

**The Patient's Perspective of Compression Textiles for
Venous Leg Ulcer Treatment: an in-depth qualitative study**

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Abstract

While a good deal is known about the patient's lived experience of their venous leg ulcer(s), the same cannot be said for the patient's perspective of the compression textiles used to treat their venous leg ulcers. This under-researched perspective is important in the field because a patient's adherence to therapy, compliance with health professionals in the management of their chronic condition and the outcome of their leg ulcer journey may depend on their opinion. Exploration of the patient's views on the products used in their therapy may also inform the future development of improved compression textiles.

To explore the patients' perspective, a phenomenological approach was taken, conducting in-depth, semi-structured interviews with 19 people who had experience of venous leg ulceration currently or within the previous two years. The setting for this study was across two NHS Trusts in Northern England. The transcribed interviews were analysed using interpretive phenomenological analysis. Three superordinate themes emerged: faith in compression, living with compression and how life with compression might be better. While some of the findings support previous research in the field (such as the ubiquitous nature of pain in the patient's experience and narratives), the focus on the patient's perspective of compression textiles yielded new insights and information.

Some of these indicate a need for further research in specific areas. For example, a need to improve our understanding of individual differences in emotional response to compression bandaging. Information emerged that may be useful in guiding future, improved practice in the treatment and management of venous leg ulcers, such as the participants desire for increased autonomy in the management of their ulcerated legs.

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Chapter 1

Introduction

This chapter sets out the purpose of the study and describes the context and background to the phenomena being researched. To do this the chapter begins with a statement of study intent. This is followed by an overview of the background to the study, comprising venous leg ulcers and their diagnosis, what is known about their aetiology; prevalence, incidence, recurrence, co-morbidity and cost of treatment.

Treatment options are then discussed, with particular reference to compression therapy – bandages and hosiery. Other elements of the issues affecting the phenomena under study include patient quality of life and well-being and how the patient is thought to experience their venous leg ulceration. This includes reference to the role of the health care practitioner (HCP) as part of the patient experience.

Examination of the issues above is the foundation upon which the development of my research objective is built.

1.1 Purpose and scope of current research

The focus of this research is to explore, in depth, the perspectives patients with venous leg ulcers hold towards compression and the textiles used in compression therapy and to reflect how they make sense of their world as venous leg ulcer patients. The current study does not aim to build theory around the knowledge gained through interviewing these participants but to add to existing knowledge and provide new insights into how these people attribute meaning and value to facets of their lives.

1.2 Venous Leg ulcers

The most common type of leg ulcer is venous in origin and represents circa 75% of all chronic leg ulcers (Alavi et al., 2016). They frequently cause pain, disability, embarrassment, depression, altered body image, social stigma

and considerable personal inconvenience (Briggs and Closs, 2006; Rumsey and Harcourt, 2005; Finlayson et al., 2017).

Venous leg ulceration is one of many types of chronic leg ulcer, others include arterial leg ulcers, diabetic ulcers, ulcers related to rheumatoid arthritis and those related to malignancy. Roughly 20% of patients with venous ulceration also have arterial ulceration. Chronic leg ulcers are complex, chronic wounds which are often difficult to heal and may recur (McLafferty, 2014).

The focus of this research is venous leg ulceration. Venous leg ulcers are typically slow-healing and can be present from four weeks to several years (McLafferty, 2014; Dealey, 1999; Marklund et al., 2000; Nelzén et al., 1996; Harding et al., 2015), and, in practice, people with venous leg ulcers frequently experience recurrence (Baker et al., 1991; Vowden and Vowden, 2006). See Section 1.2.4 on recurrence, below, for more detail.

A venous leg ulcer is defined by the American Venous Forum as 'a full-thickness defect of the skin, most frequently in the ankle region, that fails to heal spontaneously and is sustained by chronic venous disease, based on venous duplex ultrasound testing' (Lal, 2015). By definition, chronic venous ulcers are areas of broken skin, usually below the knee, around the ankle, that have been present for more than six weeks (Walker et al., 2002; Lal, 2015). Ulcers of long duration and greater size are known to be markers of a poor prognosis (Margolis et al., 2004a). They are typically painful and heal slowly, resulting in an impaired quality of life, social isolation and reduced work productivity (Persoon et al., 2004; Vowden and Vowden, 2008).

1.2.1 Diagnosis

Differential diagnosis can be problematic. According to Gillespie (2010), there is an urgent need for better education on diagnosis and classification of the different types of ulcer. And in a study by Walsh and Gethin (2009) there was evidence of poor levels of confidence in nurses around the diagnosis of leg ulcers. Using real world evidence from The Health Improvement Network (THIN) Guest et al. (2015) found that 19% of the leg ulcers registered were recorded with no specific aetiology.

The importance of correct diagnosis cannot be over-emphasised. It is essential that the ulcer assessment is carefully undertaken to ensure that appropriate treatments are facilitated. For example, compression therapy should not be used when there is significant arterial pathology in addition to the venous insufficiency (Neequaye et al., 2009). The need for rigorous evaluation of any leg ulcer is absolute, not just venous leg ulcers. The Scottish Intercollegiate Guidelines Network gives clear guidelines to underline the importance of careful and informed assessment (SIGN, 2010). Incorrect diagnosis can lead to incorrect treatment and this can result in further harm to the patient with the leg ulcer. Detailed analysis of the type of venous pathology in venous leg ulcers is also of great importance regarding the best treatment programmes and prognosis for the individual (Hjerppe et al., 2010).

1.2.2 Aetiology

While the precise aetiology of venous leg ulcers is not fully understood, they are known to be caused by changes in the blood flow in the leg veins – either in the form of a blockage (known as occlusion), such as deep vein thrombosis and/or weakness in the valves of the veins (venous incompetence) (O'Meara et al., 2012). That weakness results in blood being insufficiently powered up the leg in the circulatory system and increased pressure in the veins (Nelson and Jones, 2008). Signs of this process of deterioration or vascular deficit sometimes emerge as varicose veins, varicose eczema, pain, oedema, deposition of scar tissue (known as fibrin) and dark skin pigmentation (McLafferty, 2014).

The papers describing venous ulcer aetiology cite a number of theories which seek to explain how a change in blood flow in the veins and valves can lead to damage, such as venous stasis, arteriovenous shunting, fibrin deposits, a history of deep vein thrombosis and inadequate capillary loops. (Cornwall et al., 1986; Coleridge Smith et al., 1988; Browse and Burnand, 1982; Fernandes Abbade and Lastoria, 2005). In effect, the result is venous insufficiency and hydrostatic pressure in the veins (Nelson and Jones, 2008; O'Meara et al., 2012; Nelson and Adderley, 2017).

Factors which can contribute to venous leg ulceration include a history of deep vein thrombosis (DVT), leg trauma, arthritis, obesity, pregnancy and sedentary lifestyle. These can result in damage to the valves in the leg veins which compromises blood flow. Reduced venous blood flow can also result from a low functioning calf muscle pump action. These factors, singly or together, can contribute to the breakdown of the skin leading to ulceration (Doughty and Holbrook, 2007).

Other common causes of ulceration in the lower limb include diabetes mellitus (15%–25%), where the ulcer is usually located on the foot, arterial ischaemia (10%–20%), or a combination of two or more of these aetiologies (McLafferty, 2014). Less common causes include infections, malignancies and vasculitis (Morison and Moffatt, 1994). Up to 20% of venous leg ulcers are estimated to co-exist with arterial problems (Morison et al., 1998; Margolis et al., 2004b; Humphreys et al., 2007).

Independent risk factors for delayed ulcer healing and poorer prognosis have been found in people who are older, people who have experienced venous ulceration for some time, those with evidence of nutritional deficiency and people who have ulcers over a large surface area (Margolis et al., 2004a; Guest et al., 2017).

1.2.3 Prevalence and incidence

Venous leg ulcers are of interest in this research and are estimated to be the biggest single presentation of leg ulcer type. They are the most common cause of lower limb ulceration in the Western world, with prevalence estimated to be 0.1% in the adult population and reported to be as high as 2% in adults aged 80 and over (Nelson and Adderley, 2017), with a higher incidence in women than men: ratio 1.25:1 (Henke et al., 2010; Margolis et al., 2002).

Nelzén (2008) reviewed 11 venous leg ulceration prevalence studies conducted in Europe and Australia and estimated prevalence as 0.1% to 0.3% (Nelzén, 2008). Grothier and Pardoe (2013) estimate that circa 200,000 adults are living with a chronic leg ulcer in the UK. The Scottish Leg Ulcer Project (Finnie, 1999), however, estimated a total of 400,000 patients affected by chronic leg ulcers in the UK. The variation should be noted in

these population statistics. According to Guest et al. (2015), the figure is in the region of 278,000 but they add that this is likely to be an underestimate due to the large number of unspecified leg ulcers (19% of all leg ulcers) recorded in the UK.

It has already been noted that estimated prevalence figures for leg ulcers, and specifically venous leg ulcers, vary quite widely. However, it is generally thought that roughly 1% of the Western population will develop a venous leg ulcer in their lifetime and the incidence of an active venous leg ulcer is estimated at between 0.1% and 0.3% of the population; prevalence increases with age, as set out in a European study by Harding and colleagues (Harding et al., 2015).

1.2.4 Recurrence

A review of studies considering venous leg ulcer recurrence found that recurrence rates still increase several years after healing and reported data from 0% recurrence at six months to 56% recurrence at 60 months (Reeder et al., 2013). The review concluded that a composite figure (meta-analysis) with such a varied sample of research studies would not contribute to the evidence base. Gohel and Poskitt (2013) refer to recurrence rates as high as 69% but point out that within the ESCHAR trial (Barwell et al., 2004) recurrence rates were reported as 12% at one year and 31% at four years. It should be noted, however, that these last sets of figures apply to patients who had received vascular surgery as well as compression, rather than compression alone.

There is evidence in another Cochrane review publication (Nelson and Bell-Syer, 2012) that compression helps to prevent recurrence or re-ulceration. This review of the available literature found four randomised controlled trials (RCTs) and no meta-analysis was possible due to the heterogeneity of the studies and the samples therein. One study showed a significant prevention of recurrence with compression versus no compression (Franks et al., 1995). However, possible selection bias casts the findings into a less clear light. Another study presented an incomplete outcome due to the number of participants who withdrew due to 'stocking-related reasons' (Vandongen, 2000). The majority of these withdrew from the class III compression arm of

the trial, indicating that they could not tolerate the high level of compression – a finding in itself, but not offering the sought for evidence regarding the value of compression in preventing recurrence. On balance, the review (Nelson and Bell-Syer, 2012) shows some evidence in support of the finding that continued compression therapy helps to prevent recurrence of venous leg ulceration. It should be noted that the report was updated in 2014 and no new RCTs on this subject were found.

However, simple routine provision of hosiery products to patients has been shown to have only a small effect on recurrence rates if not supported with additional communication and motivation (Fassiadis et al., 2002). Where compression hosiery is provided as part of a programme of patient education or with other additional support, for example, psychological support, application aids and/or carer assistance, there is a considerable reduction in recurrence (Fassiadis et al., 2002; Finlayson et al., 2010; Moffatt et al., 2009).

