consequently, its effect on bringing about behaviour change (Bandura 1991; Bandura 1986; O'Leary 1985).

### **3.7 General and disease – specific self-efficacy**

Following Bandura's usage, most researchers have treated self-efficacy, or at least the efficacy expectation component, as a task-specific or behaviour-specific construct (Bandura 1982, 1977). Rapley and Fruin (1999) however argue that when applied to the self-management of complex chronic illness healthcare regimens, general self-efficacy must account for the initial and on-going phases. For example, research outcomes that have one task (task specific) or behaviour change as a focus cannot warrant generalization to the complex regimen situation since these involve multiple tasks, each with its own efficacy belief and expectation. It may be that, in the case of a complex regimen of care, a more general sense of self-efficacy is important at the start, while task-specific efficacy is of more importance later. Task-specific efficacy beliefs may initially be low and increase as the person persists and masters the various new skills and behaviour changes. If this is the case, it could be that a high general self-efficacy is acting to mediate the relationship between initial behaviour-change efforts and the development of task-specific efficacy expectations (Rapley and Fruin 1999).

Van der Bijl and Shortridge-Baggett (2001) on the other hand point out that Bandura (1997a) cautioned researchers that, to increase accuracy of prediction, "self-efficacy beliefs should be measured in terms of particularized judgements of capability that may vary across realms of activity, different levels of task demands within a given activity domain, and under different situational circumstances" (pg. 6). In other words, efficacy beliefs should be assessed at the optimum level of specificity that corresponds to the criterion task being assessed and the domain of functioning being analysed. Maibach and Murphy (1995) argue that some researchers have incorrectly interpreted generality of self-efficacy to mean generalized self-efficacy, that is, a sense of efficacy that operates across all situations and domains of functioning. Van der Bijl and Shortridge-Baggett (2001) further propose that treating generality of self-efficacy in this way distorts the self-efficacy construct as described by Bandura. The problem with assessments of generalized self-efficacy is that people are required to make judgements about their capabilities without a clear activity or task in mind. Pajares (1997) concurs with this view and suggests that general self-efficacy

instruments have little explanatory and predictive value in contrast to domain-related measures.

### **3.8 Measuring self-efficacy objectively - Self-Efficacy Scales**

The self-management studies reviewed used self-efficacy (SE) scales to measure outcomes, which were generally disease-specific. A “dirty” search revealed over 26 different scales for diabetes, asthma, multiple sclerosis, arthritis and heart failure. Additional scales for other medical conditions, such as cervical screening in Mexican/American low-income women (Fernandez et al. 2009); Coping Self-efficacy (Chesney et al. 2006), Coping with Epilepsy SE (Dilorio et al. 1992) and various adaptations of the General Self- Efficacy Scale (Jerusalem and Schwarzer 1979) were found. The literature relating to the main SE scales used for diabetes and arthritis was reviewed and the characteristics of each scale and development methodologies will now be presented in Table 5 and Table 6.

**3.9 Table 5 – Overview of the main diabetes/arthritis SE scales and their characteristics**

Disease	Scale	Study	Identification of items	Selection of items	Development of SE domains	No. if items/domains	Answer options	Self- or interviewer administered
Diabetes	Self-Efficacy Score for Diabetes Scale (SED)	Cullen et al . 2007	Adapted from SED (Grossman et al 1987) Experts	Interviews with patients and experts. Data driven - FA	1 domain only determined by factor analysis	Reduction from 35 to 11 items 1 self-efficacy domain	6 point Likert scale	Self-administered
Diabetes	Self-Efficacy for Diabetes Self-Management Scale	Iannotti et al 2006	Literature (unsystematic search)	Experts for relevance. Data driven – elimination of items with ceiling effects	1 domain determined by factor analysis	10 items 1 self-efficacy domain	10 point Likert scale	Self-administered
Diabetes	The Confidence in Diabetes Self-Care Scale (CIDS)	Van der Ven et al. 2003	Literature (unsystematic search)	Experts/patients	1 domain determined by Factor analysis	20 items 1 self-efficacy domain	5 point Likert scale	Self-administered
Diabetes	Self-Efficacy for diet adherence scale	Kavookijan et al. 2005	Literature (unsystematic search)	Experts/patients	Data driven – factor analysis	9 items 1 self-efficacy domain	5 point Likert scale	Interviewer administered
Diabetes	SE-Type 2 scale (Diabetes Management SE Scale)	Van der Bijl et al. 1999	Literature (unsystematic search)	Experts	4 domains determined by factor analysis	20 items 4 domains	5 point Likert scale	Self-administered
Diabetes	The Multidimensional Diabetes Questionnaire (MDQ)	Talbot et al. 1997	Experts Patients	Not reported	1 domain determined a priori	7 items 1 self-efficacy domain	VAS 0-100	Self-administered
Diabetes	No name	Gerber et al. 2006	Adaptation of IMDSES	Data driven	Unclear how many domains	12 items 1 self-efficacy	4 point Likert scale	Interviewer administered

						domain		
Arthritis	Arthritis Self-Efficacy Scale	Lorig et al. 1989 (a)	Experts Patients	Data driven – Factor analysis	3 domains determined by FA	20 items 3 domains	10 point Likert scale	Self-administered
Arthritis	Rheumatoid Arthritis Self-Efficacy Scale (RASE)	Hewlett et al. 2001	Patients Experts	Experts Data driven by FA	8 domains determined by FA	28 items 8 domains	5 point Likert scale	Self-administered
Arthritis	Parents' Arthritis Self-Efficacy Scale (PASE)	Barlow et al. 2000	Unsystematic literature search	Not reported	2 domains determined by FA	14 items 2 domains	7 point Likert scale	Self-administered

### 3.9 Table 6 – Assessment of measurement properties

Disease	Instrument	Study	Test-retest reliability	Internal consistency reliability	Validity	Responsiveness
Diabetes	Self-Efficacy Score for Diabetes Scale (SED)	Grossman et al., 1987	Not assessed	Kuder-Richardson coefficient alpha	Correlational approach (diabetes self-management instrument, urine and blood glucose)	Not assessed
	Self-Efficacy Score for Diabetes Scale (SED)	Cullen et al., 2007	Not assessed	Cronbach's alpha	Correlation approach (other self-efficacy scale, diabetes self-management instrument, health behaviour, HbA <sub>1c</sub> )	Not assessed
Diabetes	Maternal Self-Efficacy for Diabetes Management Scale	Leonard et al., 1998	Not assessed	Not assessed	Correlational approach (self-management of child)	Not assessed
	Maternal Self-efficacy for Diabetes Scale	Cullen et al., 2007	Not assessed	Cronbach's alpha	Correlation approach (other self-efficacy scale, diabetes self-management instrument, health behaviour [diet and exercise], HbA <sub>1c</sub> )	Not assessed
Diabetes	Insulin Management Diabetes Self-Efficacy Scale (IMDSES)	Hurley, 1990 not retrievable; Hurley et al., 1992	T-test, Pearson correlation coefficient	Cronbach's alpha	Not assessed	Not assessed
	No specific name	Gerber et al., 2006	Not assessed	Not assessed	Correlation approach (health literacy, HbA <sub>1c</sub> )	Not assessed

<b>Disease</b>	<b>Instrument</b>	<b>Study</b>	<b>Test-retest reliability</b>	<b>Internal consistency reliability</b>	<b>Validity</b>	<b>Responsiveness</b>
Diabetes	Self-Efficacy for Diabetes Self-Management (SEDM)	Iannotti et al., 2006	Intraclass correlation coefficient	Cronbach's alpha	Correlation approach (diabetes self-management instrument, health behaviour, HbA <sub>1c</sub> )	Not assessed
Diabetes	Self-Efficacy for Diet Adherence Scale	Kavookjian et al. 2005	Not assessed	Cronbach's alpha	Not assessed	Not assessed
Diabetes	No specific name	Littlefield et al. 1992	Not assessed	Cronbach's alpha	Not assessed	Not assessed
Diabetes	No specific name	Miller et al. 2007	Not assessed	Cronbach's alpha, coefficient H	Not assessed	Not assessed
Diabetes	No specific name	Moens et al., 2001	Not assessed	Cronbach's alpha, inter-item correlations	Not assessed	Not assessed
Diabetes	The Multidimensional Diabetes Questionnaire (MDQ)	Talbot et al., 1997	Not assessed	Cronbach's alpha	Correlational approach (diabetes self-management instrument, depression, HbA <sub>1c</sub> )	Not assessed
Diabetes	SE-Type 2 Scale (Diabetes Management Self-Efficacy Scale)	van der Bijl et al., 1999	Pearson correlation coefficient	Cronbach's alpha, inter-item correlations	Not assessed	Not assessed

<b>Disease</b>	<b>Instrument</b>	<b>Study</b>	<b>Test-retest reliability</b>	<b>Internal consistency reliability</b>	<b>Validity</b>	<b>Responsiveness</b>
Diabetes	The Confidence in Diabetes Self-Care Scale (CIDS)	Van der Ven et al., 2003	Pearson correlation coefficient	Cronbach's alpha, item-total correlation, Cronbach's alpha excluding item	Correlational approach (diabetes self-management instruments, diabetes-related emotional stress, HbA <sub>1c</sub> )	Not assessed
Arthritis	Children's Arthritis Self-Efficacy Scale (CASE)	Barlow et al., 2001	Not assessed	Cronbach's alpha	Correlational approach (HRQL instruments, symptom scales, functional status measure)	Not assessed
Arthritis	Rheumatoid Arthritis Self-Efficacy Scale (RASE)	Hewlett et al., 2001	Correlation coefficient	Inter-item correlation	Correlational approach (other self-efficacy scale, HRQL instruments, symptom scales)	Mean changes (t-tests) after administering interventions where changes were expected

### **3.10 The General Self-Efficacy Scale (GSE Jerusalem and Schwarzer 1995)**

This scale was developed in 1995 in Germany, was later revised and adapted to 26 other languages by various co-authors. The purpose of the scale was to create an instrument to assess a general sense of perceived self-efficacy in order to predict coping with daily hassles as well as adaptation following stressful life events. The strengths of the GSE are considered to be its universal adaptation for use. Reliability and validity of the GSE has been tested in samples across 23 nations, with Cronbach's alphas ranging from .76 to .90, with the majority in the high .80's, and the scale is considered to be unidimensional. The authors suggest that it is suitable for a broad range of applications and can be used to predict adaptation after life changes and as an indicator of quality of life at any point in time. The major weakness of the GSE is that, as a general measure, it does not tap disease-specific behaviour change and therefore, in most applications, it is necessary to add items to cover the particular content or intervention to be measured.

### **3.11 Conclusion of Chapter 3**

A variety of scales have been developed to measure self-efficacy in many chronic diseases (Lorig et al., 1989; Dilorio et al., 1992; Hewlett et al., 2001) and are used to measure the effectiveness of self-management programmes. Other more generalised scales such as the General Self-efficacy Scale (GSE) (Jerusalem and Schwarzer 1979) and the Chronic Disease Self-efficacy Scale (CDSS) (Lorig et al. 1996) have been developed, however Bandura (1986) advocates a disease-specific scale to measure self-efficacy, arguing that a measure in general efficacy would be inadequate for tapping an individual's efficacy in managing tasks associated with a specific condition (Dilorio et al. 1992). Thus, in order to measure self-efficacy in relation to venous leg ulceration, a disease-specific scale which measures self-efficacy in relation to the behaviours associated with prevention of leg ulcer recurrence must be used. However, the developing scale will be tested against the GSE in order to assess construct validity and specificity to leg ulcer patients. The following chapter outlines the aims and objectives of the study together with the author's positionality and rationale for choice of methodologies.

## **4.0 Chapter 4 - Research Methodologies**

### **4.1 Introduction – Aims and Objectives**

The aim of this study was to develop and validate a self-efficacy scale for patients with healed or non-healing venous leg ulceration, using a combination of qualitative and quantitative methods.

The objectives were:-

- To establish, through review of the literature, whether self-efficacy is the most appropriate theoretical framework for achieving health behaviour change in patients with healed leg ulceration.
- To generate qualitative data from the users' perspective, eg. health professionals, patients and carers/relatives in order to generate self-efficacy statements to be included in the scale (Phase 1).
- To use quantitative methodology to reduce the data and test for internal/external reliability of the developed scale (Phase 2a and 2b).
- To test the developed scales against the Generalised Self Efficacy Scale in order to assess construct validity and specificity to leg ulcer patients over time (Phase 2c).

This chapter commences with a discussion on the researcher's positionality and frame of reference for the study. The influence of these on the choice of methodologies will be discussed and defended. To set the scene, an overview of my personal epistemological beliefs and positionality will be discussed and how this pragmatic approach was reconciled with two divergent methodologies.

### **4.2 Positionality – a pragmatic approach**

As a practitioner/researcher (Consultant Nurse-Tissue Viability) working within primary care at the time of this study, I was aware of the difficulties of maintaining healed venous leg ulceration, primarily from the health professional perspective. This knowledge was gleaned from my own clinical practice but also supported in the literature where recurrence rates are reported as depressingly high (Vowden and Vowden 2006). Current practice is to recommend that patients wear lifelong compression hosiery following healed ulceration combined with a regime of self-care activities, such as leg elevation, foot/leg exercises to promote venous return, skin care routine and general health promoting activities such as weight control, smoking cessation etc. to prevent recurrence. These activities are professionally determined, lack a strong evidence base and are not exclusively disease-specific (van Hecke et al. 2008) and, as the recurrence figures illustrate, may be considered largely

ineffective. Very little is currently known about patients' views on self-care activities or the various activities they perform daily in order to prevent their ulcer recurring. The current paucity of literature on patients' views of preventing the recurrence of their ulcer highlights the existence of a theory/practice gap in nursing knowledge of patient with venous leg ulcers (Stevenson, 2005).

### **4.3 Practice-theory Gap**

Stevenson (2005) asserts that the gap between theory and practice remains alive and well in nursing and suggests that the "way in which research questions and findings are framed in university contexts may "miss the point" for practitioners who know only too well what the "real" issues are for them" (2005, pg. 196). Cronen (2001) concurs with this and asserts that in practical theory development, it is expected that important contributions to theory will come from practitioners in the course of their work and that those who are primarily theorists will engage with practitioners and become involved in applied work.

Hartrick-Doane and Varcoe (2005) however contend that although the development of theoretical nursing practice has been a central focus within the nursing discipline over the past few decades, the practice/theory connection continues to be in need of further exploration and articulation. For example, in their research, Liaschenko and Fisher (1999) noted that one rarely hears practising nurses use the language of nursing theory unless they have been asked to do so by academic or institutional bodies. Similarly, within nursing education, theory is often presented as an abstract body of knowledge that is learned outside of the practice area and in isolation from everyday nursing work (Hartrick-Doane 2002; Hartrick-Doane and Varcoe 2005). Subsequently, for many nurses, the word "theory" conjures up images of some dry, academic abstraction that has no relevance to the "real" world of nursing practice. This tendency to objectify theory – to separate it out from every day "real" practice and think of it as "something to be applied and used" has had profound implications for theory development and nursing practice (Hartrick-Doane and Varcoe 2005). It has not only constrained the theory-development process but also ultimately served to limit nurses' choices, clinical decision making, and their capacity for ethically responsive practice (Hartrick-Doane, 2002). In contrast to this objectifying approach to theory, Hartrick-Doane and Varcoe concur with pragmatic philosophers who believe that all so-called theory is always already in practice and suggest that, whilst not necessarily a new idea in nursing, its significance has not been adequately examined. This practical approach to research is known as "pragmatism" (Cronen, 1984) which is particularly suited to nursing, a predominantly practical discipline.

#### 4.4 Origins of Pragmatism

The term “pragmatism” is derived from the Greek word for action, from which the words “practice” and “practical” originate (Barnhart 1995; James 1907; 1998). Roth (1969) recounts that pragmatism was first introduced into philosophy by Charles Pierce in 1878, who pointed out that beliefs are really rules for action. Pierce contends that the sole significance of a thought or concept was the conduct it produced. Pragmatism is a process for clarifying the meaning of a thought and rests upon the principle that meaning is determined by unpacking a concept and/or theory with respect to the practical consequences in future experience (Roth, 1969). So, for example, pragmatism might ask what a particular concept or theory leads us to expect, to focus upon, to attend to, and to do in our nursing practice (Hartrick-Doane and Varcoe 2005). As a process, pragmatism attempts to interpret each theory by tracing its practical consequences. Central questions pragmatists may ask include the following: What difference would it practically make to anyone if *this* notion rather than *that* notion was held to be true? What concrete difference will any idea or theory make in anyone’s actual life? What experiences will be different? What is the value of any theory or ideas in experiential terms? If no practical difference can be traced, there is no difference and the thought (or theory) is meaningless in that particular situation (Roth, 1969).

William James (1907) further developed the pragmatic perspective, highlighting that all theories are merely approximations – “They are only a man-made (sic) language, conceptual shorthand “(pg 147). James also contended that “truth” is something that *happens* to an idea and ideas or theories become true, are *made* true by events (James 1907, pg. 163). Pragmatism is determining the value of an idea by its outcome in practice and conduct (James 1907; 1998) and stresses critical analysis of facts, applications and outcomes rather than abstraction and verbal solutions (James 1907).

In contrast to many philosophical or theoretical perspectives, pragmatism does not stand for any special results; it is only a process of inquiry and choice. But the significance of that process is the fundamental change it offers in our approach to theory development and to nursing practice (Hartrick-Doane and Varcoe 2005) in as much that it does not look at any particular results but offers an attitude of orientation to take into practice. This attitude involves looking away from static abstractions and categorical ways of thinking and looking towards possibilities and as such, pragmatic thinkers believe that reality and truth for individuals are very much based on what is

useful to them, with people accepting as true those ideas that work for them in the broad sense (Edwards and Titchen 2003).

Approaching practice with this pragmatic understanding of theory and truth compels the researcher to adopt an inquiring stance, to pay attention and inquire into his/her own personal experiences, the experience of others, existing knowledge such as formal theory and research, and the contextual elements and structures that shape experiences and practice. In the context of nursing, a pragmatic inquiry may include questions such as “Are our ways of describing things, of relating them to other things so as to be responsive to patients as well as possible?” “Is our knowledge of things adequate to the way things are in nursing practice?” “Do available theories address and inform the questions and challenges that arise in our nursing work?”

As a nurse/researcher in clinical practice, I was aware of the importance of encouraging patients to self-care in order to prevent their leg ulcer recurring but felt that current leg ulcer prevention strategies, such as merely providing patients with compression hosiery, often with inadequate explanation, were unresponsive to patients’ needs. It was hardly surprising, therefore, that many patients feel unable or unwilling to follow this advice. A pragmatic, patient-focused approach rather than professionally-led was required in order to understand which self-care activities patients performed and any difficulties they faced in carrying out them out.

I consider myself a pragmatic nurse/researcher, “a professional doer who shapes reality rather than a doer who merely attends to the cogs of reality according to prescribed patterns” (Dickoff and James 1968, pg. 102). Hartrick-Doane and Varcoe (2005) contend that perhaps one of the most significant implications of a pragmatic approach to theory/practice is that it places “theory development” firmly in the domain of practising nurses and recognizes the capacity all nurses have to use their inventiveness for knowledge development to address situations and challenges of everyday practice, and to create and re-recreate their knowledge in each moment of practice. This approach resonates closely to my own perspective as a practitioner/researcher, who knows, from experience in practice, the difficulties patients face in maintaining the integrity of their skin, once leg ulcer healing has taken place and so the decision was made to approach this study from a pragmatic viewpoint. Throughout the next chapter, I will continue to describe how my pragmatic epistemology influenced the current study and directed my choice of methodological approaches.

#### 4.5 Choice of Methodology – Phase 1 - qualitative

As discussed earlier, my choice of research topic was influenced by my experiences and knowledge gleaned from clinical practice. A researcher's choice of paradigm will influence their work since their worldview and accompanying ontological, epistemological, and methodological assumptions will guide how they think and act during the research process (Norton, 1999).

The methodology considered to be appropriate for Phase 1 (item generation) of this study was qualitative, since the purpose was to explore the dynamic, holistic and individual aspects of living with healed venous leg ulceration from the participants' perspective. It could be argued that the data could have been extracted from the existing body of literature; however, it was important to capture data which was meaningful to the participants themselves and which provided a true reflection of their worldview. The dynamic and flexible nature of qualitative methodology would allow themes to emerge naturally through the data collection process rather than be mere extensions of the academic literature (Rubin and Rubin 1995).

There is an on-going debate between the proponents of qualitative and quantitative research. Some proponents of qualitative methodology accuse quantitative methods of "squeezing the meaning out of concepts, producing distorted or inconclusive results" (Hopkins, 2004). Conversely, qualitative methods have been criticised by positivists for deriving large conclusions from results produced by small, biased samples and that qualitative methodology is more about creative art than science (Clarke, 1995). Thus, the friction centres on beliefs about knowledge, validity and truth, and is referred to as the paradigm debate (Holloway and Wheeler 2002). It is not the author's intention to further explore or discuss this paradigm debate but to justify my choice of using diverging methodologies for each phase of the study and how I reconciled the use of "purist" methodologies with a pragmatic approach, without producing "sloppy mishmash research" as opined by Janice Morse (1991, pg. 15). On criticising Swanson-Kauffman's (1986) combination of phenomenology, grounded theory and ethnography, she argued "*Such mixing, while certainly "do-able", violates the assumptions of data collection techniques and methods of analysis for all the methods used. The product is not good science.....*" (Morse 1991, pg.15)

#### **4.6 Statement development**

It could be argued that a positivist approach, using for example, a quantitative survey design may have elicited information on self-care activities for patients. Equally, a questionnaire, with closed or open-ended questions would have enabled data to be collected however, little information on the subject was found during the literature review on which to create a survey or a questionnaire. In addition, much of the literature retrieved focussed on health professionals' assumptions of why patients would not wear their compression hosiery to prevent recurrence. Review of the literature on the development of self-efficacy scales for other conditions revealed that many of the scales had been developed using the literature only to develop statements, or expert professional opinion (van der Bijl et al. 1999; Hewlett et al. 2001; McDowell et al. 2005) with little or no patient involvement. Since the purpose of the data collection process for Phase 1 was to elicit the patients' views and concerns specifically, I felt that the quantitative approach would not allow me, as a researcher, to enter the world of the participants and try to understand the problems they faced in everyday life of living with healed leg ulceration from their perspective. It was decided to emulate the qualitative approach of Kendall and Bloomfield (2005) who used focus groups comprising of parents in order to develop a scale to measure parenting self-efficacy.

#### **4.7 Phenomenology**

Methodologies used to conduct qualitative research include phenomenology, ethnography and grounded theory. Phenomenology, it could be argued, may have been an appropriate methodology for the study since my aim was to explore the lived experiences of patients with healed leg ulceration (Giorgi, 1997, pg. 236). The goal of phenomenological research is to seek the "essences", essential or invariant characteristics of a phenomenon and to achieve this, "naive" subjects are asked to respond to a question, either by interview or description (Giorgi, 1997). In other words, an individual is encouraged, through asking them a broad and general question, to describe their experiences of a phenomenon. A phenomenological approach requires that an individual describes their experiences in a relatively "uncontaminated" way and therefore, a group method of data collection involving interaction between several participants is not compatible with phenomenological research (Webb and Kevern 2001). The phenomenologist is required to "bracket" their prior perceptions during data collection in order to reduce potential bias; however, I felt that this would be problematic for me as I had considerable experience of the phenomenon in question. In addition, my purpose was not to

understand the essence of living with a venous leg ulcer and so a phenomenological approach was ruled out as an appropriate methodology for Phase 1 of this study.

#### **4.8 Ethnography**

Ethnography is a research design, originated from the social science, whose purpose is to chart, graph, or describe a “people” or culture. Its aim is to be holistic – to describe the people “in the round” or as completely as possible (Brink and Edgecombe 2003). Ethnography is the study of naturally occurring human behaviour through observation and ethnographers try to describe what a people “do” as well as what they “believe”. Data is collected through a combination of methods such as participant observation and focus groups; however, the focus group does not take the place of observing what is going on while it is going on. The researcher would have to observe these people day after day in their natural environment to observe what they do in all kinds of circumstances, since a focus group would only tell the researcher what the participants *think* they do. If I wished to know about the difficulties patients experience daily in performing self-care activities from an ethnographical perspective, I would need to observe their behaviour in differing situations to discover not only what they decide but also what contexts influence their decisions and what other people, and their relationship to the decision maker, influence these decisions. From a pragmatic perspective, I felt that this methodology would not allow me to collect the type of data I required for item generation for the scale development.

Having considered and ruled out phenomenology and ethnography as appropriate methodologies for Phase 1 of my study, I turned to the grounded theory literature in order to consider whether this methodology would provide an epistemological and ontological fit, firstly with the aims of my study and secondly, my personal pragmatic view of the world.

#### **4.9 Brief Overview of Grounded Theory**

The discovery of grounded theory (GT) as a method, style, and paradigmatic approach to research analysis was borne out of an intriguing partnership between Barney Glaser and Anselm Strauss (Glaser and Strauss 1967; Walker and Myrick 2006). It would appear that Glaser, originally educated and trained in quantitative research, was initially hired by Strauss, a social scientist, in the late 1950's to collaboratively analyse Strauss's seminal research on dying (Glaser and Strauss 1967). Cutliffe (2000) presumes that Strauss's intent was to capitalise on Glaser's experiences of using a highly systematic, yet exceedingly integrated method of data

analysis and interpretation with qualitative data at a time when the scientific community viewed qualitative methodology with suspicion in favour of reductionist quantification. Their research approach was a departure from the dominant positivism in the social sciences, because it was intended for the discovery of theory grounded in data as opposed to the verification of extant theory (Glaser & Strauss, 1967). The grounded theorist generates substantive theory through direct exploration of how people respond to, manage, and negotiate meaningful events, situations, and circumstances in their natural settings (Porr et al. 2012). GT's roots lie in symbolic interactionism, which itself stems from pragmatist ideas of James, Dewey, Cooley and Mead (Hammersley, 1989), and most notably, the concept of the looking glass self (Cooley, 1992).

#### **4.10 Symbolic Interactionism**

The epistemological origins of GT come from symbolic interactionism. Symbolic interactionism seeks to determine and explain what symbolic meanings, artefacts, clothing, gestures and words have for groups of people as they interact with one another (Porr et al. 2012). Symbolic interactionists hold the view that people construct their world based on their individual perceptions of that world and construct their realities through their interaction with others, using symbols, interpretations, words and language to create meaning (Porr et al. 2012; Wasserman et al. 2009). Furthermore, Porr et al. assert that interpersonal communication is achieved when communicators produce and receive messages that carry meaning for both. Thus, symbolic interactionism provides a theoretical perspective for studying how individuals interpret objects and other people in their lives and how this process of interpretation leads to behaviour in specific situations. Symbolic interactionism therefore has tremendous potential to increase the understanding of human health behaviour and is particularly pertinent to nursing research (Porr et al. 2012). It appeared to be an ideal framework to explore patients' experiences of performing self-care activities, which was the aim of Phase 1 of my study.

#### **4.11 Divergent methods of Grounded Theory**

As a research method, grounded theory is often heralded as revolutionary in the history of the qualitative traditions. Yet, at the same time, it is the most frequently discussed, debated, and disputed of the research methods (Ryan 2013). One of the most provocative controversies surrounding grounded theory involves a methodological split between its co-origators, Glaser and Strauss (Walker and Myrick 2006).

In 1996, Strauss had teamed up with a nurse researcher, Juliet Corbin and had published 4 books in which he introduced Corbin as “*his research teammate*” (Strauss 1987, pg. 16). This new partnership however, resulted in an evolving methodological and paradigmatic rift, not only between Glaser and Strauss, but between Glaser and other GT researchers (Boychuk Duchscher and Morgan 2004; Bowers and Schatzman 2009). It was a split that became public when Strauss and Corbin (1990) released their version of grounded theory, which Glaser (1992) aggressively argued was not, in fact, grounded theory but a new method, which he called full conceptual description. As a result, two slightly differing methodologies emerged, described by Stern (1994) as “Glaserian” and “Straussian” GT.

Ryan (2013) questions whether GT is an analytical strategy rather than a method in qualitative research. Furthermore, Silverman (2006) defines “method” as a technique to gather data in the context of the overriding methodology (Silverman, 2006). Both Glaser’s and Strauss’s versions of grounded theory use coding, the constant comparison, questions, theoretical sampling, and memos in the process of generating theory. Moreover, both versions adhere to the same basic research process: gather data, code, compare, categorize, theoretically sample, develop a core category, and generate a theory. The problem is that these similarities in language and process make any discussion of differences confusing. The point is that, at a superficial level, there are no recognizable differences, because both versions appear similar. What is crucial, however, is that the differences lie not in the language or general processes but in how these processes are carried out (Walker and Myrick 2006). These will now be briefly discussed and an argument will be developed that GT, considered a pure methodology (Morse, 1999) can be successfully adapted to a pragmatic study.

#### **4.12 Grounded Theory and pragmatism – can they co-exist?**

Review of the literature indicated that there is no clear cut way to proceed with a grounded theory study, as each researcher brings their own personal stance, disciplinary perspective and own way of conducting it (Wasserman et al. 2009; Bowers and Schatzman 2009; Clark 2005; Charmaz 2006). This, in itself, could be construed as indicative of a pragmatic approach to its methodology. One of the major criticisms of the first generation of grounded theorists, including Juliet Corbin, Strauss’s co-writer, is that they did not write about grounded theory as a methodology; rather, they wrote about the various strategies and techniques that could be used to analyse data. This, however, has been rectified in the latest edition of Corbin and Strauss’s book, which includes a chapter outlining pragmatism and

symbolic interactionism as the underpinning philosophies of Strauss's grounded theory. A pragmatic approach appeared to provide the perfect fit for my study (Corbin and Strauss 2008).

My study is a nursing inquiry into practical issues that patients face in their everyday lives, and I therefore considered that a practical theory was required. Cronen (2001) suggests that a practical theory consists in instrumentalities (theoretical principles, definitions, descriptions, case examples, models, and methodologies) that grow in richness as the theory is used. Thus, practical theory is a device that helps conjoint exploration of a situation that is within the actors' view (Cronen and Chetro-Szivos 2001). Cronen and Chetro-Szivos (2001) consider that a practical theory is not the end product of practical inquiry but that two create one another and the process involved consists of "loops" in which inquiry informs theory and theory informs inquiry. This was congruent with my study, since the aim of Phase 1 was to develop self-efficacy statements from the data analysis in order to develop a scale which would be empirically tested and validated in Phase 2. The primary aim of the study, however, was not theory development and since the central tenet of grounded theory is to develop an emergent theory from the data, the tension in using this methodology became apparent to me. Johnson et al. (2001) however argue the case for pluralism in qualitative nursing research, suggesting that nursing as a "unique" area of human activity, may require its own nursing research methodology and that calls for "purism" in methodologies, whilst often well-meant, is not founded on any *a priori* or logical principles.

#### **4.13 Theoretical sensitivity and use of the literature in Grounded Theory**

The issues of theoretical sensitivity and use of the literature review represent fundamental differences between Glaserian and Straussian approaches. Strauss and Corbin (1990; 1998) claimed that a preliminary review of the literature before beginning data collection would enhance theoretical sensitivity with a more detailed literature review being undertaken later, in order to support the emerging theory (Clarke 2009). Glaser, however, disagreed about reviewing the literature prior to entering the field, claiming this would taint the researcher's view of the field and constrain the generation of categories.

Cutcliffe (2005) suggests that decisions about the literature depend on two factors. Firstly, whether the researcher has little knowledge about the phenomena and process of interest and remains unsure about the most suitable approach and

secondly, suggests that prior reading may be required if the researcher wishes to clarify and build an emergent theory on these. Glaser, on the other hand, claimed that the problem would emerge in the study in the process of theoretical sampling, open coding and constant comparative analysis in response to early interviews and observations (McGhee et al. 2007). Elliott and Jordan (2010) argue, that in reality, in order to secure funding for research, preliminary review of the literature is required in order to formulate the research question.

Moreover, as Holton (2007) and Heath (2006) have pointed out, there are sources of a priori knowledge other than the literature; for example, researchers carry into the analysis accumulated experiences and preconceptions arising from their discipline or profession. As a clinician and researcher, I felt I was already theoretically sensitive to the subject under study due to my prior knowledge gleaned through clinical practice. Glaser's views on theoretical sensitivity resonated with the "bracketing" advocated by phenomenologists and my perceived inability to do this, therefore, had been one of the reasons for rejecting phenomenology as a potential methodology. However, my knowledge of the problem of recurrence of leg ulceration had been coloured by reviewing the literature, which predominantly reflected the health professionals' views. Within the literature, patients are "blamed" for their ulcer recurrence because they do not appear to comply with professional advice and apply compression hosiery regularly. In addition, the application of hosiery is viewed as the only valid self-care activity available to them. The goal of my inquiry then was to develop a theoretical description of the basic social process that was problematic to my participants in the investigation (Glaser, 1978). As mentioned previously, I had already developed theoretical sensitivity to the phenomenon under study, albeit, from the health professionals' perspective (Charmaz 2006; Holton 2007) and felt that if I chose to pursue the Glaserian approach to GT, that is, to allow a theory to emerge purely from the data analysis process, the aims and objectives of the study may not have been fulfilled. I decided that the Straussian approach was more congruent with my personal ontological and epistemological beliefs, and in particular, their approach to theoretical sensitivity, viewing the use of literature as a basis of professional knowledge, referring to it as "literature sensitivity" and Cutcliffe (2005) who saw it as "accumulated knowledge" was more suited to the aims of my study.

#### **4.14 Constant comparative data analysis - the "emergence vs. forcing debate"**

The aim of this phase of the study was to generate statements for inclusion into a scale as opposed to developing a grounded theory per se. The key to achieving

this would lie in the data analysis process. A fundamental principle of Glaserian GT is the inductive reasoning of the analytical process; this is the process of reasoning from specific observations rather than predictions. Glaser (1992) argued that the theory should be allowed to emerge from the data directly without interpretation and should be verified with the data. Strauss, however, advocated a descriptive approach which supported directive questioning and interpretation and much more fragmentation of the data (Elliott and Jordan 2010).

Both Glaser's and Strauss's versions of GT use coding, constant comparison of data, theoretical sampling and memos in the process of generating theory. Moreover, both versions adhere to the same basic research process: gather data, code, compare, categorise, theoretically sample, develop a core category and generate a theory (Walker and Myrick 2006), although Strauss and Corbin advocated breaking the transcription into small units, almost word for word, leading to many codes. This was criticised by Glaser as over conceptualisation and a debate ensued known as the *emergence vs. forcing* debate (Glaser, 1992; Walker and Myrick 2006; Elliott and Jordan 2010). The debate centres around Glaser's adherence to a strict emergence model of theory generation in which the theory emerges directly and rigorously out of the data, is then returned to the data for verification, and then emerges victoriously, devoid of interpretatism (Boychuk Duchscher and Morgan 2004). At an operational level, Glaser's coding methods appear rather simple, quite focused and more in keeping with the original version of GT (Walker and Myrick 2006). Strauss and Corbin, on the hand, advocated the use of complex coding methods as strategies to examine the interface between structure and process and developed a more structured or rule-governed approach to data collection and analysis – this process was criticised by Glaser as “forcing” the data (Draucker et al. 2007)..

As mentioned previously, the reported distinctions in the two approaches, methods and general intent of GT are not easy to comprehend, however attempts to combine Glaser and Strauss's methods in order to glean the best of both worlds is not easily done (Boychuk Duchscher and Morgan 2004) nor desirable and should only be attempted by experienced researchers. Glaser (1998) suggests that researchers should stop talking about grounded theory and get on with doing it, setting aside “doing it right anxiety”, but adhere to the principles of constant comparison, theoretical sampling and emergence and discover which approach helps them achieve the balance between interpretation and data that produces a grounded theory (McCallin 2003; Mansourian 2006).

My personal ontological/epistemological beliefs are more congruent with Strauss and Corbin's grounded theory, however, since the original aim of Phase 1 was to produce statements from which the evolving scale was to be developed as opposed to developing a grounded theory per se, I felt it was more appropriate to describe the methodology used for this phase of my study as "drawing on" the ontological principles underpinning Straussian grounded theory, but using the central tenet of both Glaserian and Straussian methodology, constant comparative analysis as the data analysis process.

Cutcliffe (2005) requires researchers to locate their epistemological/ontological stance either within the Glaserian or Straussian camp. However, this requirement may generate "doing it right" anxiety (McCallin 2003, Heath and Cowley 2004; Mansourian 2006) for novice researchers undertaking grounded theory research, such as myself, with the result that the focus of staying true to the methodology of the approach chosen at all costs overshadows the original aim of the study, that is, the generation of new knowledge. This anxiety is further intensified by experienced researchers who have published papers criticising fellow grounded theorists, highlighting methodological mistakes, further suggesting that each approach must be employed in accordance with its own philosophy and, more importantly, its individual operational practices (Starks and Brown Trinidad 2007).

As a clinician/researcher, my personal epistemological beliefs are located within the pragmatic philosophy and, as such; do not provide a comfortable fit with either Glaser or Strauss, although the social constructionist epistemology, as advocated by Charmaz (2006) appeared a closer fit epistemologically. Having considered that my study did not fit distinctly within either the Glaserian or Straussian methods, I concur with Boychuk Duchscher and Morgan who took the pragmatic stance, on which both Glaser and Strauss and Corbin appear to agree, that the underlying philosophy of how grounded theory is best applied is applicable to both methods, which is:-

- The discovery of enduring theory that is faithful to the reality of the research area
- Makes sense to the persons studied
- Fits the template of the social situation, regardless of varying contexts related to the studied phenomenon
- Adequately provides for relationships amongst concepts
- May be used to guide action.

Boychuk Duchscher and Morgan (2004 pg 606)

It could be argued that my pragmatic approach to conducting this study within the grounded theory methodology violates the central tenet of grounded theory; the generation of a substantive theory inductively from the data as opposed to theories hypothesised prior to data collection (Glaser and Strauss, 1967), since my primary aim was not to generate theory per se. According to Elliott and Jordan (2010), this could be viewed as “premature closure”, however, grounded theory, developed primarily for use in the social sciences, and is now continually evolving and adapting, in particular for use in nursing research. Nursing, as a discipline, is currently experiencing philosophical pluralism, with a prevalence of pragmatic ideas (Meleis, 1999). Rather than a philosophy, however, pragmatism tends to be viewed as a way of doing philosophy that provides major implications to solve disputes involving nursing science, theory, and practice (Warms and Schroeder 1999) and as such, is integrated with theory and action, so one can be continuously modified with maintaining the integrated mutual relevance (Im and Chee 2003).

Hartrick-Doane and Varcoe (2005) suggests that the tendency to objectify theory – to separate it out from every day “real” practice and think of it as a “thing” to be applied and used, has profound implications for theory development and nursing practice, limiting nurses’ choices, clinical decision-making and their capacity for ethically responsive practice. In view of this, I considered that a self-efficacy scale for patients with healed leg ulceration, derived from real life statements gleaned from the people most affected by the problem, would have more applicability in practice and benefit patients more than the production of a substantive theory. However, as the intention was to present this thesis in two separate parts, Phase 1(qualitative-statement development) and Phase 2 (quantitative-scale development), I decided that the pragmatic approach would be to present the data analysed at the end of Phase 1 as categories of substantive coding, as opposed to theoretical coding.

Dixon-Woods et al. (2004) however assert that the tendency to select some of these techniques to create ad hoc and ‘a la carte’ approaches to qualitative research and still retain the label ‘grounded theory’ is very unhelpful. Bond (1992) however, contradicts Dixon-Woods et al. and argues that:-

*“what is important is the credibility of the research, the amount of confidence we have in the findings and not necessarily the particular methodological tradition that underpins it..... There is strength in diversity, as long as there is rigour.”*  
Bond (1992, pg. 95).

All research methodologies have been developed as procedures to guide researchers in producing good quality studies and, as such, they are to be regarded as recipes. In the case of grounded theory studies, there is a danger that the value of the study will be measured by how rigorously the researcher adhered to the recipe as opposed to the quality of the finished result, the findings and how relevant they are to nursing practice. Glaser and Strauss developed GT as a method for study within the social sciences and it has now a popular method for conducting nursing research studies. As a discipline, however, nursing needs its own research methodology that meets its pragmatic needs, is useful to nurses and their patients, and further develops nursing theory by guiding action. A pragmatic adaptation of the current GT methodology would fulfil these criteria and nurse researchers using this approach need to “put their heads above the parapet” and invite debate on this issue in order to develop a robust methodology which will narrow the theory-practice gap that currently exists within nursing practice.

In conclusion, it is my opinion that pragmatism and grounded theory, as a methodological approach, can co-exist, provided the researcher is transparent in articulating his/her epistemological and ontological beliefs from the onset, acknowledging how this reflexivity will impact on how the study is conducted, and how the data is collected, analysed and reported.

#### **4.15 Phase 2 Quantitative methodology – mixing paradigms**

At the beginning of this chapter, I justified my positionality as a pragmatic researcher, and have further argued that a pragmatic approach to grounded theory, the methodology used for Phase 1 to develop statements, can indeed co-exist. The aim of phase 2 was to reduce the number of statements for inclusion within the developing scale using quantitative data analysis. The proposed methodology for this process is situated within the positivist paradigm. As a consequence, this apparent juxtaposition of combining diverging paradigms, which are underpinned by conflicting philosophical assumptions, will need further exploration and explanation. This chapter continues with a brief discussion on the prevailing “paradigm war” and the “incompatibility thesis” voiced by purist methodologists. In addition, I will further develop the argument that pragmatism, as a third research paradigm, offers an alternative, practical solution to bridge the divergent qualitative and quantitative paradigms and is, therefore, an ideal partner for mixed methods research.

#### **4.16 “The Incompatibility Thesis” – does it exist?**

Kuhn (1962) first articulated the idea of a paradigm, and when asked to explain exactly what he meant by the term, pointed out that it was a general concept, an “accepted model or pattern” and included a group of researchers having a common education and an agreement on “exemplars” of high quality research or thinking (Kuhn, 1970). In relation to research paradigms, this means a set of beliefs, values, and assumptions that a community of researchers share concerning the nature and conduct of research. These beliefs include, but are not limited to, ontological, epistemological, axiological, aesthetic, and methodological beliefs (Feilzer, 2010). Burke Johnson and Onwuegbuzie (2004), paraphrasing Kuhn, liken a research paradigm to a research culture or an organizing structure for conducting research.

The dominant research paradigms or worldviews that are presented as being fundamentally opposed to each other are those of positivism/post positivism and constructivism/interpretivism (Creswell and Plano Clark 2007), and ardent supporters or “purists” of either paradigm, have engaged in disputes over the superiority of one over the other (Burke Johnson and Onwuegbuzie 2004.) This continuing divide has been named the “paradigm war” (Feilzer, 2010). Feilzer rather simplistically contends that the main difference between the two paradigms centres around the existence of truth and reality, with the positivist view of a singular reality, the one and only truth which is out there waiting to be discovered by objective and value-free inquiry. This belief underpins and guides quantitative research methods. In contrast, qualitative researchers accept that there is no such thing as a single objective reality and that “subjective inquiry is the only kind possible to do” (Feilzer 2010, pg 6) and for that reason; social constructivists favour qualitative methods (Creswell and Plano Clark 2007; Erlandson et al. 1993). Both sets of purists view their paradigms as the ideal for research and, implicitly if not explicitly, advocate the existence of the *incompatibility thesis* (Howe 1988) which posits that qualitative and quantitative paradigms cannot and should not be mixed (Burke Johnson and Onwuegbuzie 2004).

The choice of research questions and research methodology is a reflection of the researcher’s epistemological understanding of the world, even if it is not articulated or made explicit. Feilzer (2010), however, contends that adhering to one particular paradigm could be interpreted as prescriptive, resulting in intellectual constraint in terms of curiosity and creativity and blind researchers to aspects of social phenomena, or even new phenomena and theories. Onwuegbuzie and Leech (2005) further suggest that researchers treat epistemology and method as being

synonymous, which is erroneous since the epistemology does not dictate which specific data collection and data analytical methods should be used. Furthermore, they posit that the purity of a research paradigm is a function of the extent to which the researcher is prepared to conform to its underlying assumptions. Dzurec and Abraham (1993) contend that if differences exist between quantitative and qualitative researchers, these differences do not stem from different goals but because these two groups of researchers have operationalized their strategies differently for reaching these goals. Bryman (1984) and Niglas (2004) concur with Onwuegbuzie and Leech's view and have subsequently demonstrated that practitioners are predominantly guided by technical rationale rather than epistemology in their selection of methods, implying that methodology is, in practice, commonly agnostic to epistemology. As a result, Onwuegbuzie and Leech (2005) believe that mono-method poses "the biggest threat to the advancement of the social sciences" (pg. 375). They further contend that purists tend to focus on the philosophical differences between the two dominant paradigms rather than on the overwhelming similarities.

Primarily, both qualitative and quantitative procedures involve the use of observations to address research questions and as noted by Sechrest and Sidani (1995), both methodologies describe their data, construct explanatory arguments from their data, and speculate about why the outcomes they observed happened as they did (pg. 78). Onwuegbuzie and Leech (2005) further suggest that, whilst not emphasized by purists, both sets of researchers use techniques in their research to minimise bias, verify their data and minimise other sources of invalidity that may potentially threaten the findings of the study. For example, both quantitative and qualitative researchers may attempt to triangulate their data, using multiple quantitative or qualitative methods (Denzin, 1978), for example, a quantitative researcher might triangulate several measures of achievement, whereas a qualitative investigator might triangulate interview data with observational data. Furthermore, like interpretivists, quantitative data analysts, to some degree, attempt to provide explanations of their findings, as well as seeing interpretive, narrative conclusions pertaining to the implications of their findings (Dzurec and Abraham 1993).

According to Dzurec and Abraham, meaning is not a function of the type of data collected (i.e. quantitative vs. qualitative), but instead results from the interpretation of data, whether represented by numbers or words. Whereas quantitative researchers utilize statistical techniques and subjective inferences to make decisions about what their data mean in the context of an a priori theoretical or conceptual framework, qualitative researchers use phenomenological procedures and their

views of reality to discover meaning (Dzurec and Abraham 1993). Both sets of researchers select and use analytical techniques that are designed to obtain the maximum meaning from their data, and manipulate their data so that the findings have utility with respect to their respective worldviews. Moreover, both types of researchers attempt to explain complex relationships that exist within the social science world (Onwuegbuzie and Leech 2005), with quantitative researchers utilizing multivariate techniques, whereas qualitative researchers incorporate the collection of thick, rich data into their design, gleaned from prolonged engagement with their participants, persistent observation and other strategies (Lincoln and Guba 1985).

Onwuegbuzie and Leech (2005) however suggest that neither paradigm is without criticism, with both displaying inherent methodological weaknesses in the articulation and pursuit of truth or the reality of the subject under study. On discussing the issue of using statistical tests for data analysis in pursuit of absolute truth, a central tenet of the positivist paradigm, Onwuegbuzie and Leech (2005,) contend that the low power of null hypothesis significance tests in many published quantitative research studies indicates “a level of accuracy that is so low that it could be achieved by just flipping a coin!” (pg. 378). Interpretivists, on the other hand are also not safe from their criticism. Their claim that multiple, contradictory but valid accounts of the same phenomenon always exist is extremely misleading, inasmuch as it may lead many qualitative researchers to adopt an “anything goes” relativist attitude, thereby not paying due attention to providing an adequate rationale for interpretations of their data. That is, many qualitative methods of analyses “often remain private and unavailable for public inspection” (Constas, 1992). In an attempt to respond to the long-lasting, circular and unproductive debates discussing the advantages and disadvantages of quantitative versus qualitative research, mixed methods research has been developed to fill the chasm between the qualitative and quantitative paradigms and is evolving as a third research paradigm (Feilzer, 2010).

#### **4.17 Mixed methods – a pragmatic choice?**

Mixed methods research has been defined as a methodology where:

*“a researcher or team of researchers combines elements of qualitative and quantitative research approaches (e.g. use of qualitative and quantitative viewpoints, data collection, analysis, inference techniques) for the broad purposes of breadth and depth of understanding and corroboration”* Johnson et al.( 2007; pg. 123)

The origins of mixed methods research can be traced to its use among fieldwork sociologists and cultural anthropologists early in the 20<sup>th</sup> century (Creswell, 1999). Its intellectual roots are associated with the early works of Campbell and Fiske (1959),

Greene et al. (1989) and latterly, Collins et al. (2006) (Creswell 2007; Tashakkori et al. 1998; Johnson et al. 2007). Seen as a viable alternative to purist positivism/interpretivism, as a research paradigm, the mixed methods approach incorporates a distinct set of ideas and practices that separate the approach from other main paradigms (Denscombe, 2008). As a result it is becoming increasingly articulated, attached to research practice and recognized as the third major research paradigm (Johnson et al. 2007).

Although mixed research has become popular, its potential has not yet been fully realized or acknowledged as an acceptable methodology for research within the social sciences (Denscombe, 2008; Morgan, 2007; Onwuegbuzie and Leech 2005). Onwuegbuzie et al. (2010) suggest that this may be because many researchers do not mix qualitative and quantitative approaches in optimal ways. In response to this, Collins et al. (2006) have provided researchers with a framework for optimizing their mixed research designs in what they called a rationale and purpose model, conceptualizing four rationales for mixing approaches. The four rationales are:

1. **participant enrichment** (i.e. the mixing of quantitative and qualitative techniques to optimize the sample, such as increasing the sample size),
2. **instrument fidelity** ( i.e. maximising the appropriateness and/or utility of the instruments used, whether quantitative or qualitative),
3. **treatment integrity** (i.e. mixing quantitative and qualitative techniques to assess the fidelity of interventions, treatments or programmes) and
4. **significance enhancement** (mixing quantitative and qualitative techniques to maximize researchers' interpretations of data).

According to Onwuegbuzie et al. (2010) mixed research is an ideal methodology for developing quantitative instruments, which is the aim of this PhD study and my rationale for using mixed methods are for the purpose of instrument fidelity and significance enhancement of the data (Collins et al. 2006).

Coyle and Williams (2000) used a combination of grounded theory and positivist methodology to explore health service users' views on satisfaction with health care in order to develop a quantitative scale. Through a process of dimensional analysis (a variant of grounded theory data analysis), the key variable "personal identity threat" emerged and the researchers then developed a quantitative scale in order to operationalize the concept. Having emphasized the possible epistemological difficulties in combining two opposing paradigms, they asserted that the developed

instrument “demonstrated that the social construction of meaning (personal identity threat) in a specific social context had a more general application” (2000, pg. 1238). In addition, they concluded that the finished instrument would be more sensitive to patients’ subjective experiences of health care because it was grounded in people’s actual accounts. They do point out, however, that despite being firmly grounded, the instrument could still be inconsistent with the interactionist perspective on which the qualitative study was founded. Questionnaires have difficulty in capturing the ambiguity, flux and contradiction of everyday subjective realism demanded by interactionism (Coyle and Williams 2000) and can de-contextualise meaning and distance social action from its natural setting. They warn instrument developers not to ascribe psychometric properties to instruments on a “once only” basis, but to consider that reliability and validity are not properties of the instrument, but are a technical description of the relationship between the instrument and a set of social realities at one point in time. They recommend a cyclical process of on-going utilization of qualitative data to help ensure that quantitative findings do not de-contextualize meanings or detach them from their social context.

The aim of Coyle and Williams’s study mirrors that of my own and has informed my rationale for using mixed methods to achieve the aims of my study. Coyle and Williams provide a reflexive and insightful account in order to explain and defend why they combined two differing epistemologies. Since the publication of their paper in 2000, a growing number of researchers have published literature offering pragmatism as an alternative paradigm to solve the dilemma of articulating the philosophical underpinnings of mixed methods (Burke Johnson and Onwuegbuzie 2004; Gilbert 2006; Tashakkori and Creswell 2007; Creswell and Tashakkori 2007; Greene 2008).

Onwuegbuzie et al. (2010) have outlined a mixed methods technique called crossover analyses, which represent the highest form of combining quantitative and qualitative data analysis techniques because the researcher often has to make Gestalt switches (Kuhn, 1962), that is, to switch from a qualitative lens to a quantitative lens and vice versa. In order to perform crossover analysis, the researcher is required to mix and combine the assumptions underpinning both methodologies. For example, in the case of this study, my constructivist analytical stance (underpinned by an ontology that assumes the existence of multiple contradictory, but equally valid accounts of the phenomenon under study can prevail) which guided Phase 1 will be blended with a post positivist analytical stance, which assumes that all social science research should be objective (Phase 2). The use of exploratory factor analysis to examine the structure of themes that have emerged

from the qualitative analysis in Phase 1 will be a means of furthering construct validation and according to Greene et al. (1989), combining interpretations of findings stemming from both qualitative and quantitative data analyses has the potential to yield stronger meta-inferences.

Whilst methodological purists posit that quantitative and qualitative methods stem from diverging ontological, epistemological and axiological assumptions about the nature of research (Bryman 1984; Collins 1984; Tashakkori and Teddlie 1998), mixed method research is seen by some as bridging the gap between the two dominant paradigms. In response to the quantitative-qualitative paradigm war, three major schools of thought have now evolved – *purists*, *situationalists* and *pragmatists* (Rossman and Wilson 1985). The difference between these three perspectives relates to the extent to which each believes that qualitative and quantitative approaches co-exist and can be combined.

Finally, on the other end of the continuum, pragmatists, unlike purists and situationalists, contend that a false dichotomy exists between quantitative and qualitative approaches (Onwuegbuzie and Leech 2005). Pragmatists believe that quantitative methods are not necessarily positivist, nor are qualitative techniques necessarily interpretivist and as such, pragmatists advocate integrating methods within a single study. Moreover, Sieber (1973) articulated that because both approaches have inherent strengths and weaknesses, researchers should utilise the strengths of both techniques in order to understand better social phenomena. Indeed, pragmatists ascribe to the philosophy that the research question should drive the method used, believing that “epistemological purity doesn’t get the research done” (Miles and Huberman 1984, pg. 21). Furthermore, Miles and Huberman (1984) point out those researchers who ascribe to epistemological purity lose sight of the fact that research methodologies are merely tools that are designed to aid our understanding of the world.

In line with Onwuegbuzie and Teddlie’s suggestion, I reflected that Phase 1 (qualitative methodology) could be considered exploratory, in that the aim was to ascertain the previously unknown patients’ view of self-care as opposed to that of the health professionals. Phase 2 could be considered confirmatory in that I wished to verify that I had interpreted the data correctly and could ensure that I had captured the statements, which participants felt were most important and relevant. Mixed methods research, therefore, appears to be a pragmatic solution to the problem;

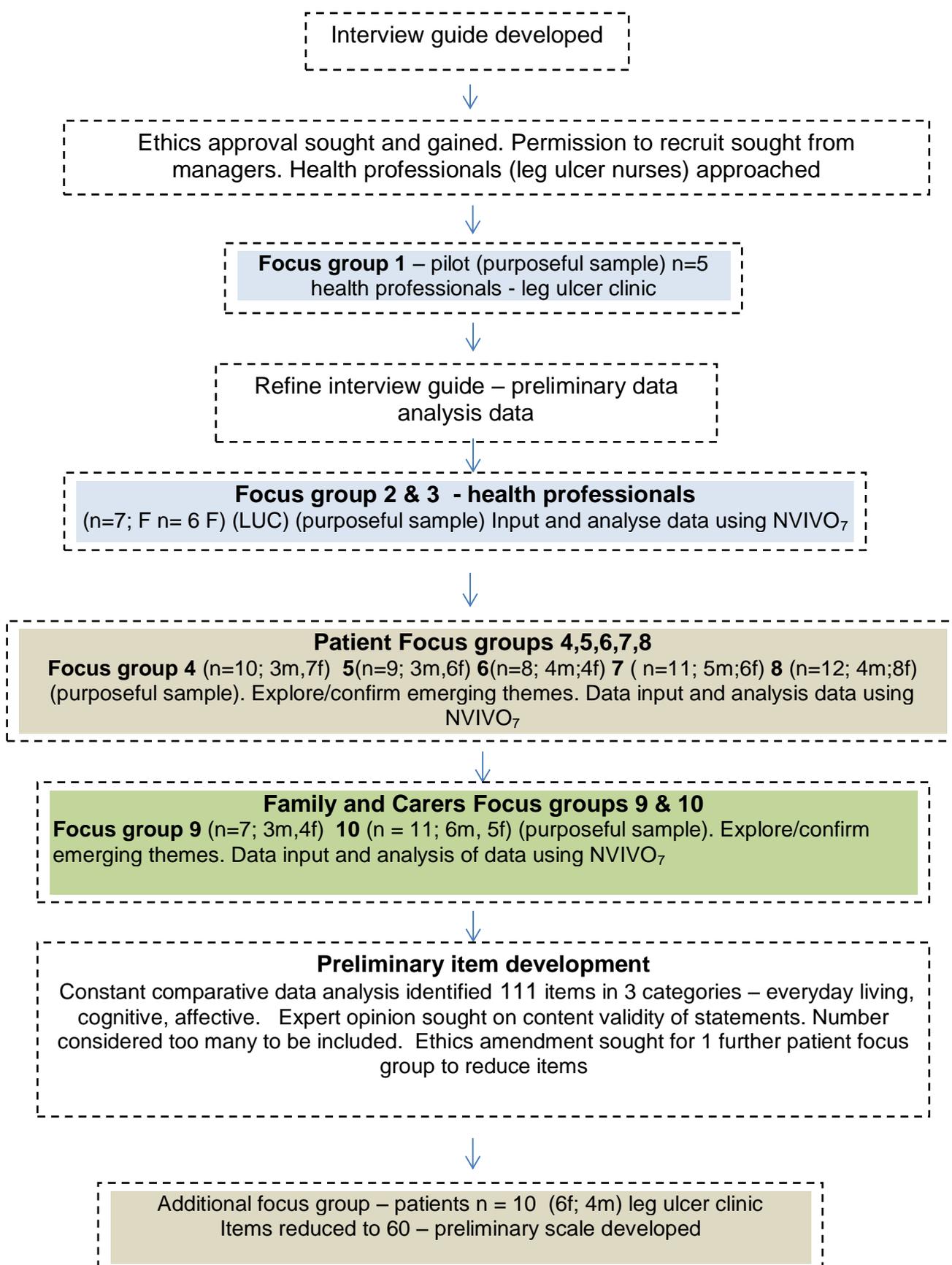
however, the difficulty lies in articulating the underlying epistemological philosophy with this approach.

Pragmatism orients itself toward solving practical problems in the “real world” and in that sense, allows the researcher to be free of mental and practical constraints imposed by the “forced choice dichotomy between post positivism and constructivism (Feilzer, 2010) and does not have to “be the prisoner of a particular research method or technique” (Robson 1993, pg. 291). The goal of mixed methods research is not to replace either of these approaches, but rather to draw from the strengths and weaknesses of both in single research studies and across studies (Burke Johnson and Onwuegbuzie 2004). According to Burke Johnson and Onwuegbuzie, “the bottom line is that research approaches should be mixed in ways that offer the best opportunities for answering important research questions”. (2004, pg. 16). Creswell (2007) highlights that pragmatism focuses on outcomes not antecedent questions and posits that truth is what works at the time and recognizes that research is always situated and purposeful.

#### **4.18 Conclusion of Chapter 4**

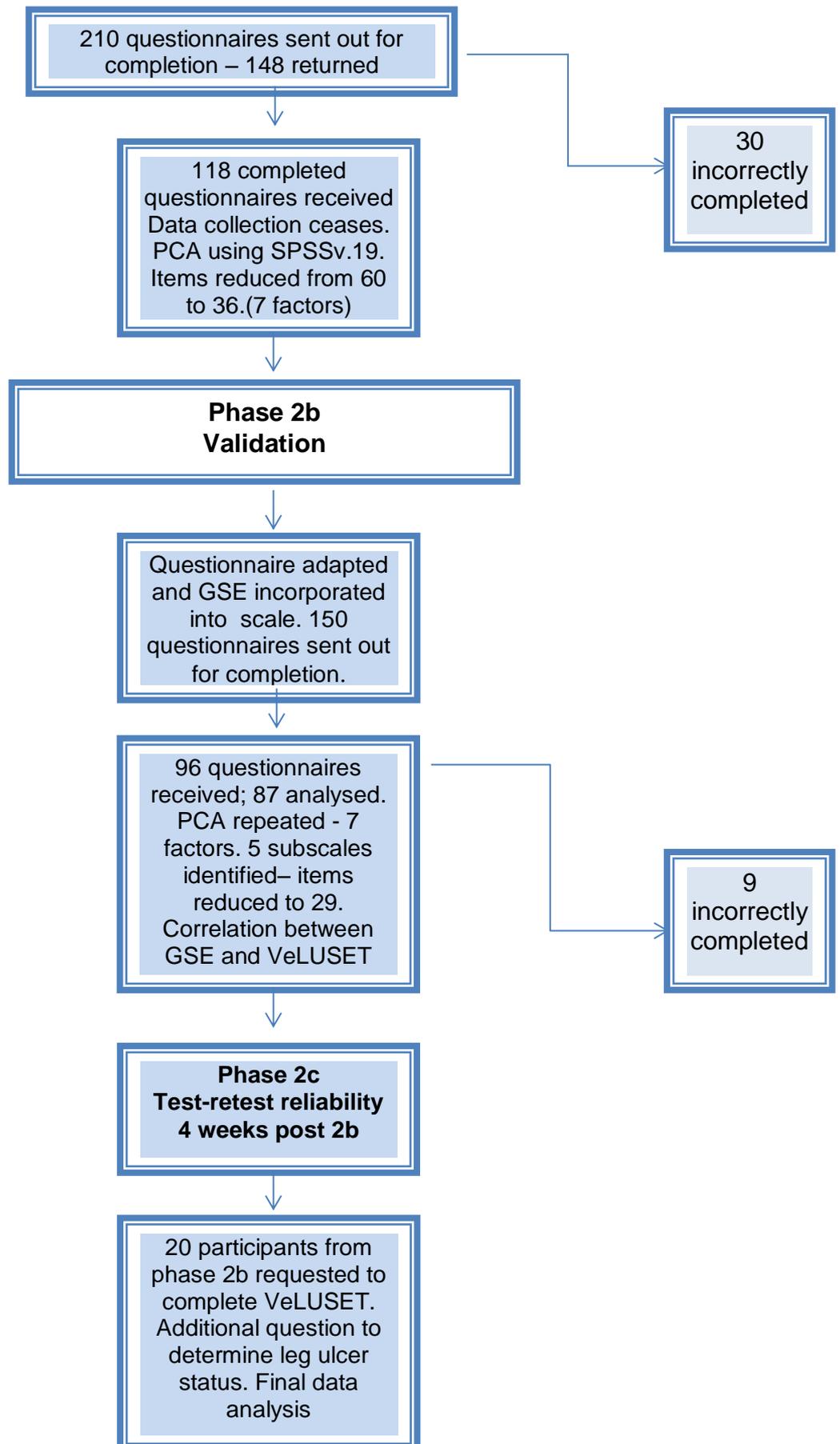
This chapter has described my positionality as a nurse researcher together with a justification of combining this pragmatic worldview with my choice of diverging methodologies. The next chapter describes the methods and research design for Phases 1 and 2, together with a description of how this pragmatic approach affected sample selection, data collection and analysis. Issues of reliability, validity and ethical considerations are also discussed. Flowcharts detailing recruitment of participants, data collection and data analysis for both phases are given below (Fig 1 and 2).

**4.19 Fig 1 Phase 1-Qualitative  
Data Collection & Analysis Flow Chart**



4.20 Fig 2 Flowchart – Phase 2a, 2b, 2c

**Phase 2a Preliminary Item reduction**



## **5.0 Chapter 5 – Research Designs and Methods**

### **5.1 Aim and objectives of the study**

The aim of this PhD study was to develop a tool to measure perceived self-efficacy in patients, aged 60 years and over, with healed or frequently recurrent venous leg ulceration. The objective for Phase 1 was to generate qualitative data from the patients'/health professionals/carers/relatives' perspective in order to generate self-efficacy statements to be included in the scale. The objectives of Phases 2 (a, b & c) were: (1) To use quantitative methodology to reduce the data and test for internal/external reliability and face validity (Phase 2a,b) (2) To test the developed tool against existing scales (e.g. the Generalised Self Efficacy Scale) in order to establish validity and specificity to venous leg ulcer patients after time (Phase 2c).

This chapter describes the methods and research designs used for Phases 1 and 2 (a, b&c) of this study. Recruitment of participants, data collection processes, data analysis and ethical considerations will be described, together with a sample of a focus group interview. The research design of Phase 1 of the study is detailed below, and the chapter will commence with a description of this initial phase. The research design for Phases 2 (a,b&c) quantitative data analysis/item reduction and preliminary validation of the scale will be discussed further in the chapter.

### **5.2 Ethics approval**

Prior to commencement of the study, consent to proceed was sought from the NHS Local Research Ethics Committee (LREC) and the local Primary Care Research and Development Office. Following a verbal presentation of my research protocol, several amendments were requested (see appendix 3). Some of the amendments were difficult to achieve, for example, the Committee requested a letter from a counsellor who would be willing to provide a counselling service to participants if required. In addition to this, a letter from the counsellor's line manager was also required, giving permission for the counsellor to provide this service if required. Following extensive enquiries within the PCT, it was decided that, should the need arise; participants would gain access to counselling via the normal channels, i.e. via GP referral. Fortunately, there was no need for this throughout the entire study

The LREC also required evidence that the participants for the focus group had been screened for cognitive impairment. The rationale for this was that a member of the LREC (physiotherapy background) felt that this would be an issue pertinent to

patients with venous leg ulceration since “they have obviously got impaired circulation, including degenerative changes to the brain”. It was apparent to me that this reviewer was unaware of the aetiology of venous leg ulceration as opposed to arterial leg ulceration, in that it is a condition caused by congestion in the venous circulation due to faulty valves, resulting in high pressure in the lower leg. Despite explaining the difference in aetiologies, evidence of screening for cognitive impairment was required.

As a clinician primarily, I felt that any evidence of cognitive impairment would manifest itself very early on in the focus group and that the use of a formal assessment tool, for example, the 6CIT (6 Item Cognitive Impairment Tool) (Brooke and Bullock 1999) would appear patronising and could, indeed, impact negatively on my relationship with the participants during the group discussions. I decided, therefore, that, as the recruitment of participants would be facilitated by health professionals involved in their leg ulcer care, I would ask the health professionals to consider this when approaching potential participants in order to recruit for my study and I added “cognitive impairment” to the exclusion criteria. This could be seen as a potential limitation of the study, since it could be argued that the health professionals may only approach patients expressing positive attitudes to performing self-care for their leg ulceration. This was certainly not the case as both negative and positive attitudes emerged through data analysis, and these “deviant” cases will be discussed in more detail within the findings section of this chapter.

### **5.3 Public involvement**

In 1996, the National Institute for Health Research (NIHR) established a national advisory group (INVOLVE) to support public involvement in NHS, health and social care research (NIHR 1996). The aim of INVOLVE is to ensure research is carried out in a partnership with public involvement as opposed to the public just being passive research subjects and to monitor governance issues. Patient involvement is now seen as an essential part of the process by which research is identified, prioritised, designed, conducted and disseminated (NIHR 1996). Although not public involvement per se, every LREC has several lay members on the reviewing committee who comment on the proposed research and suggest amendments to the proposal if necessary. Current good practice in research requires review of the proposed research proposal by a member of the public prior to submission to the LREC. In the case of this study, the research proposal was reviewed by LREC lay members and no comments or amendments were received. Planning this study commenced in 2006 when this requirement for public involvement was not yet widely

embedded within the research process and this must be acknowledged as a potential weakness of the study.

However, whilst not invited to be formally involved in the research process, the ethos of engaging participants had a strong influence on the choice of research design, data collection process and subsequent development of the final SE tool. During each focus group, the patients (and family/carers) were invited to voice their opinions on the relevance of the items and subjects discussed and were given the opportunity to confirm or reject the findings. During phase 2, patients were encouraged to comment on the pilot scale at every stage and offer suggestions for improvements with layout etc. As a result, the developed tool emerged as an instrument that was entirely shaped by the patients' views and priorities. Public engagement, therefore, became a two-way process, involving interaction and listening, with the goal of generating mutual benefit.

#### **5.4 Phase 1 – qualitative research design – item generation**

A qualitative approach was required to elicit views on the self care activities patients were asked to perform and the difficulties they experienced daily in complying with this. Data from health professionals and patients' carers/relatives was also collected in order to develop items to be included in the developing tool. Having reviewed the literature, focus groups were considered to be an ideal method to collect rich, meaningful data in a relatively short space of time.

#### **5.5 Focus groups as a data collection method**

Grounded theory methods specify data analytical strategies but not data collection methods (Denzin and Lincoln 2000). Consequently, there is a paucity of information within the literature on how data should be collected. Having reviewed the literature on conducting focus groups, this appeared to be an appropriate method of data collection for Phase 1- item generation since it was felt that focus groups would yield rich data within a relatively short space of time.

Focus groups are strongly associated with qualitative approaches to social research, the dominant theme being the provision of a rich understanding of people's lived experiences and perspectives, situated within the context of their particular circumstances and settings (Murphy et al. 1998).

The main purpose of focus group research is to draw upon respondents' beliefs, attitudes, and feelings by exploiting group processes. There are many stated advantages to interaction between participants and, indeed, many see this as key to the method in that the group interaction may result in data emerging that would not emerge if other methods were used. (Kitzinger, 1994). However, Kitzinger (1994) adds that many researchers justify using focus groups as a means to generate data as a result of the group interaction but then fail to discuss this interaction in their analysis. The importance of the group interaction generated by my focus groups emerged quite early on since it highlighted the apparent lack of knowledge on the aetiology of their leg ulceration and the confusion over conflicting advice given by health professionals to some of the participants. This data allowed me to create codes, giving the method a high level of face validity (Krueger, 1994), as participants of further focus groups confirmed, reinforced or contradicted these findings. These codes may not have emerged within individual in-depth interviews, although other authors have challenged this and have suggested that focus group interviews do not produce more ideas than an equivalent number of individual interviews (Fern, 1983). MacLean et al. (2004) however, suggest that comments from one participant may trigger a chain of responses from others (snowballing) and participants' responses may be more spontaneous and therefore give a more accurate picture of a person's position on a given issue (spontaneity); that is, people speak only when they have definite feelings on a subject and not because a question requires a response.

MacLean et al. (2004) further suggest that focus groups are participant-centred and allow issues to be explored *in situ*, whilst steering the researcher away from armchair theorising (pg. 146). This was important to me, since the aim was to develop a patient centred scale which reflected the participants' reality of caring for their healed ulcer, rather than assumptions gleaned from the literature which described health professionals' assumptions. Research from the perspective of patients, furthermore, means that patients are engaged as "partners" as opposed to merely information givers in the process of research from beginning to end (Heyman 1995). Krueger (1994) suggests that, as partners, patients should be able to share their experiences with researchers and be heard, with an equal influence of patients and researchers in formulating questions and setting priorities, in effect, bridging the 'gap of understanding'. An essential feature of research from a patient's perspective is the collaboration between researcher and patients and, as a result, the exchange and integration of experiential and scientific knowledge (Bagseven et al 2002; Flinterman 2001), albeit, within a "friendly" method of data collection. It is suggested that they are able to do this through participants providing an audience for each other, which

leads to a wider variety of communication – jokes, singing and anecdotes – and that this may actually tell us more about what people “know” (Fern, 1983).

Webb and Kevern (2001), in critiquing reports on the use of focus groups as a research method, discuss the methodological incompatibilities documented within the literature, for example the use of focus groups to collect data for phenomenological studies and urge researchers to ensure that the methodological underpinnings of their proposed research are compatible with the focus group method of data collection and discuss these fully in their reports (Gray-Vickery, 1993).

To conclude, therefore, on review of the literature, the focus group method of data collection appeared to be appropriate for Phase 1 of my study, the aim of which was to generate items for my developing scale, primarily from the patient’s perspective. From a pragmatic viewpoint, this method would allow me to collect data quickly, using the constant comparative method of analysis used in GT, which in turn, would result in a high level of face validity. Drawing on the views of Barbour and Kitzinger (1999) and Coyle and Williams (2000) who suggest that focus groups are particularly suited to the development of questionnaires or instrument design in that they develop an understanding of key issues by refining the phrasing of specific questions (Fowler 1993; Hyland et al. 1994; Sim and Snell 1996) these particular attributes contributed to my rationale for using focus groups to generate data for this phase of my study.

### **5.6 Sampling in Grounded Theory -Theoretical or Purposeful?**

Grounded theory uses non-probability sampling. In order for concepts and categories to emerge during the data analysis, the need for sampling of specific data sources continues until each category is saturated (Cutcliffe, 2000). Therefore, at the beginning of the study, no limits are set on the number of participants, interviews, or data sources. The researcher continues selecting participants until they are saying nothing new about the concept being explored. Thus, the selection of participants is a function of the emerging hypothesis and the sample size a function of the theoretical completeness (Baker et al. 1992).

Sampling within grounded theory is therefore described as “theoretical” rather than purposeful (Glaser and Strauss 1967; Glaser 1978; Becker 1993) in that it is driven by the emerging theory. However, other authors of qualitative research do not make such a distinction (Lincoln and Guba 1985; Morse 1991). Indeed, they suggest that the terms theoretical and purposeful sampling are interchangeable.

Glaser (1978), Sandelowski et al. (1992), Becker (1993) and Coyne (1997) each provided distinctions between theoretical sampling and purposeful/selective sampling, in as much that, purposeful sampling involves the calculated decision to sample a specific locale according to a preconceived but reasonable initial set of dimensions. In contrast, theoretical sampling has no such initial calculated decisions. The grounded theory researcher seeks further interviewees in order to add to the fullness of the understanding of the concept. Hence, theoretical sampling is seen as integral part of the process of grounded theory (Cutcliffe, 2000), although it should be noted that, before the researcher has begun to collect and analyse data, the researcher has no evolving theory which can act as a guide for further theoretical sampling.

Baker et al. (1992) maintained that the researcher using grounded theory initiates the sampling process by interviewing significant individuals. Perhaps it is these significant individuals that Morse (1991) is referring to when she describes a good informant as one who has the knowledge and experience the researcher requires, has the ability to reflect, is articulate, has the time to be interviewed, and is willing to participate in the study.

Lincoln and Guba (1985) argue that maximum variation within theoretical sampling is best achieved by selecting each unit of the sample only after the previous unit has been taped and analysed. This first set of data and subsequent analysis acts as a “gatekeeper” and sets the ‘tone’ or highlights the direction of further theoretical sampling. Cutcliffe (2000) asserts that “it is reasonable to say that the literature on sampling in qualitative research is confusing and conflicting” (pg. 1478) but goes on to say that if the researcher can describe his/her sampling strategy in sufficient detail, this should minimize any confusion regarding sampling (Morse, 1991b), improve the quality of the research (Coyne, 1997), avoid method slurring (Baker et al. 1992) and provide some clarification of the use of theoretical sampling in nursing research. Table 7 gives details of the focus groups and characteristics of the participants.

**5.7 Table 7. Details of focus groups and participants – Phase 1**

<b>Focus Group</b>	<b>Participants</b>	<b>Duration</b>	<b>Number</b>	<b>Male</b>	<b>Female</b>	<b>Age Range</b>
1	Health professionals <i>(Pilot)</i> <b>Purposeful</b>	83 mins	5		5	26-62 yrs
2	Health professionals <b>Purposeful</b>	98 mins	7		7	23-60 yrs
3	Health Professionals <b>Purposeful</b>	80 mins	6		6	30-48 yrs
4	Patients <b>Purposeful</b>	87 mins	10	3	7	61-82 yrs
5	Patients <b>Purposeful</b>	79 mins	9	3	6	60-79 yrs
6	Patients <b>Purposeful</b>	92 mins	8	4	4	61-83 yrs
7	Patients <b>Purposeful</b>	93 mins	11	5	6	63-75 yrs
8	Patients <b>Purposeful</b>	89 mins	12	4	8	60-79 yrs
9	Family & Carers <b>Theoretical</b>	95 mins	7	3	4	58-82 yrs
10	Family & Carers <b>Theoretical</b>	101 mins	11	6	5	55-83 yrs
	<b>TOTAL</b>		<b>86</b>			

### **5.8 Recruitment of health professionals**

It was decided to conduct focus groups with health professionals initially prior to proceeding to conduct focus groups with patients. The rationale for this to gain the health professional perspective on the self-care activities they asked patients to perform. This data could then be validated or rejected by the patients themselves at consequent patient focus groups.