1.2.5 Co-morbidities

The picture is further complicated by the level of co-morbidity found in patients with leg ulcers. This can make treatment decisions challenging. Thus, while compression is indicated for many cases of venous leg ulcer, it is contra-indicated in arterial ulcers (Bryant and Nix, 2012). As an example of the incidence of co-morbidity a study by Heinen et al. (2007) reported that over two thirds of patients with venous leg ulcers were found to have co-morbidities. Poly-morbidity is not unusual, especially in those in the 60–65 and older age groups (Graham et al., 2003). The venous leg ulcer patient may have an additional diagnosis of osteoarthritis, for example, or diabetes, swelling, and lymphoedema or hyperlipidaemia (Gillespie, 2010). These complications add to the constellation of symptoms and negative effects experienced by the patient and, in this way, combine to amplify the loss of well-being experienced (Chase et al., 1997; Green et al., 2013; Hjelm et al., 2003).

While co-morbidity or poly-morbidity contributes to the effect of venous leg ulceration on the patient's life and well-being (Persoon et al., 2004), not all negative effects experienced by the patient on a daily basis can necessarily

be attributed to the venous leg ulcer. For example, if the patient also has rheumatoid arthritis, their restricted mobility may not be solely attributable to bulky bandaging or pain from the ulcer (Wilson, 2004).

1.2.6 Cost

Bosanquet (1993) reported the estimated annual cost of leg ulcer treatment to the National Health Service (NHS) in the UK was between GBP 230 million and GBP 400 million during 1990–1991. A later study estimated the cost of leg ulcer care within individual UK district health authorities at GBP 212,700 to GBP 333,377 annually per district (price year 1999) (Simon et al., 2004). Ragnarson Tennvall and Hjemgren (2005) estimated that the average cost of treating a venous leg ulcer in the UK was between EUR 814 and EUR 1,994 (price year 2002), with higher costs associated with larger and more chronic wounds. Vowden et al. estimated that in Bradford, GBP 1.69 million was spent on dressings and compression bandages, and GBP 3.08 million on nursing time (2006–2007 prices) (Vowden and Vowden, 2008). However, it should be noted that this report relates to the care of all types of wounds, not just venous leg ulcers. The management of venous leg ulcers is estimated to cost the NHS between £168 and £198 million per annum by Posnett in 2009 (Posnett et al., 2009). Guest et al. (2017) offer a conservative estimate of £941million for the year 2012–2013, based on data from THIN.

The lack of reliable, comprehensive figures is generally thought to be due to a somewhat ad hoc multi-disciplinary responsibility for the assessment, management and care of patients with venous leg ulcers. Other contributing factors include people with ulcers who never present at the GP surgery or hospital clinics. A lack of diagnostic certainty may also play a part (Gillespie, 2010; Guest et al., 2015).

While there is some uncertainty remaining regarding the cost per head of venous leg ulceration, we know enough to understand that this chronic pathology is widespread among older age groups – debilitating, time consuming and costly.

1.3 Treatment options

There are many ways of treating venous leg ulcers other than compression, including, most commonly, skin graft, oral pentoxifylline, laser treatment, vascular surgery and impregnated dressings.

It is also demonstrated that surgery to remove peripheral veins could be useful in a preventative capacity for a proportion of cases (Barwell et al., 2004). And it would appear that the role of surgery in the management of venous leg ulcers is currently growing; particularly promising is the greater use of venous ablation described by Davies et al. (2013) in the EVRA study. Oral pentoxifylline has also been shown to have beneficial results in combination with compression therapy (Nelson and Adderley, 2017).

1.3.1 Compression

Compression therapy is the main treatment option for venous leg ulcers.

Two main forms of compression therapy are used, bandaging and hosiery, for the healing and prevention of recurrence of venous leg ulcers.

1.3.2 Classification

There is a lack of agreement in the classification of standards of performance for compression systems.

A classification system provided by Clark in 2003 in an EWMA position document (Clark, 2003) provides an illustration of the generally accepted classification in the UK. See Appendix A.1. Partsch et al. (2008), in their ICC consensus, believe this classification system requires review. According to their consensus, Clark's classification system overlooks a number of relevant aspects and measures pertaining to effective compression, such as sub-bandage pressure measurements at the medial gaiter region, while the patient is upright and supine, and clinical proficiency of the healthcare professional applying the compression bandage (Partsch et al., 2008).

1.4 Types of compression systems and compression textiles

Compression systems commonly used for venous leg ulcers are listed (from Clark, 2003) in Appendix A.1: Classification of compression bandages and hosiery.

Compression stockings (or hosiery) can be used to treat open ulceration. They are classified in a similar way to bandages, according to the level of compression applied to the limb. Importantly, stockings are subject to less operator variability than bandages.

Compression is not the only route to ulcer-healing, however. As O'Meara et al. (2012) demonstrated in their systematic review, healing was observed in venous leg ulcers in the control groups in two trials, where compression had not been applied – 38% and 25% respectively. While these healing statistics from the control group were significantly lower than in the group receiving compression, the figures are nonetheless representative of a wider picture of venous leg ulcer healing and, perhaps, they put the 'gold standard' of compression therapy in a more realistic perspective. The review is based on 39 RCTs and covered a total of 48 comparisons. It provides detailed and comprehensive information on each RCT, including assessment of risk of bias at several points, as well as reliability of outcome figures. The process of review is clearly explained and transparent. For ease of assimilation, the RCTs are grouped in terms of type of comparator used in control groups. From this, eight RCTs claimed to compare compression with no compression. However, four of these eight could well have included some instances of compression in the control group, as the control group consisted of patients seen by a district nurse and treated 'in the normal way'. Another did not report healing figures but reduction in size, and yet another was deemed by O'Meara and colleagues (2012) to contain high risk of bias and reported unclear outcomes.

The report from Nelson and Jones (2008) also demonstrates healing in the no-compression group of each of the RCTs or systematic reviews they included. In two cases (systematic reviews), the difference in healing rates

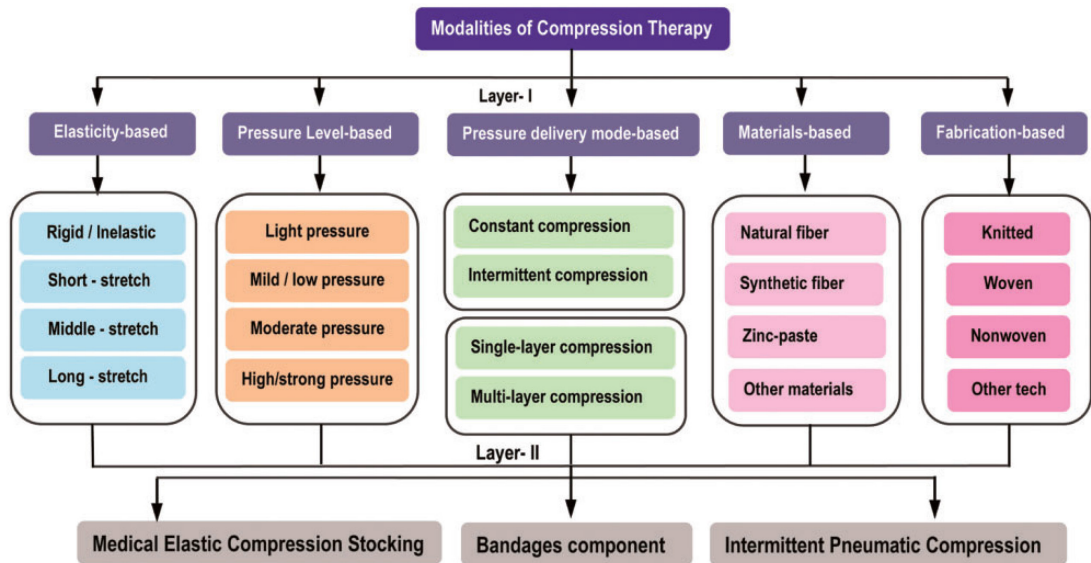
was not significant: the healing rate in the control groups was particularly high. However, the number of patients in each group was not high – 34 and 42 participants – and this result should be viewed with caution. In the other six studies, the difference in outcome between compression and no compression was significant, indicating that compression therapy, where not contra-indicated, is, indeed, the treatment of choice for venous leg ulcers.

The Cochrane review devoted to venous leg ulcers, by O'Meara et al. (2012), concludes that compression increases ulcer healing rates compared to no compression, that multi-component systems of compression therapy are more effective than single-component systems, and that multi-component systems containing an elastic bandage appear more effective than those composed of inelastic constituents. All the above data comes with the caveat that efficacy is also influenced by the practitioner's skill in the application of any form of compression (O'Meara et al., 2012). This is a central point.

The discussion about which compression product out-performs the others continues, however, with manufacturers closely involved in the debate. As there are several hundred products available to choose from the discussion is likely to go on for some time. Skill in application might be more pertinent than minor differences between products (Keller et al., 2009, Fassiadis et al., 2002; Finlayson et al., 2010; Moffatt et al., 2009).

Also relevant to this debate is the technology behind the compression textiles produced and employed in chronic venous insufficiency, generally, and venous leg ulcers, particularly. There are many modalities of compression therapy, but no international consensus on which configuration of characteristics works best. Figure 1.1 illustrates the modalities of compression therapy and demonstrates the variety of possible combinations within one compression system.

Figure 1.1: Modalities of compression therapy



Taken from Liu et al. (2016), p. 1124

Nor are the classification systems the same in every country – if they exist at all. For example, there are thought to be five major classification systems for compression hosiery and these adopt different thresholds of pressure, as measured at the ankle, for different classes of product. Thus, the UK's British Standard pressure sets Class 1 between 14 and 17mmHg, but the German Standard is between 18 and 21mmHg (Liu et al., 2016). It is not just the classification systems that vary: Wegen-Franken et al. (2006) measured the exerted pressure and stiffness of nine different products within Class II. They found that all nine had widely ranging stiffness. Given that stiffness is one of the three most important characteristics of stockings (along with elasticity and hysteresis), this seems to indicate a factor to which HCPs should give closer scrutiny when choosing between different brands.

Whichever classification or product is used, textile technology has a central role in construction compression garments that meet expected medical efficacy. Textile materials, structure and fabrication directly affect the way the compression garments perform. Hosiery, for example, can be prepared in a circular knitted format or as a double-faced open-width knit. The two behave differently and have different values in terms of production efficiency, depending on medical requirements (Liu et al., 2016). The best fitting stocking is an open-width, knitted, custom-made product. Circular knitted stockings tend to be a single layer (thinner) and seamless, and are

apparently more aesthetically pleasing to the patient (Wegen-Franken et al., 2006).

Compression bandages are usually constructed using warp knitting (raschel or tricot) and use woven or non-woven technologies. Warp knitting comes in many different forms. The different properties of the bandage, such as elasticity or rigidity, depend on the form, whether it is open or closed loop, or netted structure.

Laplace's and Pascal's laws contribute to define the working mechanisms between the compression system and the leg of the patient with a venous leg ulcer. Laplace's law explains how compression pressures can vary under static conditions and Pascal's law explains the dynamics of compression pressure. These principles continue to guide and define the technology of medical compression textiles.