Letters of invitation to participate, together with information leaflets explaining the study (see appendices 4,5,6,7) were sent to staff at local PCT leg ulcer clinics. No inclusion/exclusion criteria were applied to this sample; merely the requirement that they worked within a venous leg ulcer clinic. Nursing management agreement was sought and obtained. It was decided to hold the focus groups during the lunch break

at the leg ulcer clinics and refreshments were provided. This ensured that the nurses were not inconvenienced and would, therefore, be more likely to attend.

### **5.9 Pilot Focus Group**

The first focus group took place and was considered to be a pilot to test the appropriateness of the questions and to ensure that the equipment used to tape the conversations was functioning correctly and adequate for data collection and transcription. The participants for this pilot focus group were all female, aged between 26 yrs. and 62 yrs., very experienced leg ulcer specialist nurses and well known to me, both as colleagues and latterly, as a manager. I reflected that this managerial relationship may affect the nurses' responses and so I deliberately attempted to maintain a non judgemental manner during the discussions. Having gained written consent, I reiterated the need for confidentiality before commencing data collection and requested that participants speak clearly and singularly, so that the conversation could be heard and transcribed in its entirety. During the course of the discussion, I was immediately struck by the apparent negativity expressed by these nurses in reaching concordance with both treatment and prevention strategies, the dominant statements being expressed as "its a waste of time", "patients don't want to listen", and an almost "why bother" attitude. The potential of this negativity to impact on patients' self-efficacy was concerning but also confirmed that the nurses had felt relaxed enough with me to open up and voice their honest and true opinions. The potential for HP negativity to impact on patient SE, however will be further discussed in the Discussion chapter of this study.

### **5.10 Amendments to focus group design**

Having transcribed the tape recording immediately following this first focus group, it was also apparent to me that I had been asking 'loaded' questions as opposed to neutral questions, resulting in my leading the discussions and setting the agenda. Aware of this, the decision was made to recruit a colleague as a facilitator for successive focus groups (Sim 1998; Stewart and Shamdasani 2000). The purpose of the facilitator was to ensure the conversation flowed by asking questions, picking up on comments made and exploring them in more depth and trying to involve the more reticent participants in the conversation whilst allowing me to observe non-verbal cues and group interactions, taking more of a detached stance during the focus groups (Stewart and Shamdasani 1990). The facilitator was a fellow Tissue Viability Clinical Nurse Specialist, who was very familiar with my study aims and the purpose of data collection by the focus groups. Straw and Smith (1995) suggest, however, that clinicians are not necessarily the best facilitators, as they may become "trapped by

the need to create a supportive/therapeutic environment rather than concentrate on the primary need for data collection that is central to the focus group session". This certainly was not the case in my study and the advantage of having two people present during data collection was apparent as we were able to hold debriefing sessions after completion of the focus groups, discussing and debating the main themes that had emerged. The tape was transcribed immediately after data collection, so that the conversation remained clear in my mind, this proved to be a very lengthy task due to the amount of data collected. Following transcription of the tape recording, I completed a Contact Summary Form (Miles and Huberman 1994) which detailed the main issues which had emerged from data analysis, a summary of information received for each question posed, anything that was new, salient or interesting and what new or remaining target questions needed to be considered when planning the next focus group. Despite the initial problems encountered in conducting this first pilot focus group, the emerging dominant themes were, nevertheless, useful and were used to follow up and explore in greater detail within the two successive health professional focus groups.

Interestingly, the next two focus groups were very different from the first, in that the staff expressed very positive views, described innovative strategies they employed to encourage patient adherence with treatment, including the building of close relationships with their patients and encouraging patients to interact with each other whilst awaiting their appointment at the leg ulcer clinics. The Contact Summary Form from the previous pilot focus group enabled me to explore, explain, and endorse the issues raised in more detail with these focus group participants (Hollis et al. 2002). This variance between focus groups in terms of attitudes etc. illustrated the need to analyse each focus group transcript individually as a "unit" of analysis as opposed to analysing the transcripts in their entirety (Sim, 1998), a process facilitated by the constant comparative method employed.

The staff recruited for these focus groups were employed by a neighbouring Primary Care Trust and I considered whether their more positive approach may have been as a result of higher staff morale due to enhanced staffing levels, a supportive management or other organisational factors, or maybe they were portraying this positive attitude because they saw me as a Manager (Tissue Viability Team Lead) rather than a colleague and felt uneasy in expressing their true feelings on the subject, suspecting maybe that there may be a hidden agenda to the study, as opposed to the nurses from the first focus group who knew me well (Hollis et al. 2002). The impact of familiarity between focus group participants was studied by Fern

(1982) who tested the independent responses of group members who did and did not know each other and concluded that both focus groups were equally effective. Following the three focus groups conducted with health professionals, no new themes/categories emerged and so, following data analysis of the health professionals' focus groups, it was decided to conduct data collection with leg ulcer patients to validate or reject the accuracy of the data obtained from the health professionals

### 5.11 Focus Groups with Leg Ulcer Patients

The administrator for the local Leg Ulcer Service and the nurses running leg ulcer clinics in the neighbouring P.C.T. were approached and requested to assist in the recruitment of participants for the focus groups. Details of the inclusion/exclusion criteria were supplied.

Exclusion Criteria	Inclusion Criteria
Confirmed arterial aetiology	Healed or recurrent venous leg ulcer
Cognitive impairment e.g. dementia	Able and willing to give informed consent
Non-English speaking	English speaking
Age < 60 yrs.	Age > 60 yrs.

Letters of invitation to take part, patient information sheets, and other supporting documentation were provided (see appendix 4,5,6,7) and suggestions for possible dates for the focus groups were supplied. These dates were set up 4 weeks in advance in order to allow the participants to read the documentation thoroughly and ask questions, if necessary. Again, the decision was taken to conduct the focus groups at the local leg ulcer clinics in order not to inconvenience participants, since they would normally be attending the venue for their leg ulcer treatment anyway and appropriate refreshments were provided.

The recommended maximum number of participants for focus groups given in the literature varies from between six and twelve (MacLean et al. 2004; Sim 1998; Mansell et al. 2004). In this case, the average number of participants per focus group was eight, and the average duration of each focus group was 89 minutes. It is further suggested that researchers should over-recruit since the drop-out rate on the day is high (MacLean et al. 2004) however, every person invited to participate in the study was keen to participate and attended the focus group as promised. This could be seen as an indicator of the amount of interest shown in the subject under study.

The five focus groups with patients were conducted in a similar format to the health professional focus groups. On commencement, the participants were thanked for attending; I introduced myself and the facilitator, and then asked the participants, in turn, to introduce themselves. This was designed to 'break the ice' but also allowed me to become familiar with participants' voices, which would aid transcription of the tapes. Some researchers recommend asking participants to say their name for the purpose of the tape prior to contributing to the discussion; however I considered that this would be cumbersome and may interfere with the flow of conversation (MacLean et al. 2004; Kitzinger 1995; Sim 1998). The study aims and ground rules for the focus group were explained (Webb, 2002) and written consent was obtained, each participant retained a personal copy for future reference, together with my contact details. I then proceeded to explain confidentiality issues, explaining that, although the conversation would be audio-taped in order to facilitate verbatim analysis, no identifiable reference to individuals would be made in the transcripts.

A focus group discussion guide was prepared, based on the topics to be discussed (Webb, 2002). On collecting data for a grounded theory study, Glaser (1992) asserts that the GT researcher should "never, never ask the research question directly in interviews as this would preconceive the emergence of data" Wimpenny and Cass (2000), however, point out that interviewers conducting unstructured interviews may, in practice, actually have a general interview guide. Fielding (1994) further suggests that interviewers may wish to have a list of topics they want participants to talk about but that they are free to phrase the questions as they wish, ask them in any order that seems sensible and 'even join in by discussing what they think of the topic'.

The interview guide was not intended to facilitate a rigid debate; however, it was important to maintain a focused discussion, using trigger questions (Webb, 2002). Each focus group commenced with the same general question "Tell me about living with a healed/recurrent venous leg ulcer?" Whilst not the subject under study, this primary open-ended question was posed out of respect for the participants, in that it allowed each individual to relax and tell their unique stories and feel that their experiences were valued. Gibbs (1997) urges researchers not to underestimate the benefits to participants in that the opportunity to be involved in decision making processes, to be valued as experts and to be given the chance to work collaboratively with researchers, can be empowering for many participants, although she adds that this may not be the case for all participants, particularly the shy or inarticulate members. The subsequent interview guides were adapted as a result of

the constant comparative data analysis process and contained trigger questions relating to the difficulties patients had voiced in maintaining their healed ulcers (Stewart and Shamdasani 1990) from previous focus groups. As data collection progressed, the questions became more specific and this allowed the participants to confirm or disagree with the topics under discussion. There is a trade-off in terms of amount and reliability of the information generated by open-ended versus closed-ended questions (Stewart and Shamdasani 1990) in that the amount of data obtained tends to increase with the openness of the questions; however the reliability of the data and the possibility of replication decrease as the questions become more open-ended. This approach may appear to be at odds with Glaser's (1992) views on generating theory and could be considered reductionist, however the aim of data collection, in this case, was to find patterns of recurring statements made by the participants and so a pragmatic decision was made to use closed-ended questions in order to generate the data required.

### **5.12 Tension between divergent roles - researcher or clinician?**

As the major themes emerged from the interaction within the focus groups, I was faced with two ethical dilemmas which challenged my role as researcher versus clinician. Firstly, some of the participants discussed how they managed to apply their stockings with application aids provided by staff at the leg ulcer clinic. It became apparent, however, that some participants had never been offered these aids despite experiencing difficulties with application of their hosiery and questioned why this was. As a prescribing nurse, I resolved this by demonstrating the different types of aids available and issued FP.10 prescriptions for the individual participants. I later informed the relevant health care professionals that I had done this, mindful of the fact that I did not wish to appear to be criticising their care.

The second dilemma became apparent to me very early on during data collection. During every focus group conducted with patients and carers, the question of the aetiology of venous leg ulceration was discussed by the participants, and in many cases, they appeared to have very little understanding or had been misinformed or had misunderstood the explanation given. The lack of knowledge of the aetiology and treatment of venous leg ulcers in this client group has been highlighted in the literature (Hamer et al. 1994; Edwards et al. 2002). Hamer et al. found that only 50% of patients knew how their leg ulcer had occurred, despite having had explanations by health care professionals. These findings were confirmed by Edwards et al. (2002) who found that only 34% of patients questioned knew how their ulcer had started. In a similar vein, Clarke Moloney et al. (2005) found that there was limited value in

providing information leaflets for this client group. (See the Discussion chapter for more in-depth discussion). Clearly, these findings have implications for improving self-efficacy levels in this client group, given the importance of knowledge in this health behaviour change model and will be discussed within the Discussion chapter.

From a researcher perspective, however, offering an in depth explanation at this stage would have involved transcribing a large amount of data which would not be relevant to the research question. As a clinician, however, I felt obliged to provide an explanation as requested and so the decision was made to turn off the tape recording, provide the necessary explanations and then turn the tape recorder on again and resume the focus group. This was greatly appreciated by the participants, many of whom commented that participation in the focus groups had been a cathartic experience for them. These comments were encouraging for me and gave me a sense of reciprocity as I felt that I had given 'something back' to the participants who had given their time to participate in the study, as opposed to the 'smash and grab' mentality of data collection, sometimes expressed in the literature as poor researcher practice. Smith (1992) reinforces the need to provide appropriate debriefing and support to respondents following data collection and this was adhered to during this study. On completion of five focus groups, no new issues or categories emerged and so data collection with this sample ceased.

### **5.13 Focus groups with family members/carers**

Analysis of the data following the 'patient' focus groups had revealed the important role family and carers played in maintaining their healed venous leg ulcers and so it was decided to conduct focus groups with this group, using theoretical sampling (Glaser and Strauss 1967). Glaser (1978) indicated that theoretical sampling occurs when "the analyst jointly collects, codes and analyses his data and decides what data to collect and where to find them, in order to develop his theory as it emerges" (pg. 36). Initial sampling decisions are based on a general sociological perspective or general problem, but once data are collected and coding begins, the researcher is "led in all directions which seem relevant and work" (pg. 46). However, although grounded theorists emphasize that theoretical sampling is critical to the development of a conceptually-dense theory (Charmaz, 2000); little guidance is available on how to make those "real-life" decisions. With this in mind, it was decided to approach the administrator of the Leg Ulcer Service and health care professionals in the leg ulcer clinics and request that they recruit participants from carers/family of their patients. No formal inclusion/criteria were set, merely, the requirement to live with or care for somebody who had/or has a venous leg ulcer. Two focus groups were conducted,

where salient issues that had emerged from the previous patient focus groups were explored, confirmed, or rejected. Data collection ceased when no new issues or categories emerged from the data and saturation had been achieved.

During and following transcription, it was necessary to ensure that the transcript remained loyal to the process and reflected the discussion that had taken place. Charmaz (2002) concurs with this and reiterates that the process of transcription has ethical implications, particularly in remaining loyal to what was said or not said, and the maintenance of anonymity. As a former secretary, I had the requisite skills to transcribe the tapes verbatim on my home computer, although this proved to be a very time-consuming process. During transcription, all names or identifiable comments were removed to ensure confidentiality, and on completion of data collection, the tapes were stored in a locked safe at my home, to which nobody but me had access as required by the ethics committee.

Following each focus group, participants were asked whether they wished to receive a copy of the transcript. Some participants requested copies of the transcription, which were duly sent; however, no further comments were received by the researcher. An exception was one participant who had apparently misunderstood that this was a research study and expected the focus group discussion to be presented in the format of minutes of a meeting. He also expressed concern that the transcript had contained poor grammar, complete with “aahs” and “uhms” (MacLean et al. 2004). Stewart and Shamdasani (1990), however, advocate that including incomplete sentences, half-finished thoughts, pieces of words and odd phrases ensures that transcription remains true to the flow of the discussion and that too much editing and cleaning of the transcript is undesirable. This was explained to the participant who reluctantly accepted the format of the transcript.

#### **5.14 Constant comparative data analysis**

Analysis began as soon as each focus group had been completed. The dominant categories to emerge from each focus group were consequently explored, challenged, or affirmed with the participants in the subsequent focus group by adapting the topic guide accordingly. Consequently, data analysis proceeds by a continual, reciprocal interplay between concepts and theories held by the researcher and the data provided by the participants (Strauss and Corbin 1994). This interplay between concepts and data is reflected in a constant making of comparisons, a major feature of the grounded theory approach to data analysis (Strauss and Corbin 1994).

### **5.15 Use of qualitative analysis software – NVIVO<sub>7</sub><sup>®</sup>**

The entire Word™ document was then imported into the NVIVO<sub>7</sub><sup>®</sup> (QRS Int. Ltd.) programme and multiple codes were created, both as topic areas or emerging ideas (Charmaz, 1990; McCann and Clark 2003a). Each successive focus group transcript was analysed using the same methodical process and the most dominant emerging codes were incorporated into the next focus group guide, where they were confirmed or rejected by the participants. Following each successive focus group, the transcripts from prior focus groups were re-read to ensure that no themes or emerging ideas had been inadvertently overlooked or ignored (Glaser 1978, pg. 58).

During the course of my PhD study, I had attended training on the use of NVIVO<sub>7</sub><sup>®</sup> (QRS International Ltd), a computer-assisted qualitative data analysis software programme and looked forward to using this to assist with my data analysis. Since the early 1980's, various programmes have been developed to facilitate qualitative data analysis and which are now being used frequently by qualitative researchers. Review of the current literature on the use of such programmes, however, indicates that some researchers have reservations about their use in qualitative data analysis (Denzin and Lincoln 2000; MacMillan and McLachlan 1999; Coffrey et al. 1996). Criticisms include the domination of a particular methodological or epistemological approach (Denzin and Lincoln 2000), unrealistic expectations of the software packages as theory builders (MacMillan and McLachlan 1999), reliance on the software as a mechanism for rigour (Maxwell, 1998) and the inability to be able to see the data as a whole unit (Kelle, 1997). This last point became problematic for me as I continually felt the need to refer back to the transcripts in their entirety in order to read units of data in context and so the decision was made to use some of NVIVO<sub>7</sub><sup>®</sup>'s features to organise and store the huge amount of data generated by the focus groups in combination with the more traditional paper 'table top' method of data management (Weitzman, 2000).

### **5.16 Constant comparative analysis or content analysis?**

It could be argued that content analysis would have been an appropriate approach to data analysis, defined as "a systematic, replicable technique for compressing many words of text into fewer content categories based on explicit rules of coding" (Weber 1990; Krippendorff 1980; Holsti 1969). Widely used for qualitative data analysis, content analysis describes a family of analytical approaches ranging from impressionistic, intuitive, interpretive analyses to systematic, strict textual analyses (Hsieh and Shannon 2005). The specific type of content analysis approach chosen by a researcher varies with the theoretical and substantive interests of the researcher

and the problem being studied (Weber, 1990). Hsieh and Shannon (2005) suggest that the aim of conventional content analysis is “to provide knowledge and understanding of the phenomenon in question” (pg. 1278), which makes it more appropriate to phenomenological research, which was not congruent with my study aim, which was to generate statements in order to develop an objective measure. One of the disadvantages of using content analysis is that, generally speaking, analysis occurs after data collection has ceased and so, in order to ensure “reproducibility”, Kondraki et al. (2002) advise using a minimum of two coders. From a pragmatic researcher perspective, I needed to collect data as quickly as possible, and by using the constant comparative method of moving between data collection and analysis in an iterative fashion, could ensure “reproducibility” by asking participants from successive focus groups to confirm or reject my preliminary findings. (see appendix 8 for a sample interview transcript).

Throughout the complex constant comparative and intentionally circular process of data analysis, the memo facility of NVIVO<sup>7</sup>® (QRS Int. Ltd.) was used to summarize my ideas about what was occurring within the data and how the codes were created (Denzin and Lincoln 2000). The individual codes created within the NVIVO<sup>7</sup>® software became data displays (Draucker et al. 2007; Miles and Huberman 1994), in that all the data relating to that particular code were condensed into a more manageable form, and together with the memoing provided an audit trail of my analysis.

A further feature of the software allowed me to ascertain how frequently each particular code occurred within the transcripts overall (see Tables 8, 9, 10). This approach did not focus merely on specific words used by the participants, which, it could be argued, is a positivist approach to data analysis (Kondraki et al. 2002), but also incorporated the participant’s narrative (see sample transcript) and my interpretation of what was actually being said. It could be argued, from a positive paradigm perspective, that this was a potential bias in data analysis, however, Strauss and Corbin (1990) define this ‘knowing’ as theoretical sensitivity where there is an awareness of the subtleties of the meaning of the data. Pope et al. (2000) suggest that simple frequency counts are sometimes used and may provide a useful summary of some aspects of qualitative analysis. Kondraki et al. (2002) further argue that the counting of data ‘has a place in qualitative research’ (pg. 349) however, Sim (1998) rejects this, stating that, in focus groups, the fact that some members of the group may or may not voice a viewpoint may be a reflection of the specific pattern of interaction at the time. From a pragmatic perspective, however, it

was important to establish the hierarchical importance of these codes from the participants' point of view in order to develop statements and so this software facility proved to be a very useful tool in the analysis.

Once the open coding process had been completed, the analysis progressed to creating major categories, or tree nodes within the NVIVO<sub>7</sub>™ (QRS Int.Ltd.) programme. These tree nodes were further refined by identifying linkages and reducing the numbers of open codes by grouping them together (Pope et al. 2000). From here, it was possible to select key themes or categories for further investigation, using the 'cutting and pasting' facility of NVIVO® (QRS Int. Ltd.) The tree nodes were named – ***affective, cognitive*** and ***everyday living***. The tables below give details of the frequencies that the open codes occurred within each tree node.

**5.17 Table 8. Tree Node –Affective**

<b>Open codes</b>	<b>No. of refs</b>
Fear of recurrence (leg ulcer)	<b>28*</b>
Fear of trauma	<b>27*</b>
Body image	<b>24*</b>
Optimism vs. pessimism (of recurrence)	<b>19*</b>
Having faith and confidence	<b>18*</b>
Supporting each other	<b>14*</b>
Avoiding situations	<b>13*</b>
Being checked out	<b>13*</b>
Seeking reassurance	<b>12*</b>
Stigma and embarrassment	8
Hope for the future	7
Being vigilant	5
Why me?	5
Comparing self to others	2
Not having negative thoughts	2
Despair	2
Dread (of recurrence)	2
Feeling angry (about ulcer)	2
Feeling unclean	1

\* Indicates frequencies of open codes within each tree node from transcriptions.

### 5.18 Table 9 –Tree Node – Cognitive

<b>Open Codes</b>	<b>No. of Refs</b>
Knowledge and education	<b>34*</b>
Receiving conflicting information	<b>19*</b>
Identifying skilled health professionals	<b>18*</b>
Becoming assertive	<b>17*</b>
Prior experiences	<b>16*</b>
Becoming an expert	<b>16*</b>
Lack of professional knowledge	<b>16*</b>
Navigating the system	<b>16*</b>
Looking for reasons	<b>14*</b>
Being stereotyped	<b>13*</b>
Perseverance	<b>13*</b>
Taking control	<b>11*</b>
Doing as you are told	9
Taking a risk/being in denial	9
Learning from others	7
Setting goals	7
Confidence in compression	7
Trivialisation (of ulcer by others)	6

### 5.19 Table 10 – Tree Node - Everyday Living

Open codes	No. of refs
Difficulties with applying compression hosiery	27*
Familiar routines and normalising	24*
Difficulties in performing self-care activities	23*
Limitations on everyday life	22*
Carrying on regardless	19*
Support of friends and family	14*
Self-treatment	13*
Maintaining contact with health professionals	12*
Seeking expert help and advice	12*
Changing health behaviours	12*
Adaptation and innovation	12*
Restrictions	11*
Financial problems	10
Interference with everyday life	8
Moving between bandages and hosiery	8
Life dominated by leg ulceration	2
Costing the NHS too much money	2

## **5.20 Preliminary Items for scale development**

The codes were examined and ranked in order of frequency, ranging with the most frequently mentioned code at the top, to the codes with fewer frequencies at the bottom of the list within the three domains. From here, self-efficacy statements were developed for the open codes that recurred most frequently, for example:-

1. I am confident that I will be able to put my compression stockings on every day
2. I am confident that I will be able to make putting my compression stockings on part of my everyday routine

The readability statistics facility on the Word® (Microsoft Windows® XP Office 2001) programme was used to determine readability levels, resulting in a Flesch Reading Ease Score of 72, and a Flesch Kinkaid Grade Level of 8.5. According to Ley and Florio (1996) and Bernier (1993), 88% of people would be able to understand this list, and whilst acceptable for this particular client group, further testing in Phase 2 would reveal whether this was indeed the case. In total, 111 items were generated.

## **5.21 Expert reviewers**

The next phase of the scale development was to invite comments on these preliminary items from expert reviewers. 4 leading academics were approached ; 3 who are considered to be experts within the field of self-efficacy and one reviewer who has published extensively on venous leg ulceration and is considered an authority in that field. They were requested to comment on the following:-

- Whether the statements appear to have content validity regarding venous leg ulceration
- The degree of unnecessary overlap between statements
- The extent to which they reflect the self-efficacy construct (face validity)
- Any areas considered absent that may be important
- Any other comments

Patients were not approached for their opinions at this stage. A few comments were made about the length of the proposed scale, the wording and duplicity of some of the statements, and suggestions for possible items for inclusion, however, all agreed that the statements reflected the self-efficacy construct and demonstrated strong content validity.

## **5.22 Additional focus group**

The large item pool (111 items) was considered too large to include in a pilot scale and so an amendment to the Ethics approval was submitted requesting permission to

conduct one additional focus group in order to reduce the items to a more manageable number. Following ethics approval, an additional focus group with 10 leg ulcer clinic patients (some of whom had attended the previous focus groups) was held. The items were discussed individually, and items that they considered to be repetitive or inappropriate were eliminated following consensus of the group. Involvement of the participants at this stage resulted in a reduction of items from 111 to 60 in total.

### **5.23 Issues of validity and reliability in qualitative research - are they valid?**

Qualitative research is increasingly recognized and valued and its unique place in nursing research has been highlighted by many (Cutcliffe and McKenna 1999). Despite this, some researchers continue to raise epistemological issues about the problems of objectivity and validity of qualitative research findings (Altheide and Johnson 1994). Validity and reliability are the quality criteria upon which quantitative research is judged; however there is much debate within the literature as to the appropriateness of applying these criteria to qualitative research (Barbour, 2001; Coyle and Williams 2000; Cutcliffe and McKenna 1999) since the philosophical underpinnings of the two approaches are at odds with each other.

Cavanagh (1997) suggests that qualitative researchers should strive to achieve reliable and valid results. Furthermore, he argues that qualitative researchers should give consideration to three different types of validity, content, hypothesis and predictive. Cavanagh (1997) also attempts to develop arguments for using measures of stability to determine the credibility of qualitative research findings and furthermore, recommends that the rigour of qualitative research should be judged using criteria and terminology that has been constructed in order to test the validity of result obtained from quantitative studies. Jasper (1994) and Appleton (1995) concur with Cavanagh (1997) and assert that, since qualitative research methods are often criticized for failing to address issues of reliability and validity, researchers cannot ignore these parameters. In light of this criticism, some qualitative researchers “import” quantitative terms and then “translate” them into terms more often associated with qualitative studies, such as “truth value” (Cutcliffe and McKenna 1999). In addition, checklists have been developed to guide reviewers of qualitative work through the process of assessing quality, although Barbour (2001) suggests that these may prove counterproductive if used prescriptively, resulting in a case of “the tail wagging the dog!” (pg. 1115).

In considering these arguments, there is a need to examine the philosophical underpinnings of both approaches (Cutliffe and McKenna 1999). A researcher who adopts a quantitative approach to the collection of data views the world through a particular type of lens which suggests that the world can be explained and understood in terms of universal laws and objective truths (McKenna, 1997). Its positivist and empiricist underpinnings suggest that there is only one reality and consequently, a measure of the accuracy of this reality is validity.

On the other hand, however, the qualitative researcher views the world through a very different lens, based on the belief that there is no one singular universal truth, the social world is multi-faceted, it is an outcome of the interaction of human agents, in a world that has no unequivocal reality (Cutliffe and McKenna 1999). It is concerned with describing, interpreting, and understanding the meanings which people attribute to their existence and to their world.

McKenna (1997) postulates that some concepts within nursing are so abstract and nebulous that it is impossible to investigate these concepts using empirical measurements and consequently, they lend themselves to qualitative enquiry. Cutliffe and McKenna (1999) however assert that the strength of some nursing theories lies in making practitioners think about their practice in creative and interesting ways and this implies that some theories produced by qualitative methods may not lend themselves to having their credibility established due to the extent of their inherent abstraction. Others have suggested that the essential reflexive character and subjectivity of qualitative studies render them incomplete, non-objective, and consequently impossible to check for complete authenticity of their findings (Altheide & Johnson 1994; Schutz 1994). Hammersley (1992) disagrees with this argument that no criteria can be produced which can help to establish the credibility of qualitative research findings. He suggests that all qualitative researchers should make some efforts towards this goal, otherwise researchers could be “conjuring up concepts, propositions and theories entirely from their imagination which do not reflect the phenomenon or situation under investigation” (pg. 69). Cutliffe and McKenna (1999) concur with this viewpoint, describing this type of theorizing as “a process of writing fiction” (pg. 376). However, others have suggested that the difference between fiction writing and research is that the researchers produce a “text” which is in turn read and interpreted by the audience. The readers therefore construct their own meanings or readings from the text. Altheide and Johnson (1994) adopt a similar position and suggest that a critical question for qualitative researchers to consider is how interpretative methodologies should be

judged by readers who share the same philosophical, epistemological, and methodological underpinnings? Qualitative researchers, therefore, have identified a variety of approaches to judge the credibility of their findings and these warrant examination.

#### **5.24 Reliability and validity in qualitative research – is it necessary?**

When conducting quantitative studies, the term 'reliability' is used to suggest that if the same study were reproduced repeatedly, then the results should be exactly the same. This concept is considered inappropriate when discussing qualitative research; however, qualitative researchers still need to demonstrate that their findings are the result of a rigorously conducted process (Morse, 1999).

Lincoln and Guba's (1985) four quality criterion were developed specifically for the interpretative paradigm, and whilst under constant refinement by the originators, (Lincoln 1995) and others (Beck 1993), the key features are *credibility*, which corresponds roughly with the positivist concept of internal validity, *dependability*, which relates more to reliability, *transferability*, which is a form of external validity and *confirmability*, which is largely an issue of presentation (Rolfe 2006).

#### **5.25 Credibility in qualitative research**

Burnard (1991) maintains that when researchers are generating patterns or themes from qualitative data, they can enhance validity and guard against researcher bias by enlisting the assistance of a colleague. Both individuals then produce categories, independently of one another (Cutcliffe and McKenna 1999). This process is known as 'multiple coding' (Barbour, 2001). Similarly, other authors suggest enlisting the assistance of an 'experienced' or 'expert' colleague to verify the data categorization, preferably one who is an expert in the area investigated (Appleton, 1995). However, Cutcliffe and McKenna (1999) argue that this approach has several philosophical and epistemological difficulties. Firstly, since qualitative studies are normally indicated when there is an absence of theory pertaining to the phenomenon under study, how likely is it that such 'experts' or 'experienced colleagues' will exist? In addition, they assert that the process of theory induction and the production of categories/themes is dependent upon the unique creative processes between the researcher and the data (Munhall and Boyd 1993; Schutz, 1994) and question whether two people will interpret the data in the same way, particularly as it is likely that one person will have been involved in the entire research process and have a more in-depth familiarity with the data and the subjects' world. There is another potential problem with this

approach. Enlisting the help of others to verify categories/themes somehow suggests that if more than one person thinks or agrees with the categorization, then this must be more accurate than one person's categorization. If this argument is expanded, it begins to support the positivistic philosophy that there is only one accurate interpretation, only one reality, and that the accuracy of an interpretation is increased as the number of people agreeing increases (Cutcliffe and McKenna 1999). In addition, Armstrong et al. (1997) give an example of where six experienced researchers who independently coded one focus group transcript and were unable to reach consensus on coding frameworks.

Others discuss participant validation or "member checking" as a technique to enhance credibility (Guba and Lincoln 1989; Mays and Pope 2000) however, Sandelowski (1993) suggests that whilst considered by some researchers as the strongest available check on credibility, this technique is not without limitations since if reality is assumed to be multiple and constructed (as it generally is in qualitative research), then 'repeatability' is not essential or necessary' (pg. 3). Other example of difficulties with member checking is that the account produced by the researcher is designed for a wider audience, whereas the participant will invariably focus on their individual perspective and may not recognise the perspectives of others. For this reason, Mays and Pope (2000) recommend using this technique as a process of error reduction as opposed to credibility checking.

Within this study, both techniques of "expert" and "member" checking were utilised to enhance credibility, however the purpose of the expert panel (in self-efficacy and/or venous leg ulceration) was to confirm that the statements derived from data analysis reflected the construct of self efficacy and were relevant to venous leg ulcer patients, rather than checking the credibility of the data analysis process itself. In the case of the member checking process, no feedback, affirmative or otherwise, was received by the participants, implying that they agreed with what had been presented to them. However, this should be viewed with caution since the lack of response could have due to several other factors, such as reading difficulties or the reluctance to appear to be critical of the researcher.

Barbour (2001) discusses the use of the grounded theory approach to data analysis as a technique to ensure rigour in qualitative research, the assumption being that if the researcher adheres to the somewhat prescriptive but systematic process of data analysis, all explanations or theories will be derived from the dataset itself rather than from a researcher's prior theoretical viewpoint (Knaack 1984, Lynch-Sauer 1985,

Munhall and Oiler 1986, Drew 1986). She goes on to add that “in reality researchers are unlikely to obtain research funding without having carried out a thorough literature review or having formulated some idea of the content of the data required to be collected”. (pg. 1116). Bryman and Burgess (1994) have criticised the use of grounded theory as “an approving bumper sticker” invoked to confer academic respectability rather than as a helpful description of the strategy used in analysis. Melia (1997) claims that, in reality, many researchers use a pragmatic variant of grounded theory, whereby they can achieve added value by identifying new themes from the data alongside those that could have been anticipated from the onset. All too often, however, the tension between these two different sorts of insight – and its potential to illuminate the topic being studied - is not explored in the presentation of the findings (Melia 1997). Uncritical adoption of grounded theory, therefore, can result in explanations tinged with the “near mysticism” that Melia (1997) derides in the original grounded theory texts (Barbour 2001). As discussed at the commencement of this chapter, my study was situated within grounded theory from a pragmatist perspective, and the primary aim of data analysis was not to develop theory per se but to draw on the qualitative findings to inform the SE scale. In addition, whilst acknowledging the paucity of literature on the subject under study, I did have some prior understanding due to my clinical practice. This could be defined as a “sloppy mishmash” (Morse 1991) or “method slurring” (Baker et al 1992). Whitemore et al (2001), however, contend that the rigorous application of methods exemplifies a systematic approach which appears to give credence and legitimacy to the validity of qualitative research, but at the expense of creativity. Janesick (1994) defined this as “methodolating – a slavish attachment and devotion to method” (pg. 215) that results in an overemphasis on methods to the exclusion of the creativity of research. Despite these difficulties, consensus is emerging regarding a pluralistic approach to knowledge development and that “the utilization of a particular method should not be seen as an absolute ontological commitment” (Booth et al 1997, pg. 807). Patton (1990) also adopts this stance, commenting that a philosophical approach to pragmatism matches the best method with the specific research questions and issues as opposed to universally advocating a specific approach, resulting in enhanced richness of knowledge development.

## **5.26 Reflexivity in conducting research**

Koch and Harrington (1998) further add to the argument of evaluation criteria for qualitative research and reconceptualised rigour by suggesting that researchers provide a reflexive account into their research by signposting to readers “what is

going on” whilst researching, allowing the reader to travel easily through the worlds of the participants and the researcher and decide for themselves whether the text is believable or plausible (their term for rigour) (pg. 882). Nolan and Behi (1995, pg. 587) enter the debate over the criteria that differentiate “good” and “poor” research and support the claim that there are no hard and fast rules. Reflexivity means sensitivity to the ways in which the researcher and the research process have shaped the collected data, including the role of prior assumptions and experience, which can influence the most avowedly inductive studies. Personal and intellectual biases need to be made plain at the outset of any study in order to enhance the credibility of the findings (Mays and Pope 2000). With this in mind, I have attempted to develop a reflexive account of the research process, made clear my positionality as a researcher, declared my epistemological beliefs and acknowledged that my prior knowledge of the subject, gained through clinical experience, may have influenced and shaped the data collection process. In addition, by presenting my findings in a transparent manner, I am providing an audit trail to allow the reader to follow the decisions I took when analysing the data.

### **5.27 Triangulation of methods**

The issues of demonstrating dependability, theoretical transferability, and confirmability within qualitative research continue to be contentious within the literature (Lincoln and Guba 1985). Within this study, the design incorporates methodological triangulation in order to confirm the truth (Appleton 1995). In recent years, the benefits of combining qualitative and quantitative methods in health research have been accepted by many researchers (Shih 1998, Waddington and Fletcher 1998, Barbour 1999). It is generally agreed that integration will capitalize on the strengths of different methods, while compensating for their weaknesses (Puch 1998). Puch (1998) recommends distinguishing between combining findings, combining data, and combining methods. Examples are the presentation of the findings from two types of investigation, without combining methods or data. Secondly, two types of data can be brought together during the analysis, which contribute to the findings (Coyle and Williams 2000). Finally, studies can combine methods, data, and findings in an attempt to synthesize various research strategies, such as surveys and fieldwork, at different stages of the research process. Miles and Huberman (1994), for example, suggest that the data from qualitative studies can be used to develop quantitative measures, as is the case with this present study. Cutliffe and McKenna (1999) argue, however, that if both sources of data provide

inaccurate results, then all this method would do is to confirm and support an inaccurate theory.

Smith and Biley (1997) assert that establishing truth value or representativeness can be attained using three types of triangulation:

- Triangulation by means of constant comparative methods. If a label appears repeatedly, then the researcher can be satisfied with its existence.
- Triangulation regarding the variety of data collection methods. If each method produces the same, then the truth value is increased.
- Triangulation regarding the variety of participants – the more people assert the importance of an issue, the more they can be trusted.

Cutcliffe and McKenna (1999, pg. 379)

It is intended to use the first and third types of triangulation, defined by Smith and Biley (1997) within this study in order to develop a quantitative instrument; however, it could be argued that the epistemology underpinning this approach is positivist and therefore inappropriate for qualitative studies (Cutcliffe and McKenna 1999). Given these arguments, it appears that some forms of triangulation can help establish the credibility of qualitative research findings, yet if used as the only method, data triangulation could be regarded as inappropriate. Nevertheless, Cutcliffe and McKenna (1999) concede that if data triangulation or other triangulation methods are used in conjunction with other attempts to illustrate representativeness, then it should lend credibility to the findings (pg. 379).

The issue of combining methods of differing epistemologies and the inherent tensions that inevitably result will be discussed in more detail in Phase 2 of this study. As discussed earlier within this chapter, the aim of data analysis in Phase 1 was to develop self efficacy statements for the developing scale, grounded in the data gleaned from the patients' perspective, which was achieved. However, as stated earlier, the intention was not to create a grounded theory per se, but to continue to develop and refine the categories to enable presentation of the findings. These qualitative findings will now be presented within the next chapter.

## **6.0 Chapter 6 Qualitative findings**

### **6.1 Emergent themes**

The purpose of this section is to present the major findings of the qualitative phase of the study which emerged through the constant comparative data analysis process. The open codes within the three major tree nodes – affective, cognitive and everyday life were further analysed and categorised in order to develop common overarching themes. 6 major themes emerged together with sub-categories, and these were:

#### **1. Looking for reasons**

- 1.1 Trauma
- 1.2 Avoiding situations

#### **2. Living with continual uncertainty**

- 2.1 Prior experiences
- 2.2 Fear of recurrence
- 2.3 Constant vigilance
- 2.4 Coping strategies
- 2.5 Seeking reassurance
- 2.6 Being checked out

#### **3. Restricted lives**

- 3.1 Limitations on everyday activities
- 3.2 Maintaining personal hygiene
- 3.3 Body image
- 3.4 Difficulties in performing self-care activities

#### **4. Knowledge and education**

- 4.1 Lack of education on the part of health professionals
- 4.2 Lack of knowledge on the part of the patient
- 4.3 Receiving conflicting information

#### **5. Normalising and adapting**

- 5.1 Remaining optimistic
- 5.2 Carrying on regardless
- 5.3 Perseverance
- 5.4 Adapting and innovation
- 5.5 Friends and family support

#### **6. Developing expertise**

- 6.1 Navigating the system
- 6.2 Being assertive
- 6.3 Control issues in the patient/professional relationship
- 6.4 Identifying skilled health professionals

In an attempt to provide an audit trail for readers to follow, the participants' narratives will be presented and discussed here in order to demonstrate how the categories and

subcategories were created. The findings presented may not follow the exact sequence listed above since many of the categories are interlinked and intertwined.

## 6.2 Looking for reasons

### 6.2.1 Trauma

As an introductory question, I had asked each participant in turn to tell me their story about their venous leg ulcers, when and how they had developed. This category related to how the participants reasoned why they had developed a venous leg ulcer or had developed a recurrence, and is closely aligned to knowledge/education which was a major category to emerge during data analysis. The comments illustrated the lack of insight participants appeared to have about their condition, which has been discussed elsewhere within the literature (Hamer et al. 1994, Charles 1995, Bland 1999; Edwards et al 2002). The participants linked the development of an ulcer with a traumatic event but did not appear to associate this with the underlying condition, chronic venous hypertension:

- FG9 (2)** *“it turned out that I had M.R.S.A. (in hospital) and it’s left my leg with varicose eczema, but it’s been a case of an injury caused the ulcer”*
- FG9 (4)** *“Well, yes, when mine started – I was out in the garden working and I tripped on a flowerpot and banged my leg.”*
- FG8 (2)** *“I think it’s due to bad knocks, you know. I had a bad knock on my leg and I treated it myself for a long time, but it just was not getting better so I went to the doctor about it, I had to”.*
- FG7(3)** *“Well, the first ulcer I had was on the other ankle, started about 18 months ago, I think it started from a shoe rubbing, you know, and I was sitting in the doctor’s surgery and I told the nurse and she said “No, that doesn’t cause it, but it does, doesn’t it?”*
- FIG(2)** *“Ughmm, the first one on my right leg, I tripped over a plastic wash basket and my leg just wept and I went to the doctor’s and it healed but it also turned into an ulcer and the other leg, urghmm, my grandson threw a toy and it hit my leg”*

Although the majority of the participants appeared to link a traumatic injury with the development of a leg ulcer, one participant suspected that her ulcer had been caused by a Doppler test:

- FG8(2)** *“I had them on both legs and eventually they cleared up after 6 months and I went about 4 years clear, just wearing stockings. But then I came over here (Leg ulcer clinic) for a Doppler test, had the test and they said everything was O.K., but two days later, I had an ulcer come upon this leg, for what reason I don’t know.”*

Furthermore, some participants described how they were often preoccupied with avoiding situations where a potential trauma injury could recur, for example, a supermarket trolley, and how this affected their everyday life (Mudge et al 2006). Several participants avoided spending time with their small grandchildren or pets in order to prevent accidental knocks. One participant described how he had decided to wear a child's shin guard under his trousers on both legs in order to prevent a further trauma. His fellow participants were impressed with this innovative strategy and several male participants stated that they would try this also. This fear of trauma and its association with ulceration has been widely discussed in the literature (Nudds 1987; Hamer et al. 1992; Moffatt et al. 2004a; Mudge et al. 2006) and appears to be a valid concern for patients, reflecting the importance of acknowledging lay beliefs which are models of illness explanations that patients employ in order to understand the illness experience in the context of their everyday life (Ryen 2004). This emerging theme within this study concurs with the widely-held view within the literature that many leg ulcer patients are unable to adequately describe or explain the aetiology of their condition (Salaman et al. 1995; Edwards et al 2002; Moffatt et al. 2004; Mudge et al. 2006) despite having received explanations.

Salaman et al. found that 50% (n=8) of patients questioned denied ever having received an explanation; however 75% of patients appeared to understand the importance of compression therapy, although 62% felt it was not effective. Edwards et al (2002) interviewed 101 patients, median age 75 yrs. (range 23-91, 54% female) in order to determine level of knowledge on aetiology of venous leg ulceration and found that only 66% knew the cause of their ulcer, with 28% citing trauma as the cause. Thirty-nine percent did not know what the term 'venous' meant. 'Trauma' was frequently described by the participants as a psychological problem, with only 7% associating the word with a knock or a wound. In Edwards et al's study, over half of the patients (64%) expressed an interest in acquiring further information, particularly on how they could assist ulcer healing. This was also apparent during the patient/carer focus groups in this study where the data collection process had to be interrupted in order for me to provide an explanation as requested by the participants. Hamer et al. (1992) found that 20% of patients could not remember or did not know the cause of their leg ulceration. Nudds (1987) investigated whether leg-ulcer healing rates improved following provision of detailed patient information. The findings indicated that patients who understood the pathophysiology of leg ulceration appeared to be more committed to wearing compression hosiery or bandaging than

those who did not. Mandal (2006) found that some patients refused to wear compression hosiery following ulcer healing because they thought they were “cured” (Cullum et al. 1999). As a result, Moffatt and Franks (1998) to suggest that patient education may have a role to play in promoting patient adherence. The challenge is to provide information which can be delivered in a way that suits all leg ulcer patients, bearing in mind the multi-cultural demographics of the United Kingdom, and the variance in reading abilities across populations. The “Look after Your Legs” (LAYL) initiative developed by Freeman et al. (2007) is an innovative support group designed to promote self-care messages to patients with healed leg ulceration. In order to address the difficulties in conveying information to patients, the nurses have developed a CD which features health behaviour messages using “rap music”, which has been translated into various languages to include all ethnic groups. This is a highly innovative approach to the problem; however it may not suit the needs of elderly venous leg ulcer patients. The development of self-care programmes in the future may provide the ideal venue for delivering information with continuous reinforcement of health behaviour change messages and at a pace that suits most patients. The implications of failing to provide explanations on enhancing self-efficacy will be discussed in more detail within the Discussion chapter.

### **6.2.2 Avoiding situations**

When further explored with the participants, they described to me how they lived in constant fear of another injury and the avoidance strategies they employed in everyday situations, where they considered that there was a risk of further trauma, for example, having the grandchildren around to visit, or visiting supermarkets:

- FG9 (2)** *“Laughs, well, I avoid my grandson now (all laugh), well, he was only 2, he’s 4 now, so I’m weary about my legs now”*
- FG9 (4)** *“Well, the other thing is, supermarket trolleys, I’m really scared of them now. If I know a shop is busy and crowded, I’ll sit in the car to avoid them so it does affect our everyday life really, cos (sic) I’m always frightened I’m going to get it knocked and start one off, you know!”*
- FG8(1)** *“What I’m more concerned about is somebody walking into me, with a pram or something, or a trolley in the supermarket (heads nodding in agreement)”*
- FG7(3)** *“And the other thing is, getting on and off public transport, you know, have to be very, very careful, I mean, these new buses, with the low floor, they are very good if the driver is good enough to come in close to the kerb, I found that some of them don’t bother and its quite a step down, you know, you have to be careful you don’t catch your leg”*

**FG9(5)** *“Well, I had somebody go into the back of my ulcer with a supermarket trolley and I was terrified it would make the ulcer bigger but “touch wood” it was O.K. but things like that, I’m really worried about. Or if I go to my grandchildren’s birthday parties, you get kids running around under your feet; I think “Oh God, I hope they don’t knock my legs”*

**FG4(2)** *“I know exactly what these people are talking about, I had ulcers for years and the worst bit is being worried if you knock it, it will start up again and worrying (sic) things like supermarket trollies, makes you scared and stops you going out, really, and that’s frustrating specially when you’re young, getting on with your life, you know, got things to do. I can see exactly where all these people are coming from!”*

This fear of a repeated trauma experienced by the participants was acknowledged and validated by the nurses who cared for them who commented:

**FG2(2)** *“I do feel that they may worry about things, shopping trollies and things”*

**FG2(4)** *“Yeah, shopping trollies – they are scared to knock their legs again, and gardening, things like that. I think it makes them more cautious about doing certain things, normal activities around the house and that”*

**FG2(5)** *“It’s not just that, it just makes them edgy and wary of certain things, like shopping trollies and things. They have to be more careful where they walk, around sharp corners, cats, things like that”.*

Interestingly, two of the nurse participants from the first health professional focus group (FG1), where the consensus opinion was that of pessimism with regards to recurrence prevention, commented:

**FG1(2)** *“I mean, I’ve had a lady who scratched or did something to her leg so that we have to go and see her – she definitely didn’t want to be discharged!” (from district nurse caseload)*

**FG1(1)** *“Yeah, - I do find it’s the same patients that seem to have the same accidents though!” (All laugh)*

These two participants were implying, by using a common language understood by many nurses who care for leg ulcer patients, that for some patients, an open venous leg ulcer was beneficial, in that they could continue to maintain contact with their nurses in order to counteract feelings of isolation. This phenomenon, known in the literature as “knitting needle syndrome” or “a social ulcer” (Wise 1986, Ertl 1992; Moffatt 2004), is based on anecdotal evidence only but continues to be perpetuated by community nursing staff. Leg ulcer patients, particularly those who are housebound and rely on district nursing services are often described as socially-isolated (Walshe 1995; Franks and Moffatt 1998; Husband 2001a) due to reduced face to face contacts. This may, however, be a somewhat stereotypical and over-

simplistic view since social isolation as a concept is very complex and merely increasing the number of contacts a person receives may not necessarily relieve feelings of social isolation and loneliness (Brown 2003). This will be discussed in detail in the Discussion chapter.

### **6.3 Living with continual uncertainty**

#### **6.3.1 Constant vigilance**

The fear of ulcer recurrence resulted in participants becoming extremely vigilant, constantly examining their legs, and looking for signs that signalled the return of their ulcer:

**FG4(2)** *“Oh God, yes, for years and years with some months remission (describes the lengthy healing period) and then, you know, for no apparent reason they start up again.”*

**FG6(2)** *“Oh yes, at the moment, every single blemish, I think, “Oh God, here it comes*

**FG7(3)** *Now, of course, when I look at my ankle, I see a little red mark sometimes and I think, “Oh my God, what’s that, but its nothing usually”*

**FG4(1)** *“I think it’s probably the worry that one’s going to come back, just one little tap, or anything like that”.*

**FG7(2)** *“Oh yes, you’re petrified, everything you do, you’re watching your legs all the time, aren’t you?”*

The participants described how they remained vigilant once their ulcer had healed, constantly looking for signs that their ulcer was returning. The majority had suffered several recurrences and were aware of the visual clues that a recurrence may develop, for example any skin blemish or red mark. Patients with recurrent venous leg ulceration have to learn to live and adapt to a life with on-going uncertainty and the participants in this study described using coping strategies which bore similarities to those attributed to the Theory of Uncertainty in Illness (Mishel and Braden 1988). According to Mishel, individuals select adaptive coping behaviours which are broadly problem-focused or emotion-focused in order to cope with the uncertainty. Problem-focused coping strategies include vigilance, information-seeking and the use of social support, whereas emotion-focused strategies include avoidance, wishful thinking and selective ignoring when events producing uncertainty cannot be altered. Whilst associated with chronic conditions such as diabetes or cancer, it would appear that Mishel’s theory may be germane to leg ulcer patients also since it was evident that some of the participants employed such problem-focused strategies. According to

Mishel (1990), patients living with uncertainty over time may view the uncertainty in a positive or negative way. The Theory of Uncertainty in Illness is inextricably linked to psychological theories such as internal/external locus of control, self-efficacy and learned resourcefulness (King and Mishel 1986; Mishel and Murdaugh 1987; Mishel 1990) and its potential relevance to leg ulcer patients will be expanded upon in the Discussion chapter.

### **6.3.2 Prior experiences**

These participants had experienced several episodes of open ulceration throughout their lives and consequently relied on visual signs gleaned from past experiences, such as an area of redness on their leg, to determine whether their ulcer was returning or not. When the signs abated and no ulcer developed, they were reassured although this event did not necessarily become a cue for action, i.e. seeking help or wearing the prescribed compression. In contrast, some of the health professionals believed that participants' prior experiences could have a negative or positive effect on adherence with compression therapy:

**FG1(3)** *"That's what I mean about the timeframe. If you've had a leg ulcer for two years and then it heals, you are going to be more likely to want to wear something that stops them coming back, aren't you?"*

**FG3(2)** *"But equally, if you have a leg ulcer and it heals really quickly, you might say to yourself, well, that was easy, it only takes a few weeks to get better why bother with stockings!"*

**FG3(4)** *"Yeah, agree with that. I had a lady like that, but when her ulcer came back eventually, she couldn't wait to get her stockings back on – it's surprising how many people think – "Oh, its only a little red mark".*

The health professionals appeared to be inadvertently articulating performance mastery experience, a fundamental tenet of self-efficacy theory (Bandura 1992, 2004). Performance mastery experience is a composite of prior experiences associated with carrying out a specific behaviour according to Bandura (1992, 2004). This forms the cognitive process associated with preconceptions about ability, perceived difficulty of task, effort needed and circumstances that will influence a change in efficacy belief (Bandura 1977). Enactive experience which leads to success is the most powerful source of efficacy information (Maddux and Lewis 1995). In the case of vigilance, this may have been the manifestation of a coping behaviour in response to living with constant uncertainty.

### 6.3.3 Coping strategies

Patients with recurrent venous leg ulceration learn to live and adapt to life with ongoing uncertainty. The following participants were employing emotion-focused strategies including avoidance, wishful thinking, selective ignoring, hope and belief in God when events producing uncertainty cannot be altered (Mishel 1998). Whilst associated with chronic conditions, such as diabetes or cancer, it would appear that Mishel's theory may be germane to leg ulcer patients who have to deal with uncertainty constantly:

- FG6(2)** *"But thank God, this great place and the good girls (Leg Ulcer clinic) are helping me now and at least I have got something to look forward to now, light at the end of the tunnel, and please God, it has got better."*
- FG6(4)** *"I'm worried cos (sic) its started to heal but the other side, its still tender where the other one used to be, oh God, oh I'm praying that it doesn't develop into another one....."*
- FG7(4)** *"Fortunately now, my legs have healed and I'm just keeping my fingers crossed, they will be alright"*
- FG6(2)** *"I'm worried cos it started to heal but the other side, its still very tender where the old one used to be and I banged it on the bed, oh God, so I'm praying it doesn't develop into another one....."*
- FG9(1)** *"And so I keep them well creamed and just hope for the best....."*
- FG3(2)** *"I think as well, for the ones that have been healed a while, you tend to get the ones who wont use hosiery. Although they have been through it they think "oh, it's alright, it'll be alright and then they are so disappointed when they come back again".*

The Theory of Uncertainty in illness is extricably linked to psychological theories such as internal/external locus of control, self-efficacy and learned resourcefulness (King and Mishel 1986; Mishel and Murdaugh 1987; Mishel 1990) and will be expanded upon within the context of venous leg ulcer patients within the Discussion chapter.

### 6.3.4 Seeking reassurance

In acknowledging this uncertainty that their ulcer may return, the participants described how important it was for them to maintain contact with their nurses and to have a point of contact should they have concerns about their ulcer returning. The importance of maintaining this contact was also articulated by some of the health professionals:

- FG3(2)** *"I think they (patients) are always worried that it is going to break down again and they seem quite anxious. Some of them, uhmm, don't seem*

*to want to stop coming to the leg ulcer clinic or stop having visits. I think you add to their security, if you like, cos you are looking all the time and notice if there are any changes (in skin) or that"*

**FG3(3)** *"For some of them, it's a social outing, I think, they like the contact with us. Last week I had someone who had healed and so I said "So you won't be coming any more", she seemed quite upset!"*

**FG3(1)** *"Oh yes, I agree with what's been said, but I will just say that, particularly in the elderly, once they've healed, they do seem to miss the visits, but they know that if an ulcer breaks down again, we'll be back in again".*

Interestingly, the participants from this particular focus group (health professionals) viewed their patients' desire to maintain contact with them in a positive way and acknowledged that this contact was reassuring, borne out of the patients' desire to prevent an ulcer recurring. Conversely, some of the participants from previous health professional focus groups had labelled this behaviour as "attention-seeking", with the implication that that the patients wanted their ulcer to return in order to benefit from the contact with the nurses. The participants on the other hand, both patients and carers/family members explained how they valued this connection with their nurses, reassured that they had a point of contact if they suspected their ulcer was recurring:

**FG4(2)** *"It's nice because it's a point of contact (Leg ulcer clinic), you know, even when it's healed, it's a place that you can just come and see people who are happy to advise you....."*

**FG5(2)** *"I know she can't continue coming now, but already she's thinking" Oh God, what do I do if something happens.....but I know we've got the phone number....."*

**FG7(2)** *"I think the good thing about this is that although you come once a week to have the leg dressed, you can contact somebody if you've got a problem, you know you can phone and you always get a nice person who can give you advice if you're worried".*

### **6.3.5 Being "Checked out"**

The participants also regarded the routine Doppler ultrasound as beneficial and looked forward to being "checked out". Two participants (family member and one patient) said:

**FG5(2)** *"And you know, I bring her back here, you know, every three months for a Doppler, is it? which I call her MOT and they check her for everything, you know. At first she used to be really nervous, but now she loves it. She's not a very outgoing person, anyway, my mum, so that's why I tend to go with her – to put our minds at rest, you know, its like support".*

**FG9(4)** *“Well, I must say that I am extremely grateful to have the Doppler test every 3 months because I think the girls here are absolutely lovely, I enjoy seeing them. I’m always pleased to see them and I always enjoy saying “See you in three months” and it does mean that you are checked up on constantly”.*

Most of the participants viewed the Doppler test as a form of MOT, and one participant described how a cardiac condition was diagnosed as a result:

**FG9(5)** *“I was coming here for some time and then I was told I’ve got something else wrong with me..... They took my pulse and said “You’ve got an irregular pulse (atrial fibrillation) so go to your doctor. I went to the doctor and now I’m on Warfarin, so if I hadn’t been told here that my heart was giving me a bit of trouble, I wouldn’t have known!”.*

For others, however, the routine Doppler appointment was viewed as a time of uncertainty, one participant described his trepidation:

**FG6(1)** *“Can I just say something, cos I’ve got, virtually, you know, have had a “well leg” for over a year. When I went for my Doppler last week, there was a patch of eczema and T. said “Well, I think we’ll put you back into bandages for two weeks, that might go.....Now, that terrified me, to think that I would have to go back into those bandages again.....”*

One participant, who suffered with diabetes and had persistently high blood glucose levels found the routine Doppler tests tedious as she knew that this would result in further investigations of her diabetes:

**FG9(3)** *“I don’t like the offshoots of the Doppler to be honest – the, urghmm, diabetes test. When I came last time, A. said “well, it’s very high – go your doctor’s. So I got sent over to the hospital for a blood test and the blood test came back and that, but I hate having blood tests, my veins are so deep seated, so I always end up with bruising, I come back with bruises all over the place.....”*

This particular participant’s view is presented as a negative case (Strauss and Corbin 1990) in that it deviated from the perspectives of the majority view. According to Strauss and Corbin (1990), negative cases are useful, not to negate the current findings, but to add variation and a depth of understanding which needs closer investigation. This particular participant may have been using “selective ignoring” and “distancing” as an emotion-focused strategy (Mishel 1990) in order to cope with the uncertainty of her life with diabetes.

## 6.4 Restricted Lives

### 6.4.1 Limitations on everyday activities

The participants and their carers talked about how living with the continuing vigilance and dread of ulcer recurrence impacted on and limited their everyday activities, which, in many cases, were severely curtailed. Many of the other participants appeared reluctant to visit their garden, maybe anticipating that an ulcer may reappear, through trauma, in what was considered to be a high risk environment:

**FG4(5)** *“With my husband, it’s difficult to get him to do anything. He’s keen on his garden, but mostly he leaves me to do it now.....”*

**FG4(7)** *“It all started with a bite in the garden and that ulcerated her leg. She wont go in the garden and sit these days. In the conservatory, but not in the garden”*

**FG4(6)** *“Well, when P. was bad with ulcers, she was afraid of falling, so she wouldn’t go in the garden. She loved her garden, she did, pottering around, but she wouldn’t go in it.....”*

Others described how normal, taken for granted everyday activities, such shopping and climbing the stairs in shops became a huge challenge in an effort to avoid trauma to the legs:

**FG4(5)** *“Also, I don’t think a woman of her age should be going upstairs and downstairs, sideways, one step at a time, its not the way to do it. At home, it’s OK, but when you’re out and about and you’ve got people behind, waiting to come down, and you have to take one step at a time, sideways, that’s restrictive.....”*

**FG4(4)** *“M’s like that. When we go to the stores, she won’t use the stairs cos she doesn’t want to hold people up, you know. They get impatient cos they can’t see what’s wrong, like. It’s certainly changed my outlook now”*

**FG7(2)** *“It is a problem, getting to sleep in bed with this, you’ve got to move but you’re frightened too, in case you knock your leg and then, you worry about your partner as well, don’t you?”.*

### 6.4.2 Maintaining personal hygiene

A major issue for all participants appeared to be the difficulty in maintaining personal hygiene when an open ulcer was present, or when compression hosiery was being worn. This was not surprising since it is frequently raised within the quality of life literature (Price and Harding 2004; Edwards et al. 2005, Heinen et al. 2006).

- FG5(1)** *“Well, I think one of the biggest problems is personal hygiene with the wife – especially with the legs done up, like..... You know, its difficult to shower or bath with the legs done up.....”*
- FG6(2)** *“Well, I agree, but I find, the actual hygiene part, you know, having a bath or shower for me, I mean, I used to do that everyday, but now I have to top and tail, stand on one leg, you know..... (laughter)”*
- FG8(2)** *“Well, yeah, that’s right. If I could get it on, you know, on my own it wouldn’t be so bad. I mean it’s awkward for showering and things, yeah, it’s restricting”.*

It is common practice for leg ulcer health professionals to advise patients to wear their hosiery continuously for up to seven days if they are unable to put them on/off independently. This recommendation would appear to be for the benefit of the health professionals, rather than for the patient and may be due to potential financial constraints within the NHS. Within the PCT where I am employed, the application of compression hosiery is considered not a “nursing” task but rather a “social” task, i.e., part of personal care. As such, the patient is means-tested and required to pay for a Social Services carer to perform this for them. The financial implications to a patient are obvious and so, in reality, this very rarely happens. This also serves to illustrate the short sighted view and low priority given to the prevention of venous leg ulcer recurrence, both locally and nationally by health service commissioning bodies and as a result, many leg ulcers will recur, resulting in increased NHS expenditure in terms of dressings and nursing time.

From the patient’s perspective, to wear constrictive elastic hosiery continuously for seven days may be considered unacceptable, however, there are now aids available to enable patients to shower/bathe whilst wearing bandages or hosiery. Two participants were already using these aids, one successfully and the other, not quite so successfully:

- FG7(2)** *“Well, I go out and about despite my leg, you know, once a week I go to the clinic for dressings and things, but the other thing is, having a bath, isn’t it? It’s almost impossible to have one, with one leg hanging out over the side, but now I’ve got one of these plastic things, they are a Godsend, and its no longer a problem, they are amazing, they really are really are.....”*
- FG7(4)** *“Well, I’ve got one of those. the trouble is, when I’m in the bath, it fills with water and blows up like a balloon..... (all laugh). Then you’ve got to ease the air out of it.....”*

The remaining participants expressed interest in these products and, as mentioned previously, as a clinician, I felt obliged to advise the participants about the aids

available and so left product information on conclusion of the focus groups. It would appear that some of the health professionals may have been making assumptions about their patients without exploring their areas of difficulty in more depth and by supplying the appropriate aids, may have been able to reduce the participants' distress at their inability to perform a very basic human requirement. This issue also raised concerns for me from a clinician's perspective in that some of the health professionals' knowledge may not have been up to date.

#### **6.4.3 Restrictions on leisure pursuits**

Some of the younger participants described how they enjoyed going on holiday or staying away from home and the forward planning required in order to continue caring for their ulcers:

**FG7(3)** *"What gets me is if you are going somewhere, you know. If you are staying in a hotel, or with a relation, you're frightened about the leakage if an ulcer came back. I was in one place, and I'd forgotten to take me (sic)you know, bits and pieces, and at that time it was particularly vulnerable – so I tried to sleep with carrier bags over my legs, and, (laughs).....it's most uncomfortable, you know.....!"*

**FG8(2)** *"I find holidays quite difficult, I have to take all my paraphernalia – I mean, in case I need to change a dressing....."*

Several participants explained how having had a healed leg ulcer and the fear of recurrence had resulted in restriction of their leisure pursuits:

**FG6(6)** *"But I find that being careful and.....(hesitates), and sensible is the best way to be, so I don't go on my motorcycle any more....."*

**FG6(4)** *"Oh yes, I agree. I used to go on a bicycle a lot but couldn't do that now – too scared of knocking my legs". After all, it only takes one whack doesn't it? And then you start all over again, and it takes so long to heal!"*

**FG7(4)** *"Well, I've had my veins done twice, and they wanted to do them again but I said "No, thank you!!". But I do find they curtail a lot, like swimming and that, cos, like previously said, I'm vain so I don't go swimming now".*

#### **6.4.4 Restrictions on appearance and body image**

Having to wear compression hosiery or stockings impacts negatively on the body image of both male and female patients and has been highlighted frequently in the literature (Mudge 2006, Douglas 2001, Walshe 1995, Hyland et al. 1994). The female participants appeared to be grieving for their loss of femininity. One participant, who had developed leg ulceration at a very early age, said:

**FG5(3)** *“I have never really felt like I was attractive, like other women of my age. They were all out in short skirts, no tights and that and I was in, what I call, granny tights. They were thick, just like my granny used to wear. so I used to feel terrible. I used to feel really awful, I used to dread going anywhere.....”*

Two other female participants agreed:

**FG6(3)** *“And I could never wear skirts, then went into trousers and I really felt, as time went on, that it stopped me doing some of the things I wanted to do. But I do feel, you know, sometimes that I have missed out on things sometimes, you know, when I couldn’t wear a nice dress”*

**FG7(2)** *“I must admit, last year in the summer, I did wear dresses – this year I can’t because of the ulcers so I just wear the thinnest trousers I can. I think, as you said, for a man it must be difficult whereas for a woman, they would expect you to wear stockings or tights. But my husband said to me about a year ago, “Why don’t you put a skirt on S, we are going out to dinner, cos all my family know about it, you know and I said “Well, no”, cos when you’ve got a skirt on, it then looks like– look at poor me – so I don’t!”*

This negative impact on body image was not just confined to the female participants.

One male participant described how other people stared at him when wearing his hosiery:

**FG7(3)** *“Psychologically, ughmm, I’m a bit self-conscious sometimes, you know. Not too bad at this time of year, but when I get out and about during the summer, I like to wear shorts, but its amazing how people look at you; they must think I’m wearing the wife’s stockings, or something!”*

Another male participant felt that because the stockings were so thick and skin-coloured, they were seen as “medical”:

**FG3(4)** *“It’s always the stigma attached to wearing them.....(pauses) something that you’ve had medically prescribed, and it’s the colour of them”*

Even when the ulcers had healed, patients were left with the visual evidence that they were not cured. The skin changes that had resulted from venous hypertension (lipodermatosclerosis) were a permanent reminder of the ulcer:

**FG2(7)** *“Well, my legs are still dark, so I said to the nurse “is that ever going to go away?” She explained that it was the condition, but it affected me badly, I’m very conscious of it.....”*

**FG4(4)** *“I know with my husband, he’s very conscious of it cos (sic) it’s left the leg brown, like!”*

One male participant explained how the staining to his leg had resulted in an embarrassing incident on holiday:

**FG7(3)** *“I had an incident last year when I went away on holiday abroad. You know you can’t go swimming with the stockings on, so I took them off and got into the pool. A little girl ran past me and said “Mum, look at that man’s legs”. Mummy talked to the hotel management and so I was banned from the pool. I did go swimming, but in the sea, not in the pool!”*

**FG6(4)** *“I know what you mean, I started when I was 40, that’s 30 years ago, and I was in the very, very thick elastic tights, you know. I was one of the sales, you know, on the fashion floor, in \*\*\*\*\*, Clifftown Road, and it was because I had always been on my feet, had skinny legs and then, eventually, they broke out and I got an ulcer. I went to Q Surgery, they were ever so good to me, and I must admit that we must have tried everything and anything, and I must admit, like you, I had to take the tights off and had to have bandages on and, at 40, I must say, I was a little bit – you know, vanity, vanity. And I couldn’t wear skirts, and then went into trousers, and I really felt, as time went on, that it stopped me doing some of the things I would have liked to do”.*

The health professionals acknowledged that wearing compression hosiery could impact negatively on their patients’ body image and discussed how they persuaded their patients to choose hosiery that was cosmetically more acceptable, like black ribbed socks. This issue is currently being addressed and companies are developing compression stockings that have a normal appearance which may help address the issues raised by the participants.

#### **6.4.5 Restricted everyday activities**

For some of the participants, even normal activities, like visiting grandchildren or social occasions, filled them with dread:

**FG5(1)** *“Oh yes, I try and avoid situations where I might be at risk, you know, like avoiding children, dogs, things like that”*

**FG7(2)** *“But you have to watch the young granddaughter. My daughter says constantly – “don’t go near Nanny’s leg; don’t go near Nanny’s leg!”*

**FG8(2)** *“And, of course, you can’t really play with the grandchildren very much, so I’m a bit fed up, really”.*

One participant, who had suffered repeated ulceration over many years, gave a moving account of how her condition had adversely affected her life:

**FG5(2)** *“But years ago, I used to dread it. I’ve actually been to the school for the children’s plays, you know. And I’ve had to sit and the children have sat in front of me and I’ve heard the children turn round and say about the smell, you know. You’re frightened to go anywhere; you’re terrified of being in a closed place. I used to hate queuing, and that, cos I could smell it before anyone else, if I could avoid going out, I would, you know!”*

#### **6.4.6 Difficulties in performing self-care – compression**

This sub-category was created to encompass participants’ descriptions of the difficulties they experienced every day in caring for their healed leg ulcer. As was expected from review of the literature, participants’ difficulties in applying compression hosiery emerged as a major sub-category. This was acknowledged by both health professionals and patient participants alike. The nurses appeared to sympathise and commented:

**FG4(3)** *“A lot of the older people find it hard to do.....and that’s why they don’t wear them because they can’t get them on.....”*

**FG4(5)** *“I know what you mean. I’ve said to him, “your stockings will help”, but he says “it’s easy for you to say, you can put my stockings on easy here, but I can’t get them off at home”*

**FG4(4)** *“Sometimes they can’t put them on properly but they do their best. But then they come back to the clinic with skin bulging over the top or where they have slipped down, it can cause damage and then they refuse to wear them again”.*

**FG8(2)** *“Yeah, I agree. Having to wear a stocking is a bit restrictive, you know, cos (sic) I can’t take it off at night, so its sort of there permanently”.*

Despite these difficulties, the majority of these particular participants appeared to manage to apply their stockings; however, this was not achieved without a struggle and the participants described how they had developed strategies over time to apply the stockings:

**FG9(1)** *“Well, I found those easier to put on (stockings with zips) but the knee parts of my legs are uhmmm, (laughs) quite plump and to try and pull it round and then zip it, well, you need three hands to do it!”*

**FG9(3)** *“I can get it on alright, but I do a lot of “tutting” when I get it off (laughs) I’m sitting there, you know, thinking “how an I going to get this off”, but I must take it off before I go to bed, so I can feel free from it, you know”.*

**FG5(8)** *“I’ve got elastic stockings and there’s only one complaint, they are very comfortable when they are on, but, boy, do I have a job getting them off. I was given an applicator, or whatever they call it, it’s alright but too messing around. I pull these stockings on, but to get them fully up, I have to put the silk one first, that’s supposed to help the other one glide on. It takes me a good 5 to 6 minutes to put it on.....”*

Several application aids have now been developed, such sliding applicators and hosiery with zip openings, however, they still require a certain degree of dexterity and there remains a potentially sizeable group of patients, who will continue to struggle with either applying or removing their hosiery and may need to rely on health professionals to assist them rather than self-caring for their ulcer:

**FG8(3)** *“Well, it makes me feel, well, old.....Well, I know I am old but it makes me feel old, the hardest thing is, I can’t put the stockings on my own. I do try, but my hands, you know, I’ve got arthritis, so I have to rely, you know, on the leg ulcer clinic to put it on.....”*

Van Hecke et al (2008) questions whether this group of patients should be considered non-adherent to treatment, as suggested by some health professionals and prefer the term “intolerant” to treatment, a view shared by Brereton et al. (1997). This potential limitation to the successful implementation of a health behaviour change model, such as self efficacy, in this patient group, if they are physically unable to change their behaviour, or do not see the application or compression hosiery as an self efficacy outcome expectation (Bandura 1989) will be discussed in more depth within the discussion chapter.

#### **6.4.7 Skin care**

The participants recognised the need for wearing compression hosiery to prevent their ulcers recurring; however, as discussed previously, for the majority, this was not easily achieved. Since the purpose of data collection was to explore what self care activities, as well as the wearing of hosiery, the participants undertook to prevent recurrence and the possible difficulties they encountered in trying to perform these tasks. Several of the participants described how they had been advised to apply emollients daily in order to keep their skin moisturised but were often unsure which products to use. The health professional participants acknowledged this confusion and commented:

**FG2(2)** *“I think if patients have got prescriptions for emollients and creams, they think they are important and will apply them daily to their legs. Some I think would do it, if they could, but I think trouble occurs when you say to patients “You need to find yourself a nice moisturiser” and we have been*

*a bit vague, as health professionals and then they will say “I’ve got a nice tub of cocoa butter” or something unsuitable and you then have to say, “its not really the right cream for your legs”.*

**FG3(3)** *“Like you say, about the creaming, especially the elderly population, they’re just used to a bit of soap and water, so they often can’t see the point, you know, a nice, soft emollient”.*

**FG3(2)** *“It’s sometimes easier if we can supply the emollient, that’s better somehow, particularly if they get it prescribed by us or the doctor, that definitely helps.....”*

**FG3(4)** *“They don’t seem to understand the importance of skin care and moisturising their legs, do they? Sometimes it’s just a battle, not just the stockings but the creaming of the legs, they say “Oh no, I just can’t do that, nurse!”*

It was apparent from these comments, however, that the nurses believed that patients would not apply their emollients because they did not appreciate the need to do so. This, however, did not appear to be the case, since the patient participants appeared to be aware of the need for skin care, but were sometimes physically unable to do so due to difficulties in manipulating their hosiery:

**FG8 (3)** *“That’s right, I’m able to roll it down (stocking), and cream it but I’m not able to roll the stocking up again!”*

#### **6.4.8 Leg elevation**

Elevating the legs at heart level is considered to be a contributory factor in the prevention of ulcer recurrence (Brooks et al. 2004), although currently there is limited robust evidence in the literature to support this (Dix et al. 2005). When questioned, the health professional participants felt that very few patients were able to do this regularly:

**FG1(2)** *“But also, when we talk about putting their feet up, we are talking about putting them up above the level of the heart – how many people can sit like that, it’s just not practical, is it?”*

**FG1(1)** *“What about asking them to elevate the foot of their bed – is that practical?”*

The patient participants confirmed the difficulty in elevating their legs regularly and attributed it to pain:

**FG6(2)** *“They tell us to put our legs up, you know, but I find it very difficult, you know. I do try, but it’s very difficult, I’ve got my bed raised....”*

- FG6(3)** *“I tend to forget, to be honest – they say “put your legs up, put your legs up” but I get cramp in the back of my legs, so avoid it if I can”*
- FG7(1)** *“I can’t do it, you know, too painful!”*
- FG7(3)** *“Oh yeah, definitely – I can’t put my feet up, no way, far too painful”*
- FG7(2)** *“Well, yes, they tell you to sit with your legs up but I can’t, it would kill me, the only way I get relief is by putting my feet on the floor”*
- FG7(4)** *“Oh no, I can’t. I’m far happier sitting like this (feet on floor), the only way I get relief from the pain”.*

The last two participants’ comments indicated that they may be suffering from a clinical manifestation of peripheral vascular disease, a symptom of which is increased pain on leg elevation, relieved by dependency and where compression hosiery may be contraindicated. It was clear, however, that many patients find leg elevation to the level of the heart difficult to achieve, mainly due to pain from arthritic hips etc. (Dix et al 2003; Dix et al 2005; Brooks et al. 2004, Herber et al. 2007). Unless pain experienced on elevation is addressed, it is clear that any attempt to bring about health behaviour change and encourage patients to perform this particular self-care activity will be unsuccessful and detrimental in terms of their performance accomplishments (efficacy-based and outcome-based futility) (Bandura 1997).

#### **6.4.9 Leg exercises and walking**

Interestingly, whilst there is some evidence in the literature to support the theory that exercising the calf muscle pump, by means of moderately strenuous physical activity such as walking and limited periods of standing may reduce the recurrence of venous leg ulceration (Smith et al. 1990; Abadi et al. 2001; Padberg et al. 2004; van Uden et al. 2005; Heinen et al. 2007a), only one of the patient participants mentioned this very important self-care activity:

- FG7(2)** *“I find things like the exercises and that really difficult to do. With his Parkinsons, you know, we used to go out for walks, but can’t now, that’s why I thought the physio might be able to help, give us some ideas about what you can do to help yourself, but its difficult and very frustrating...”*

Clearly, this is an area where it may be possible for patients to self care effectively if individually tailored exercise programmes were created in collaboration with members of the multidisciplinary team, such as physiotherapists or occupational therapists. As a clinician, I was concerned that, all the participants recruited to take

part in these focus groups were attending leg ulcer clinics, and were largely ambulant, only one actually mentioned exercise as a self care activity to prevent recurrence. Patients with reasonable mobility are in an ideal position to be able to undertake this important self care activity; however, it would appear that some of the health professionals caring for these leg ulcer patients were unaware of this fact.