According to Partsch (2014), the compression garments currently available for venous leg ulcer therapy fall into five categories:

Compression bandages

Compression hosiery

Self-adjustable Velcro-devices

Compression pumps

Hybrid devices

These latter hybrid devices, which are a more recent development, offer a combination of sustained pressure, automatically kept at constant levels, and intermittent waves of pressure which can be used when the patient is at rest.

By continuing to research and develop new materials, production techniques and product design, the performance of compression therapy can continue to improve (as illustrated by the hybrid device described above) to provide better levels of comfort; higher levels of biocompatibility; good dimensional stability; finer control of elasticity, stiffness and hysteresis (level of memory, lack of ability to revert to previous form); dynamic and sustained pressure delivery (degressive compression, in the case of venous leg ulcers); good

performance in long-term use, while offering more regulation of moisture levels and temperature at the ulcer site (Liu et al., 2016).

1.4.1 Adherence to compression products

Adherence to compression is pivotal for maintaining healed legs; the concept of 'forever healing' from Chase et al (1997) underlines this and highlights the need for continued compression – probably for a lifetime – and at the highest level of pressure the patient can tolerate, that is compression strength III (Nelson and Bell-Syer, 2012), along with the psychological support and education mentioned above (Fassiadis et al., 2002).

While the publications from the Cochrane Group (and others) cited above are part of the essential evidence for the use of compression therapy in managing venous leg ulcers, the Cochrane reviews focus on the effectiveness of the treatment intervention. What they do not address is an in-depth and detailed exploration of patient perspectives regarding compression. Here lies a substantial gap in our current knowledge. The focus of my research is aimed at addressing that gap; it is specifically about the patients' lived experience of compression. This does not receive mention in the Cochrane reviews, being outside the pre-determined remit of a Cochrane review.

It is worth noting that the patients' experience of compression and their attitude towards its effectiveness, and to the products themselves, may well impact on the success of the compression therapy (Annells et al., 2008; Jull et al., 2004). This relates to variables such as non-adherence, scepticism of efficacy, learned helplessness, lack of understanding of their condition or lack of clear communication between health care professional and patient. These potential problems will be considered in a little more detail below.

1.4.2 Risks and adverse events associated with compression therapy

Pressure damage used to be common and was shown to be caused by inappropriate use of compression, for example where occult arterial disease was present. Poor fit of hosiery and sub-optimal technical skill were also mentioned (Callam et al., 1985; Barwell et al., 2004).

More recently, national clinical guidelines in the UK recommend that all patients presenting with a leg ulcer be screened for arterial disease using Doppler measurement of the ankle-brachial pressure index (ABPI) by suitably trained staff (Royal College of Nursing, 2006; SIGN, 2010).

However, as already mentioned, Guest et al. (2015) has collected data to indicate that a high level of undiagnosed leg ulcers is still present. Guest and his colleagues (2015) further provide evidence that only 16% of patients with a leg or foot ulcer had a Doppler reading.

A number of other co-morbidities, such as diabetes, can also impact negatively on treatment with compression therapy.

1.4.3 Challenges to the success of compression therapy

While many patients experience no issues with compression therapy and although there is considerable evidence to show that compression therapy is the treatment of choice for venous leg ulcers, there are a number of problems that have been associated with it (O'Meara et al., 2012). These may include:

The professional/patient relationship where the patient may not trust or understand the healthcare professional's explanations and where the healthcare professional may expect concordance with their goal to heal the ulcer – which may not be the top priority with the patient – who may seek everyday comfort (and therefore loosen or remove their compression therapy) rather than clinical healing (van Hecke et al., 2009). Van Hecke and colleagues conducted a systematic review of 31 research papers, looking at why patients with leg ulcers do not adhere to treatment. The review indicates that there were many and diverse reasons for non-adherence offered by both nurses and patients. The two groups however, offered a slightly different profile of reasons, and those offered by the nurses appeared to be focused on more patient-related factors, while one of those offered by the patients was inadequate information and communication from the HCP.

The professional/patient relationship is generally acknowledged as an important factor in the overall well-being of patients with venous leg ulcers. Many studies focusing on patient quality of life and well-being have found that the quality of that relationship may have substantial impact on the

patient, their well-being and, not least, their willingness to comply with therapy (Annells et al., 2008; Ebbeskog and Emami, 2005; Haram and Dagfinn, 2003; Ribu and Wahl, 2004; van Hecke et al., 2008).

Also, largely derived from researching the patients' lived experience, the quality of the nursing encounter and bandaging skill, for example, has featured as a theme in the Swedish study by Ebbeskog and Emami (2005). A proportion of the patients with venous leg ulcers, interviewed in depth, across a range of studies, have mentioned the nurse's brusque or judgmental attitude to them (Morgan and Moffatt, 2008a), bandaging incorrectly performed (Ribu and Wahl, 2004), frequent changes of nursing staff (Haram and Dagfinn, 2003), insufficient nursing time and resource to fully provide for the patient in a holistic and patient-centred way (Haram et al., 2003; Walsh and Gethin, 2009). These failings were found despite guidelines which underline the need to 'see' the patient and not the 'leg' (Morgan and Moffatt, 2008a).

Patient well-being and quality of life, which are negatively affected in numerous ways, are often seen as having life-changing quality in the patient with a venous leg ulcer (Gonzalez-Consuegra and Verdu, 2011).

There has been considerable research, both quantitative (Jones et al., 2008; Lindholm et al., 1993) and qualitative (Chase et al., 1997; Upton et al., 2014; Walshe, 1995), and a review of qualitative studies by Briggs and Flemming (2007), devoted to the well-being and quality of life of patients with venous leg ulcers; from developing measurement scales for assessing quality of life specifically for patients with venous leg ulcers (Anand et al., 2003), such as the Nottingham Health Profile (Franks and Moffatt, 2001), to studying the spectrum of factors that can impinge negatively on the patient (Adni et al., 2012; Bentley, 2006; McMullen, 2004; Upton and Andrews, 2013). Much of the qualitative research has been conducted by asking the patients to explain their lived experience of venous leg ulcers (Douglas, 2001; Gonzalez-Consuegra and Verdu, 2011).

Patient adherence, or non-adherence, where patients are unwilling to adhere to compression therapy, has been reported to have a number of causes or difficulties (van Hecke et al., 2008). Patient adherence has been

identified as an important factor in healing and recurrence of venous leg ulcers (van Hecke et al., 2011), but at present the evidence for the fundamental origins of poor adherence to therapy in venous leg ulcers is scant. Estimates of the level of non-adherence vary widely from 30% (Briggs and Flemming, 2007) to over 50% (Edwards, 2003). A number of factors have been highlighted, however, including lack of patient understanding of their condition, poor communication between health care professional and patient, and inability to tolerate the pain and discomfort associated by some with compression bandaging (Brereton et al., 1997; Edwards, 2003). A suggestion that merits further scrutiny is that the patient's mind set, the patient's psychological attitude to their condition and the prescribed therapy, is critical to adherence to therapy (Jull et al., 2004). The evidence around poor adherence to drug regimens in other conditions, for example in diabetes (Leichter, 2005), is more robust and some authors, such as Parker (2012), have extrapolated these latter findings to inform research into adherence with compression.

The above factors are inter-related, and together they create a complex picture of factors that may negatively affect the venous leg ulcer patient. They connect the nurse–patient relationship, patient quality of life and adherence, self-image and more. It is not suggested that these cases are necessarily in a majority, but that they emerge as regular themes when patients with venous leg ulcers talk about factors that impact on their daily lives.

Another potential difficulty that sometimes emerges is patients' issues with the compression bandaging or hosiery itself. There is a dearth of literature that specifically focuses on this topic. In the literature that does exist there are passing mentions of a number of issues with compression which are very rarely followed up in any depth – (Brown, 2010b) and this is the area for my research. The background to this project is discussed below.

1.5 Contextual factors

Referred to above are some of the many aspects that affect the life of a person living with a venous leg ulcer. The inter-relatedness of these aspects

provides a complicated experiential context for the patient, penetrating every aspect of the person's being from sleep to mobility (Upton and Andrews, 2013), from apparel to social functioning (Briggs and Flemming, 2007), from pain to shame (Briggs and Closs, 2006; McMullen, 2004). In the substantial body of qualitative work that already exists, it can be seen that a venous leg ulcer, and the compression therapy used to treat it, affects the patient's daily life in many different ways. According to the literature, for the majority of patients, it does so negatively. A venous leg ulcer is life-changing; as Chase et al. put it, a venous leg ulcer is a 'forever change' (1997).

Looking closely at some of the qualitative reports of the patient's lived experience, for example in the work of Green et al. (2013) and Hyde (1999) in Australia, Tobón (2010) and Krasner (1998) in the US, and Hopkins (2004) in the UK, it can be seen that the information provided by the patient is often not specifically attributed: so the patient may refer to pain (and often does) but we are not told whether that pain is thought to be due to the ulcer, the bandaging, the oedema or even whether it is referred pain, as in, for example, Green et al. (2013) and Hopkins (2004). On broader searching it becomes apparent that very little data from the existing research directly refer to the compression itself or the textiles used in providing compression to the ulcerated leg or covers this topic in any detail.

Venous leg ulcer patients have often endured ulceration for years, rather than months, and, in the course of that time, they have become 'expert' patients (Ebbeskog and Emami, 2005; Lindsay and Vrijhoef, 2009); they have coping strategies which enable them to sleep (Upton and Andrews, 2013), to maintain hygiene (Mudge et al., 2006), to avoid excessive pain (Krasner, 1998), leakage and odour (Hopkins, 2004; Jones et al., 2008), and how to dress to conceal their bandages (Kapp et al., 2014). They also report that they can tell whether a nurse is bandaging their leg 'correctly' (Brown, 2010a), whether there will be a positive relationship with a new nurse, and whether the brand or product being applied is going to suit them (Ebbeskog and Ekman, 2001). Thus, they have a wealth of knowledge and perspective concerning both the affective problems and the practical issues of living with a venous leg ulcer and compression therapy. This current study seeks to discover more about their thoughts on compression products.

Even where their comments about compression are attributed to a specific cause or origin, these comments are not always followed up for further detail – probably because this is not within the remit of the research design applied to the investigation as, for example in Reich-Schupke et al. (2009). As the volume of qualitative work in the field grows, this situation is changing and we know increasing amounts about the patient's perspective on many facets of their life. An area that does not yet seem to have attracted detailed exploration is the patient's perspective of their compression therapy and the textiles used in their manufacture. This is the area on which the current research project focuses.

It is in the context of these considerations and existing knowledge that this study arose. The purpose of the study is to begin an exploration of the patient's experience of compression therapy and the textiles used in their treatment.

Within this objective is the need to acknowledge the complex inter-relationship between these respondents' perceptions of compression and compression products, and their views on the entirety of their condition as venous leg ulcer patients.

Respondents will take part in an in-depth discussion with the investigator. The transcripts from these interviews will be studied intensely for the core meaning and 'truth' expressed by each person, using IPA.

Chapter 2

Literature Review

This chapter describes the process of conducting two iterations of the literature search and an assessment of the data yielded. The first iteration specifically searched for patients' views, attitudes and perspectives of compression therapy. This first search procedure yielded so little that a second, more broadly defined search was undertaken in the hope of being able to sift out more relevant data from a range of research already undertaken.

The results from each iteration of the search are summarised, highlighting features of interest to the current study. To conclude the chapter, there follows a discussion and summary of the literature searches.

2.1 Search objective

The objective of conducting these literature searches was to discover what was already known about patients' perspectives regarding compression therapy and the textiles employed in compression treatment. The level of detail and precision of definition of this existing knowledge was also of interest. For example, pain may come from a variety of sources. In the previous research, was the pain attributed to a specific source and how was it described? In the context of this current research, if pain was ascribed to the compression therapy rather than, say, the ulceration, this differentiation has pertinent consequences for both the patient's behaviour and the researcher's understanding.

2.2 The experience of compression as a treatment for venous leg ulcers

There have been several pieces of research on the 'patient's lived experience' of living with a venous leg ulcer (Briggs and Closs, 2006; Annells et al., 2008; Green et al., 2013; Flaherty, 2005), and some research has discussed the management of the bandage or hosiery used to treat the venous leg ulcers (Briggs and Flemming, 2007).

Qualitative research has also reported on the patient's well-being and quality of life with reference to the compression devices themselves and their effects – bulkiness, heat, itch, too tight, too loose (Hareendran et al., 2005; Herber et al., 2007; Briggs and Flemming, 2007) – including pain experienced by those who have venous leg ulcers (Cwajda-Bialasik et al., 2012; Husband, 2001; Vuolo, 2009). There is a paucity of research that specifically focuses on the patients' experience of compression and the bandage or hosiery applied to the wound.

2.3 Literature searches

As described at the beginning of the chapter, a focused search and a more broadly defined search were conducted. Details are set out in Sections 2.3.1 to 2.3.4, below.

2.3.1 Focused search

The aim of the first search was to identify research that specifically focused on the patients' attitude to compression therapy. Thus the inquiry centred on data from research that stated its main objective to be researching the patients' experience and perspective about compression therapy and, possibly, the textiles used in compression products used to treat their venous leg ulceration.

See Appendix B.1.1 and B.1.2 for search terms and PRISMA diagram.

A search of the following databases was undertaken to identify relevant articles:

MEDLINE, CINAHL, EMBASE, PsychINFO and Scopus (search date July 2014).

MEDLINE	(OVID)	1996–2014
CINAHL	(EBSCO)	1960–2014
EMBASE	(OVID)	1996–2014
PsychINFO	(OVID)	2002–2014
Scopus	(WEB OF SCIENCE)	1996–2014

Studies were included if the following criteria were met:

- the research was available in English (original or translation).
- the stated focus of the paper was to look at patient's attitudes to, and experience of, compression therapy.
- the research was available as a full text article.

Exclusion criteria included:

- articles only available in a foreign language (translation not available).
- attitudes to and experiences of compression therapy were not mentioned or were not the stated focus of the research.

2.3.2 Results

The search identified 257 potentially relevant articles (see Appendix B.1.2). Thirty-two were eligible for inclusion and were retrieved in full text for further assessment. One paper specifically stated that it set out to capture the patient's lived experiences with compression (Reich-Schupke et al., 2009). The research was undertaken in Germany and it was taken into account that there may be international variations in the types of compression used, for example, the use of thigh-length hosiery (Reich-Schupke et al., 2009), which is rarely used in the UK.

The study considers compression as the gold standard therapy in phlebology. Two hundred consecutive phlebology patients were asked to participate and 110 were included.

The research was conducted via a multiple choice written survey with a few open-ended options attached to some questions. The survey used was an adapted version of the Tübingen Questionnaire, designed to measure quality of life during compression therapy. The authors do not say whether the adapted version they constructed had been validated prior to this research. This type of survey allows for little richness of attitude to be reported (it is not a part of the design); there was no interviewer present to probe for details and/or meaning, and no external pressure to respond to the open-ended opportunities (Brannen, 2005) – nor is there any indication that such depth was sought (Reich-Schupke et al., 2009).

Taken from the whole sample (n=110) the main side effects of compression therapy are summarised in Table 2.1, below.

Table 2.1: Patient reporting of the effects of compression devices.

(from Reich-Schupke et al., 2009)

Reported effects of compression therapy	
Adverse effects	
dryness of the skin	59%
itchy legs	33%
slippage of compression device	29%
uncomfortable constriction of leg	25%
scaling of the skin	25%
sweating	22%
Favourable effects	
reduction of leg symptoms	37%
sense of lightness in the leg	28%

Because of the different compression needs of different patient populations (for example, long term compression for the healing of venous leg ulcers and limiting recurrence versus short term post-operative compression for patients who have undergone vein surgery), it would have been helpful to have separate data reported to allow for results relating specifically to venous leg ulcer patients.

Some analysis was presented by type of intervention. When analysing the demographics, the age of the patients was considerably higher among venous leg ulcer patients than the other groups; when analysing quality of life issues, those with ulceration experienced a lower quality of life than the other groups, except on the item concerned with 'hope'. The item 'hope' was not explored for further information.

Patients with venous leg ulcers presented a different profile with respect to age and quality of life, and this difference is likely to have implications for other elements of the patient's lived experiences, the impact of their condition upon their daily activities and emotional well-being. However, it is in the quantitative tradition to aggregate when presenting results and not necessarily to probe for any depth of meaning behind a basic finding.

There appears to be little research *specifically* devoted to patient's attitudes to compression. It is the intention of this project to contribute to this evidence with in-depth, qualitative data gathering.

However, the passing mentions of the patient's experience of compression in other articles, where it is not the stated primary focus, are also important and therefore a broad-based search to learn more about what is known on this topic was also conducted.

2.3.3 Broad-based literature search

This second iteration of the search looked for any mention, anywhere in the text, of the patient's lived experience of compression therapy or compression textiles.

Research on conducting searches in the healthcare domain has found that CINAHL is among the more sensitive search engines (Glanville et al., 2008; Flemming and Briggs, 2006; Shaw et al., 2004; Barroso et al., 2003), although not particularly specific in its yield. The sensitivity is the proportion of retrieved references that were correctly/appropriately retrieved.

The specificity is the proportion of incorrectly retrieved (irrelevant) references; the higher the specificity, the lower the proportion of irrelevancies (Hielkema and Wessels, 2013).

Research exists on developing search strategies for qualitative research (Pearson et al., 2011; Montori et al., 2005; Wilczynski et al., 2007; Wilczynski et al., 2004; Wong et al., 2006; Coffman and Weaver, 2010). Nomenclature can be challenging when conducting literature searches – both from the authors of qualitative research and the databases' keywords and frameworks (Shaw et al., 2004; Grant, 2004; Barroso et al., 2003; Gorecki et al., 2010).

2.3.4 Parameters of the search

Four databases were used for the search (CINAHL, EMBASE, MEDLINE and PsycINFO). CINAHL was viewed as the primary database as it has been shown to perform better for retrieving qualitative research than other commonly used healthcare databases, such as EMBASE and MEDLINE

(Flemming and Briggs, 2006; Shaw et al., 2004; Hielkema and Wessels, 2013; Evans, 2002).

Two main Mesh headings from CINAHL were used: 'lived experience' or 'living with' to capture breadth of patient information. See Appendix B.2.1 for the strategies. Terms were drawn from *Compression for Preventing the Recurrence of Venous Leg Ulcers* (Nelson and Bell-Syer, 2012) to maximise relevant hits in the databases for articles concerning venous leg ulcers, compression bandages and hosiery.

Search dates:

CINAHL	(EBSCO)	1960–2015
EMBASE	(OVID)	1996–2015
MEDLINE	(OVID)	1996–2015
PsycINFO	(OVID)	2002–2015.

Articles were included if they were available in English and reported on research involving adult humans only (Coughlan et al., 2013).

The number of articles retrieved by EMBASE (OVID) was 23. The majority of these duplicated those found in CINAHL. MEDLINE (OVID) identified one article out of the nine retrieved that had not been found in CINAHL.

PsycINFO (OVID) retrieved no relevant articles. After full text screening of a total of 78 papers, a further 38 were rejected on the grounds that they did not refer to compression therapy or textiles from the patient's perspective, or that the article was not a research report (e.g.: a protocol registration from a research nurse in Brazil). A total of 40 papers was included. Figure B.1: the PRISMA chart, illustrates the selection path.

In screening the full papers, any mention was sought of the patient's state of mind regarding their experience of compression therapy, their feelings and attitudes toward compression therapy, and any comment regarding the textiles or type of compression device used (i.e.: bandage or stocking).

So, as long as there were primary data from patients – whether by survey, interview or observation – the article met the eligibility criteria. Analysis of the search does, however, respect the difference in detail provided through

different methods. See Tables B.1–B.4 in Appendix B.3 for listings of attributable/non-attributable reporting.

Initial reading/analysis of the 78 papers did not identify many clear statements on the causality of symptoms, experiences and views. The reporting of findings might mention pain, itching or lack of mobility, but there was no attribution of these features of the patients' experiences. There is an important distinction to be made between the reported findings which are directly attributed to compression, or textiles used in compression, versus findings that are not attributed to any cause, although both are interesting in the context of this project. Where attribution is clearly stated, no assumption on the part of the reader is required; where there is no attribution, inferring the involvement of compression/compression textiles could be an unsafe assumption. These mentions also provide rich ground for further research in the field, to establish whether these mentions can be attributed – to compression or other factors – or not.

2.3.5 Quality appraisal

Appraisal of quantitative studies has been well established (Evans, 2002; Kable et al., 2012; Daly et al., 2007; Brannen, 2005; Seale, 2002). Appraisal of qualitative research is still a matter of debate (Petticrew, 2009; Petticrew and Roberts, 2003; Briggs and Flemming, 2007). For instance, authors have questioned whether all studies regarding patient experience and reporting be incorporated, irrespective of their quality, or should only those studies deemed to be of high quality be included (Gilgun, 2004; Hannes, 2011; Pope et al., 2007; Spencer et al., 2003; Dixon-Woods et al., 2007).

Although quality of design and conduct are important, the overarching aim of this literature search is to identify any mention of the patient's lived experience of compression bandaging, in terms of therapy and compression textiles anywhere in the text and, therefore, no articles were rejected on the grounds of quality (Briggs and Flemming, 2007).

2.3.6 Critical appraisal of the literature from the broad-based search

In conducting this appraisal process, the researcher has been guided by a number of authors (Brannen, 2005; Cresswell, 2013; Cresswell and Plano-Clark, 2011; Dixon-Woods et al., 2007; Hannes, 2011; Rychetnik et al., 2002). A number of assessment tools have been useful in focusing on key aspects of appraisal. The two tools chosen for use in this study were CASP for qualitative research, systematic reviews, trials and cohort studies (2013), and Malterud (2001).