#### **6.4.10 Weight Control and Smoking**

Obesity and smoking are considered to be risk factors in the development of venous leg ulceration (Lopez and Phillips 1998; Zimmet 1999; Kunimoto 2001; Leach 2004; Vowden and Vowden 2006) due to increased pressure in the abdominal venous system and poor tissue oxygen perfusion, resulting in suboptimum healing, although there is a paucity of evidence to support this. These two important lifestyle factors have been proven to be modifiable using interventions based on social learning theory to strengthen efficacy beliefs (Bandura 2004), such as Weightwatchers® (Shannon et al 1990) and smoking cessation programmes (Mothersill et al 1988; DeBusk et al. 1994; Schwarzer and Fuchs 1995). The patient participants appeared to demonstrate some awareness of these issues when questioned about self care activities and appeared to realise that losing weight may help stop their ulcer recurring:

**FG6(2)** *“I also think it’s the weight thing, isn’t it? It doesn’t help being heavy”.*

**FG6(1)** *“I’ve lost over 5 stone now and it’s helped, I think. My legs are still big, always will be.....”*

**FG7(2)** *“Yeah, I agree, as soon as I put weight on, my legs play up, so I have to be careful and keep my weight down”.*

One participant described how she tried to exercise but found it increasingly difficult as she suffered from severe arthritis in the hips and her husband had Parkinson’s disease:

**FG7(2)** *“I find things like the exercise and that, it’s really difficult to do, with his Parkinsons, you know. We used to go out for walks, but we can’t now. And regards to diet, its difficult, cos, if you don’t work off those calories that you’re eating, you just keep putting weight on.....”*

When questioned, none of the participants admitted to having a smoking habit openly. This may have been due to the stigma now attached to being a smoker and was therefore not pursued any further. The health professionals, on the hand, whilst acknowledging that patients should be encouraged and supported in changing their

risky health behaviours, appeared to be reluctant to do so and some even exhibited a defeatist attitude to behaviour change:

**FG1(2)** *“They probably don’t think that far ahead – they probably think, we’ll get this healed (leg ulcer) and when I’m better, then I’ll give up smoking, lose weight, or whatever!”*

**FG1(3)** *“I don’t think that many patients worry about that, people lose their limbs and still carry on smoking, don’t they? So, I don’t think a leg ulcer would stop them, do you? (All laugh....) And weight, that’s a huge issue, isn’t it? They are all getting bigger all the time, it’s their lifestyle.....”*

**FG3(2)** *“You can talk about diet to people and yet, with some of them, you really have to be blunt, almost to the point of rudeness..... (laughs)”*

**FG2(4)** *“Yes, but they don’t necessarily equate diet and nutrition to healing their ulcer, do they? They say to us “Yes, but what’s that to do with my leg?” And people are getting heavier, aren’t they?”*

**FG2(3)** *“It’s not so much about weight, its more about diet – I don’t think they get it sometimes. Sometimes you have to tell them, do it this way or that way and it gets them thinking a bit. It always comes back to education, doesn’t it?”*

#### **6.4.11 Changing Health Behaviours**

The health professionals in the leg ulcer clinics were ideally placed to give patients advice and encouragement on smoking cessation and weight management, as one acknowledged:

**FG1(4)** *“I think, if they are attending a leg ulcer clinic, they’ve got more health awareness, then that’s often a door open to them to come back through again. They seem to take more ownership of their health then.....”*

However, there appeared to be some reluctance to do so and this could have been attributed to two reasons. Firstly, the majority of nurse participants could be considered “mature” and, as such, had undertaken their nurse training prior to Project 2000, when health education and health promotion skills were introduced as part of the curriculum for nurse training (Latter 1998). As a result, therefore, the nurses may have felt they lacked the necessary skills to carry out these health promotion activities as part of their role.

Secondly, the nurses staffing the leg ulcer clinics were all from a district nursing background, where the dominant client group is elderly/older patients, who generally

require a reasonably intensive nursing care input. Biggs (1993) postulates that this particular client group is often inclined to be stereotyped as being highly care dependent, or even “passive recipients of care” (Ebbeskog and Emami 2005) and therefore not willing or able to participate in their care (Jewell 1996). It may be that the nurses in this case have stereotyped their patients in this way, particularly since the literature has also demonstrated that some leg ulcer patients do not want information about their leg ulceration (Hamer et al. 1994, Edwards et al 2002; Edwards 2003). Biggs (1993) further suggests that this stereotypical attitude may further lead to power differences related to professional status and age-related status. It is further suggested that the resultant communication, within the medical arena, ‘represents a clash between two differing ‘cultures’ – one technical and scientific, the other embodying the lived reality of the older person” (Clark 1996, pg. 748).

Briggs and Flemming (2007) concur and describe how the patient-professional relationship can have a positive impact when the focus of care shifts from healing to helping patients gain control over their lives. This shift in perspective on the part of the health professionals may influence the older person’s attitude towards participating in health care decision making and relationships with health care practitioners (McWilliam et al. 1994; Briggs and Flemming 2007). The health professionals in this study focused on patient-related factors when describing non-adherence, such as poor motivation, lack of knowledge, unwillingness to persevere with treatment (Van Hecke et al. 2008). Kyngas et al. (2000) however state that healthcare professionals often underestimate the complexity of “*adherence*” and are often unaware of the multiplicity of factors related to it, such as patient-related factors, treatment regimes, psychosocial influences and interpersonal relationships (Van Hecke et.al 2008).

The negativity towards their patients voiced by some of the HPs may have been due to ‘work disengagement’, described by Demerouti et al. (2000) as an antecedent of burnout in health professionals. The impact of this on clinical practice and the patient-professional relationship in encouraging patients to participate in their care (Sahlsten et al. 2007) will be discussed in more depth within the discussion chapter.

However, not all HP participants voiced a pessimistic view on encouraging their patients to change their behaviours. Participants of HP FG2 and HP FG3 appeared to exhibit a very empathetic and supportive attitude and approach to their patients. The participants consisted of seven female senior nurses; aged 23-60 years (HP

FG2) and eight female senior nurses aged 30-48 years (HP FG 3) who were employed in leg ulcer clinics in a neighbouring PCT. Although they made similar comments on patient non-adherence with treatments as the previous participants, they appeared to understand the importance of assessing patients' aims and expectations of treatment and the role of education, good communication skills and empathetic negotiation in achieving concordant and therapeutic relationships with their patients. They emphasised the importance of education and explanations to leg ulcer patients individually in order to achieve adherence with specific behaviours, such as the wearing of compression hosiery. One HP participant commented that she would start with the lowest level of compression, building up to optimum levels once the patient was tolerating this, always provided an application aid or selecting a slightly larger size stocking to facilitate easier application. Her rationale for this was that some compression would be beneficial rather than none at all (Cullum et al. 1999; 2001). She appeared to be willing to go the "extra mile" to help her patients and she had also discussed the issue of weight control and how she would sit down with the patient and discuss their eating habits, making suggestions as to how they achieve weight loss and even downloading weight loss programmes from the internet.

Furthermore, a participant from HP FG2 illustrated how she used goal setting to involve and motivate her patients to participate in their care. For example, when a leg ulcer was nearly healed, she would encourage the patient to discard the extra wide shoes required to accommodate the compression bandage system and purchase new "normal" shoes which would accommodate the hosiery. These HPs were inadvertently drawing on a major component of self-efficacy theory, goal setting, to achieve adherence with treatment.

## **6.5 Knowledge and education**

### **6.5.1 Information needs of patients**

Contrary to the findings of Hamer et al. (1994) and Edwards (2003) that some patients do not desire more information about their condition, it became clear throughout the data collection and analysis process of this study, that many of the participants actively sought more information about their condition.

The issue of knowledge/ education and the desire for more information emerged as an overarching theme which linked several of the other categories throughout the whole process of data collection. Many of the participants of the focus groups

(patients and their carers/family) requested more information on their condition or clarification on instructions they had been given by health professionals in the past.

**FG5(1)** *"I don't think patients know a lot about leg ulcers cos (sic) nobody explains it to you, why you've got it, you know"*

**FG5(3)** *"I didn't realise there was a reason that people got this....."*

**FG4(2)** *"You have to find it out yourself, don't you – there's very little help out there!"*

**FG4(1)** *"What I would like to know is what causes the ulcers?"*

**FG5(1)** *"Also, why don't they talk about the smell – it took us a while until we realised where it was coming from – I was looking all round the house, looking for something that smelled. Nobody said to me – "it's the ulcer and it's quite normal for this to happen" – we had to work that out ourselves. Also, with the hosiery, it would be nice for someone to explain why it's needed!"*

As a clinician, I found this remark quite disconcerting since, with appropriate wound care and frequent dressing changes, venous leg ulceration should not produce offensive odours. However, it would appear that this occurs frequently since this issue has been frequently voiced by patients within the quality of life literature (Walshe 1995, Charles 1995, Ebbeskog and Ekman 2000, Rich and McLachlan 2003) and was reiterated by several participants in this study. Perhaps by acknowledging this possibility and forewarning patients and their carers, the levels of anxiety that can result from developing odours, could be reduced for some patients.

The health professionals also recognised the importance of knowledge and how an apparent lack of understanding could impact on patient outcomes (Briggs and Flemming 2007). Interestingly, their approach and attitudes to educating patients varied considerably between individual focus groups. In the first focus group, where the nurses appeared frustrated and resigned to the fact that patients would not follow their advice, participants commented:

**FG1(4)** *"Ughmmm, I suppose intelligence comes into it somewhere – if they are not intelligent, they may find it difficult to understand treatments, making decisions about their health, they may think – "oh, that's the nurse's job!"*

*"I'm not sure all the patients understand the significance of it all. isn't it? "I'm not sure all the patients understand the significance of it. It's all education, isn't it? I know of some patients in the community, and we are constantly saying, "Put your feet up, put your feet up, but they don't. Then they get admitted to hospital, put their feet up, their leg ulcer improves and they think the hospital has done something marvellous – but it's the bed rest that's done it. Then they come home from hospital, the legs deteriorate and it's our fault!"*

**FG1(2)** *“We should really be discussing these issues with them when they first come sort of start gently, like a dripping tap, but we are not very good at that, are we? We tend to say, “Oh it’s healed, here’s a pair of hosiery, put them on daily, come back in 3 months for a Doppler” and we don’t really know whether they wear them or not. 9 out of 10 of them, when they’re out of that door, they don’t bother. It’s all about education, and how important they feel their ulcer is, cos (sic), to a lot of them, its not important is it, this little thing on their ankle, in the grand scheme of things, is it?”*

This nurse was aware of the need for health professionals to give patients advice at a pace that allowed them to absorb and retain the information received, however her comments reflected a pessimistic attitude that some health professionals share when attempting to engage patients in leg ulcer prevention strategies (Van Hecke 2010). Her final comment on the importance patients place on preventing an ulcer, however, may be justified. A qualitative study conducted by the author of this study found that, for many patients with multiple co-morbidities, a leg ulcer paled into insignificance compared to living with a chronic cardiac problem or debilitating arthritis (Brown 2005a).

Conversely, participants from the other health professional focus groups appeared to adopt a more pro-active, positive and empathetic approach to educating their patients.

**FG3(1)** *“I think it’s important to explain to them the chances of recurrence and how to prevent them coming back”*

**FG3(2)** *“It’s quite hard for them to accept that it is a lifelong condition, not short-lived, and we can’t cure them but can help to prevent the ulcer returning, even if we have told them that at the beginning of their treatment”*

**FG2(1)** *“You’d like to think that the information you have given them when they have a leg ulcer, the sorts of things, like elevating their legs, things like that, which they carry through, and still do, sort of habit forming”*

**FG2(3)** *“Yeah, continually reinforce it..... Some people really do take on board that if you elevate your legs, it will really make a difference!”*

As discussed previously, in my role as clinician, I felt ethically obliged to provide explanations as requested, even though it was not the focus of data collection. It became apparent that participants had received conflicting advice from health professionals:

**FG7(1)** *“That’s the problem isn’t it? One person says, “you’ve got to sit with your legs up”, another one will say “Make sure you walk a lot and exercise”. So what are we supposed to do?”*

**FG6(2)** *“He had an ulcer years ago, nearly 40 years ago and they told him to sit with it up all the time, so that’s what he does!” (all laugh)*

**FG9(3)** *“There they all are with their bandages and so forth, and none of them have their feet up although there are stools. And I noticed in hospital that they didn’t tell her to put her feet up, do they believe in that now, or not?”*

The problems associated with ensuring that leg ulcer patients are well informed about their condition have been repeatedly discussed within the literature (Nudds 1987, Hamer et al. 1994, Roe et al. 1994, Edwards et al. 1998) and studies have demonstrated that some patients continue to have a lack of understanding despite attempts by health professionals to provide explanations (Roe et al. 1995; Clarke Moloney et al. 2005). This lack of knowledge about the aetiology of venous leg ulceration and the contradictory information received on self-care strategies has major implications for improving self efficacy in this client group since, if patients are unclear about what the self efficacy outcome expectations are, how can they commit to judging their personal efficacy expectations? Paraphrasing Edwards (1999), who suggests that health education does not mean purely giving out information, clearly health professionals need to facilitate and work with patients to identify their needs, thus advancing them towards enhanced self efficacy and self empowerment. Some of the participants, however, displayed considered insight into their condition and so it was evident that in some cases, the health professionals’ approach to information giving had been effective:

**FG5(3)** *“Well, I’ve had my ulcers for years and it was explained to me – I’ve got poor circulation and that’s why I have to wear stockings, so maybe I’m lucky in that respect. They do sit down and take time with you here and answer any questions you may have and do you little drawings and things. Mind you, I’m the type of person who will just ask anyway if I don’t know But not everybody is like that, are they?”*

**FG6(4)** *“Well, they tell you everything now here, don’t they? Things like sitting with your legs up, for how long and how high, and how long to walk for. And if I can’t do that, they suggest other ways.....”*

The nurses based at the leg ulcer clinic which these two participants attended had clearly reflected on how they could improve information giving; one commented:

**FG3(4)** *“The other thing is, where I work, not everybody can read and write and so you have to, sort of, ask, can you read the leaflet? – it’s quite difficult really. It would be nice to have a CD or DVD or something with diagrams etc. It’s amazing really; you have to be quite diplomatic, sometimes. To say, would you like a leaflet, would you like me to read it to you, but then, you know.....people learn in different ways. Some people like a*

*pamphlet and sit down and read it, others don't. Some people prefer to have the one-to-one thing....."*

## **6.5.2 Lack of knowledge on the part of health professionals**

The importance of imparting knowledge in an attempt to achieve a concordant relationship will be discussed in greater detail within the discussion chapter, however, the apparent lack of knowledge was, however, not confined to the patient participants alone. Many of the participants gave examples of health professionals who demonstrated very little knowledge of venous leg ulceration:

**FG6(2)** *"You go to the doctors, but they're not really interested, are they? They go "Oh no, that's fine, it's not broken (the skin), you're alright". I was I was treated at the doctors for 3 months and told "No, it's not an ulcer", Until it got that bad..... you know, it was smelling. I didn't know what it was. And then I happened to see a locum (GP), he took one look at it and said "you've got an ulcer there, my dear!" but the doctor, you know, the main doctor, he didn't have an answer....."*

**FG7(1)** *"Cos (sic) the doctors don't want to know, do they? I went to my doctor's he said "I don't know anything about leg ulcers – I'll transfer you to somebody who does". But you know, doctors don't seem to have this sort of information....."*

**FG7(2)** *"I just wanted to say, as we were saying before, the doctors don't know much about ulcers, if we didn't have this group (Legwatchers Support Group), I don't know what we'd do, I really don't. Cos when I first had this one, I went to the surgery, and one of the nurses put one of those plasters on, which wasn't her fault but it caused a terrible reaction, blisters and that. So, when I went back, I told the nurse in charge – she didn't actually say anything, but she knew it was wrong and then went onto to burst the blisters. When I got home, I was in so much pain, my husband said "Look – what has she done to your leg!!" You know, she wasn't a specialist, she didn't really know what she was doing!"*

A comment made by a participant who had been referred to a surgeon for vascular assessment:

**FG7 (3)** *"Years ago, I had skin irritation on my legs (varicose eczema) and the Consultant said "That's good, whilst you've got that, you won't get a leg ulcer....." That's when I was at B Hospital (famous teaching hospital in London) – saw a professor there who said "There's nothing I can for you.....!"*

This incident occurred many years ago prior to the late 1980's when graduated compression therapy was introduced as the gold standard treatment for venous leg ulceration. Nevertheless, the previous comments illustrate the low priority given to

the treatment of venous leg ulceration by some health professionals, GPs in particular, who tend to defer assessment and treatment to nurses:

**FG7(4)** *“My doctor just had a look and said – “Nurse’s job!!!”*

This apparent disinterest in leg ulcer management and wound care generally may be in some way influenced by the fact that these activities do not attract Quality Outcome Framework (QoF) points, which are linked to financial incentives for GPs (DH 2004). These patients are generally seen by practice nurses, or referred onto other nursing services (i.e. leg ulcer clinics) for management and care. In addition, wound care has traditionally been seen as a nursing task in the United Kingdom. Interestingly, this is not the case in some European countries, for example, Germany or Belgium, where doctors are the primary providers of care for leg ulcer patients. One participant confirmed this:

**FG8(3)** *“Well, I knocked it open when I was on holiday in Germany. Went to a German doctor, he prescribed me support stockings, but no ulcer dressings so it got worse, bigger.....”*

The doctor in question correctly diagnosed and treated the underlying cause of the patient’s ulcer, venous hypertension, but may not have been familiar with the topical management, i.e. a suitable wound dressing. It could be argued that this would have reflected the “bio-medical” focus of treating the aetiology, whereas selection of dressing products continues to remain predominantly within the domains of nursing. However, the participant’s emphasis on the topical treatment of his ulceration, wound dressings, rather than the compression hosiery as an effective management strategy reflected his lack of understanding about the aetiology of his ulcer

## **6.6 Developing Expertise**

### **6.6.1 Navigating the system**

Many of the participants had suffered numerous incidences of ulcer recurrence in line with published figures (Ruane-Morris 1995, Fassiasdis et al (2002b; Gohel et al. 2005; Vowden and Vowden 2006). Over time, they became familiar with the optimum treatment for venous leg ulceration and had an awareness of local leg ulcer service provision. The participants however described how they continued to experience difficulties in accessing appropriate care for themselves or their family member:

- FG5(2)** *"I can't understand that when this thing broke out again with my mum, the GP didn't even want to look. You know, it takes me ages to try and get her to the surgery and then when I got here, the GP didn't even look at her legs....."*
- FG5(3)** *"I found the same with my wife, she was coming to the surgery for nearly 5 months, absolutely no interest whatsoever, didn't want to know. Later I found out about the ulcer clinic myself, contacted them and things started to change. As far as the GP was concerned, legs are nothing to do with me – see the nurse!"*
- FG6(2)** *"Cos the doctors don't want to know, do they? I went to my doctor's – He said "I don't know anything about leg ulcers – I'll have to transfer you to somebody who does" – but you know, you expect the doctor to have this information, don't you?"*
- FG9(3)** *"I only found out about this place when the group (Self-help group) first started – there was an article in the local paper so I phoned up and just turned up. None of the doctors' surgeries knew about it....."*
- FG9(2)** *"When I attended the doctor's surgery, you know, the nurse used to put a pack on my leg and say "keep it up"! Then she said, "We can't do your legs here any more, so she made an appointment to come here, you know and then I went to another clinic after that. Why can't they just tell you in the first place where to go?"*

This theme emerged from both the patients' and carers/family FGs who described how they had experienced difficulty in accessing specialist treatment for their leg ulcers. Several participants explained how they had been attending the practice nurse (PN) for many months before referral onto a leg ulcer specialist centre was considered. Unfortunately, delay in assessment and implementation of appropriate management has been shown to impact on healing rates (SIGN 2010). Furthermore, one participant explained how his PN had dressed the ulcer for 6 weeks and then announced "Well, it's been here for 6 weeks, so it's an ulcer now and I can't treat you any more!" Technically, the PN was correct, since the definition of a VLU is a "non healing wound to the lower leg which does not show signs of healing within 6 weeks" (SIGN 2010). However, since this particular participant had a history of venous ulceration, this had resulted in a significant delay in the instigation of the correct treatment. A further participant had accessed the local leg ulcer clinic himself after his wife had suffered futile treatment by the PNs for 5 months.

### **6.6.2 Becoming assertive**

Over time, the participants learned to distinguish between optimum and suboptimum standards of leg ulcer care delivered by health professionals and described how they

became assertive if they felt the care they or their relative had received fell below acceptable standards. One carer participant described how she had to become assertive in order to ensure her mother received the care she needed:

**FG5(4)** *“Although I’m not a fan of A. Medical Centre, you know, when I wasn’t getting any joy with the person who was supposed to be treating my mother, I took her to A. Medical Centre and said – “Look, I want her seen now!!” The doctor did come out, he did go and get the nurse but she just said “This needs to be treated” and gave us a month’s worth of antibiotics.....”*

**FG5(2)** *“So I’ve become a bit of an expert now, really. With the last one, you know, when it went on and on, I started drawing round it and I told the nurse and he kept leaving it and I could see a line of, like poison, so I did something about it, to me, he wasn’t any good, no. So I went straight to the surgery and got tablets for it. but it could have been healed up so quick, if he’d done what the normal girls would have done!”*

Three participants described how they liked to be informed and involved in their care or that of their relative and were not afraid to ask questions:

**FG5(4)** *“Mind you, I’m the type of the person who will just ask anyway if I don’t know – but not everybody is like that, are they?”*

**FG5(6)** *“But I’d say, “Well, I have to go with you, I need to know what’s going on”. So I always go along with her (her mother), you know, so I know what’s going on cos I don’t think she’d ask questions.”*

**FG4(6)** *“Yeah, I like to get involved in it all, you know. When she’s at the clinic they do all the work, but I’ll always get up and have a good look and then I say “What are you going to put on there today, or that’s better today!”*

These participants were of a younger age group and were patients (or relatives/carers) attending a leg ulcer clinic where the staff appeared to actively involve their patients in their care. As a result of this partnership working, these participants may have felt empowered to ask questions. It would appear; however, that this is not necessarily the norm for leg ulcer patients, as is borne out in the qualitative quality of life literature, where patients are reported as describing feelings of “powerlessness” (Chase et al. 1997, Ebbeskog and Ekman 2001), “helplessness” (Hyland et al. 1994, Charles 1995) and “loss of control” (Ebbeskog and Ekman 2001).

### 6.6.3 Identifying skilled nurses

Over time, both patients and their carers/family members learned to distinguish between optimum and suboptimum standards of leg ulcer care and became assertive in ensuring they or their relative had access to the best care. One carer participant related how the GP had dismissed his wife's ulcer as trivial and had merely prescribed topical antibiotics. Through prior experience, the husband knew that compression bandaging was the optimum treatment, and insisted on referral to specialist services. Some of the HPs however commented negatively that some patients tried to dictate how their ulcer was treated. This was compounded by occasional articles published in the media, describing a new wonder treatment for healing venous ulcers, whilst underemphasising the need for compression to correct the underlying pathology. On the other hand, other HPs involved their patients in their care and welcomed the patient's input. The patient participants explained how they became familiar with the nurses staffing the leg ulcer clinics over time, were reassured by their competence and skill and were able to distinguish between competent and less competent bandagers. As a result, when unfamiliar or inexperienced nurses treated them, they became anxious, particularly if the bandages felt uncomfortable or fell down. Despite the introduction of local and national guidelines and local competency assessments (RCN 2006), there continues to be variance in the application of compression bandages which has been widely discussed in the literature (Charles 1995; Walshe 1995; Heinen et al. 2006).

**FG7(1)** *"That's right, this is just one of the things I find though – you go to one and she's got a completely different idea from another, dressings and even how the bandage goes on – and you say something to them, they say "Oh, no, that'll do" and it's a waste of time, you know, whereas, another one, the bandaging is really comfortable, I mean, I've got a bandage on at the moment and that's been comfortable all the week. Now, one of the other ones – she put the bandage on and it all rucked up and it really irritated..... anyway, that's it!"*

**FG6(7)** *"I just wanted to say A, as we were saying before, as the doctors don't know much about ulcers, if we didn't have this group, I don't know what we'd do, I really don't. Cos when I first had this one, I went to the surgery, and one nurse put one of those plasters on, which wasn't her fault, and it caused a terrible reaction, blisters and that, and when I went back to her, she burst them all, just like that. So when I told the actual nurse in charge, of course, she couldn't actually say anything, but she knew it was wrong..... And when I got home, had a bath, was in so much pain, I cried..... And my husband said "Look, what has she done to your leg!!!" You know, she's not a specialist, she didn't know what she was doing, but when you come here, I know, whatever they are doing or saying, I trust them!"*

After having compression therapy applied, sometimes over a period of many years, the participants were able to identify those nurses who possessed good bandaging skills and those whose skills were not so effective. They valued the continuity of care provided by specialist leg ulcer nurses who, by demonstrating advanced bandaging skills, inspired confidence in their patients:

**FG5(3)** *"I have to say, the people at the clinic are first class – really professional. Do the NHS proud, I think. They know what they are doing, just get on with it. Professional people – you just have to have confidence in them, you know what I mean?"*

**FG7(2)** *"My ulcer started after I had an operation to remove my vein but it never cleared up. They referred me to the community nurses, they were very good, but nothing happened, so I came here (Clinic). But it's due to the treatment here, I think, where you've got specialist nurses to do this...."*

**FG8(2)** *"I think it's important to go to see specialists, you know, it's got to be 100% hasn't it? I mean, they are dealing with it, day in, day out, they get very knowledgeable, I can't complain....."*

**FG7(1)** *"I go to the clinic and sometimes I think, oh God, not her again, you know because some of the nurses there are excellent and know what they are doing, but others haven't a clue....."*

**FG7(2)** *"Well, I must admit that I find when the regular ones aren't there, the treatment's different. They've all got different ideas, and I mean, they even put bandages on differently, they don't put them on the same way, you know, it's true, everyone's slightly different....."*

The issue of lack of continuity and varying treatments has been widely discussed by participants in qualitative leg ulcer studies within the literature (Charles 1995; Walshe 1995; Heinen et al. 2006) and continues to be an important issue for leg ulcer patients despite the introduction of local and national guidelines on leg ulcer management and wound care formularies and protocols on wound care product selection.

#### **6.6.4 Control issues in the patient/professional relationship**

The issue of control in the relationship was raised by both health professionals and patient participants, albeit from differing perspectives. Some patient participants tended to defer to the health professionals' knowledge and spoke about "doing as they were told":

**FG4(2)** *"My husband had an ulcer years ago, nearly 40 years ago and they told him to sit with it up all the time, so that's what he does now..... (all laugh)"*

**FG4(3)** *"Well, he's doing what he's been told then, but then I suppose that creates*

*A burden for you doesn't it, cos (sic) you're picking up all the jobs....."*

**FG5(2)** *"Yeah, but in the case of my mum, if somebody said to her – you've got to wear that, say, bright green stocking, she would wear it, not question it at all, if she's told to"*

**FG5(1)** *"I think when you are a new patient, anyway, you don't like arguing or questioning. I mean, when I first started, I mean, if they'd said, you've got to do this, do that, I would have done it without question. They are the nurses, they know best, don't they? I'm only the patient!"*

**FG8(2)** *"If you want to help yourself, you just do as you are told, don't you?"*

As the participants developed closer relationships with their nurses, their confidence grew and they began to question elements of their care:

**FG7(2)** *"I have a debate every week with the nurses, you know, about having the bandages, but I always do as I'm told in the end".*

The health professionals' attitudes towards patient participation in their leg ulcer care varied between groups. One group in particular appeared to want their patients to accept responsibility for their leg ulcer care but seemed reluctant to embrace the concept of patient participation. Rather than negotiating *with* the patients, they seemed to place the responsibility for care either with the patient or with themselves, not as a shared decision:

**FG1(3)** *"Well, I think it should start in the clinic when they first come. Some of them really want to help heal this ulcer. But some have got a bit of an attitude, like "you are not going to tell me what to do!"*

**FG1(2)** *"Well, some people don't want to accept responsibility for their ulcer, do they? They think that we, as health professionals, should do all the work, but we can't do everything, can we? They think that they have no control over what happens to their ulcer and whether it will return".*

**FG3(3)** *"I think that the majority of older patients are like that, but then you do get some patients who say "This is my leg – I want this dressing or that dressing on it. I know best cos (sic) I've had this leg ulcer for, say, three months".*

The relationship and the interaction between patient and health professional appeared to play a large part in influencing patients' behaviours and had resulted in both positive and negative outcomes (Briggs and Flemming 2007, Van Hecke et al. 2008). Some of the nurse participants used goal setting as a strategy to encourage adherence to treatment or used visible evidence to demonstrate ulcer improvement:

- FG3(2)** *“Another problem can be the shoes, can’t it? When they come here, they can’t get their shoes on, so we get them bigger shoes. Occasionally, we can’t start treatment until they get some decent footwear and I always encourage them, once they get into stockings, to throw away their footwear, so it’s like reaching a goal for them!”*
- FG2(2)** *“And we’ve got a lady, who’s really pleased. We got the Cosytoes® footwear for her. She couldn’t put them on before, could she? She’s absolutely thrilled that the swelling’s gone down so much now”*
- FG3(3)** *“We traced the ulcer and keep taking photos so she can see the outline As it’s improving and she’s well into it now, asking everybody “has you seen the picture of my ulcer – look how it’s healing!”*
- FG3(5)** *“They do like their pictures, don’t they, the patients. It’s handy for us too, cos (sic) you can’t always remember, can you? So to have the pictures in front of you, it’s quite nice and it’s quite nice for the patient too!”*

Several patient participants described how they had found this strategy useful in adhering to treatment:

- FG9(1)** *“Well, I think it’s important to always have a goal ahead. I can remember when one of our grandsons was married, and oh, was I in a state. He said to me “I want you to dance with me at my wedding!”. Anyway, it healed and I danced at his wedding, and then, of course..... (laughs) a few weeks later, this other one started!”*

These health professionals, inadvertently, were using strategies designed to enhance self efficacy and patient motivation, with positive effects. It may have been because both the nurses and the patients had accepted the reality that their condition was “chronic” as opposed to an “acute” event and the focus of care had shifted from healing to helping patients gain control over their lives (Briggs and Flemming 2007). Relationships which generated negative outcomes seemed to occur when patients’ desires to lead a normal life and choose their care conflicted with that of the health professionals. This will be discussed in greater detail within the discussion chapter.

## **6.7 Normalising and adapting**

### **6.7.1 Remaining optimistic**

Several of the patient participants continued to remain optimistic that one day they would be ulcer-free:

- FG6(2)** *“Well, I’ve had ulcers on and off for 40 years, but, at the moment, I’m having a good break... Fortunately now, my legs have healed and I’m keeping my fingers crossed that they will be alright. There is always possibility that they will come back.....”*

**FG7(2)** *"I think you've just to think positive, when I had breast cancer years ago, I got better cos I kept positive, positive thinking, yeah, that's right!"*

**FG5(4)** *"It's been closed up twice, you know. I've been to the hospital, they reckon there's nothing they can do, cos it's got no veins. But in the the last month or so, it's been really good, so I'm keeping my fingers crossed."*

Other participants appeared to exhibit external locus of control tendencies (Rotter 1966), believing that recurrence was dependant on the actions of others, such as God:

**FG4(3)** *"But thank God, this great place and these good girls (nurses) are helping me now, there's light at the end of the tunnel, to come along and hope, but please God, its got to get better....."*

**FG7(3)** *"I'm worried cos it's started to heal but the other side, it's still very tender where I banged it on the bed, oh God, I'm praying that it doesn't develop into another one....."*

**FG6(2)** *"All I can say is that I must have been a wicked person in my previous life to suffer like this....."*

**FG6(6)** *"Oh yes, every blemish, I think, Oh God, here it comes again!"*

Alternatively, these comments could be attributed to the emotion-focused coping strategies components of the Theory of Uncertainty in Illness (Mishel 1990).

### **6.7.2 Carrying on regardless**

It was evident that many of the participants had learned to adapt their lives in order to live reasonably full lives despite having a chronic condition:

**FG6(7)** *"I have carried on with my life to the best of my ability for over 40 years, have brought up a family and have just continued doing the jobs I would have done anyway....."*

**FG6(4)** *"Well, to be honest, I just carry on with things. It hasn't stopped me, well not within the last 3 years anyway, it's just that it won't sort of heal"*

**FG5(7)** *"It never stopped me doing anything really. I still went to camp with the Girl's Brigade and things like that, took the strong painkillers and just got on with it."*

**FG9(6)** *"Life's got to go on, hasn't it? You can't be thinking about your legs all the time....."*

**FG9(7)** *"And I think its mind over matter, sometimes, isn't it? If you are really*

*determined, I'm sure it is. And I think you've just got to carry on regardless otherwise you'll get depressed, I think, and that's fatal!"*

The importance of self-efficacy theory in enabling patients to adopt adaptive strategies in chronic conditions will be discussed in detail within the discussion chapter.

### 6.7.3 Perseverance

Several participants appeared extremely tenacious, describing how they struggled with their hosiery on a daily basis, but by developing strategies, refused to admit defeat:

**FG8(3)** *"I would just like to add about aids and things. I find that I have worked out how best to put my stockings on with the frame and know exactly how to sit, so I've got it off to a fine art, really. You just have to experiment until you find the best way for you....."*

**FG4(6)** *"She spends a lot of time getting them on and off. It takes a bit of time and I try and help if I can. She doesn't like wearing them, specially in this hot weather, but she perseveres"*

**FG5(3)** *"She always puts her hosiery on, always, and when she can't – I'll sit like that and try and do it for her, but she says "Oi, get out of it, I can do it myself!"*

**FG8(3)** *"Coming back to the stockings, I find it quite hard too. But I've got it off to a fine art now. I was scared about sticking my nails through so I bought a pair of thin rubber gloves, they help me, anyway".*

According to Bandura (1997), this is performance mastery experience, which when successful, is a very powerful source of self efficacy information (Maddux and Lewis 1995). The ability to persevere with an activity against the odds and to share success within a peer group which Bandura called vicarious experience, together with positive verbal encouragement, has been shown to be a strong predictor of health behaviour change and may encourage others to emulate their success (Maddux and Lewis 1995; Bandura 1997). This will be discussed in further detail within the discussion chapter.

### 6.7.4 Adapting and innovation

For some participants, the acceptance that they had a chronic condition that had become a part of their life appeared to motivate them to develop innovative ways of coping which enabled them to live fairly normal lives:

**FG4(5)** *"When P. was bad with ulcers, she was afraid of falling, wouldn't go in the garden. She loved her garden, pottering around, but she wouldn't go in it. So I put a rope round the garden, fixed it on posts and things, so that if she stumbled, she could grab hold of it and steady herself. Thank God, she's never needed it, but if she ever did, it is there, like a prop!"*

**FG3(6)** *"Well, coming back to worrying about getting your leg knocked. I've come up with something that helps me. I put shin pads, you know, like the ones cricketers wear, under my trousers, so I don't worry now..... (all laugh)....."*

**FG9(3)** *“The shoes are a problem, aren’t they? Well, I have found an old pair of shoes and I cut them down the sides, so it’s opened them up a bit, to avoid the ankle rubbing, you know, which did me quite well really cos (sic) now I can go shopping and things”*

### **6.7.5 Friends and family support**

There is evidence within the literature on coping and successful adaptation to a chronic condition that link social/peer support and positive self-efficacy beliefs to successful adaptation and improved adherence to treatment regimes (Lindsay 2001, Magura et al. 2002, Garay-Sevilla et al. 1995). The patient participants in this study appeared to benefit from the social interaction with their peers at the leg ulcer clinics and also the support from their family and friends:

**FG4(4)** *“I want to leave it for now, but I just want to say, it’s been marvellous to air my views like this and we’ve all got similar problems to report, haven’t we?”*

**FG4(3)** *“When J. started off with it, she felt so alone, that there’s nobody else in that condition, either in hospital or out here. so when she came here, (LegClub®), it was marvellous for her, to know she’s not alone”*

The beneficial effects of support were recognised by the health professionals also:

**FG3(1)** *“Yeah, they all get to know each other in the waiting room, look out for each other. They say, “Why are you taking me in, its \*\*\*\*’s appointment time? They get to know each other and when they don’t see them, they ask “Where’s \*\*\*\* today?” And that builds up between themselves, that’s nothing to do with us, is it?”*

**FG3(6)** *“I’ve got a lady, she’s been coming for about 2 months now and she’s been speaking to another lady, who’s had an ulcer for years. They’d spoken about that while they were waiting for their appointments”*

For most of the participants, the support they received from their spouse or family helped them cope with the constant uncertainty of recurrence:

**FG6(6)** *“I think its all about having support, isn’t it? As I’ve said, my husband has been seriously ill, but even then, he’s just there all the time. Not once has he said “Pull yourself together, it’s only a small ulcer”. He helps me as much as he can!”*

**FG7(4)** *“And, as you know, my life has been dominated by this. But thank God I have got a very, very good, supportive husband, don’t know what I’d do without him, actually”*

According to Bandura (1997), social support is vital to enhancing self-efficacy since positive feedback from significant others or professionals will act as a reward to induce individuals to carry out and maintain a specific behaviour. Although verbal encouragement alone may be limited in terms of promoting self-efficacy, if combined with positive appraisal of the behaviour by the individual, it can help to reinforce their view that the self-change was a success (Bandura 1997; Maddux and Lewis 1995). This source of self-efficacy will also be discussed more fully within the Discussion chapter.

## **6.8 Conclusion of qualitative findings (Phase 1)**

This chapter has presented an overview of the major findings of this study, which have also been published in full elsewhere (Brown 2010a, Brown 2010b). The dominant categories identified were: looking for reasons, living with continual uncertainty, restricted lives, knowledge and education, developing expertise, and normalising and adapting, and these resonate with those of previous qualitative studies exploring the lives of patients living with venous leg ulceration (Briggs and Flemming 2007, Mudge et al. 2006, Douglas 2001, Flanagan et al. 2001, Edwards 2003, Krasner 1998a,b; Bland 1996).

As discussed in the methodology and methods chapter, the intention was not to develop a grounded theory per se, but to draw on the data analysis process of grounded theory methodology to analyse the data and develop statements to inform the development of a self-efficacy tool for patients with venous leg ulceration. The major categories identified within this study may form the basis for further expansion and development of a “grand theory” in the future.

## **6.9 Barriers to progression**

As mentioned earlier in the chapter, on completion of the qualitative phase of this study, the number of statements considered relevant for inclusion into the developing scale was 111. It had been envisaged that the primary aim of Phase 2 would be to pilot the proposed scale with patients, using factor analysis to reduce the statements into a more manageable scale. However, it was considered that it would be too arduous to expect elderly participants to complete and comment on such a large number of statements and so the research proposal was amended to include one extra focus group with participants to reduce the number of statements prior to piloting the developing scale.

A substantial amendment to protocol was submitted for Ethics approval and this was successfully obtained within 2 weeks (appendix 3) (September 2009). However, it was also necessary to gain Research and Development approval within the two PCTs where the data collection was to take place and this proved to be a very complex and time-consuming process. At the commencement of the study, R & D approval had been obtained via Essex Primary Care Research and Development Office and this approval covered both PCTs. However, this office has now been disbanded and it was necessary to apply for R & D approval from each relevant PCT. Unfortunately, my study was classified as non-portfolio according to the National Institute of Health Research and consequently I was unable to obtain support from the Comprehensive Local Research Network, an organisation which had taken over the role of the Primary Care R & D office. The process for obtaining R & D approval for non-portfolio studies appeared to be very fragmented and poorly coordinated and involved a large number of email communications and telephone calls in order to determine the point of contact for obtaining R & D approval within PCTs.

Finally, I requested the assistance of the Strategic Health Authority (NHS East of England) who is the sponsor of this PhD study to intervene and R & D approval was finally obtained in March 2010, seven months after submission of a substantial amendment to protocol. This process had resulted in a substantial and unforeseen delay in my timescale for completion of the study and should be considered by future students when undertaking non portfolio research within the National Health Service.

Following receipt of Ethics and R & D approval, a small focus group was held with 10 patients. The patients were given a draft copy of the scale and asked to comment on the validity of the statements, and asked whether they were duplicated and if they felt each individual statement should be included. At the end of the focus group, the number of statements had been reduced from 110 to 60. This was felt to be more manageable and the process of designing the developing scale commenced. The next chapter describes how the items developed from the qualitative phase informed the development of the VeLUSET and the quantitative phase of item reduction through the factor analysis process.

## **7.0 Chapter 7 Preliminary validation and development of the VeLUSSET - Phase 2**

This chapter describes the administration of the pilot scale and the process of reducing the items, developed from the qualitative phase, into the developing scale. The process of factor analysis will be described and additional data analyses will be also being presented.

### **7.1 Pilot scale (Phase 2a)**

A pilot scale was developed for preliminary administration in order to commence the process of item reduction (appendix 11). The qualitative phase had generated an item pool of 60 for potential inclusion in the scale and many of the items bore strong similarities with each other. DeVellis (2003), however, recommends over inclusion at this preliminary stage since the process of item reduction will result in multiple redundancies. Furthermore, the internal consistency reliability of the items is not known at this stage. (See appendix for copy of pilot scale).

#### **7.1.1 Instrument layout**

The front sheet of the scale introduced the purpose of the study and requested details such as name (this was optional to maintain anonymity if desired), date of birth, sex, whether first ulcer, age of onset of ulcer, how many ulcers, whether healed and if applicable, time to healing for demographic analyses (see appendix for sample of pilot scale).

#### **7.1.2 Response scale**

The next consideration was the choice of response scale. The standard method for measuring self-efficacy beliefs is to present respondents with statements listing differing levels of tasks and ask them to rate the strength of their beliefs in mastering the task on a scale. Self-efficacy scales traditionally use Likert (1932) scales and the SE scales reviewed used 4,5,6,7 and 10 anchors. These are either presented as numbers on a scale or possible responses, for example “strongly agree” (1) ranging to “strongly disagree” (10) on a continuum. In order to decide how many anchors to use for the developing scale, the literature was reviewed.

Cummins and Gullone (2000) suggest that the view that fewer points are advantageous emanates from the types of psychometric data early researchers wanted to report on reliability (internal and test-retest) and convergent/divergent validity, which is highly dependent on reliability. They argue that when Cronbach (1946; 1950) expressed the

view that fewer points increased sensitivity, he did this in the context of his field of research – education. His scales consisted of knowledge-based questions where a simple “true” or “false” answer was required and multiple responses would have resulted in “guesses” or acquiescence by the students who did not know the correct answer. Cummins and Gullone (2000) suggest that the number of points used must reflect the underlying construct being measured and argues that, for example, sensitivity for measuring subjective quality of life is increased when a higher number of response choices are offered.

Dawes (2008) conducted an experiment to determine whether data characteristics change according to the number of scale points used. Scales of eight questions using 5, 7 and 10 points was administered to three groups (group n's = 300, 250, 185). The 5 and 7 point scales were rescaled to a comparable mean score out of 10. The study found that the 5 and 7 point scale produced the same mean score as each other, once they were rescaled. However, the 10 point format produced slightly lower relative means than either the 5 or the 7, although in terms of other data characteristics, there was very little difference in terms of variation about the mean, skewness or kurtosis. In terms of distribution, more scale points provide more options for the respondent and may result in less skewed data, particularly if more positive responses to the construct being measured are expected. In the case of a 5 point scale, there are only 2 options for a positive response 4 and 5; similarly for a 7 point scale, only 5, 6, and 7, whereas for a 10 point scale, the options are 6,7,8,9 and 10. Dawes's study, however, was a telephone survey and he suggests that the use of a 10 point scale may be problematic for the telephone interviewer in terms of clarification of the scale descriptors and the difficulty for respondents in retaining and differentiating the points. He does comment however, that most people are familiar with the notion of rating “out of 10” (Dawes 2008).

In his guide to constructing self-efficacy scales, Bandura (2006) recommends using a 100-point scale, ranging in 10 unit intervals from 0 (“Cannot do”), through intermediate degrees of assurance 50 (“Moderately certain can do”) to complete assurance 100 (“Highly certain can do”). His rationale for this is that people tend to avoid the extreme points so a scale with only a few points will shrink to only one or two response options (Bandura 2006). Another consideration is the use of odd numbers as opposed to even numbers. De Vallis (2003) suggests that the use of odd numbers implies a central “neutral” point and may result in respondents selecting the midpoint as a means of avoiding a choice, resulting in equivocation.

Review of the literature revealed that the number of responses to use appeared to be a contentious issue and it was decided, therefore, to use a Likert scale with a 11 point format (0 – 10) since most people are familiar with this (Dawes 2007) whilst retaining the same scale structure and descriptors as Bandura suggests for the developing scale.

### 7.1.3 Reverse-phrased items

The 60 statements were listed randomly and readability statistics checked using the Microsoft Word 2010 programme which indicated a reading level of between fifth and sixth-grade, ensuring an appropriate level for the instrument (Fry 1977). Of the 60 statements that comprised the scale, 52 were positively worded and 8 were negatively worded. It has been suggested that including negatively worded items will alert inattentive respondents that the statement contents may vary (Swain et al 2008). Furthermore, Swain et al. (2008) suggest that when scales contain a mix of positively and negatively worded statements, researchers can compute an indirect measure of acquiescence bias within the analysis since acquiescent respondents tend to agree with all items, thus inflating the scale means when reverse-scored.

Some of the statements incorporated both magnitude and confidence levels of SE (Todd et al. 2000) and were designed to challenge the respondents which, according to Bandura (1986), is the best way to measure SE. Examples were “I am confident that I will be able to put my legs up to the level of my heart daily for 2 hours” and “I am confident that I will be able to take a walk for at least half an hour every day”. Following the introduction of the study, instructions for completion were given:

*“The following statements have been put together after talks with fellow leg ulcer patients. Using the scale below, please enter a number in each box to show how much you agree or disagree with each statement. The scale ranges from 0 (completely disagree) to 10 (completely agree). You may use any number between 0 and 10. There are no right or wrong answers. Please answer **all** the statements”.*

The scale was presented at the top of each page to remind respondents to use the scale.

0	1	2	3	4	5	6	7	8	9	10
Completely disagree				Moderately agree			Completely agree			

Despite these explicit instructions, however, 30 questionnaires were returned with just ticks or a yes/no answer in the boxes and could not be included in the analysis.

## **7.2 Preliminary administration of pilot scale (Phase 2a)**

Following discussions with my statistics supervisor, it was decided that a sample of minimum 150 participants would be required to enable factor analysis to be performed and several leg ulcer clinics throughout the neighbouring PCTs were approached for potential participants. The researcher visited the clinics in person to explain the study and inclusion/exclusion criteria to the staff and leave questionnaires for completion. A stamped, addressed envelope was provided for a response to ensure that the participants did not incur any financial costs in order to participate in the study.

A total of six leg ulcer clinics were approached, however recruitment was very slow, with staff expressing difficulty in recruiting participants due to heavy workloads and staff shortages. The decision was taken by the researcher to attend the leg ulcer clinics in person in order to recruit participants and this proved slightly more successful. Several of the leg ulcer clinics provided contact details of patients they felt would be keen to participate in the study and a total of 210 questionnaires were sent out or distributed by hand. Contact details were kept in a locked filing cabinet and handled as per the ethics committee's requirements. Unfortunately, the process of recruiting participants to complete the questionnaires took nearly 1 year instead of the estimated 4 months and resulted in a significant delay in completion of this study. A total of 210 questionnaires were sent out, of this number, a total of 148 completed questionnaires were returned, of which 30 questionnaires were returned incorrectly completed and had to be discarded. A total of 118 questionnaires were analysed. This response rate of 41 % for questionnaires is considered to be average (Edwards et al. 2002) however 118 responses to perform factor analysis is considered by some to be too small a sample, as the literature suggests a minimum sample size of over 300 is needed, or 10 participants per statement (Field 2009). Edwards et al. (2002), in a systematic review on strategies to increase response rates to postal questionnaires, suggest that the layout, for example, double-sided questionnaires as well as the length and interest in the subject under study will influence response rates. In this case, the questionnaire was very long and was double-sided to reduce postal costs, and this may have deterred participants from completing them. It has been suggested that sending out a reminder letter will increase response rates (Puffer et al 2004), however in this case, this strategy would have involved a considerable financial outlay for the researcher and so was not considered. As mentioned, the difficulties experienced in recruiting patients to complete the questionnaire had led to a delay of one year and so following discussions with my

supervisors, it was decided to discontinue recruiting and commence data analysis. The small sample size is clearly a limitation of the study and must be acknowledged as such.

### **7.3 Demographic data**

The data from the questionnaires were entered into SPSS v.19 to prepare for analysis, with the reverse-phrased questions being reverse-scored as recommended in the literature (Pallant 2010). Initial descriptive statistical analyses were performed to describe the characteristics of the samples, to check for missing or erroneous data and to ensure the variables did not violate the assumptions underlying the proposed factor analysis (Pallant 2010). The descriptive data analyses for both phases 2a (pilot) and Phase 2b (Version 1) are presented below in Table 11.

7.4. Table 11. Patient demographics – Phase 2a and 2b

Patient demographics	Phase 2a (n = 118) pilot		Phase 2b (n = 87) V.1	
	Male	Female	Male	Female
Sex distribution	50.4% (n = 58)	49.6% (n = 57)	46% (n =40)	54% (n = 47)
Mean age of participant	74.15yrs (range 60-95; s.d. 10.966)		74.36yrs (s.d. 10.416)	
Smoker	Yes 13.6% (n= 16)	No 82.2% (n = 97)	Question removed following pilot	
Do you have a carer?	Yes 3.4% (n = 4)*	No 48.3% (n = 57)*	Yes 17.2% (n =15)	No 82.8% (n =72)
Is this your first leg ulcer?	Yes 45.3% (n = 53)	No 54.7% (n = 64)	Yes 31.3% (n =25)	No 66.3% (n= 53)
How many ulcers have you had?*** 1 – 3 4– 7 7 >	<b>Mean 4.05 (s.d. 4.366)</b> <b>Trimmed mean 3.33**</b>  50% (n = 59)* 23.7% (n = 28) 9.3 % (n = 11) Range 1 -19		<b>Mean 3.51 (s.d. 4.319)</b> <b>Trimmed mean 2.92**</b>  74.3% (n = 58)* 12.8% (n = 10) 15.3% (n = 10) Range 1 - 28	
Has it healed now?	Yes	No	Yes	No
	47.9%(n= 56)*	52.1%(n= 61)	32.5% (n=26)	67.5% (n=54)
If healed, how long did it take? (months)***  1- 3 months 3-6 months 6-9 months 9-12 months 12 – 24 months > 30 mths	Mean 12.13 mths (s.d. 18.425) <b>Trimmed mean 9.13 mths**</b> (s.d. 18.425**  12.7% (n = 15)* 18.6% (n = 22) 4.2% (n = 5) 7.6% (n = 9) 5% (n =6) 4.9 % (n =6) Range – 1 – 120 mths		Mean 23.65 mths (s.d. 64.358) <b>Trimmed mean 11.33 mths</b> (s.d. 64.201)**  12.5% (n = 3)* 4.6% (n = 4) 3.4% (n = 3) 6.9% (n = 6) 3.4 % (n =3) 3.3% (n = 3) Range 1-372 mths	
If it has not healed, how long have you had it? (months)***  1 – 12 months 12 -24 months 24-48 months 48 – 72 months > 72 months	<b>Mean 32.57 (s.d. 75.054)</b> <b>Trimmed mean 19.20mths (s.d.75.054)**</b>  30.4% (n = 36)* 10.1% (n = 12) 4.2% (n = 5) 4% (n = 5) 3.2 % (n =5) Range 1 – 364)		<b>Mean 30.57 (s.d. 59.96)</b> <b>Trimmed mean 19.77mths (s.d. 59.964)**</b>  30.8 % (n = 27)* 17.1% (n =15) 7.9% (n = 7) 3.3% (n = 3) 6.6 % (n =6) Range (1 – 371)	
Age first ulcer developed?	Mean 68 yrs s.d. 16.687 (range 70)		Mean 60.24 yrs s.d. 16.792( range 73)	

\* Indicates missing data where figures do not total 100% \*\* 5% trimmed mean pairwise exclusion \*\*\* grouped into categories for presentation purposes

## 7.5. Factor Analysis (Principal Component Analysis) – an overview

Although not considered a true statistical test, factor analysis (FA) is a data reduction technique used primarily for questionnaire or scale development (Pallant 2010). Factor analysis allows the investigator to determine how many latent variables underlie a set of items (DeVellis 2003) and condenses a large set of variables into a smaller set of factors or sub-scales.

According to the literature, there are two approaches to FA; exploratory and confirmatory. Exploratory FA is used in the early stages of research in order to explore the relationship among a set of variables (Pallant 2010). Confirmatory FA, on the other hand, is a more complex technique used to test or confirm specific hypotheses or theories concerning the structure underlying a set of variables. The term FA encompasses a variety of different, although related techniques (Field 2005), the main distinction is between what is called principal components analysis (PCA) and factor analysis (FA). These terms, however, are used interchangeably within the literature. Both techniques attempt to produce a reduced number of linear combinations of the original variables in a way that captures or accounts for most of the variability in the patterns of correlations, although they do this in a different way (Pallant 2010). In PCA, the original variables are transformed into smaller sets of linear combinations, with all the variances being used. In FA, factors are estimated using a mathematical model, whereby only the shared variance is analysed (Tabachnick & Fidell 2007).

Although both approaches often produce similar results, recommendations on which method to use in the literature vary, according to which author you read. Stevens (1996) recommends PCA and suggests that it is “psychometrically sound and simpler mathematically and avoids some of the potential problems with “factor indeterminacy” associated with FA” (1996; pg. 363). Tabachnick and Fidell (2007) in their review of PCA and FA conclude that “if you are interested in a theoretical solution uncontaminated by unique and error reliability....FA is your choice. If, on the other hand, you simply want an empirical summary of the data set, then PCA is the better choice” (1997, pg.635). For the purpose of this study, PCA was chosen as the extraction method as its purpose is to “summarize most of the original information (variance) in a minimum number of factors for prediction purposes” (Hair et al 1998; pg. 100). Field (2009) cautions, however, that when using PCA, the conclusion reached is

restricted to the sample used and generalisation of the results can only be achieved if different samples reveal the same factor structure.

### **7.6. Assessing suitability of the data for Principal Component Analysis**

Pallant (2010) suggests that there are 2 main issues to consider when determining whether a data set is suitable for principal component analysis (PCA): sample size, and the strength of a relationship among the variables (or items). As discussed earlier, my sample of 118 would be considered too small to conduct PCA by some researchers. Whilst this must be acknowledged as a weakness of the study, I consider the development of this scale to be preliminary and anticipate that other researchers will wish to further validate it with other samples in the future. The data was subjected to preliminary analysis to ensure that the 4 assumptions which include sample size and factorability of the correlation matrix (0.3 or greater), significance of Bartlett's test of sphericity ( $p < .05$ ) and the Kaiser-Meyer-Olkin Measure of Sampling Adequacy (KMO) range from 0 to 1; with .6 suggested as the minimum value Kaiser 1970; 1974) were not violated and the data were suitable for PCA (Pallant 2010). In this case, the KMO range was .814, Bartlett's test of sphericity reached statistical significance and inspection of the correlation matrix revealed the presence of many coefficients of .3 and above, supporting the factorability of the correlation matrix (Pallant 2010).

### **7.7. Process of factor extraction and rotation methods**

The purpose of factor extraction is to determine how many categories are sufficient to capture the bulk of the information contained in the original set of items (DeVellis 2003). In the initial phase, FA assumes that only one major category is required to contain all the items and account for the entire pattern of responses. It then assesses how much of the association between individual items the original concept can explain (Pallant 2010). If it appears that one category (factor) has not explained all the covariation between the items adequately, the single factor is rejected and a second factor is identified. This continues until the amount of covariation that the set of factors has not accounted for is acceptably small (DeVellis 2003).

#### **7.7.1 Kaiser's criterion and Scree Plot**

PCA does not necessarily give a logical structure to a set of variables and researcher interpretation is required in order to determine which group of factors best represents

the underlying relationships among a group of related variables. According to Pallant (2010), this may result in two conflicting needs: the need to find a simple solution with as few factors as possible and the need to explain as much of the variance in the original data set as possible. Two techniques to aid the decision are Kaiser's criterion and the Scree Plot (Cattell 1966).

In Kaiser's criterion, or the eigenvalue rule, only factors with an eigenvalue of 1.0 or more are retained for further investigation. The eigenvalue of a factor represents the amount of the total variance explained by that factor (Pallant 2010), although Kaiser's criterion has been criticised as resulting in the retention of too many factors in some situations.

Another approach in deciding on how many factors to extract is the Catell's Scree Plot (1966). In SPSS, each of the eigenvalues of the factors is presented on a plot and inspection of the plot indicates a point at which the shape of the curve changes directions and becomes horizontal. Catell recommends retaining all factors above the elbow, or break in plot, as these are the factors that contribute the most to the explanation of the variance in the data set (DeVellis 2004).

### **7.8. Preliminary results**

The procedure for conducting PCA using SPSS was followed according to Pallant (2010), however in the "Missing values" box, 'replace with the mean' had to be computed as there were only 51 complete data sets. There are two basic types of rotation: *orthogonal* and *oblique*. Orthogonal means the factors are assumed to be uncorrelated with one another; oblique allows the factors to correlate, making interpretation more difficult. Analysis was performed using both extraction methods, orthogonal and oblique, also unweighted Least Squared, maximum likelihood together with various iterations and factor loadings of between 0.5 and eigenvalues of 1.0 and above.

Factor loadings are the correlation coefficients between the variables and the factors. According to DeVellis (2003), factor loadings should be .7 and above; the rationale being that the .7 level corresponds to about half of the variance in the indicator being explained by the factor. However, he acknowledges that the .7 standard is a high one and real-life data may well not meet this criterion, which is why some researchers, particularly for exploratory purposes, will use a lower level.

Following a discussion with my statistics supervisor, it was decided to use factor loadings of 0.5 and above.

The most logical structure for the data appeared using the orthogonal method - equamax rotation; eigenvalues of 1.0 and above, and factor loadings of 0.5 which converged in 22 iterations and extracted nine factors. Following interpretation of the output, nine factors were extracted and this result was confirmed by Cattell (1966) scree test. No logical structure emerged using the alternative extraction methods.

Interestingly, inspection of the factors demonstrated that all the negatively phrased items had loaded onto one factor despite being reverse-scored. This confirmed my suspicion that the participants had found these difficult to complete. Cordery & Sevastos (1993) have suggested that possible mechanisms for artifactual factors include lack of ability to understand the negatively worded items and carelessness in reading items (Spector et al. 1997). Schriesheim and Hill (1981) noted that negatively worded items are often less reliable and valid than positively worded items and advise caution including these within a scale. The decision was taken to remove those eight statements from the developing scale. In addition, 3 outliers were found and following discussion as to the importance of these items, they were also removed from the analysis. Repeat FA analysis was performed as above incorporating these amendments, and a logical structure now emerged with 7 factors with eigenvalues exceeding 1, which explained the variance of 37.4 %, 17.4%, 6.6%, 6.0%, 4.2%, 3.5% and 3.1% respectively (78.2%). An inspection of the Cattell scree test revealed a clean break after the 7th component confirming that 7 factors needed to be retained, thus reducing the total of statements from 60 to 36 as the remaining 24 items failed to reach the chosen threshold for loading on a factor. Inspection of the factor structure identified that 2 factors had similarities in terms of item characteristics and were therefore combined with other factors, resulting in 5 factors overall which formed the sub-scales. Tables 12 and 13 give the factor structures following PCA for both the pilot scale (Phase 2a) and VeLUSET v.1 (Phase 2b).

7.8.1 Table 12 Rotated Component Matrix – Phase 2a (pilot)

	Factors						
	1	2	3	4	5	6	7
understand why	.676						
nurse 3/6 mths	.711						
understand how com	.699						
check comp	.654						
check regularly	.638						
health problems	.649						
comp on		.845					
comp off		.849					
everyday routine		.785					
lead normal life					.609		
suitable shoes					.604		
ask for aids							
both legs							
getting help	.515						
help others							
be careful				.777			
extra care				.725			
plan days				.683			
compression - recurrence			.547				
remain positive			.685				
shower/bath			.606				
avoid sitting down			.539				
help not treat myself			.658				
tight compression							
stop going out			.539				
wear types of clothes					.693		
enjoy myself					.649		
Even if ulcer comes back	.573						
elevate legs						.700	
legs 2 hrs daily						.792	
Exercises			.562				
avoid knocks				.589			
avoid standing						.591	
walk 30 mins							.549
lose weight		.505					
wrong information							.655
confident why							.724
recognise signs							.501
where to go				.517			
ask questions				.563			

7.8.2 Table 13 Rotated components matrix – Phase 2b

Item	Factors						
	1	2	3	4	5	6	7
understandwhy	.830						
leadnormallife			.746				
legsup		.594					
remainpositive				.616			
checkfit	.651						
compon		.713					
notstopgoingout			.696				
comeventhough	.730						
avoid knocks					.737		
askquestions				.504			
trytoseenurse	.861						
understandwhystocks	.681						
compoffdaily		.755					
exercises						.542	
healthprobs		.515					
onandoffasroutine		.747					
helpstopcoming		.582					
checkdamage							
elevateevenifhurts							
knowwhy				.716			
Gethelp		.532					
Lose weight						.679	
avoidstanding						.556	
asknurse							
avoidsittingdown						.570	
tellbecareful					.689		
goutandenjoy			.645				
recognisesigns				.551			
takeextracare					.684		
wronginfo				.656			
showeorbath							
suitableshoes							
knowtogethelp							.644
weartypesofclothes							.731
plandays							.583
takewalk						.643	

### **7.9. Further validation and refinement of the VeLUSSET (Version 1) Phase 2b**

The questionnaire incorporated the remaining 36 items which were listed at random and a similar layout to the pilot questionnaire was used. (See appendix 12). The scale was also named the VeLUSSET (Version 1) (Venous leg ulcer self-efficacy tool). The 10 items comprising the General Self-Efficacy Scale (Schwarz and Jerusalem 1995) were listed at the end of the VeLUSSET in a separate table in order to assess the VeLUSSET's construct validity and specificity to leg ulcer patients. A minimum sample of 80 participants was deemed adequate for the next phase and recruitment commenced.

### **7.10. Sample Recruitment for Phase 2b**

In view of the difficulties and long delay experienced in Phase 2a in engaging HPs to recruit participants, an alternative approach was adopted. Since the study did not require site-specific ethics approval, colleagues within the Tissue Viability field who ran leg ulcer clinics from a wider geographical area were approached to recruit participants on an individual basis and asked how many questionnaires they would realistically be able to administer to their patients. The agreed number was then posted out together with pre-paid postage for the responses. This appeared to be more effective, and 87 questionnaires were returned (150 sent out in total) representing a high response rate of 58%. Demographic data for this sample were collated and analysed, the results of which are presented in Table 11. The responses were entered onto SPSS v.19 and FA was computed using the previous combination of equamax, eigenvalues of 1.0, loadings of 0.5 and 25 iterations and 7 factors were extracted, explaining 37.6 %, 17.4%, 6.7%, 5.9%, 4.2%, 3.4%, 3.1% of the variance respectively (78.3%). The factor structure was similar to that computed in Phase 2a, and resulted in an overall item retention of 30. Six items failed to meet the specified criteria for loading onto a factor (see Table 13).

### **7.11. Internal consistency reliability – Cronbach's Alpha**

Internal consistency reliability is concerned with the homogeneity of the items within a scale (DeVellis 2003) and is typically equated with Cronbach's (1951) coefficient alpha ( $\alpha$ ) which is widely used as a measure of internal reliability. DeVellis suggests that ideally the Cronbach alpha coefficient of a scale should be above 0.70, although lower values (0.40) are acceptable for a scale with few items or a newly developed

scale. *Alpha* is defined as the proportion of a scale's total variance that is attributable to a common latent variable which underlies all the items. The *alphas* for the total scale were computed using SPSS v.19. Overall *Alpha* for the total scale (Phase 2b) was 0.931 (0.935 based on standardised items; n =30), indicating good internal consistency reliability, although the sample size was relatively small. A table outlining the Cronbach's Alphas for the individual items is given in the appendix. The corrected item – total correlation matrix was inspected to ensure that none of the scores were below 0.3 which would indicate that the scale is measuring something different from the scale as a whole. The values given in the *Cronbach's Alpha If Item Deleted* output were lower than the overall scale *Alpha*, indicating that no items needed to be deleted in order to improve the scale's overall *Alpha*. The *alphas* for each sub-scales were:

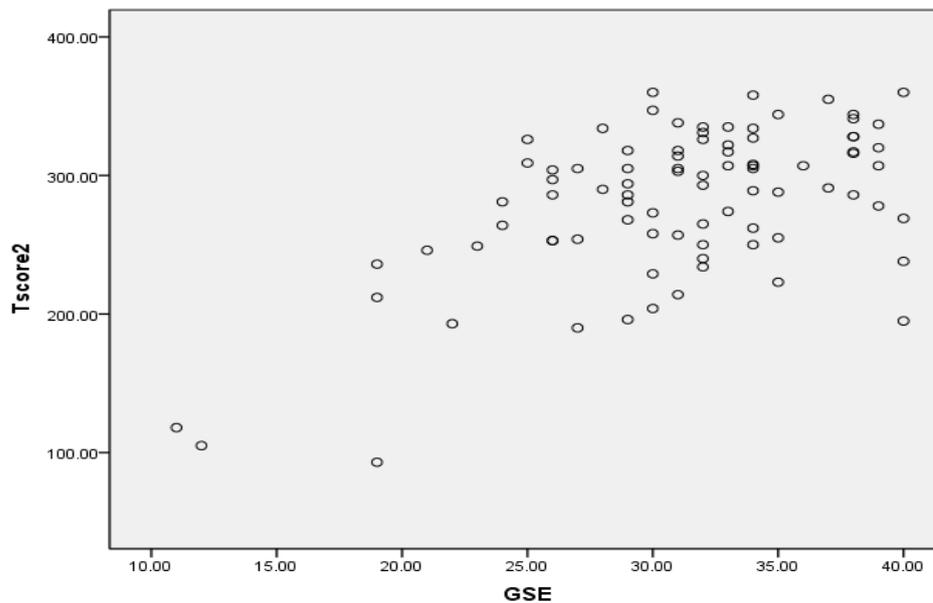
General Self-Care (5 items)	$\alpha=.834$
Daily Self-Care Tasks (12 items)	$\alpha=.851$
Normal Living (4 items)	$\alpha=.753$
Developing Expertise (6)	$\alpha=.828$
Avoiding Trauma (3)	$\alpha=.804$

### 7.12. Additional data analyses – GSE vs. VeLUSET

Correlations between the GSE scores and the VeLUSET scores were computed using Pearson product-moment correlation coefficient. Results indicated a strong positive correlation between the two scales ( $r=0.564$ ,  $n=87$ ,  $p <0.001$ ) 31% shared variance. The table below gives descriptive statistics for both scales.

	N	Minimum	Maximum	Mean	Std. Deviation
VeLUSET total scores	87	93.00	360.00	282.3218	54.17059
GSE total scores	87	11.00	40.00	31.0575	5.93248
Valid N (listwise)	87				

A scatterplot was created to assess distribution of scores. On close inspection, the 3 outliers (numbers 61, 72, 59) were found to have low scores on both VeLUSET and the GSE.



Alphas for the GSE were computed ( $\alpha=.901$ ) and mean inter-item correlation was .48, with values ranging from .71 to .108, which is often the case with scales with a small number of items (Pallant 2010). Mean score for the GSE was 31 (sd 5.93248) using the current sample, however Schwarzer and Jerusalem (1995) have found the mean score to be 29 when using a much larger sample size.

### 7.13 Test-retest reliability analysis – Phase 2c

20 participants who had completed a questionnaire in Phase 2b were approached 4 weeks later to complete another questionnaire in order to assess the reliability of VeLUSET over time. According to DeVellis (2003), the rationale for this is that if a scale reflects a meaningful construct, it should assess the construct on separate or repeated occasions. An additional question was included in the test-retest questionnaire, enabling the respondent to indicate whether a change in their leg ulcer status had occurred within the 4 week period, i.e., healed, recurred etc (appendix 13). Table 14 gives raw individual total scores for first and second administration of the VeLUSET.

### 7.13.1 Table 14 Raw Test re-test scores

Participant No.	Total Score (Phase 2b)	Total Score (Re-Test)
6	304	310
5	307	329
18	360	287
41	328	331
49	286	312
39	288	327
2	305	302
34	334	294
35	307	337
32	286	301
3	253	325
9	305	312
12	338	250
13	314	243
16	262	308
45	249	294
22	317	331
23	334	329
25	255	271
46	318	314

Correlation using Pearson product-moment correlation coefficient indicated a very strong positive relationship between the test and retest scores ( $r = .92$ ;  $n = 20$ ,  $p < 0.001$ ).

### 7.14 Additional analyses

A Chi-square test for independence was computed to explore the relationship between gender and healed ulcer but indicated no significant association (Phase 2a ( $n=118$ ,  $\chi^2=.38$ ,  $p=.84$ ,  $\phi = 0.3$ ) Phase 2b ( $n = 87$ ,  $\chi^2 = .94$ ,  $p = .33$ ,  $\phi = .12$ ). It was not possible to explore the relationship between the presence of a carer and healed ulcer/recurrent ulcers due to missing data ( $n = 20$ ). The relationship between age and healed ulcer was computed but this also indicated no significant association  $\chi^2$  ( $n=114$ ,  $\chi^2=.034$ ,  $p=.56$ ,  $\phi = .03$ ).

An independent-samples t-test was conducted to compare the VeLUSSET self-efficacy scores for males and females. There was no significant difference in scores for

males (M = 289.82, SD = 39.95) or females (M = 275.93, SD = 63.57;  $t(85) = 1.19$ ,  $p = 0.24$ , two-tailed. The magnitude of the differences in the means (mean difference = 13.8, 95% CI: -9.22-37.00) was very small.

### 7.15 Final items and sub-scales of the VeLUSET

Table 16 outlines the final layout of the VeLUSET following factor analysis. The individual sub-scales are given together with the items which reached the specified threshold of loadings of  $>.50$ .

**7.15.1 Table 15 Items and sub-scales of the VeLUSET**

<b>Domain – General Self-Care</b>	<b>Factor Loading</b>
Understand why need to wear hosiery for rest of life	.830
Check fit of hosiery regularly	.651
Confident will wear hosiery even though ulcer may come back	.730
Try to see nurse every 3/6 months to get new hosiery	.861
I understand why compression stockings will help stop ulcer coming back	.681
	overall $\alpha = .834$

<b>Domain –Daily Self-Care Tasks</b>	<b>Factor loading</b>
I am confident that I will be able to put my legs up to the level of my heart daily for 2 hours	.594
I am confident that I will be able to put my compression stockings ON every day	.713
I am confident that I will be able to take my stockings OFF daily	.755
I am confident that I will wear my compression stockings even though I have other health problems	.515
I am confident that I will try to make putting my compression stockings on and off part of my everyday routine	.747
I am confident that my compression stockings will help stop my ulcer(s) coming back	.582
I am confident that I will try to get help if I cannot put my stockings on or take them off myself	.532
I am confident that I will be able to the leg exercises (heel raises/ankle circles) that I have been asked to do every day	.542
I am confident that I can lose some weight in the next 3 months if I need to	.679
I am confident that I will be able to avoid standing for long periods during the day	.556
I am confident that I will try to avoid sitting down for too long during the day	.570
I am confident that I will be able to take a walk for at least half an hour every day	.643
	overall $\alpha = .851$

Domain – Normal Living	Factor loading
I am confident that I will still be able to lead a normal life even if my ulcer comes back	.746
I am confident that having a leg ulcer will not stop me going out if I want to	.696
I feel confident that I will still be able to go out and enjoy even though I wear compression stockings	.645
<b>I am confident that I will be able to wear the types of clothes I want to even though I have to wear compression stockings*</b>	<b>.731*</b>
* $\alpha = .817$ if item removed	overall $\alpha = .753^*$

Domain – Developing Expertise	Factor loading
I am confident that I will try to remain positive that my leg ulcer will heal even when it comes back	.616
I feel confident that I will be able to ask questions if there is something I don't understand about my leg ulcer/treatment	.504
I am confident that I know why I have a venous ulcer	.716
Able to recognise signs that ulcer is returning	.551
I am confident that I will be able to tell if a health professional gives me the wrong information about my ulcer/treatment	.656
I am confident I know where to go to get help if I think my ulcer is coming back	.731
	overall $\alpha = .828$

Domain – Avoiding Trauma	Factor loading
I am confident that I know how to avoid getting my legs knocked	.737
I am confident that I will be able to tell other people to be careful around my legs	.689
I am confident that I will take extra care to stop my legs being knocked	.684
	overall $\alpha = .804$

## 7.15 Serendipitous findings

### 7.15.1 Footwear

One item which appeared problematic was related to the wearing of specific types of clothing which had emerged from the focus group data and had been phrased: *I am confident that I will be able to wear the types of clothes I want to even though I have to wear compression stockings*". This item was retained following FA with a loading of .731 and an individual item *alpha* of  $\alpha = .716$ . However, when *alphas* were computed for that particular sub-scale "Normal Living", SPSS indicated that the

alphas for that particular sub-scale would increase to from .753 to .817 if the clothing particular item was deleted.

In addition, an item relating to wearing suitable shoes when wearing compression stockings had produced a factor loading of .604 and had been retained within the same factor as the item relating to wearing clothes (factor loading .693) during the first FA. However, the shoes item was eliminated after the second FA as it failed to meet the threshold of  $>.50$  whereas the clothing item was retained. The relationship between these two items warranted further investigation and Pearson product-moment correlation coefficient was computed which revealed a positive correlation between the two of  $r=0.49$ ,  $n = 87$ ,  $p <.001$ . However, the clothes item appeared to have low correlation scores with the other items in the subscale.

**Item-Total Statistics**

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Squared Multiple Correlation	Cronbach's Alpha if Item Deleted
leadnormallife	24.78	24.754	.618	.458	.655
notstopgoingout	24.21	25.375	.609	.431	.661
gooutandenjoy	23.98	25.581	.698	.500	.617
weartypesofclothes	24.31	32.379	.306	.123	.817

The decision was taken to leave the clothing item within the subscale since this it may have been that the “shoes” responses had been incorporated into the “clothing item” during the FA process. In addition, this is a preliminary validation study of the VeLUSET and future validation studies may result in some items in the scale being added or deleted by future research and application.

### **7.17 Minor adjustments to layout of VeLUSET**

Feedback from both HPs and participants was that they felt the scale was very repetitive in that each item commenced with: *“I am/feel confident that.....”* This positive criticism was acknowledged and the layout of the VeLUSET was changed slightly to reflect this (see appendix). Each sub-scale of the VeLUSET commences with the leader statement “I am confident that:” and the individual items appear under the heading. This is now in line with the majority of self-efficacy instruments.

## 7.18 Conclusion of Chapter 7

The process of item reduction using FA and orthogonal rotation method has resulted in the development of a robust disease-specific self-efficacy instrument with 30 items reduced from 60. Statistical analyses suggest that there is no relationship between age and healed ulcer or sex and healed ulcer.

Correlations between the General Self Efficacy Scale and the VeLUSSET scores using Pearson product-moment correlation coefficient indicated a strong positive correlation between the two scales; although there was no significant difference between the scores for males and females.

Preliminary reliability studies have revealed that the VeLUSSET has good internal consistency with an overall scale  $\alpha$  of .931, which is considered well for a newly developed scale (DeVellis 2003), although the limitations posed by the small sample must be acknowledged. Alphas calculated for the sub-scales were also good (.834; .851; .753; .828 and .804). Correlation with the GSE also indicated a strong positive relationship between the two scales. Furthermore, temporal stability of the VeLUSSET was computed using test-retest reliability which also revealed a very strong positive relationship between the test and retest scores.

These results indicate that the VeLUSSET, although still in need of further validation, can be considered a reliable instrument to measure patient's SE levels in performing self-care within clinical practice. Within the next chapter, a discussion will be presented on how the items, developed through the qualitative phase and retained following factor analysis, informed the development of the VeLUSSET. These items will be discussed within the context of the venous leg ulcer and self-efficacy literature and the decisions to include or exclude them will be justified. Furthermore, recommendations on how self-efficacy theory may assist patients in overcoming their difficulties in performing self-care activities will be offered. The chapter concludes the study and includes a discussion on the strengths and weaknesses of the study; implications for practice and recommendations for further research in this area. A reflexive account of the researcher's experiences of conducting a primary research project is also presented here.