Table 2.2: The 40 articles selected for study

The 40 articles selected for study	
Qualitative research	21
Research reviews	4
Quantitative research	12
Mixed method research	3
Total number of articles found	40

2.3.7 Qualitative studies

Within the 21 qualitative papers, the research questions ranged widely: the experiences of older people (Ebbeskog and Ekman, 2001; Ebbeskog and Emami, 2005; Hyde et al., 1999; Tobón, 2010), attitudes to the quality of nursing care (Brown., 2010a; Haram and Dagfinn, 2003; Rich and McLachlan, 2003), experiences of healed ulcers (Flaherty, 2005), adherence issues, effect on daily activity and psychosocial effects (Edwards, 2003; Hopkins, 2004; Mudge et al., 2006), as well as the patient's lived experience (Green et al., 2013; Kapp et al., 2014; Krasner, 1998; Walshe, 1995; Wellborn and Mocerri, 2014). Most studies reported a similar range of items relating to the patient's lived experience of compression therapy.

Two-thirds of the qualitative papers stated they used a phenomenological approach in their research (see Table B.4, Appendix B.3), but few provided any evidence of phenomenological analytic procedures and one paper

appears to confuse phenomenology with pragmatic research (Walshe, 1995). Another paper that names phenomenology as its underpinning philosophy has a sample of 37 respondents (Chase et al., 1997). This is unusually large for this method, where a sample is typically in the order of 10 to 15 (van Manen, 1990; Paley, 1997; Benner, 1994; Smith et al., 1999; Cohen et al., 2000; Dowling, 2005; Cresswell, 2013; Smith et al., 1999). In general, there is an absence of description of recruitment strategy and variation in method, where some participants kept a diary for 12 weeks, others did not, and only seven of the 37 participants were interviewed – yet all findings were aggregated.

2.3.8 Review articles

Of the four review articles, three aggregate data in the form of themes (Briggs and Flemming, 2007; Parker, 2012; Persoon et al., 2004); McMullen (2004) did not. By doing so they may be losing sight of important relationships between some of the reported items. Briggs and Flemming (2007) illustrate their thematic analysis (and the patient's leg ulcer journey) fully and clearly, making particularly good use of graphs and diagrams. While all their retrieved articles were qualitative, because the aetiology of ulceration was not always clearly defined in these articles, Briggs and Flemming (2007) aggregated data about 'ulcers' generally, rather than 'venous leg ulcers', in particular. Their methods were robust and clearly explained – the appropriate databases were used as search engines – they convincingly demonstrate the similarity of experience across studies, discuss the 'leg ulcer journey' to illustrate the patients' experience and provide a clear coverage of the important outcomes in the discussion section. Some of the articles included in their review, however, were of less reliable quality, which means that we can be less confident in drawing conclusions from these data.

Persoon et al. (2004) dealt with a range of research methods in their review and handled this by having slightly different themes for qualitative and quantitative research. Again, defined aetiology was lacking.

These two reviews, whilst well conducted, highlight the poor quality of the articles reviewed.

Parker (2012) identified five themes, calling his synthesis a meta-analysis. The psychosocial perspective of his focus produced the richest data because the research was interpreted to a psychosocial end. The other reviews, by grouping the data retrieved thematically, risked missing the complex inter-relationships and multiple facets of the items of data. McMullen (2004) presented the complexity of the issues clearly. The lack of thematic organisation, however, made this article less conclusive.

2.3.9 Quantitative research

Among the 12 quantitative articles, compared to the qualitative studies, there was relatively little attributed information to be gathered, and the bulk of this information was observed rather than direct patient report (not, for example, in the form of a quote). The range of research questions was wide: from dressing-related pain in 15 countries (Price. et al., 2008) to single nation risk factors for leg ulcer recurrence (Franks et al., 1995). The quality of these articles was variable: from providing little information about the method of recruitment and about the thought given to the welfare and support of their sample over extended periods of the research projects, to a paper of good quality and clear reporting (Lindholm et al., 1993).

What characterises all the quantitative papers is the absence of probing for further detail of their findings. This is only to be expected and receives mention here only because, for the purpose of this project, the search of quantitative studies contributed relatively little to knowledge on the topic. There might be a comment from a patient about bandage slippage or preference for one compression system over another but there would be no formal collection of these data or evidence of probing for detail and meaning.

2.3.10 Mixed method

Of the three mixed method papers, one reported on a behaviour change programme (van Hecke et al., 2011), another on the impact of odour and exudate (Jones et al., 2008) and the third on the development of a condition-specific quality of life scale (Price and Harding, 2004). All gave clear accounts of the research process of their projects. The research would be replicable and the articles were congruent throughout. They offered little in terms of compression-attributable data and these data tended to be brief

comments attended by little or no supporting text: viz; discomfort, embarrassment of a wet, smelly bandage and greater adherence to compression therapy following a nurse-led intervention.

It would seem that whatever the research method for the patient's lived experience similar data are reported. This lends weight to the inclusion of these parameters in further, detailed research on the patient's lived experience.

2.4 Results

The items of data found through this search have not been combined into themes, as is often done in reviews. The reason is that the complex inter-relationship between these facets is such that groupings can be misleading. For example, pain is often classified as a physical symptom (Gorecki et al., 2011) and it is also a psychological facet of some importance (Krasner, 1998). Further, the corollaries and ramifications of pain can colour almost every other aspect of the patient's condition, well-being and outlook (Upton and Andrews, 2013).

Also, because of the paucity of detail that accompanies these items of information, there is little to reveal how patients themselves, view them. It is not always clear whether it is pain and discomfort, for example, that disrupts sleep, or the odour and exudate from the ulcer (Upton and Andrews, 2013). And with this lack of information there is no way of ascertaining how the patient understands a piece of data, attaches meaning to it and how it fits within the context of the patient's experience, their life-world.

Figure 2.1: Network of factors drawn from literature review below attempts to illustrate the complexity and inter-relationships of the many factors affecting the venous ulcer patient. This is not a fully comprehensive map but serves to demonstrate the level of inter-relatedness and, therefore, the need for further research and clarity.

Notable on this map is:

Figure 2.1: Network of factors drawn from literature review



See Appendix B.4 for Key to studies listed in Figure 2.1: Network of factors drawn from literature review.

2.4.1 The centrality of pain and discomfort

Pain (not specifically attributed to the compression device) is a 'central and recurring theme', (Briggs and Flemming, 2007), that affects many areas of the patient's life and well-being. Persoon et al. (2004) found that 'patients in all studies mention pain as the first and most dominant experience'. Pain is exhausting, debilitating and depressing. Pain is not seen as just a physical symptom (Briggs and Flemming, 2007).

The word 'discomfort' may or may not be a synonym or euphemism for 'pain' in this context (Closs and Briggs, 2002). Rather than assuming that it is, the two terms are kept separate.

'Discomfort' features widely. The mentions of discomfort were rarely accompanied with any details to amplify them, but in Jones et al. (2008) they quote a patient as complaining of the discomfort of a 'wet, smelly bandage'. Walshe (1995) reports discomfort from bandages being too tight and Bentley (2006) mentions the discomfort of 'off-the-shelf' hosiery causing discomfort because it did not fit the patient's leg shape well.

'Pain' from compression also featured in a number of studies (Edwards, 2003; McMullen, 2004; Douglas, 2001; Stevens, 2006; Haram and Dagfinn, 2003; Green et al., 2013). These were references to pain thought to be caused specifically by the bandaging or hosiery, rather than pain attributable to the venous ulceration. Persoon et al. (2004), in their review, found that 'patients in all studies mention pain as the first and most dominant experience'.

2.4.2 The weight of shame and embarrassment

Shame and embarrassment is widespread in this patient population and contributes to the social isolation typical of their difficulties (Brereton et al., 1997; Briggs and Flemming, 2007; Douglas, 2001; Hopkins, 2004; Hyde et al., 1999; Green et al., 2013; Mudge et al., 2006; Stevens, 2006; Walshe, 1995).

The corollaries of shame and embarrassment are denial, vigilance and social isolation. Self-imposed social isolation is a major consequence of leg ulceration and compression therapy. This can have several negative effects,

including depression and loneliness (Jones et al., 2008). Shame, in this context, also includes self-disgust (Ebbeskog and Ekman, 2001; Parker, 2012). The leg can become somehow disembodied in an attempt to deny the existence of the wound and the difficulties associated with it (Ebbeskog and Ekman, 2001; Rich and McLachlan, 2003). This can have significant impact on body image and self-esteem. Rich and McLachlan (2003), for example, report on a patient who would pretend to others that she had suffered a sprained ankle to explain the bandaging, rather than admit to leg ulceration.

Research has been undertaken in chronic illness and how this affects self-image, for example, Charmaz (1983) and Rumsey and Harcourt (2005), but in this review of literature there was little specific information reporting this.

The concept of constant vigilance was reported by Hopkins (2004) and Brown (2010b). It is echoed in other papers as anxiety about exudate leaking through bandaging (Edwards, 2003), smell becoming noticeable to others (Hyde et al., 1999), or of being knocked, if socialising (Ebbeskog and Ekman, 2001).

2.4.3 More physical effects of venous ulceration

Central among the physical negative effects were hygiene and bulk, and their inter-connectors of clothing, footwear, skin irritation, odour and exudate, and reduced mobility.

Hygiene is a considerable problem, involving mobility issues in some cases, but mostly the need to keep bandaging dry – which makes bathing or showering problematic. In one case, the perceived problem was that the nurse had not cleaned the bandaged area during dressing change (Chase et al., 1997; Green et al., 2013; Mudge et al., 2006; Persoon et al., 2004; Walshe, 1995).

The **bulkiness** of compression therapy is, obviously, attributed. Bulk was seen as negative and, as Ebbeskog and Ekman (2001) reported, there was a desire to hide it from others. However, there was an indication that hosiery may be more socially acceptable in the view of venous leg ulcer patients.

There were also many consequences to a bulky textile on the lower leg, such as difficulties with standard footwear, as Edwards (2003) indicated.

Also, **feeling compelled to wear trousers**, as noted in McMullen (2004) and Parker (2012). This can be distressing to some and may lead to altered self-image/loss of femininity (Persoon et al., 2004). Elderly female patients seem to be especially affected by this latter aspect (Hyde et al., 1999).

Reduced mobility was in some cases attributed to the bulk of the bandaging, in others it was pain and, in a few, it was co-morbidities such as obesity or arthritis.

Odour and exudate (sometimes referred to as 'smell') were causes of widespread concern. Some patients were reported to be very aware of the possible smell and the embarrassment of excessive leakage. Odour may be caused by the wound, the exudate, a possible infection or the length of time the compression device has been on the leg (Bryant and Nix, 2012; Morison et al., 1998). These factors are related to shame and embarrassment, the need for constant vigilance and social isolation.

Many forms of **skin irritation** were mentioned: rash, redness, heat, dryness, itch. Both health care professionals and manufacturers were exhorted to find solutions (e.g. Chase et al., 1997; Ebbeskog and Ekman, 2001). This is echoed by Dr Reich-Schupke and colleagues (2009), who wrote about the need to address localised skin problems.