## **8.0 Chapter 8 Discussion**

### **8.1 Introduction**

The aim of this study was to develop a tool to measure patients' perceived self-efficacy in performing self-care activities which may help prevent ulcer recurrence. The need for such a tool was demonstrated by the demographic data given in the previous chapter which demonstrated that 60% of the participants had suffered from multiple recurrences, (4 ulcers -5% trimmed mean per patient with a mean healing time of between 9-11 months), which reflects those quoted recently within the literature (Vowden and Vowden 2006; Guest et al. 2012). Administration of the VeLUSSET in clinical practice in the future may be beneficial in enabling HPs to target areas of self-care that patients find difficult to perform as a means of reducing recurrence.

A mixed methods design with two phases (qualitative and quantitative) was used to achieve the aims and objectives. According to Stewart et al. (2010), enhanced validity in developing self-report measures is achieved by the use of qualitative data to generate items relating to the construct under study. Data generated by interviewing patients were used to develop the conceptual structure and dimensionality of the construct and provide items which describe the construct in the language and context of those who have experienced the phenomenon (Mishel, 1990; Strauss and Corbin 1994). The findings of both phases are now drawn together within this final chapter, together with a discussion on how the literature was reviewed to determine specificity of the items to venous leg ulcer patients. The decisions to include or exclude items based on the factor analysis results will also be justified. Furthermore, an explanation of how the antecedents of self-efficacy theory, used as the theoretical underpinning for future interventions, may help HPs to increase patients' confidence in their ability to perform self-care behaviours in the future.

### **8.2 The patients' perspective**

As previously discussed, it was important to explore the patients' perspective of how they performed self-care activities to prevent their ulcer recurring once healed or how they had adapted to life with recurrent ulceration. Review of the literature on self-efficacy tools for other chronic conditions had revealed that many scales had been developed incorporating items drawn from literature review or from the health professionals' perspective only. Bandura (2006) asserts however that if self-efficacy scales contain items which have little or no impact on the domain of functioning, the

scale will have little predictive value. Frei et al. (2009) concur with Bandura and Stewart et al. (2010) on this point and suggest that the input from patients in developing a disease-specific scale is crucial in order to make sure that the most relevant areas of potentially low self-efficacy are included. The chapter now continues with a discussion on the individual items developed from the qualitative phase and how self-efficacy theory can predict and manipulate patients' confidence to their ability to adopt leg ulcer-related health behaviour changes.

### **8.3 Domain –Daily self-care tasks**

#### **8.3.1 Compression hosiery**

The qualitative data revealed that the patients interviewed found the application and removal of their hosiery problematic; this was an expected finding since it has been frequently referred to in the literature (Samson and Showalter 1996; Flanagan et al 2001; Heinen et al 2007a; Raju et al 2007; Moffatt et al 2009). The fact that some patients also found removal of the hosiery difficult was a little surprising to me, however this may have been due to lack of manual dexterity, some increase in oedema if their legs had not been elevated sufficiently or they had not been offered application aids, which can assist with both application and removal of hosiery (Acti-glide®, Activa Healthcare). Kapp and Sayers (2008) suggest, however, that if patients with poor manual dexterity cannot apply compression hosiery independently, it is likely that they will also be unable to manipulate aids.

The HPs interviewed in this study had acknowledged the difficulties patients faced in applying hosiery, and this has been discussed by other researchers (Kapp and Sayers 2008). In Kapp and Sayer's review on the prevention of venous leg ulcer recurrence, HPs described how they attempted to adapt the level of compression to the patient's ability to apply hosiery. A strategy frequently used by HPs to encourage tolerance of compression is to start with a low level of compression, and, as tolerance increases, increasing this until the therapeutic level of compression is achieved (Kappa and Sayers 2008). Some of the HPs interviewed in this study had described how they persuaded their patients to persevere with hosiery, giving them goals to work to, such as attending their son's wedding without having to wear cumbersome compression bandages, or discarding clumsy shoes which had been purchased to accommodate bulky compression bandages.

The HPs were using goal-setting as a strategy to motivate their patients to adhere to their advice. Van der Bijl and Shortridge-Baggett (2001) assert that self-efficacy affects thought patterns which can enhance or undermine performance. According to

Bandura (1995) and Maibach and Murphy (1995), these cognitive processes include goals and aspirations and visualisation of positive and negative performance scenarios. People with high levels of self-efficacy will set themselves high goal challenges and have a firm commitment to achieving their goal, whereas those with low self-efficacy visualise failure and dwell on the many things that may go wrong (van der Bijl and Shortridge-Baggett 2001).

An item relating to goal setting was included in the scale in Phase 2, since many patients in the qualitative phase had voiced the benefits of positive thinking and goal setting, however this item was eliminated on the first and subsequent factor analyses (factor loading  $<.50$ ). This was surprising, however it may have been that the proportion of participants with low self-efficacy had outweighed those with high self-efficacy levels when the developing tool was piloted and the responses to that particular item reflected the fact that those particular participants felt ulcer recurrence was not under their control and the ulcer would recur despite their efforts to prevent this (Bandura 1977).

Heinen et al. (2012) have demonstrated positive results with adherence to elevation and conducting leg exercises (intervention group) by using motivational interviewing by specially trained nurses in cognitive behavioural techniques. The Lively Legs self-management programme drew on elements of the self-efficacy construct using goal setting and cognitive-behavioural behaviour strategies tailored to individual patients to motivate their participants to perform these self-care activities. Interestingly, the authors reported an increase in adherence to compression hosiery in both groups and suggest that this may have been due to the six month follow up and/or a heightened awareness and increased emphasis on the importance of wearing hosiery by staff involved in recruiting patients in the study.

A dropout rate of 26% was reported due to difficulties in tolerating compression, particularly in patients with mixed aetiology ulcers. Nevertheless, although the sample in this study had open ulceration and the focus was on length of wound days rather than recurrence prevention, the preliminary results indicate the effectiveness of goal setting on bringing about desired health behaviour change in this population. Many of the participants in the qualitative phase of this study were unaware of the need to wear compression hosiery life-long, or even how compression would help reduce recurrence. The impact of knowledge deficits on enhancing self-efficacy will be discussed more fully later in this chapter, however the two items relating to the wearing of life long compression hosiery and the wearing of hosiery despite the

possibility of recurrence were retained within the developing scale following factor analyses (factor loadings .676 and .830; .547 and .730 respectively).

Many leg ulcer patients have existing co-morbidities which may prohibit them from wearing hosiery, for example, poor manual dexterity from arthritis or the inability to bend sufficiently to apply the hosiery due to spinal conditions or obesity (Franks et al. 1995; Flanagan et al. 2001; Moffatt et al. 2009a; Kapp and Sayers 2008). This issue may become even more problematic in the future as the incidence of leg ulceration in the older age group is likely to increase (Nelzen et al. 1995; Moffatt et al. 2004; Vowden and Vowden 2006). The demographic data obtained in this study confirmed this where the mean age of the participants in this study was 74 years (sd 10.966) with age of first ulcer onset being 64 years old (sd 16.687). In these particular cases, the decision not to persevere with the application of hosiery may have been related to their perceived severity of the ulcer, perceived susceptibility to the risk of recurrence and potential cost/benefit of wearing hosiery (Munro et al. 2007).

The importance of these factors in bringing about a desired behaviour change has been incorporated into the Health Belief Model (Conner and Norman 1999). According to the model, a person will evaluate these factors and a high susceptibility, high severity, high benefits and low barriers are likely to result in the individual adopting the recommended behaviour (Blackwell 1992). These factors underpin many health behaviour change models (Becker 1974; Rogers 1983; Ajzen 1988) and the considerable overlap between the various constructs within the models has been commented on (Whitehead 2001). The explanatory power of these models in predicting a desired behaviour change, however, has been criticised as simplistic since they fail to explain the intention to change behaviour, in other words – simply knowing that you need to adopt a behaviour does not mean that you will (Schwarzer 1992b). However, self-efficacy as a theoretical construct differs by virtue of its specificity (Bandura 1986) and its recognition of the two mechanisms that influence behaviour; outcome expectations and efficacy beliefs. (see Chapter 3 for an in-depth discussion on self-efficacy theory) Although two separate mechanisms, their influence on achieving behaviour is synergistic (Bandura 1986) and has been found to be a robust predictor of behaviour change (McCauley et al. 1993; Schwarzer and Fuchs 1995; Stretcher et al. 1986; Taylor et al. 1985). The cognitive element involved in successful behaviour change is amenable to change using strategies to enhance self-efficacy and resulted in Bandura emphasising the “cognitive” element in his model. As a result, self-efficacy has now been incorporated into several social cognitive behaviour change models. (Whitehead 2001).

The qualitative findings had revealed that patients found other disease-specific self-care tasks, such as elevation, exercise and walking difficult and which may therefore require a high level of self-efficacy to perform. These findings also concur with the findings of the current literature (Roaldsen 2009; Roaldsen 2010; Heinen et al. 2004; Herber et al. 2007; Heinen 2007a, Heinen 2007b).

### **8.3.2 Elevation**

It would appear that many of the participants had received conflicting advice on elevation of legs and this has also been highlighted in the literature (Barwell et al. 2000; Douglas 2001; Roaldsen et al. 2006; Roaldsen et al. 2009). Some patients feel unable to elevate their legs due to unmanaged pain or other negative contributory factors (Bland 1996; Heinen et al. 2004; Brown 2005; Finlayson 2009; Van Hecke 2010). Factors such as employment status or job type have been found to preclude limb elevation (Kapp and Sayers 2008), and this should not be considered as patient non-adherence, but rather barriers to heeding professional advice (Van Hecke et al. 2010). This particular reason for non-adherence was not found within the qualitative findings of this study but may have been due to the sample age which was predominantly 60 years and over and many were approaching or post retirement age. Nevertheless, these factors will pose potential barriers to enhancing self-efficacy expectations. Antecedents in the development of self efficacy beliefs for a particular task are the four sources of information provided by direct and indirect experiences (Bandura 1977; 1986; 1995). These include performance mastery experiences, vicarious experience, verbal persuasion and physiological cues to action.

Patients in the qualitative phase of this study repeatedly described receiving advice from one nurse, with another nurse then contradicting this, resulting in lost confidence in the validity of the information given to them and as a result were unsure as to what was being asked of them. This resonates with the findings of many studies within current literature (Bland 1996; Douglas 2001; Flanagan et al. 2001; Edwards 2003; Gilmarin 2003; Mudge et al. 2006; Heinen et al. 2007) and is a potential threat to enhancing self-efficacy.

Verbal persuasion, the most used source of self-efficacy because it is considered easy to use (van der Bijl and Shortridge-Baggett 2001), has been found to increase efficacy belief and outcome expectation, leading to a change in intention to perform a particular task (Maddux et al 1982). By giving instructions, suggestions and advice, health professionals attempt to convince patients that they can succeed in a difficult task. However, of critical importance are the credibility, expertise, trustworthiness

and prestige of the person doing the persuasion (van der Bijl and Shortridge-Baggett 2001). Although considered weaker than vicarious experiences and performance mastery because they do not concern that particular individual's own experiences, Bandura (2004) suggests that verbal persuasion in isolation can be useful, particularly in people with existing high self efficacy levels. The role of information and advice given by HPs to patients and how it may impact on SE is discussed in more detail further in the chapter.

### **8.3.3 Gradations of challenge – performance demands**

Bandura (2004), in giving advice on constructing self-efficacy scales, emphasises the importance of incorporating gradations of challenges into items (performance demands). In the case of elevation, this was problematic since the exact amount or level of elevation is not clear and currently inconclusive (Dix 2003; Dix 2005; Abadi et al. 2007). However, whilst the benefit of elevation on ulcer healing when compression has been applied is inconclusive (Heinen et al 2004), there is some evidence that elevation without compression may help reduce ulcer recurrence (Heinen et al. 2004; Heinen et al. 2007; Finlayson et al. 2009). The decision was taken to set the challenge at two hours per day as a reasonable amount within the VeLUSET and to provide clarity on the importance of performing this self-care activity. This may however need adjustment in the future in light of more definitive research evidence.

### **8.3.4 Pain**

Pain has been cited by patients as one of the worst things about having a leg ulcer (Hofman et al. 1997; Krasner 1998a, Krasner 1998b; Douglas 2001; Persoon et al. 2003; Briggs 2005; Briggs and Closs 2006; Briggs and Flemming 2007; Herber et al. 2007; Edwards et al. 2009; Bistreanu and Teodorescu 2009; Gonzalez-Consuegra and Verdu 2011) and the participants in this study confirmed this was the case also. The rationale for omitting this very important negative aspect from the items in the VeLUSET therefore must be justified. The focus of data collection was to elicit their views on managing self care activities and consequently, items concerning pain do not appear in the scale. This was a deliberate decision since it would be assumed that pain would have been assessed and managed as part of the leg ulcer assessment process and prior to the administration of the VeLUSET.

It has been recommended that leg ulcer assessment documentation incorporates a recognised tool for on-going pain assessment and that subsequent management strategies are regularly monitored and evaluated (RCN 2006), although research evidence indicates that this is not always the case (Douglas 2001; Persoon et al.

2003; Briggs 2005; Briggs and Closs 2006). The impact of pain on adherence with self-care strategies has been discussed by Heinen et al (2004) and the implications of poor pain management must be considered a threat to achieving health behaviour change using the self-efficacy construct. Patients with low self-efficacy may not persist in elevation if they perceive that this results in a negative physiological cue, such as pain, and will dismiss this as unachievable. Equally, in the case of a recurrence, their prior experiences of pain on elevation may preclude them from attempting this again, reinforcing their low level of self-efficacy. Conversely, a patient with high levels of self-efficacy may seek to resolve the experience of pain by the use of analgesia in order to accomplish the task. When incorporated into clinical practice, education around the administration of the VeLUSSET will be required to ensure that pain, as a potential threat to enhancing self-efficacy, is acknowledged and managed.

### **8.3.5 Walking and exercise**

Participants in this study had identified that walking and performing exercises may be a beneficial activity that may prevent recurrence, however they voiced receiving conflicting advice in this area also. Again, this has also been widely discussed by others (Bland 1996; Douglas 2001; Ebbeskog et al. 2001; Edwards et al. 2002; Edwards 2003; Heinen et al. 2007a, b; Moffatt et al. 2009). Edwards et al. found that patients were interested in more information about the benefits of walking and exercise but found the sources of information did not meet their needs. This was certainly the case in this study also.

The evidence base on the efficacy of walking and performing exercises in preventing ulcer recurrence had been reviewed in Chapter 2 which concluded that there is some evidence that increasing mobility and moderate activity may help prevent recurrence (Yang et al. 1999; Kan and Delis 2001; Van Uden et al. 2005; Heinen 2007 (a, b); Jull et al. 2009; Meagher et al. 2012), although the exact time spent walking is difficult to establish. In relation to leg exercises, the evidence is more definitive and specific exercises, such as ankle raises and ankle circles, are generally acknowledged as most effective in improving venous haemodynamics in venous leg ulcer patients. The items concerning walking and performing exercises were incorporated into the VeLUSSET, with a specific challenge of walking for 30 minutes daily and were retained as a result of factor loadings of .594 (elevation) and .542 (exercises) respectively.

Roaldsen et al. (2009; 2010) however found that patients avoid undertaking these activities due to fear of pain or injury to the ulcer and, as has been previously

discussed, recommend counselling the patient and providing adequate analgesia to negate these fear-avoidance beliefs. An additional advantage of including these specific items with defined performance challenges within the VeLUSSET is that, once incorporated into clinical practice, HPs will be able to adopt a consistent approach to information giving, providing a credible source of information, considered by Bandura (1997) as an effective source of mastery expectation.

## **8.4 General lifestyle advice**

### **8.4.1 Weight control**

Many of the participants in the qualitative study referred to weight control as a means of reducing recurrence or enhancing healing of their ulcer. This was also a finding of Edwards et al (2002) who found that patients requested more information about weight control.

Studies on risk factors for the development of chronic venous insufficiency have indicated that obesity may play a role (Ruckley et al. 1982; Brand et al. 1988; Mulder and Reis 1990; Nelzen et al. 1994; Scott et al. 1995; Palfreyman et al. 2007) however the studies relate to the development of varicose veins and the relationship between obesity and the development of ulceration and/or recurrence is unclear. What is clear, however, is that obesity will affect the patient's mobility and the application of compression hosiery. Weightwatchers®, an intervention designed to encourage weight loss appears to draw on elements of the self-efficacy construct, goal setting, vicarious experiences, and peer support to bring about the desired behaviour changes needed to lose weight (Bandura 2004). An item on losing weight, therefore, was included in the VeLUSSET, together with a performance challenge of achieving this within 3 months (goal setting) (factor loading .679) to reflect the participants' belief that reducing their weight would reduce their risk of suffering ulcer recurrence. The issue of quitting smoking also featured frequently within the data analysis of the focus groups.

### **8.4.2 Smoking cessation**

A question about smoking status was incorporated into the demographic questions on administration of the pilot questionnaire. Although there is a paucity of evidence to support smoking history as a risk factor for the development of venous ulceration and/or recurrence, researchers have highlighted a long smoking history as a risk factor for the development of chronic venous insufficiency (Palfreyman et al. 2007; Sorensen et al. 2009) but interestingly, not for the development of varicose veins (Brand et al. 1988). In light of these findings, a discussion by the supervisory team

ensued around whether to include an item, which has been identified as a risk factor in the development of cardio-vascular, or more specifically, arterial disease, (Scott et al 1995) but not in the development of a venous leg ulcer, in the scale. In light of the fact that the issue had been raised by several of the participants within the qualitative phase and this had been supported within the literature (Edwards et al. 2001), it was decided to include this as a self-efficacy item and worded “*I am confident that I can give up smoking*”. However, the low number of smokers who responded to this question (13.5% smokers; n = 16 82.2% non smokers; n = 97) resulted in the question being omitted by factor analyses (factor loading <.50) and was subsequently removed from the developing scale.

### **8.5 Psychosocial adaptation to having chronic venous leg ulceration**

Many of the participants in the study had realised that they were suffering from a chronic condition and needed to adapt their behaviour in the long term in order to prevent recurrence. To reflect this, two items which inferred the need to maintain these behaviours life long were included, for example: “I am confident that I understand why I need to wear my compression stockings for the rest of my life” (loading .830) and “I am confident that I understand why I need to wear compression stockings even though my ulcer may come back” (loading .730).

Bandura (1997) believes that self-efficacy is a cognitive resource and influences the capacity of an individual to adapt and cope with a chronic condition. Rolland (1984) refers to two phases in the adaptation to living with a chronic disease; firstly, the “initial adjustment” period before the chronic “long haul” of a condition that will require a lifelong commitment to self-care. The early adjustment period, which may take months to years, is defined by awareness that behaviour change is necessary, including the questioning of effective strategies and personal abilities (Maddux and Lewis 1995). The “long haul” or maintenance phase of behaviour change, where the challenge is to sustain long-term behaviour change, occurs six months after the behaviour change has been initiated (Ruggiero and Prochaska 1993).

The role of self-efficacy in maintaining health behaviour in chronic conditions has been discussed extensively in the literature (Marks et al. 2005a,b) and within Chapter 3 of this thesis. Positive outcomes in terms of adopting health behaviours but also managing the negative emotions of suffering from chronic disease, for example fear, anxiety and depression have been reported (Lorig et al. 2001). Although these studies relate to conditions such as arthritis, diabetes and multiple sclerosis, these negative emotions have also been reported in the literature investigating the quality

of life of patients with chronic venous leg ulceration (Franks et al. 2003; Jull et al. 2004; Charles 2004; Price and Harding 2004; Franks and Moffatt 2006; Franks et al. 2006; Jones et al. 2006; Jankunas et al. 2007; Moffatt et al. 2009; Finlayson et al. 2010). Finlayson et al. (2010) found a relationship between depression and non-adherence with compression hosiery. Others even suggest that the symptoms of depression, which include loss of motivation and a pessimistic mood may be misinterpreted as non-adherence in this patient group and advocate training for HPs on the diagnosis of depression in leg ulcer patients which is an important but rarely acknowledged implication for practice (Jones et al. 2007; Finalyson et al. 2010).

These studies relate to patients with open ulceration; however some of the patient participants in this study, who had healed or frequently recurring ulceration also voiced these negative emotions. As a result, two items relating to preoccupation with recurrence and maintaining a positive attitude towards healing once recurrence occurred were included in the first pilot questionnaire. The item relating to maintaining a positive attitude remained following FA (loading .616); however the item relating to preoccupation and fear of recurrence failed to reach the threshold of .50 and was eliminated. This was surprising however it may have been as a result of the different personality traits of the focus group participants and the sample completing the questionnaire. Furthermore, it may have been related to optimistic beliefs, the role of which has been studied in relation to adaptation to chronic disease and controllability by performing self-care activities (Fournier et al. 2002).

Several of the participants had voiced optimistic beliefs that one day they would be ulcer-free. Optimism, as a coping resource (Lazarus and Folkman 1984) has been found to play a significant role in the adaptation to chronic disease and the link to SE theory needs to be explored. Types of optimism have been defined in the literature as functional versus defensive optimism (Schwarzer 1994), positive outcome expectancies versus efficacy expectancies (Bandura 1988) and cautious optimism (realistic) versus “cockeyed” optimism (unrealistic) (Wallston 1994). Fournier et al. found that optimism in the form of positive efficacy expectancies, an important antecedent in SE theory, is only beneficial when patients suffer from a chronic disease over which they feel they have some control by performing certain task-oriented health behaviours. In the case of chronic conditions such as MS, where the patient feels he/she has little control over the disease trajectory, positive but unrealistic thinking appears to be more beneficial in terms of mental health (Fournier et al. 2002). Taylor and Gollwitzer (1995) argue that adaptiveness of positive unrealistic thinking depends on the right point of time. Before a decision to act is

made, realism is necessary to consider the pros and cons in order to develop a positive mind-set. After the decision, people move into an implemental mind-set where unrealistic optimism is necessary to carry out their plans (Schwarzer 1999). Unfortunately, the benefits of positive unrealistic thinking may threaten physical functioning in the long term because it interferes with the decision making process and results in low self-efficacy. Fournier et al (2002) conclude that positive outcome expectancies help people to remain engaged and promote psychosocial functioning by fostering acceptance of their condition. Bandura (1994) believes that developing positive self-efficacy beliefs is a key factor in down regulating stress, depression and anxiety that result from negative thought processes.

In a study to examine whether optimism acts as a mediator in the relationship between SE, social support and well-being, Karademas (2006) found that highly efficacious people develop resilience SE which refers to the belief that one can bear the negative consequences of a stressful situation. This type of SE develops overtime as a result of exposure to repeated stressful situations, and resilience SE, as a general positive appraisal, correlates positively to optimism (Karademas 2006). Karademas's study was conducted on employees of 4 insurance companies (mean age 41yrs; n=201) Depressive symptoms and social support life scales were used as indicators of well-being and data analysis was based on self-report measures. These findings may not be applicable to the leg ulcer population, however, many venous leg ulcer patients may experience stress, depression and anxiety at the thought of recurrence and highly efficacious patients will have the ability to turn these thoughts off (Bandura 1994). Furthermore, highly-efficacious patients with recurrent ulceration may develop resilience SE which will act as a buffer against the potential stress of anticipating recurrent ulceration and will draw on their prior experience of having a healed ulcer in the past to maintain the task-specific behaviours required to overcome the temporary setback. As a result of the qualitative findings, an item which appeared to reflect perceived resilience SE (*I am confident that I will try to remain positive that my leg ulcer will heal even when it comes back*) loaded at .616 and was retained in the developing VeLUSSET.

Karademas (2006) however advocates that the study of the relationship between expectations, support and well-being is important since it allows us to understand the ways that social relationships relate to personal beliefs in shaping outcome expectations and of course outcomes. The role of social support in enhancing SE will be discussed further in this chapter.

## **8.6 Mishel's Uncertainty in Illness Theory (1981)**

As alluded to within the qualitative findings chapter, many of the participants' narratives appeared to draw on the antecedents of Mishel's (1990) Uncertainty in Illness Theory. Although not generally used in relation to venous leg ulcer patients, this theory appeared to offer an explanation as to why some leg ulcer patients voiced certain beliefs and exhibited specific behaviours. Originally developed to explore the impact of uncertainty on cancer patients, the theory has been used to explain how living with uncertainty affects patients with other conditions, where knowledge of the disease trajectory is unknown (Hoff et al. 2002; Van Pelt et al. 2006; White et al. 2005). The model seeks to explain how patients cognitively process illness-related events and then structure the meaning of those events (Mishel 1990). In particular, this theory poses that there are antecedents of uncertainty; uncertainty is neutral until it is appraised as a danger or an opportunity; and following implementation of effective coping strategies, adaptation occurs (Mishel 1990). In terms of the uncertainty experienced in certain illnesses, Michel has defined this as a cognitive state that occurs in situations in which the sufferer is unable to assign definite values to events or objects and / or is unable to predict outcomes accurately, because the cues are vague, inadequate, unfamiliar, contradictory, numerous, or lacking information (Budner 1962; Mishel 1988; Brashers et al. 2006). According to Mishel's theory, uncertainty in illness is associated with situations that may involve discomfort, incapacitation and other symptoms of illness. The evaluation on whether uncertainty is a danger or an opportunity depends on the sufferer's thought processes. In relation to leg ulcer patients, if the uncertainty is perceived as a threat to well-being based on previous experiences, i.e. a recurrent leg ulcer, it will be evaluated as a danger. According to Mishel (1990) appraisal of uncertainty as an opportunity is likely to result when in a hopeless situation, a downward disease trajectory or in situations where the sufferer can ignore or deliberately misinterpret signs and symptoms of the disease. In other words, not knowing can help a person maintain hope or optimism (Brashers 2001). Brown (2003; 2005) found that some patients prefer to take the risk that their ulcer may return rather than wear compression hosiery, which could be considered a coping strategy to manage their perception of uncertainty as an opportunity.

This fatalistic view was also expressed by participants in the current study, who described relying on others, such as God, luck ("keep my fingers crossed") "what will be, will be" (Life in general is uncertain) and bears similarities with chance locus of control (CLHC) and external locus of control perceptions (ELOC) which are antecedents of Health Locus of Control (Wallston et al 1978). (see Chapter 3 for a

more in-depth discussion). The Health Locus of Control theory (HLC) seeks to explain the impact of perceived control an individual feels he/she has over health behaviours. These particular individuals who believed their chance of ulcer recurrence relied on “powerful others” over which they had little control would probably exhibit low self-efficacy beliefs. Palank (1991) in her overview of determinants of health promotive behaviours argues that a person’s perception of control over a condition may be a significant predictor for lifestyle behaviours in general; however this will may not impact on a person’s decision to engage in changes relating to health behaviour change. She asserts that SE recognises specific personal abilities and power rather than general conceptions about control or desire for competence.

### **8.7 The role of health professionals in mediating patient uncertainty**

Brashers et al (2006) assert that people with chronic or acute illness often face uncertainty about their health and medical care, and HPs can affect the uncertainty patients experience by providing information about causes, symptoms and consequences of their illness, together with explanations about treatments etc. As such, HPs fulfil the role of credible authority, defined by Mishel as the “*degree of trust and confidence patients have in health care providers* (1988 pg. 228). According to Mishel, this role helps patients reduce their uncertainty through two pathways; firstly, HPs provide stability by explanation and consequences of symptom patterns; increasing event familiarity with information about the illness and the health care system; and by promoting event congruence by helping patients interpret their illness experiences (Brashers et al 2006). Secondly, health care providers can reduce a patient’s uncertainty by taking charge of treatment decisions. The latter element may be germane to cancer patients, who, understandably, may choose to defer any treatment decisions to medical authorities due to the potential life-threatening disease process (Brashers et al 2006). However, in relation to venous leg ulcer patients, this may be difficult to achieve since it is dichotomous with current philosophies of empowerment, patient participation and concordant relationships. In terms of reducing uncertainty when appraised as a danger, however, patients may respond by seeking information (not knowing can lead to harm); whereas when uncertainty is appraised as an opportunity, patients may avoid information (knowing can help a person maintain hope or optimism).

The qualitative findings of this study indicated that many of the patients appeared to voice feelings of uncertainty; some of whom may have perceived the uncertainty as a

danger or threat, conversely, others may have viewed their feelings of uncertainty as an opportunity. Themes that described patients' appraisals of uncertainty emerged, for example, of receiving conflicting advice, lack of knowledge on the part of health professionals, identifying skilled nurses, maintaining contact with nurses; asking questions if something is not understood; the ability to differentiate when HPs gave incorrect information; and navigating the healthcare system to access appropriate care. Understandably, Brasher et al (2006) found that when HPs lacked vital information, stigmatised their patients or gave conflicting or incorrect information, feelings of uncertainty were increased.

Although information or knowledge acquisition will not influence behaviour change in isolation (Palank 1991), knowledge of the cause of VLU and why recurrence occurs, need for treatment (i.e. life long compression therapy) and self-care behaviours are fundamental to forming positive outcome expectancies and beliefs. Strategies which incorporate these sources of SE information, such as prior mastery experiences (positive or negative), verbal persuasion and vicarious experiences of performing self-care behaviours are not, however, directly translated into efficacy judgements. Furthermore, Bandura (1994) asserts that SE beliefs influence how individuals think and react and serve to gauge their levels of confidence by the emotional state they experience as they contemplate undertaking the task required. Negative affective and cognitive reactions such as thoughts of failure and fear in undertaking a task trigger additional stress and agitation, which ensures the inadequate performance, follows as anticipated. Enhancing self-efficacy beliefs can enable a person to alter their negative thought processes, resulting in reduced stress and depression. If, however, the advice and information patients receive is contradictory, this will exacerbate the view that uncertainty is a danger and has the potential to lower self-efficacy even more.

Self-management programmes for chronic diseases, such as the Expert Patients Programme (DH 2001) provide patients with strategies for managing negative emotions such as fear and depression and equip patients with the necessary skills, knowledge and confidence to deal with disease-related problems (Lorig et al 2001). These programmes are underpinned by self-efficacy and have demonstrated positive outcomes (see Chapter 3 for a more in depth discussion).

In relation to leg ulcer patients, self-care programmes may become a potential credible source of information, meeting the information needs of patients who view uncertainty (potential ulcer recurrence) as a threat and instil a sense of control over

their condition. Conversely, patients who currently manage their uncertainty by denial, avoiding information sources or ignoring physical cues may reappraise their situation and by adopting self-care strategies, reverse their feelings of hopelessness and helplessness by exerting perceived control over the source of their potential uncertainty, i.e. a recurrent ulcer.

The items relating to receiving conflicting advice, lack of knowledge on the part of health professionals, observing physical cues that the ulcer is returning; identifying skilled nurses, maintaining contact with nurses; asking questions if something is not understood; the ability to differentiate when HPs gave incorrect information; and navigating the healthcare system were included in the first questionnaire and subject to FA. Following FA, 5 items were retained as they had reached the specified loading threshold – trying to see the nurse every 3/6 months (loading .861); confidence in asking questions (loading .504); able to distinguish incorrect information by HPs (.656); recognise signs that the ulcer is returning (loading .551); knowing where to go to get help (loading .731). The items were incorporated into a sub-category called “Developing Expertise”.

The role that Mishel’s Uncertainty in Illness Theory plays in relation to venous leg ulcer patients’ behaviours has not previously been alluded to in the literature and this is a new finding emerging from this study which warrants further investigation. Many of the patients interviewed in this study expressed how they lived with the uncertainty of recurrence and how this impacted on their lives. Furthermore, the way patients perceive uncertainty (threat or opportunity) will determine whether they seek more information from HPs or whether they prefer to use denial strategies (not knowing to maintain hope or optimism) to manage their uncertainty. It may explain why many patients do not recall information given to them or cannot explain why they have a venous leg ulcer when asked, despite being provided with this information by HPs (Hamer et al 1994; Walshe 1995; Chase et al 2000; Douglas 2001; Edwards et al 2002; van Hecke et al 2010). This chapter continues with a discussion on why the remaining items were included within the VeLUSSET.

## **8.8 Adaptation to life with recurrent leg ulceration**

Normalisation of a chronic condition, in terms of adaptation, has been defined as the ability to psychologically “bracket off” the impact of the condition, so that its effect on the person’s identity remains relatively slight (Bury 1991). Livneh and Antonek (2005) on the other hand, describe coping strategies in two broad categories: disengagement coping strategies and engagement coping strategies.

Disengagement strategies include denial, wishful thinking, blaming self and others depression, anger and hostility. This type of coping strategy is associated with higher levels of psychological distress, difficulties in accepting one's condition and generally poor adaptation to chronic disease (Livneh and Antonek 1997). Engagement strategies refer to coping efforts that include goal-oriented activities, planning and seeking social support (Penninx et al. 1991) which generally lead to higher levels of well-being, acceptance of condition and successful adaptation to chronic disease.

The participants' within this study voiced elements of both these coping strategies in describing how they had adapted over time to life with their chronic condition. Strategies included: *remaining optimistic; carrying on regardless* and *perseverance* and have similarities with Walshe's findings on normalisation to life with recurrent leg ulceration. Patients described their coping strategies as *feeling healthy* (despite the ulceration) *altered expectations* (acceptance by viewing the ulcer as part of the ageing process); and *being positive* (Walshe 1995; Renner et al 2009). Bury (1991) asserts that patients with chronic conditions are forced to make decisions about their treatment in terms of the social impact they have on their daily life. Relating this to patients with recurrent leg ulceration, there may be a trade off in that the HPs advice may clash with the goals held by the patients in terms of social and cultural pressures. For example, limb elevation is advocated to improve healing, this however will interfere with a patient's desire to play golf with colleagues from his golf club and this juxtaposition of conflicting demands may result in psychological distress and non adoption of certain self-care behaviours on the part of the patient since these self-care behaviours are a lifelong requirement.

Five items relating to patients' negative and positive adaptive coping skills and which are indicative of potential low self-efficacy were incorporated into the questionnaire in Phase 2 – preliminary FA. Factor loadings are given in brackets "*I am confident that I will still be able to lead a normal life even if my ulcer comes back*" (.609), "*I am confident that having a leg ulcer will not stop me going out*" (.539); "*I am confident that I will not allow my life to change just because I have an ulcer*" (<.50), "*I am confident that I will be able to stop worrying constantly about my ulcer coming back*" (<.50); and "*I am confident that I will try to remain positive that my ulcer will heal even if it returns*" (.685) Of these, three remained following FA and were incorporated into the scale under the sub-scale of "Normal Living". The elimination of the other two items may have been as a result of differences between personality traits and diverging coping skills between sample groups.

Global interventions to equip patients with positive adaptive coping skills include assisting patients to explore the personal meaning of their condition (changed body image, acceptance of the permanence of the condition and decreased functional capacity); providing relevant information, providing a supportive network, and teaching patients to attain a sense of mastery over their emotional experiences (Livneh and Antonek 1997). Luszczynska et al. (2007) suggest that making meaning of stressful events result from a process that encompasses a person's stress appraisal, optimistic beliefs and a strong social support and are all influenced by the mediating effects of strong self-efficacy beliefs.

## **8.9 Unexpected findings**

### **8.9.1 Difficulties with footwear**

Part of the process of normalising a chronic condition is the acceptance and adaptation to an altered body image (Luszczynska et al. 2007). Many of the patients interviewed alluded to the fact that the presence of venous leg ulceration (healed and open) had impacted on the types of clothes they were able to wear. Both men and women commented on how they were no longer able to wear the types of clothes, however, the issue of suitable footwear was raised as an important issue for them in particular. This was not surprising since it has been raised by several others in qualitative studies (Franks et al. 1995; Ebbeskog et al. 2001; Haywood 2002; Mudge et al. 2006; King 2007; Heinen et al. 2007a). Two items reflecting these issues were included in the preliminary scale *"I am confident that I will be able to wear the types of clothes I want to even though I have to wear compression stockings"* and *"I am confident that I will be able to choose suitable shoes to wear with my compression stockings"*. The item relating to clothes was retained within the initial factor analysis process and had a high factor loading of  $\alpha=.753$ . The item relating to wearing suitable shoes when wearing compression stockings revealed a factor loading of .604 and had also been retained within the same factor as the clothes item (factor loading .693) during the preliminary FA. However, the shoes item was eliminated after the second factor analysis ( $<.050$ ), while the clothing item was retained. The relationship between these two items was further investigated using Pearson product-moment correlation coefficient which revealed a positive correlation between the two ( $r =.48$ ,  $n =87$ ,  $p<.001$ ), however the clothes item appeared to have low correlation scores with the other items in the subscale (Normal living) which was surprising. Following a discussion with my statistics supervisor, the decision was taken to retain the clothes item within the "Normal Living" domain (despite achieving a lower  $\alpha$ ) as the shoes and clothes items strongly correlated and the clothes item

may have incorporated the respondents' responses to the shoes item. This illustrates the importance of researcher interpretation and knowledge of the subject under study, rather than reliance on statistical inferences as a means of reducing items for a scale (DeVellis 2003). Another explanation may be that there were marked differences between the samples who completed the first and second questionnaires in terms of recurrences; a person who had suffered multiple recurrences would have experienced the difficulties in obtaining shoes to accommodate bulky compression bandages on a more regular basis, whereas a person with just one healed ulcer and who was wearing compression hosiery, may not have perceived footwear as a problem.

### **8.9.2 Goal Setting**

Goal setting is considered to be a powerful strategy in the self-regulatory process of enhancing perceived self-efficacy in adopting specific health behaviour changes (Bandura 1988). The effects of goals on behaviour depend on their properties: specificity, proximity, and difficulty level (Bandura, 1988; Locke et al. 1981). Goals incorporating specific performance standards are more likely to motivate individuals to perform that behaviour than general goals (i.e., "Do your best"). Specific goals boost performance by greater specification of the amount of effort required for success and the self-satisfaction anticipated. Achievable specific goals promote self-efficacy because progress is easy to gauge (Schunk 1990).