2.4.4 Application of compression therapy

A number of patients reported negatively about the **quality of bandaging skill** they had experienced from some healthcare professionals. With a chronic disease and with the frequent recurrence of ulceration, many patients have a long history of venous leg ulcers and, over time, become knowledgeable, 'expert patients' (McNichol, 2014; Ebbeskog and Emami, 2005; Ribu and Wahl, 2004). A number of articles reported on patients judging the 'application of their compression therapy' as being poor. In one case, the patient was of the opinion that a poorly applied bandage had caused fresh ulceration.

There were also a number of mentions of **difficulty in applying compression** – mostly regarding hosiery – either by the patient themselves or with help (Franks et al., 1995; Brown., 2010b; Flaherty, 2005). Given that

many venous leg ulcer patients are elderly and/or present with co-morbidities that may affect their ability to manipulate hosiery successfully, this is an important issue which may require a number of alternative solutions to assist different patient types.

2.4.5 The life changing quality of ulceration and compression therapy

That these **patients experienced change** in their lives was clearly identified by six articles. This applies to many of the factors illustrated: some of the more profound being altered body image, low self-esteem, loss of control, sleep disturbance and emotional reaction (e.g. depression). For example, Ebbeskog and Ekman (2001) illustrate altered self-image in an elderly patient: the bandaging comes to symbolise the patient's altered status and a sense of being imprisoned by the ulcer (and the compression garment).

2.4.6 Mindset/belief in compression

Six primary articles allude to this concept. Mindset can be seen as central to the patient's tolerance of compression therapy, coping strategies and their **locus of control**/loss of control. For these patients, the pain, discomfort and all the other negative effects they may experience are worth enduring (Annells et al., 2008; Jull et al., 2004), whilst those without this belief that compression will heal their ulcers may have difficulties adhering to their prescribed therapy (Ebbeskog and Ekman, 2001). For example, van Hecke shows that a behaviour change programme can alter mindset, resulting in greater belief in compression and better adherence to compression therapy (van Hecke et al., 2008).

2.5 Discussion

2.5.1 Level of detailed information

Quantitative studies presented little detail on the patient's lived experience of compression, but it is recognised that this is not the main outcome for this type of research. Qualitative research is more relevant and informs this aspect of research into the patient's lived experience.

2.5.2 Pain and discomfort

Discomfort and pain that is attributed to the compression system (whether bandage or hosiery) has important possible ramifications. Mostly, these relate to adherence to compression therapy (Mudge et al., 2006; Moffatt et al., 2009; Haram and Dagfinn, 2003; Edwards, 2003), but this area also considers the nurse/patient relationship and the level of trust, patient involvement and the level of medical paternalism contained within that relationship (Kelley, 2006; Edwards, 2003; Katz, 2002; Stevens, 2006).

Further, pain and discomfort are connected to the patient's mind set, along with adherence issues (Parker, 2012; Kashdan and Rottenberg, 2010). If the patient is predisposed to believe that compression will work, discomfort takes on a very different meaning from the discomfort felt by a patient who has no such faith in their compression therapy (Jull et al., 2004; Annells et al., 2008; Ebbeskog and Emami, 2005). The patient's locus of control and all that this psychological concept carries with it, such as self-reliance and learned helplessness, is relevant (Ebbeskog and Emami, 2005; Sullivan, 1993; Lefcourt, 2014).

Pain and discomfort attributed to the compression products themselves may also indicate that there is further work for the manufacturers to do in promoting comfort and adherence to therapy (Reich-Schupke et al., 2009).

2.5.3 Inter-relatedness

To reiterate, while the items of information found relate principally to physical aspects of compression therapy, the information is also associated with less visible, psychological, negative effects of living with venous leg ulcers and compression therapy in a complex and multi-faceted relationship (Briggs and Flemming, 2007; McMullen, 2004). These less visible, psychological and negative effects act on every aspect of the patient's life and daily activities/experiences. While the items found in this search stand alone as indicators of patients' experience, it is the ramifications and corollaries of these comments that build a more complete picture of the life-changing effect of venous leg ulceration.

The exception is the 'Social shame and embarrassment' category. Its relative prominence in the data gathered indicates how important are the social restrictions self-imposed or imposed by the existence of venous leg ulcers and the compression therapy. The role of social support and human interaction has been well documented in the literature (Annells et al., 2008; Bentley, 2006; Brown., 2010a; Ebbeskog and Emami, 2005; da Silva et al., 2014).

2.5.4 Observation versus direct patient report

There is a further issue with these reports of the patient's lived experience: while some papers were well illustrated with verbatim quotes from the patients themselves (Edwards, 2003; Hopkins, 2004; Ebbeskog and Ekman, 2001; Mudge et al., 2006; Hyde et al., 1999; Walshe, 1995), there were more that reported these experiences from an observational, researcher perspective, rather than relying on comment directly from the patient. There were also a few that used quotes in a manner that did little to illuminate the point being made in the text. The question therefore arises: were these items really the patient's lived experience, consciously, cognitively presented by the individual, or were they observations of the researcher?

Not that the latter is invalid, and yet direct reporting of the patient's perception is subject to much less potential bias, assumption and interpretation – important to the phenomenological process (Carter and Little, 2007; Crotty, 1998; Mackay, 2005; Smith et al., 1999; Spinelli, 2005; Tan et al., 2009; van Manen, 1990). The closer the reporting is to the source of the knowledge, the truer the report is likely to be. And it is a truth and a meaning according to the participant that we seek to find in qualitative research (Beresford, 2005; Seale et al., 2005; Kvale, 1997). This sets parameters for the validity of reporting.

2.6 An update on the first literature search

The first iteration of the original literature search was undertaken in July 2014. Given the time that has elapsed since then, an update was conducted in order to find any further research that may have been undertaken in the interim, regarding the patient's perspective of compression textiles for

venous leg ulcer treatment. This update was set from April 2014 to April 2018, using the same search engines as before (MEDLINE, CINAHL, EMBASE, PsychINFO and Scopus). The search yielded 331 records. While 26 of the articles retrieved were of interest and related to some of the findings from the research, none of them had as their main focus the patient's perspective of compression textiles for venous leg ulcer treatment.

2.7 Summary

The comments that were directly attributable to compression in some form or another tended to be brief mentions and part of a broader, more complex picture. Rarely, if ever, was the mention elaborated on or hypothesised about.

Even where the patient's perspective on compression is present in the papers discussed, it is part of a bigger research focus, which means that any in-depth discussion on these aspects is absent (Moffatt et al., 2008).

Perhaps the closest the research comes to focusing on compression is around adherence issues, and even then, there is little detail about the discomfort and pain some patients experience with compression therapy (Edwards, 2003; van Hecke et al., 2011; Annells et al., 2008).

Chapter 3

Methodology and Methods

This chapter sets out the methodological decisions that underpin this research project and the methods employed in the collection of data. The discussion considers epistemological assumptions through to detailed procedural description of quality and rigour in data collection, and the analysis and interpretation of results. Ethical considerations, particularly those of respecting the rights and dignity of the participant, are also described.

3.1 Methodology

The current project aims to establish the meaning and value patients with venous leg ulcers ascribe to compression therapy and the textiles used to administer compression therapy.

The study aims to elicit how these patients make sense of the world (Cardinal et al., 2008), using in depth qualitative interviews and qualitative analysis to explore the subjective perceptions and lived experiences of venous leg ulcer patients in an area where, currently, little data exists.

Growing out of *epistemology*, many differing methodologies have developed, qualitative and quantitative. *Methodologies* are theories and analyses of how research should proceed - and from *methodology* a *method* is derived (Carter and Little, 2007). The *method* refers to the techniques used to gather evidence, the research action (Giacomini, 2010). There is a difference between qualitative and quantitative data and the frameworks held by the respective researchers.

The view inherent in quantitative approaches (such as the positivist position) assumes that it is possible to describe an over-arching, single 'truth' or 'reality' of the world and of the people in it. This is something seen as existing independently of the process or circumstance of viewing it (Finlay, 2006; Santiago-Delafosse et al., 2016). In other words, this is 'objective reality'. This gives us valuable information while considering facts such as the incidence of infection or levels of adherence to therapy in a patient

group. It is of less value when there is a need to understand, in depth, and possibly interpret what a research participant says.

The positivist position has a role, however, in asserting that subjective perception is incomplete and selective: the stimuli we perceive, through all our senses, are edited, analysed and interpreted before they ever reach our conscious perception. In this instinctive awareness, our brain performs all these selective processes automatically. If all the stimuli around us were to impinge on us without this automatic filtering, chaos would follow. There are too many stimuli for us to compute (Gregory, 1998; Velmans, 1999). In his work, Gregory (1998) explains that only the most 'important' information reaches our conscious brain. To be precise, we select the most important information to us; based on our life, our world context, our culture, our previous experiences and what we already believe to be true. Inevitably, there is debate about the value of this incomplete perception.

In this research the aim is not to gather 'objective' truths but to explore, using qualitative methods, the subjective perspectives and lived experiences of venous leg ulcer patients regarding compression and the textiles used in their treatment.

It is precisely this selective perception and personal understanding of the participants' experience that is important in this research study. The value of adopting a phenomenological approach is that it allows the subjective nature of the data to be examined to provide an insight into the participant experience and the value or meaning they attach to that experience. The research also seeks to advance our understanding of the experience of the described population.

3.1.1 Interpretive phenomenological analysis, phenomenology, hermeneutics and idiography

In the following sections phenomenology, hermeneutics and idiography – and how they influence this research project – and their likely contribution to the research project – will be considered. These, in line with interpretive phenomenological analysis (IPA), with its roots in phenomenology, provide a coherent methodological approach for the study. Moreover, the art of bracketing, and adopting a purely phenomenological attitude will be

addressed. However, it is impossible to do this without exploring the 'naïve' researcher and reflexivity. Briefly defined, according to van Manen (1990), bracketing describes the act of suspending your various beliefs in the reality of the natural world to study the essential, core structures and objects of the world.

3.1.1.1 Interpretive Phenomenological Analysis

Interpretive Phenomenological Analysis is a qualitative approach formalised in the UK by Jonathan Smith et al. (1997). As previously mentioned, IPA is rooted in phenomenology and, therefore, is concerned with the ways in which human beings experience and make sense of their world. As Larkin et al. (2006) state, the phenomenological attributes of IPA give 'voice' to the concerns and views of participants, while the interpretive framework of IPA allow the researcher to 'make sense' of these experiences and put them into the context of the participants world, from a psychological perspective.

Moreover, Larkin et al. (2006) state that IPA has its roots in 'minimal hermeneutic realism' which examines the language used in texts/transcripts. This viewpoint does not deny the existence of an objective reality but specifies that reality is dependent on context and on an individual's psychological and emotional state. In this way, IPA corresponds with my epistemological position: that of using careful and explicit interpretive methodology to access an individual's cognitive inner world. This provides a coherent methodological approach. See Biggerstaff and Thompson (2008), Brocki and Weardon (2006) and Giorgi (2002). This is also an essential component of the work that IPA does (Smith, 2011). In fact, it is the major underpinning of IPA.

3.1.1.2 Phenomenology

Husserl (1859–1938) is dubbed the father of phenomenology (McCormick, 2001), although Kant (1724–1804) is the seminal thinker in the development of phenomenology. Husserl pointed out that we do not perceive the world and its properties in their objective state but we grasp the corresponding subjective state – where we become conscious of them.

Husserl's work forms an integral phenomenological influence on the IPA process and defines the primary stages of analysis (Smith et al., 2009).

He was interested to find a way to develop a 'phenomenological attitude', a way of knowing and profoundly understanding the experience of a given phenomenon, which would allow a person to identify the core qualities of the phenomenon. He reasoned that if the person could reach this point, they might transcend layers of context, circumstances and appearance (Smith et al., 2009) and be able to see 'the-thing-itself'. This transcendental process was called 'epoché'. Husserl describes a series of 'reductions', stripping away distractions and false trails of a person's assumptions, prejudices and preconceptions and arriving at the essence or core of their experience of a particular phenomenon (Smith et al., 2009). The process involved a series of reflections, looking at the raw experience of a phenomenon and practising an inward intuiting of meaning, removing the layers of interpretation and preconceptions.

However, Smith et al. (2009) incur criticism from Giorgi (2011) on this score, as their nomenclature is neither consistent or, in Giorgi's (2011) view, accurate and their definitions and descriptions insufficient and misleadingly over-simplified. On this basis Giorgi is unconvinced that IPA, as described by Smith et al. (2009), is truly phenomenological. Whether misnaming 'epoché' as 'bracketing' disqualifies IPA as a methodology that draws much from phenomenology and is based in large measure on phenomenological concepts and goals, is questionable.

What is clear, however, is that from his position as a highly skilled and experienced phenomenologist, Giorgi (2011) finds objectionable the inconsistencies and errors he perceives in IPA (Smith et al., 2009). Elsewhere Giorgi is ready to applaud the research work conducted in healthcare, using IPA, as a positive development illustrating the move from philosophical phenomenology to scientific phenomenology (Giorgi, 2000a; Giorgi, 2000b; Giorgi, 2013). So inconsistency is not exclusive to Smith et al. (2009).

Total bracketing is impossible: stimuli reaching the brain through the eye (visual stimuli) have already been through considerable interpretation, selection, analysis and categorisation, without conscious awareness (Gregory, 1998; Ramsøy and Overgaard, 2004; Timmermans and

Cleeremans, 2015). This emptying of preconceptions is a useful exercise in interviewing, however. With practice and training, it is possible to reach some approximation of bracketing (achieving that empty and peculiarly receptive state). Achieving epoché is something different; it is a Husserlian concept and is more appropriately employed during analysis, where a reductive psychological attitude can be a way of profoundly intuiting the participant's meaning and life world (Finlay, 2009; Mackay, 2005; McCormick, 2001). This implies retaining a certain unknowing and openness to the world, while deliberately restraining pre-suppositions and pre-understandings.

'Epoché' is a rarely used term (at least, rarely used correctly) and from the literature, is perhaps a conceptual state rarely attempted. 'Bracketing', on the other hand, features often in healthcare research today and describes one of the central means by which phenomenological research achieves an in-depth understanding of the participant's lifeworld (Cresswell, 2013). It is the term that healthcare researchers use to refer to a process of trying to minimise bias by setting aside prior assumption and minimising the effect of the researcher's previous experience when undertaking research (Tufford and Newman, 2012). As such, it bears only passing resemblance to the concept of epoché, as discussed by Husserl, which was transcendental and solitary in nature (Giorgi, 2000b). As discussed above, this attempt at bracketing is well worthwhile if it enables the researcher to hear the respondent's truth and meaning more accurately and empathically (Moustakas, 1994; van Manen, 1990).

On the basis of the previous paragraph, the concept of a naïve researcher would appear advantageous to the process. A caveat to this tradition of the naïve researcher, however, comes from Cohen et al. (2000). They argue that it is a misconception that a piece of research can begin without a literature search. A literature search helps to give the rationale for the research and informs the researcher about the state of our knowledge in a given area. This contradicts the traditional methodology of phenomenological exploration, especially that of Husserl, who sees the researcher as 'naïve' and without any assumptions gained through prior knowledge (Seale, 2002; Korab-Karpowicz, 2001). Cohen et al. (2000)

demonstrate that the literature review placed their study within a context, however, and provided broad concepts such as Quality of Life (QoL) and chronicity of wound: clearly useful in a study of chronic leg ulcers.

In conducting a review of the pertinent literature (see Chapter 2), preparation for this current research has followed the thinking of Cohen et al. (2000).

This has provided a systematic approach to the study by providing background information and focus. Whilst naïvety sits well within the phenomenological and IPA tradition, in this current research the need for a pertinent line of inquiry and a focused aim for the research could easily have been lost if the 'naïvety' theme had been pursued and no literature search undertaken. Without the literature reviews, the relative lack of detailed data about the venous leg ulcer patients' lived experience of compression therapy and the textiles used in their manufacture would not have come to light. Nor would the small amount of data that does exist have become evident.

The main deficits arising from the literature review (Chapter 2) are:

- Lack of data on patients' views regarding compression per se and compression textiles/products
- The need for greater precision on key concepts such as pain, shame, skin sensitivities, isolation, negative feelings
- Relatively little data around the relevance of a patient's health locus of control, their mind set (e.g.: a person's positive attitude to compression being a factor that promotes adherence to therapy) and relationship with HCPs.

Even with this information to guide and prompt dialogue within the interview, the researcher faced entering a new environment within healthcare; the care and treatment of patients with venous leg ulcers. Thus, aligned with bracketing, naïvety was not a redundant concept in the current project.

IPA is also underpinned and significantly influenced by two more concepts: hermeneutics and idiography. In charting the course of the research, it is vital to consider both concepts. These are outlined below.

3.1.1.3 Hermeneutics

Another important theoretical basis to IPA is hermeneutic methodology. Literally, 'hermeneutic' originally refers to the interpretation of bible text (Hood, 2016) but now is taken to mean the process of understanding a text – such as a verbatim transcript from data collection. Questions asked in hermeneutics might concern the methods and purposes of interpretation, how to uncover the original meanings of the author (participant) and the context in which a text (transcript) was produced (Finlay, 2009). These are all central concerns of IPA also (Smith et al., 2009).

Heideggerian phenomenology is sometimes called hermeneutic phenomenology. The terms are often used interchangeably; they are similar but not the same, despite that fact that Heidegger (and other phenomenological thinkers) was engaged in both branches of philosophy. Critically, when the researcher decides to embark on research (whether as a general phenomenologist or as a hermeneutic researcher) they start a process of reflexivity. The purpose of this is to become aware of one's biases and assumptions, in order to 'bracket' them or set them aside, as outlined previously. This is in order to engage with the experience of the participant without preconceived notions about what will be related (Wilson, 2015). The use of reflexivity as an aid to bracketing, as outlined above, is the way in which a general phenomenologist would employ this phenomenon. In the hermeneutic approach, by contrast, the researcher uses the process of reflexivity quite differently (Laverty, 2003). The biases and assumptions that come to light are not bracketed or set aside, they are an integral part of the interpretive process. Heidegger's argument is pertinent because it suggests that a researcher's access to the personal world of the participant is complicated by the researcher's own experiences and understandings – but these conceptions are necessary to interpreting and making sense of the data (Finlay, 2009; Laverty, 2003).

The practice of hermeneutics in research today involves three main elements, in a circular, iterative development: 1) reflexivity, 2) dialogue and 3) interpretation. Linguistics and the differential understanding of language – via mother tongue, culture, social context, profession and so on – are pivotal

in hermeneutics: all meaning and thought is dependent on language (Forster, 2012; van Manen, 1990). For the purpose of this research project, the term is used to refer to the interpretation of the participant's words and language construction, from verbatim transcripts. Integral to IPA is the opportunity to look closely at words and expressions used, to search for meanings that may lie behind the form of words employed by any given individual.

3.1.1.4 Idiography

Idiography is the third major influence on IPA. Idiography is the study of the particular, a focus on detail and on depth of analysis (Molenaar, 2004). It is also committed to understanding how an experience or phenomenon is experienced by a particular person (or small sample of people). Because IPA addresses in its focus 'the wholeness and uniqueness of the individual' to give an in-depth picture, any attempt at generalisation or transferability may be seen as inappropriate or impossible. This can be ranked as a weakness of this analytic method.

Also, because IPA holds to an idiographic focus, which is subjective, intuitive and impressionistic, it can be difficult to establish which variables are important – especially given small sample sizes (Pringle et al., 2010).

In this the research both viewpoints were in use: the small group and the individual, with a stronger emphasis on the latter focus – the focus on understanding the meaning of something for a particular person (Smith et al., 2009). The IPA structure moves from single cases to more general statements but still allows retrieval of individual viewpoints. This makes it a flexible and detail-oriented tool designed to expand understanding – and therefore particularly useful in an exploratory work, such as this.

Shapiro (1961) and Allport (1966) are generally held to be the originators of scientific idiopathic research, developed as a complementary method to nomothetic psychological research, prevalent at the time (Barlow and Nock, 2009). It has endured and grown, either in case study format or in small sample, in-depth studies (Barlow et al., 2008). It is important to acknowledge, however, that a focus on the particular does not preclude the

general; they are not that distinct and are interdependent if we are to achieve the full picture (Smith et al., 2009).

3.1.1.5 The aim of phenomenological research

In phenomenological research, the aim is to understand the participants' perspective of their lifeworld and to reach an understanding of the individual's sense of 'meaning' and 'value' of phenomena within that lifeworld (Moustakas, 1994; Smith et al., 1999; Wilson, 2015). It is thought to be useful to approach the phenomenon under study assuming or requiring as little prior knowledge and as few prior assumptions as possible, thus introducing the least possible 'noise' or interference to the research situation. This is intended to allow the 'truth' and voice of the participant to be clear and uncontaminated (Holloway and Wheeler, 2013). As argued in Section 3.1.1.2, this endeavour can never be completely attained. It is possible, however, to practice active listening skills and to focus on leaving one's *a priori* assumptions behind, as far as possible (Spinelli, 2005). A principle of good research is to assume as little as possible and listen with as little 'noise' in the process as possible. (Banister et al., 2001; Holloway and Wheeler, 2013; Kelly, 2010a).

It is important, however, that *a priori* assumptions formed from such a literature review are not included in any analysis. The researcher should enter the process with curiosity and an open mind.

The interpretive analysis is made on the research findings from the study and any reference to prior assumptions are clearly labelled as such, as additional considerations or related theory (Cohen et al., 2000; Finlay, 2002). This would form part of a process of reflexivity from the researcher (Finlay, 2009). This concept of reflexivity is key to IPA research: a person is always a person-in-context and this is true both of participant and researcher. The researcher's reflexivity and self-awareness is an important part of the IPA process (Moustakas, 1994). It is vital, therefore, for the researcher to consider and to take steps to make explicit what it is that the researcher is bringing to the research (for example, the researcher has kept a reflective journal since 1999).