Some of the focus group participants had discussed how the setting of goals had motivated them to persevere with compression therapy, for example, to be able to wear stockings rather than bandages to a son's wedding, or to be able to discard cumbersome bandages and be able to wear "normal" shoes with hosiery. The constant comparative data analyses process had revealed, however, that this was not a common perception and this item was rejected by subsequent participants and was eliminated early in the scale development. Several of the participants had commented that they felt that ulcer healing was not under their control and did not appear to see the connection between performing self-care activities, such as exercises and elevation. Given the findings from the literature that goal-setting may be an important and effective source of self-efficacy (Locke et al., 1981; Bandura & Cervone 1983; Elliott & Dweck 1988), this may be considered an important omission within the tool development. This may have been related to low levels of perceived self-efficacy within the study sample, or sample size and must be acknowledged as a potential weakness of the study. Future validation studies on larger samples to further refine the tool may result in this item being reinstated in future versions.

### **8.10 Disease-specific versus general self-efficacy**

Existing self-efficacy literature suggests that behaviour-specific efficacy beliefs develop over time (Bandura 1991; Stretcher et al. 1986); however the early self-efficacy research involved interventions aimed at efficacy beliefs for a single behaviour. Venous leg ulceration, however, in common with all chronic conditions, will involve the adoption of multiple behaviours and associated efficacy beliefs (Rapley and Fruin 1999). As a result, individuals will vary in the strength of their efficacy belief for different behaviours, that is, the increase in behaviour-specific efficacy expectation will not be consistent across all behaviours (Rapley and Fruin 1999). Task-specific efficacy beliefs may initially be low and increase as the person persists and masters the various new skills and behaviour changes. If this is the case, it could be that a high general self-efficacy is acting to mediate the relationship between initial behaviour-change efforts and the development of task-specific efficacy expectations (Rapley and Fruin 1999). Although Bandura (1977) believes that efficacy beliefs should be assessed at the optimum level of specificity that corresponds to the criterion task being assessed and the domain of functioning being analysed, he concedes that efficacy expectations may change over time. Sherer (1990) speculates that perhaps this change represents the movement of efficacy beliefs on a continuum from general to specific (Sherer 1990) or an interaction between the two, general and specific. Pajares (1997) concurs with Sherer's views to a certain extent but maintains that general self-efficacy instruments have little explanatory and predictive value in contrast to domain-related measures (Bandura 1977).

### **8.11 General Self-Efficacy Scale versus the VeLUSET**

With Bandura's and Pajares's comments in mind, the General Self Efficacy scale (GSE) (Schwarzer and Jerusalem 1995) was incorporated into the VeLUSET during phase 2(a) into order to assess validity of the VeLUSET and specificity to venous leg ulcer patients. Correlations using Pearson product-moment correlation coefficients had indicated a strong positive correlation between the two scales ( $r = .56$ ,  $n=87$ ,  $p = 0.001$ ). Furthermore, a scatterplot revealed that the patients who had high scores on the VeLUSET also had high scores on the GSE; the 3 outliers on the scatterplot had low scores on both the VeLUSET and the GSE respectively. These results confirmed high content and predictive validity of the VeLUSET (Field 2009), although the influence of a small sample size must be acknowledged.

### **8.12 The role of social support in strengthening self-efficacy beliefs**

The importance of social support was raised by with the participants in the current study who valued the support they received from their family and friends who encouraged them to perform the necessary self-care behaviours and provided encouragement and positive feedback. Items relating to seeking help from others; asking for assistance with application of hosiery and the ability to draw on family and friends when depressed had therefore been incorporated within the pilot scale. Of these items, only 1 was retained following FA" *I am confident that I will try to get help if I cannot put my stockings on or take them off myself*" (factor loading .532), again this may have been as a result of between sample group characteristics in terms of personality traits and social support perceptions.

There is an assumption within the venous leg ulcer literature that some patients have a reduced amount of social support, are therefore considered to be socially isolated and, as a consequence, may interfere with ulcer healing or re-open their ulcer in order to prolong community nurses' visits. (Wise 1986; Moffatt 2001; Charles 1995; Brown 2003, Brown 2005; Brown 2008; Franks and Moffatt 2006; Morgan and Moffatt 2008; van Hecke et al 2010). Victor et al (2000) suggest, however, that it is more important to measure a person's satisfaction or dissatisfaction with their social network rather than enumerating how many contacts a person receives. Furthermore, some people, often alone, are not necessarily dissatisfied with their social contacts, as solitude can be a personal choice (Brown 2003). It may be that these individuals are already highly efficacious (resilience SE) and this acts as a buffer against the stress of a reduced social network. Conversely, Keeling et al. (1996) found that most patients perceived that they received less support than they actually did. Luszczynska et al.(2007) differentiate between the different aspects of support available, defining emotional support as caring and reassuring companionship; informational support as advice and guidance typically provided by HPs, and instrumental support that is provided by the people close to the person, such as spouses, friends and children. Since there are several aspects of social support, it is unlikely that an individual HP in isolation would fulfil all aspects of social support to a patient's satisfaction (Flett et al. 2003).

Interestingly, analysis of the focus group data (family/friends and carers) revealed that this sample appeared to exhibit high self-efficacy levels that had developed over time and may have been related to negative and positive prior experiences of the healthcare system; in this case, the leg ulcer services (Keefe et al. 1003). The narratives of these highly efficacious individuals were categorised into themes such

as “being assertive”, accessing appropriate treatment” and “recognising unskilled nurses”. These items failed to reach the specified threshold for inclusion (>.50) and were eliminated at the first FA; however this was not unexpected since the questionnaire had been administered to patients and not family/friends or carers.

Patients and HPs in this study commented on the benefits of interacting with fellow patients at the leg ulcer clinic and this has been confirmed by researchers who found significant pain reduction, enhanced healing and reduced recurrent rates in patients attended a social leg club (Lindsay Leg Club®) (Edwards et al 2005a, 2005b; Finlayson et al 2010; Finlayson et al 2011). McAuley et al (2003) studied social, affective and behavioural influences of exercise SE among older adults attending an exercise group and found that the highly efficacious people exercised more because they perceived the group as very supportive. One of the focus groups had been conducted with participants attending a Lindsay Leg Club® and from the data analysis; an item was developed which reflected the importance of seeing others successfully enact a self-care task (the application of hosiery). Since this source of self-efficacy belief – vicarious experience is considered to be a strong predictor in affecting behaviour change; it was included in the pilot questionnaire. However, this was eliminated at the first FA (<.50) and may have been due to the fact that none of the consecutive samples recruited attended a Leg Club® but attended leg ulcer clinics where the application of hosiery would have taken place behind closed doors.

The literature on the role of social support in strengthening SE beliefs in chronic conditions is vast (Uchino et al 2012) and will not be discussed in depth within this thesis. A short overview relating to the relevance of social support and SE to venous leg ulcer patients will now be presented although it is acknowledged that the views expressed here may not be representative of the findings of the entire body of literature.

The role of social support, such as encouragement, affirmation, boosting a positive mind as well as providing information has been found to affect SE beliefs in a positive way (Simoni et al. 2006; Luszczynska et al. 2007; Bandura 1986). Patients who receive more social support are more likely to have stronger SE beliefs which in turn are related to finding positive changes in social relations and perceived improved personal strength and resilience (McCauley et al. 2003; Warren et al. 2007; Uchino et al. 2012). These positive beliefs in turn are believed to relate to better adherence and better physical functioning (Luszczynska et al. 2007), although this is debated by some in the literature (Penninx et al. 1991). It would appear that it is not clear

whether social support has a direct effect on health outcomes or whether strong social support operates as a buffer against the negative aspects of ill health (Penninx et al. 1991). Social support is provided by friends, family, carers, health professionals and peers, however it is not a unidimensional concept and Penninx et al. concur with Luszczynska et al. who believe a distinction should be made between different aspects of social support. The support offered by family and friends would be classified as emotional and instrumental (Luszczynska et al. 2007), however, the role of the HPs in providing informational support (advice and guidance) and how this may impact of SE needs further elucidation.

### **8.13 The role of HPs in enhancing self-efficacy**

It was proposed earlier in this chapter that one of the reasons why some patients may display knowledge deficits in relation to their leg ulcer despite having been provided with information may be a result of a coping strategy associated with uncertainty. This uncertainty is further compounded if the source of information is perceived as an uncredible source (Mishel 1990). The importance of providing information using verbal persuasion, affirming success and encouraging when attempts fail is the cornerstone of enhancing SE (Bandura 1977). Pryor (2009), in discussing the role of HPs in coaching self-care skills, proposes that a HP's ability to effectively coach patients depends on the nature of the HP's understanding of the condition; their insight into a patient's situation, the repertoire of skills possessed by the patient and the manner in which knowledge and skills are applied. Some of the HP participants interviewed were already demonstrating elements of this strategy by acknowledging the difficulties patients experienced in the application of their hosiery. As a result of this acknowledgement, alternative strategies were negotiated such as the provision of application aids or reducing the amount of compression to enable easier application. Furthermore, the HPs had re-negotiated the need to wear compression hosiery consistently, acknowledging that for some, this would not be realistic or achievable. A compromise was reached, for example, a patient who desired to wear "normal" hosiery at her son's wedding but realised that she would then need to revert back to her compression hosiery (goal setting).

Patients with healed ulceration (and frequent recurrences) may seek constant reassurance and advice from HPs in order to reduce uncertainty and to maintain high levels of SE through affirmation of the successful enactment of self-care behaviours. Unfortunately, this need can lead to misinterpretation by HPs in a negative way in that it may be viewed as "attention-seeking" (Brown 2003; 2005). Bisschop et al (2004) found that high levels of self-efficacy mediated the stress of coping with

regular check ups where patients are confronted with the possibility of disease recurrence. Their study related to self-efficacy in cancer patients, albeit those with a very good prognosis, however, the findings may be applicable to leg ulcer patients also, which live with the uncertainty of recurrence. Data analysis had identified that the majority of patients valued the frequent contact and follow up appointment with the HPs, describing the re-assessment and Doppler studies as an “MOT” or “being checked out”. Others found the check- up daunting, possibly because it reinforced the possibility that an ulcer may recur and the realisation that venous leg ulceration is a chronic condition, where treatment is essentially palliative in the absence of surgery. Four items relating to maintaining contact with the HPs were included in the initial pilot questionnaire: *“I am confident that I will try to see a nurse every 3-6 months to get new compression stockings”* (.861) *“I am confident that the nurse will be able to help me if my ulcer returns”* (>.50) *“I am confident that I know where to go if I think my ulcer is returning”* (>.50) and *“I am confident that I know when to ask for the nurse’s help if I think my ulcer is coming back rather than treat it myself”* (.731). Following FA, only two items were retained with high factor loadings.

The role of HPs in providing on-going informational social support to enhanced SE in order to maintain long term self-care behaviours, however, may be underestimated. Under current service specifications (AQP DH 2011), patients with healed leg ulceration are invited back for one follow up session where new compression hosiery is prescribed and then discharged to self-care. O’Connor (2000) uses the term “staged withdrawal of nursing care” (pg. 229) to describe the transference of care from the HP to the patient, the assumption being that the patient will continue to self-care. This may be appropriate in recovery from acute illness or conditions; however, for venous leg ulcer patients, lifelong behaviour change and the maintenance of self-care behaviours are necessary to reduce the incidence of recurrence. If Ruggiero and Prochaska (1993) are correct, the “long haul” or maintenance phase of behaviour change, where the challenge is to sustain long-term behaviour change will occur six months after an initial behaviour change has been initiated (Ruggiero and Prochaska 1993, the opportunity to introduce SE enhancing strategies will be missed.

### **8.13.1 The nurse/patient relationship – shifting the power base**

The literature on the management of VLU stresses the importance of the nurse-patient relationship and how this can influence patients’ behaviours (Moffatt 2004; Briggs and Flemming 2007; Van Hecke et al. 2008). The requirement to achieve a concordant relationship, however necessitates the transfer of ‘power’ from the HP to

the patient (Galbraith 1984). This power shift can be difficult for some HPs to reconcile and the reasons for this and the potential impact on their professional practice will now be discussed in greater depth.

### **8.13.2 Cultural, contextual and behavioural factors influencing professional practice.**

As alluded to briefly in the findings chapter, the attitudes of the HPs in this study varied towards their patients and this finding needs further in-depth exploration. In one particular HP focus group, some of the participants had voiced negativity and cynicism in their ability to reach a concordant relationship with their patients. They described how they felt that giving advice to patients was a waste of time, since this advice appeared to be rarely acted upon.

According to Edward and Hercellinsky (2007), these feelings, combined with potential role conflict and role ambiguity are considered to be antecedents of professional burnout. In terms of role conflict and ambiguity, these HPs may have continued to see their roles within the context of the paternalistic medical model, where the HP is deemed the authority figure and patients are expected to carry out the recommendations for treatment. Several appeared to be using a form of “condign” power (Galbraith 1984), defined as an attempt to obtain compliance by outlining alternative unpleasant consequences if the behaviour is not performed. This approach bears similarities with the “perceived susceptibility” and “perceived benefits” dimensions of the Health Belief model (Becker 1974). However, as discussed in Chapter 3, the model has been criticised since it assumes that people are rational beings, value their health and will change their behaviour once this information is given. These nurses had failed to take into consideration the many factors, such as patients’ beliefs, previous experiences, and expectations of care that affect a patient’s choice to follow recommended treatment regimes (Moffatt 2004).

When the recommended advice was not acted upon, the nurses may have felt frustrated and questioned their role, since their expectations, and those of the organisation are that they are the authoritative “specialists”, with the requisite skills and knowledge to heal ulcers and prevent recurrence.

In an exploration of nurses’ views of their role, Bakker et al (2000) describe nursing as “the challenge of dealing with difficult situations, such as helping people who are experiencing major life problems but rewarding when patients recover because of the professional’s efforts” (2000; pg. 884.) They further discuss equity theory or the effort-reward imbalance and its potential role to trigger burnout in nursing. Equity theory is based on the premise that the social exchange processes at the interpersonal as well as the organisational level can trigger burnout as a result of a lack of reciprocity. Relating this to leg ulcer patients, the nurses may have expected the patients to invest as much energy and commitment into maintaining their healed leg ulcer as the nurses had invested in achieving initial healing. According to Demerouti et al. (2000), when this does not occur, people may suffer psychological distress and a lowering of self-esteem, together with the requirement to reframe their nursing role, from an authority figure to a partner in care, thus relinquishing the power within the relationship. As a coping mechanism, some HPs may exhibit depersonalizing attitudes to their patients, making derogatory, callous and cynical remarks, examples of which were found in the qualitative data (Cherniss 1980). Demerouti et al. (2000) call this “professional disengagement”, which perpetuates feelings of reduced personal accomplishment and job dissatisfaction.

Unfortunately, these negative feelings may be confounded by the expectations of their employing organisation, where the quality of care may be measured in terms of targets or KPIs, such as length of time to ulcer healing and low recurrence rates and which may not take the impact of patient factors into account. These nurses may then face criticism about their performance from their organisation, since funding is dependent on achieving these. Furthermore, it is hardly surprising that nurses appear to be confused about the operationalisation and philosophy of “concordance” when documents produced by the DH itself (Extension of Choice of Any Qualified Provider –VLU Implementation Pack 2011) continue to use the terminology of “compliance” and “assessing patient concordance” (2011; pg. 23), placing the onus on the patient rather than the negotiated agreement between patient and HP.

Clinical supervision has been introduced within the NHS as a means of helping staff avoid burnout and job-related stress, resulting in improved clinical outcomes (Edwards et al. 2006). Defined by the DH as a “formal process of professional support and learning, which enables individual practitioners to develop knowledge and competence, assume responsibility for their own practice and enhance patient protection and safety of care in complex clinical situations” (Department of Health 1999), there is a growing body of research that shows supervision to be effective in reducing the work-related stress of nurses. However, much of it continues to be methodologically flawed and blighted by problems of definition (Edwards et al. 2006). Indeed, the very term ‘supervision’ may be associated with some form of organisational monitoring, which is misleading and perhaps counter-productive in encouraging nurses to take part. Furthermore, additional barriers such as supervision being imposed on the individual by the organisation rather than being a component of personal and professional choice (Bush 2005) and the allocation of a supervisor, occasionally even a line manager, have resulted in clinical supervision being viewed by some nurses in a suspicious light. Many nurses also question whether clinical supervision has been implemented for their benefit or for that of the organisation, since attendance is monitored and attracts CQUIN funding for the organisation (DH 2010a).

For HPs, such as those in the study who appeared to be exhibiting early signs of burnout, group sessions with fellow leg ulcer professionals, however, may be beneficial since an important element of clinical supervision is the opportunity for practitioners to critically reflect on issues affecting their practice in order to develop personally and professionally towards achieving, sustaining and developing high quality practice (Bush 2005). Furthermore, Rolfe et al (2010) assert that the critical part of the reflective process, which involves in depth examination and questioning of the nurse’s assumptions and perspectives (personal, social, historical, cultural, political) that are embedded in his/her actions, and by tracing the origins and perspectives of those assumptions, will develop an awareness of the consequences and impact on their clinical practice. The implementation of clinical supervision for all nurses, but in particular, for those exhibiting depersonalisation, reduced personal accomplishment and job dissatisfaction, may help to lower the levels of burnout currently experienced by the nursing profession (Edwards et al. 2006).

This chapter will now continue the discussion on the decision to incorporate the remaining items into the VeLUSSET.

## 8.14 Fear of trauma

Analysis of the data from the focus groups revealed a strong recurring theme relating to the fear of a trauma injury to the leg and the development of a potential ulcer which many patient participants associated with trauma. This issue has also been highlighted within the venous leg ulcer literature by several others (Edwards et al 2002; Brown 2003; Brown 2005; Roaldsen et al 2009; 2010). Although entwined and related to knowledge deficits on ulcer aetiology and living with continued uncertainty, the fear of trauma emerged as a separate category in the data analysis. It could be argued that these items “*I am confident that I know how to avoid getting my legs knocked*”; “*I am confident that I will take extra care to stop my legs being knocked*” and “*I am confident that I will be able to tell other people to be careful around my legs*” were very similar and could have been incorporated as a single item within another category, for example, normal living or general self-care tasks. Following repeated FA, these 3 items were retained with relatively high factor loadings of .737; .689; and .684 respectively and loaded onto one factor. Following Bandura’s (2006) recommendation that patients with the condition under study should contribute to the construction of patient-focussed, disease-specific SE scales by identifying areas of potentially low SE; the decision was taken to include these items under a sub-scale named *Avoiding Trauma*.

Whilst identified as an area of low SE, I reflected on the question as to whether identifying or enhancing patients’ confidence levels in avoiding trauma, an event over which they often have little control, could be mediated by SE theory. The answer, I believe, is that a highly efficacious person may be able to visualise situations where trauma is likely to occur and take action to avoid or negate them, such as having the confidence to ask others to be careful around them. Furthermore, in the event of a trauma injury, enhanced SE levels may act as buffer against the effects of negative affective reactions such as fear, depression or hopelessness. In addition, the role of prior experiences, a strong antecedent of enhancing SE (i.e. the ulcer will eventually heal) together with the support of HPs and the successful enactment of self-care behaviours may help moderate a person’s fear of trauma and its consequences. The following chapter concludes the study; the strengths and limitations are discussed, together with a reflexive account of conducting research as a practising clinician. Implications for practice are discussed together with recommendations for further studies.

## 8.15 Conclusion

It is interesting to note from the qualitative findings of this study that many issues raised by these participants and leg ulcer patients in the past and corroborated by this research study still persist – for example, the provision of information, conflicting advice given by HPs and negative patient labelling when patients are non-adherent with treatment.

At the heart of many issues raised within this study however, is the nurse-patient relationship and how the varying attitudes and approaches of HPs had influenced how patients viewed and responded to treatment (Morgan and Moffatt 2008). If HPs display negative or pessimistic views of treatment outcomes, this may reflect and compound the patient's feelings of hopelessness and helplessness as described in the literature and impact significantly on patients self-efficacy levels in terms of outcome expectations and efficacy beliefs. A further concern was that the nurses who participated in this study were largely specialist leg ulcer nurses who had chosen to practise venous leg ulceration management at an advanced level. Gaps in their knowledge indicated that they were not always fully compliant with the NMC Code of Conduct which requires registered practitioners to keep up to date with relevant research and developments in their field of practice.

This was not the case with all participating HPs, however, and several “rising stars” emerged who indicated by their actions and attitudes that they understood and had embraced the concept of a concordant relationship and endeavoured to achieve this together with their patients. Currently, however, these enlightened practitioners may be working outside the organisational agenda which focuses on payment for healed ulceration within a given timeframe (DH 2011).

From the HPs' perspective, the juxtaposition of embracing the principles of a concordant relationship, whilst under pressure to meet the outcome indicators set for financial reimbursement of their services (DH 2011) may be difficult to reconcile. As mentioned in the Introduction, service specifications require complete closure of an ulcer healing within a given timeframe, which may not always be achievable and this was also borne out of the data collected in the course of this study. These figures here may not be reflective of national healing rates due to the amount of missing data and large ranges however, the issue of healing rates well below quoted timeframes in the literature has been raised recently by Guest et al. (2012) If it is assumed that these figures are accurate, then the leg ulcer services who care for the participants in

this study would not be able to meet the KPIs for reimbursement of their services. Furthermore, with little provision in the service specification for support in maintaining self-care behaviours post healing, there is the potential danger that a revolving door service for leg ulcer patients will evolve.

It has been argued within this thesis that chronic venous leg ulceration should be treated within a model aimed at supporting self-care and adaptation. The recurrence figures found within this study support the view that this is a chronic condition and that many patients live in constant fear of recurrence. Mishel's Theory of Uncertainty in Illness was explored in order to explain some patients' behaviours and attitudes and may be worthy of more research in the future to determine its relevance to patients with recurrent venous ulceration, particularly to understand their response to living with the uncertainty of an ulcer recurrence.

Currently there are no nationally recognised self-management programmes available specifically to meet the needs of venous leg ulcer patients, although some innovative practitioners have already recognised the need for such interventions, for example, the "Look after Your Legs" initiative and Lindsay Leg Clubs®. It is proposed, therefore, that self-efficacy theory, a robust health behaviour change model, which is simple to implement in clinical practice and has demonstrated positive outcomes, may be an appropriate theoretical framework to underpin any future self-care programmes aimed at enhancing patients' confidence in performing self-care activities successfully or encouraging their psychosocial adaptation to life with chronic venous leg ulceration.

HPs involved in the care of patients with recurrent leg ulceration must ensure that the needs of all leg ulcer patients; both those with healed and/or frequently recurring ulcers, are adequately addressed within current practice guidelines and policies. Furthermore, by raising awareness to commissioners of leg ulcer services that the KPIs within current service specifications for the management of venous leg ulceration may not be appropriate for all patients, self-care programmes may offer an alternative clinical intervention.

These self-care initiatives, however, will require objective outcome measures to support their effectiveness and demonstrate positive clinical outcomes to commissioners, in the absence of complete ulcer healing. The newly developed VeLUSSET, therefore, now provides HPs with an evidence-based, simple, validated objective measure which will demonstrate the efficacy of clinical interventions

designed to enhance patients' perceived self-efficacy levels in performing self-care activities to prevent ulcer recurrence. The development of this tool has now filled an important gap within the leg ulcer literature.

### **8.16 Strengths of the study**

The strength of this study is the mixed methods approach that enabled the qualitative findings to inform the scale development. The findings from the qualitative phase of this study were contrasted and compared to research findings within the current body of literature relating to the self-care behaviours required of patients to prevent ulcer recurrence. Affirmation with the literature has enabled the inclusion or rejection of items which relate to areas of potential low self-efficacy, to which patients can relate and which can be potentially modifiable by the use of self-efficacy enhancing strategies.

Preliminary validation studies of the VeLUSSET indicate that the scale has strong internal consistency and reliability and correlation studies with the GSE have revealed a strong positive relationship between the two scales, demonstrating the predictive qualities of the VeLUSSET. Furthermore, data analysis has indicated that the VeLUSSET has strong stability and reliability over time. The VeLUSSET is a simple but robust patient-focussed instrument to assess patients' confidence in maintaining self-care behaviours in clinical practice.

Although there are many disease-specific self-efficacy instruments currently available, there is no tool specifically for venous ulcer patients. Many researchers use the General Self-Efficacy Scale (GSE) (Schwarzer and Jerusalem 1995) to assess self-efficacy in this patient group. Bandura, however, advocates the use of condition-specific instruments since general SE scales will not tap into patients' self-efficacy judgements in performing disease-specific tasks. As such, there is currently a gap within research which this study has now sought to fill.

### **8.17 Study Limitations**

#### **8.17.1. Sample Size**

As is the case with all research studies, there are limitations to this study which need to be acknowledged. Firstly, the sample sizes for Principal Components Analysis were very small according to the literature and this may have influenced the findings in that the factor analysis may only be applicable to the sample in the current study (DeVellis 2003). Although there are no rigid guidelines within the literature, item ratios of between 10:1 and 100:1 are quoted (Costello and Osborne 2005), although

a high proportion of researchers now report conducting factor analysis based on subject to item ratios of 2:1 or less. In this study, the item to subject ratio was 2:1 (Phase 2a) and 2.5:1 (Phase 2b) which is very low, although these numbers can produce accurate factor extraction if the data set is considered robust (Costello and Osborne 2005). The intention, however, was to undertake preliminary validation of the VeLUSET only and further studies with larger sample sizes are required which may produce more accurate results in the future.

#### **8.17.2 Sample Population – issues of representativeness**

The participants recruited for this study were patients who attended a leg ulcer clinic or Lindsay Leg Club® for their leg ulcer care. These patients may have had only minor mobility limitations, which may not have impacted on their ability to walk, to perform moderate activity and ankle/leg exercises. The VeLUSET may, therefore, be inappropriate for measuring perceived SE in housebound patients, with reduced or poor immobility, cared for by community nurses who, by the nature of their physical status, may be unable to perform the specific self-care activities included in the scale. It may also be inappropriate for patients with non-healing ulceration, since the purpose of the tool is to measure SE in performing activities designed to prevent recurrence and the VeLUSET does not address the psychological aspects of living with a non-healing wound.

A further limitation is that the VeLUSET has been designed to be administered to patients of 60 years and over. Margolis et al. (2002) found that prevalence of venous leg ulceration increases significantly after the age of 65 years, rising to 1.69% in people between 65 and 95 years and this was confirmed within the author's clinical practice. The average age of the participant recruited in this study was 74 years, with sufficient agility to perform the required behaviours. However, for patients whose ages fall outside these parameters, the VeLUSET may be an inappropriate tool. For example, younger patients may have employment and family commitments that will impact on the time required to perform such activities as elevation and walking. Equally, very elderly patients may have multiple co-morbidities and lack the dexterity and agility required to apply hosiery independently or perform self-care. This could be attributed to physical barriers as opposed to low self-efficacy. The applicability of the VeLUSET to a distinct sub-sample of the leg ulcer population is a limitation on the generalizability of the scale and must be acknowledged as a limitation. However, the purpose of this study was preliminary validation only and further studies may be

needed in the future to further refine and develop the scale over time and populations.

### **8.17.3 Limited public involvement**

As discussed briefly within chapter 5 of this thesis, public involvement was not sought prior to submission of the research proposal and this may have impacted on how the study was conducted overall. INVOLVE, the organisation set up by the National Institute for Health Research (NIHR) in 1996, aims to maximise opportunities for public involvement in research and to ensure that researchers, research commissioners, research funders and the public have access to the support and guidance that they need to carry out research. Public involvement in research is defined by INVOLVE as being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them (INVOLVE Strategy 2012 – 2015) This includes, for example, working with research funders to prioritise research, offering advice as members of a project steering group, commenting on and developing research materials and undertaking interviews with research participants (NIHR 2013).

Patients were requested to review some of the documentation for the study, for example, the invitations to participate and comment on their readability etc., however, this was not a formal process. Furthermore, public opinion as to whether the study was worthwhile was not sought and this is a major omission which must be acknowledged. The need for public involvement in the research process was not considered for two reasons. Firstly, it was not considered a routine requirement in the ethics application process at the time the study commenced in 2006; and secondly, the study was a student project for an academic award and not an NHS funded research study. On reflection, however, had patient involvement been sought, it is possible that the problems encountered in recruitment of the participants may have been overcome since an identified outcome of PPI is to improve recruitment (NIHR 2012). A quick search on the INVOLVE database, however, listed only current cooperation with pressure ulcer reduction initiatives, not venous leg ulceration.

### **8.17.4 Exclusion of pain within the VeLUSSET – a limitation**

As briefly alluded to within the Discussion chapter, items relating to pain were not included within the VeLUSSET and this must be considered a further limitation of the tool. Edwards et al. (2013; in press) conducted a study to identify symptom clusters

in patients with chronic venous leg ulcers and found a high percentage of patients experienced severe pain (74%; n = 94). This high prevalence of pain is similar to previously reported rates of between 50% (Nemeth et al 2003; Briggs and Closs 2006) and 80% (Hareendran et al. 2005). In addition, Edwards et al. found that the proportion of patients found to be experiencing moderate to severe pain was consistent with previous reports of between 50% (Persoon et al. 2004) and 56% (Nemeth et al. 2003).

Leg ulcer pain has been associated with decreased energy levels (Persoon et al. 2004); interrupted sleep (Edwards et al. 2005); depressed mood (Edwards et al. 2005); restricted mobility (Hareendran et al 2005); social isolation (Ebbeskog 2001) and decreased ability to manage normal daily work or activities (Edwards et al. 2005).

The majority of studies into leg ulcer pain relate to patients with open as opposed to healed ulceration and whilst many participants in this current study had voiced issues around pain, they appeared to relate this to periods when their ulcer was open. Edwards et al (2013) found however that the scaling and inflammation of the skin in the lower limbs associated with venous eczema or chronic lipodermatosclerosis (Hareendran et al 2005) and 'tightness' or aching from lower leg oedema was a significant cause of leg pain (Edwards et al. 2009; 2013). Lipodermatosclerosis, atrophe blanche and lower limb oedema are manifestations of chronic venous disease and persist even in the absence of open ulceration. If patients with healed ulceration are to be encouraged to perform self-care behaviours, such as the application of hosiery, the pain from these clinical factors must be addressed. Older people may be reluctant to take analgesia routinely (Francis et al. 2002), and HPs may need to counsel the patient that this is acceptable in order to tolerate compression hosiery and perform moderate exercises. There is evidence in the literature that pain in patients with chronic leg ulcers is often not assessed by HPs and is inadequately managed (Edwards et al. 2009) and HPs may need education around pain management prior to the administration of the VeLUSSET.

Conversely, the self-care behaviours within the VeLUSSET and the gradations of challenge, such as elevation of lower limbs, ankle exercises and moderate walking may prove beneficial in reducing the levels of pain experienced by the patients.

Nevertheless, the amount of unmanaged pain a patient experiences will impact on their perceived self-efficacy to carry out the required behaviours and is a major

omission from the VeLUSET. Further validation studies in the future should examine whether items relating to pain need to be included as part of on-going development.

### **8.18. Reflexivity in research**

Finlay (2002) defined reflexivity as thoughtful conscious self-awareness. Within the context of research, reflexivity seeks to understand the possible effects of the researcher's behaviour or knowledge on the process of conducting research. As discussed earlier, at the time of conducting focus groups, I was the manager of a community Tissue Viability service. My probing questions to the HP participants may have been interpreted as criticism of their care; that was certainly not the intention but this had the potential to influence the issues they raised during data collection. As a result, I aimed to maintain a non-judgemental manner and the data collected from the HP focus groups appear to indicate that I may have achieved this. Aware that I had a tendency to lead the conversation in the early focus groups, I recruited a fellow Tissue Viability colleague to pose the questions while I became a more avid listener, interpreting body language and making copious notes. As I gained more experience as a researcher, this was no longer necessary.

The dilemma of performing dual roles – that of researcher and clinician came to the fore, particularly during the patient/carer focus groups. It was apparent to me that more detailed explanations were required on the aetiology of venous leg ulceration and the benefits of compression. As a clinician, I felt unable to ignore this knowledge gap – as a researcher, lengthy explanations would have resulted in hours of transcribing data which were not wholly relevant to the research question. The decision was taken to turn off the tape recorder, provide the necessary information and then continue with the tape recording. As a clinician, I was disconcerted that these patients had not been provided with adequate explanations as to how their condition had developed; as a researcher, however, I knew from the body of literature, that many leg ulcer patients do not appear to understand their condition, despite having been given this information by HPs. This dilemma of duality of roles - clinician versus researcher has also been highlighted by Carolan (2003) and is a common dilemma faced by clinicians who undertake research within their clinical area.

On the other hand, my clinical background enabled me to get to the heart of the issues raised; indeed it was this clinical knowledge that had inspired the undertaking of this PhD study. The symbolic interactionist perspective of the research design ensured that the participants and I had a shared understanding of the language spoken, in that we were both “on the same page”!! This may have been problematic for a researcher who had no prior knowledge of how life is affected by the presence of venous leg ulceration. It is my opinion that my clinical knowledge had a positive influence on the data collection process in this case, rather than adversely affected it.

### **8.19. Difficulties in recruiting participants and “gatekeeping”**

The delay in recruiting participants, particularly for Phases 2a (pilot) and 2b (Version 1) was not anticipated at the onset of the study and became a real threat to completion of the study and was dependant on the cooperation of HPs in facilitating participant recruitment.

As a novice researcher and clinician, I experienced a mixed response to my request for cooperation with my study. Whilst it is acknowledged that currently within the NHS, there are high levels of uncertainty for the future, increasing work pressures, reduced staffing levels and constant reconfigurations of service providers due to fundamental changes in how the NHS will run in the future, many HPs were unable or unwilling to recruit patients for the study, citing unmanageable workloads as the reason for this. There are several possible explanations for this. Firstly, whilst nursing is deemed to be an evidence-based discipline with the use of good quality research to inform practice, there continues to be a theory-practice gap, which was discussed within Chapter 4 in more detail.

From my own clinical experience, I concur with Hartrick-Doane and Varcoe (2005) who assert that theory may be viewed by some nurses as an “abstract body of knowledge that is learned outside of the practice area, bears little relationship to everyday nursing and is seen as a “dry” academic abstraction” (2005, pp. 83). As such, research, particularly when undertaken for an academic qualification, may not be highly valued and this has been my experience within the NHS. For example, a former NHS manager suggested that I would be better using my spare time to knit as opposed to conducting research. This nihilistic attitude towards knowledge acquisition appears to extend also to professional development, where nurses are required by their governing body to maintain an up to date knowledge base within

their specialism, but often have to do so by self-funding and in their spare time. If research activity is undervalued by nurses within senior management who are often viewed as role models, it is hardly surprising that this negativity continues to be perpetuated by more junior staff within the NHS.

Another possible explanation for the less than enthusiastic response to my request for cooperation may be that there were high levels of burnout, as discussed in 8.13.2 amongst the nurses approached for recruitment and not limited to those HPs invited to participate in the focus groups. Nurses exhibiting “professional disengagement” as described by Demerouti et al. (2000), may be reluctant to “go that extra mile” to interact with their patients in order to recruit participants for very little personal or tangible reward.

In anticipation of the problem of creating more work for the nurses, an offer was made to attend leg ulcer clinics in person in order to recruit participants and thus minimise disruption to the running of the clinics. This was met with mixed response however, and may have been due to an element of professional “gatekeeping”. As a specialist nurse in Tissue Viability, there may have been concerns that I would be scrutinising the standard of nursing practice and the nurses may have felt vulnerable to criticism of their care. This was certainly the case in conducting the focus groups with patients, where it became obvious that patients had not received the information they required, for example, the availability of various aids to make compression hosiery application and removal easier. The tensions between my divergent roles as both clinician/researcher had posed an ethical dilemma for me who I dealt with as discussed in Chapter 5 and within my reflective account of the research process.

Furthermore, the assumption that nursing practice would be open to criticism may have impacted on the patient sample recruited since the HPs may have approached only those patients with positive views of their care for inclusion in the study. This would have affected the representativeness of the sample and must be acknowledged as a limitation.

## **8.20 Implications and challenges of embedding the VeLUSET into clinical practice**

The newly developed VeLUSET can now be incorporated into clinical practice and will provide clinicians in leg ulcer clinics with an objective measure of patients' self-efficacy in undertaking those self-care activities believed to reduce ulcer recurrence.

An argument for the need for specific self-care programmes for venous leg ulcer patients has been developed throughout this thesis and the VeLUSET will provide a robust objective outcome measure for such interventions. It is important, however, to provide education to HPs around the administration and interpretation of the VeLUSET, with an emphasis on evaluating scores in each subscale, rather than a total scale score as low scores in particular sub-scales will indicate potential knowledge gaps or areas where extra support or guidance is required and will enable the HPs to target interventions accordingly.

An additional benefit of the VeLUSET is that administration may give patients the opportunity to seek clarity about certain self-care activities and will also act as an aide-memoire for staff when delivering life style advice to their patients. As a result of the items included within the VeLUSET, it will ensure that patients receive consistent, evidence-based advice on performing self-care activities, rather than conflicting advice, an issue that was highlighted during this study.

The VeLUSET will provide researchers conducting studies with venous leg ulcer patients with a validated disease-specific self-efficacy measure where this is an anticipated outcome and enquiries have been received from the University of Queensland to undertake a small pilot study with patients in Australia in the near future.

Finally, the demographics of "typical" venous leg ulcer patients are changing and validation studies in the future should be undertaken with different sample populations, such as patients <60 years of age; very elderly patients; housebound patients or patients with limited mobility; obese patients or even patients with lymphoedema since these population groups face specific physical constraints on their ability to perform self-care activities which are not necessarily related to low levels of SE and which are not included within the current version of the VeLUSET.

The real challenge, however, will be the adoption of the VeLUSET into clinical practice, if it is viewed negatively by nihilistic HPs as an additional piece of

documentation to complete; just another “checkbox” form with little understanding as to the aim of the tool and the potential benefits to both patients and themselves in terms of a potential reduction in recurrence and an evidence-based, objective measure of their nursing interventions. A paper discussing the development of the tool in a peer-reviewed nursing research journal is being prepared and it is hoped that as a result of this, raised awareness of the tool will result in HPs adopting this in their clinical practice. In the future, it may also be possible to persuade commissioners of leg ulcer services to include the VeLUSSET as a key performance indicator for quality leg ulcer care.

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## List of appendices

1. List of excluded studies from literature review on ulcer recurrence rates (Chapter 1).
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3. Ethics and Research & Development approval letters.
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