3.1.1.6 A synthesis of approaches

In the methodological approach employed, a synthesis of bracketing and reflexivity were combined so that that which could not be unknown or successfully bracketed is, at least, recorded and acknowledged and made transparent (Hood, 2016). The aim was for the interviewer to bracket assumptions and experiences prior to and during the interview process, the dialogue, while maintaining a 'third eye' (sometimes called the 'supervisory eye') to note inward or implicit processes during the interview session: these, to be considered carefully outside of the interview itself, as part of the reflexive process. Such a process can add considerable rigour and richness to the resulting data. The combination of phenomenology, idiography and hermeneutics, examining the meaning an individual attaches to their life and experiences, on the one hand, and examining the language they use to describe their perspectives on the other (Hood, 2016).

3.1.1.7 Synopsis

Phenomenology, hermeneutics and idiopathy are modes of analysis, in current understanding, employed by qualitative researchers to interpret data (Byrne, 2001). Both qualitative and quantitative researchers seek 'truth' and 'reality' but how these concepts are defined varies (Foucault and Pearson, 2001). In the context of this research, the 'reality' is understanding how the participant with venous leg ulceration makes sense of their world and the things in it (the compression therapy and textiles used), and 'truth' is the value and meaning the patient attributes to these aspects of their life.

3.2 Qualitative method and design

As previously discussed in Section 3.1, a qualitative approach was adopted for this research in order to explore, in depth, the patient's perceptions of compression textiles used in the treatment of their venous leg ulcers.

Following consideration of a range of data collection methods, phenomenology was chosen as offers the best match with the objective of the project: as it aims to establish the meaning of a given phenomenon and to explore how an individual experiences it, understanding without

necessarily offering an explanation. In the context of this research: the patient's perspective of compression textiles used in the treatment of their venous leg ulcers, this approach allows an exploratory design and enhances our knowledge and understanding in an area where comparatively little is known.

For the purpose of this research, phenomenological principles underpin the qualitative method (Mintz, 2010; Seale et al., 2005; Smith et al., 1999). This allows the interviewer to be led by the participant, without a prior, specific goal to seek and to develop theory from the findings (Seale, 2002; Hopkins, 2004; Cohen et al., 2000; Tan et al., 2009). If the findings can be linked to a theory, or amplify a theory, or serve to form the beginnings of a fresh theory, then this is a favourable outcome. The main goal is to explore the meaning attributed to their world by the 19 patients with venous leg ulcers. Active listening, a desire to learn and understand another's view, and creative interpretation, are the best skills to employ within this paradigm (van Manen, 1990; Smith et al., 1999). The research also draws on the art of hermeneutic interpretation and an idiopathic commitment. Such a process can add rigour and richness to the resulting data. This is what IPA offers.

3.2.1 Interview and interviewer

In this section, the following aspects of the decisions made about procedural matters for the study will be put forward including: type of interview chosen, researcher presentation and role.

Interview is a versatile research method that allows opportunities to explore, clarify and understand. It allows the participant to express thoughts feelings and perceptions in their own words – and, as detailed above, the choice of words used and how they are combined is critical to the collection and analysis of data within this phenomenological and hermeneutic approach (Holloway and Wheeler, 2013; Kelly, 2010b; Kvale, 1997).

3.2.2 Adopting a semi-structured approach

A semi-structured approach is a powerful technique for gathering data and, importantly to the phenomenological endeavour, it gives the participant a 'voice' (DiCicco-Bloom and Crabtree, 2006; van Manen, 1990) while offering

some guidance on the topics to be discussed. In the context of this research project, the interview guide for a semi-structured interview directed the researcher to introduce the topic with a brief background question on the history of the participant's venous leg ulcers, moving swiftly on to, 'Tell me about your experiences with compression therapy?'. See Appendix C.1 Interview Guide.

The participant was then free to talk until their spontaneous disclosure was completed. At this juncture, if important topics of interest arising from the literature review have not been mentioned by the participant, the researcher may employ prompts to facilitate further exploration, to see if they resonate with the participant's experience – providing the participant is willing to continue. The researcher might also return to points of interest in order to elucidate more detail from the participant.

3.2.3 Rapport or psychological contact

Interviewing is a skilled undertaking. It can only be successful if a level of rapport or psychological contact is built between participant and researcher: there needs to be a preparedness to be open and there must be an element of trust, on both sides. If there is antipathy rather than attunement between participant and researcher, for example, the participant is unlikely to disclose anything of their experiences that they regard as valuable or 'true' (Rubin and Rubin, 2005; Timmermans, 2010). The researcher should demonstrate an openness to, and regard for, the participant's experiences, an empathy for their situation and a genuine interest in the participant's condition. This, it is hoped, will encourage an element of trust and consequent openness in the participant, allowing them to feel safe in the encounter (Rubin and Rubin, 2005).

3.2.4 The researcher's role

The role of the researcher is of central importance to this research project in a number of ways. Lack of psychological contact or attunement, initiated by the researcher's demonstration of empathy and interest, could undermine the quality of data offered by the participant if they do not feel comfortable or 'safe' in the situation (Timmermans, 2010). It is the researcher's responsibility to manage the interview situation on behalf of the participant

(Kelly, 2010b; Meadows, 2003), such that the participant feels empowered and engaged. The interview situation is rarely one of equality and the participant may feel that they sit in a subordinate or vulnerable position – even in their own home (Malson, 2010; Rubin and Rubin, 2005). The participant is also a ‘patient’ and this label can, for some, carry with it a measure of abdication of power, of self-determination and of responsibility (Katz, 2002; Kelley, 2006). While this is possible, the concept of empowering the patient to redefine their locus of control and develop self-efficacy is much stronger among healthcare professionals today than in the more paternalistic past within medicine (Kelley, 2006). Thus, the balance of power may be more equal than in the past.

The researcher has been introduced to the participant as a university student by a member of the nursing team that cares for them. The participant is likely, therefore, to associate the researcher with an authority figure; their nurse. The patient is likely to wish to please their nursing team (as evidenced by a few participants in this research) – or at least, not to antagonise them – so they may already feel obliged to participate (Ebbeskog and Emami, 2005; Morgan and Moffatt, 2008b). These factors may lead the participant to offer data that they think the researcher expects and wishes to hear. This is known as social desirability bias and can be difficult to avoid (Grimm, 2010).

The researcher is also responsible for maintaining confidentiality, respecting the dignity and well-being of the participant’s involvement (Banister et al., 2001; Holloway and Wheeler, 2013). The researcher is also responsible for ensuring that any concerns the participant may have are promptly and fully addressed. These considerations will be set out more fully in Section 3.3.2: Ethical considerations.

3.2.5 Reflexivity and the role of researcher

Writers find it difficult to offer a clear definition of reflexivity (Dowling, 2005; Potvin et al., 2010). There is, however, a broad consensus on a basic definition: reflexivity is a process of critical thinking on what has been believed and done in a qualitative research project. It requires the researcher to undertake a self-aware analysis of their involvement in the

study process (Finlay, 2002; Holloway and Wheeler, 2013). Given the phenomenological method employed in this research, the role of the researcher includes this challenging process of reflexivity (Kinsella, 2006; McCaffrey et al., 2012).

Reflexivity assists in the process of quality assurance, providing a perspective other than the participant's words and increasing the trustworthiness and transparency of the data reporting. It adds a dimension of transparency which should allow clearer understanding of the participant's meaning and value system. It does this by showing an awareness of the researcher's own preconceptions and assumptions that may colour analysis and reporting (Banister et al., 2001). For example, the researcher's relative naïvety might be regarded as an advantage from a phenomenological perspective – in that there may be fewer assumptions and prior experiences to bracket than for, say, a tissue viability nurse.

This is relevant not just in the context of the methodological position taken but also in the ethical context of managing the interview situation with the participant in mind. As discussed above (Section 3.2.3), how the researcher introduces herself and what disclosures are made will influence the participant's level of ease and comfort with the situation. A sense of equality can be difficult to achieve in an interview situation but all possible effort should be made to ensure the patient's dignity is cared for at all times (Kvale, 1997).

The researcher has kept a personal journal since commencing study and this became more central to research activity as the fieldwork for this study began (Finlay, 2002; Finlay, 2009; Wright, 2005). The journal records personal feelings and thoughts during interviews and beyond, as well as reflexivity regarding the interactions and shared meaning perceived with the individual participants. It also contains reference to self-awareness, important to the reflexive process (Kinsella, 2006; Langdridge, 2008).

3.3 Study design

For this research, a standard and robust design of face-to-face, one-to-one, audio recorded, semi-structured, in-depth interviews was decided upon. The shape of this research design is set out in the following sections (3.3.1).

As discussed previously, informed by the epistemological position, a qualitative design was employed to fulfil the research aim. Nineteen in-depth interviews were conducted with individuals who had experienced compression therapy for venous leg ulcers within the previous two years.

A sample of 19 is unlikely to offer up data of generalisable or transferable information, in the conventional sense. What IPA can offer is what Smith (2011) calls 'theoretical transferability, rather than empirical generalisability'. IPA can give useful insights, precisely because of its subjective and detailed focus, and these can have wider implications which can influence or contribute to existing theory. IPA can contextualise the contribution the research makes to the wider literature – it can contribute to making a theory seem more valid (Pringle et al., 2010).

An example in the field of healthcare might be the belief, once held by HCPs, that venous leg ulcers rarely, if ever, caused pain. Whilst that myth has long since disappeared, any research rooted in the words of a patient participant (as in IPA) would have shown us the lie. Thus, the view of patients may be outside the perceptual field of HCPs and such additional data, rooted in the words of the participant, greatly contributes to the state of knowledge (Biggerstaff and Thompson, 2008).

3.3.1 Participants and procedure

The sample was drawn from patients who currently had a venous leg ulcer, or had had such an ulcer within the previous two years. The two year limit was set to give a reasonable probability that memory of the ulcer, compression and attendant experiences would be still fresh and accessible.

Interviewing took place during March, April and May of 2016. The interviews mostly took place in the participant's home but some preferred to be interviewed at their local GP surgery or tissue viability clinic. This was arranged for them thanks to the co-operation of the practice managers on

site. In total, 13 participants were interviewed at home and 6 were interviewed in a clinical setting.

After reiterating information about the research and inviting questions, participants were asked to complete and sign a consent form (also signed by the investigator). Once the investigator was satisfied that the participant understood and was content to proceed, a semi-structured interview was conducted and audio recorded. On average the interviews took 50 to 60 minutes and interviews ranged in length from 35 minutes to 90 minutes.

Upon completion of the interview, the investigator invited questions and comments from the participants and took time to ensure that the participants had suffered no apparent ill effects as a result of describing their perceptions of sometimes harrowing ulcer journeys. Indeed, two participants commented that the dialogue in the interview had given them new insights and 'done them good'.

For a study employing IPA, 19 participants is a large sample. This may have the advantage of avoiding some of the limitations associated with small sample sizes (often levelled at studies using IPA and small samples), but it does involve a great deal of time. IPA is a time-consuming analytic process and is more commonly used with samples of 10–12 participants. By contrast, as well as the IPA process facilitating rigour and enriching the data yielded, this lengthy analysis process may also be seen as a limitation.

The language used by participants to express their perspectives on compression therapy in interview and their experience of venous leg ulcers was paramount in this research project and this was a prime reason for adopting purposive sampling (Holloway and Wheeler, 2013). It was essential to select participants from the venous leg ulcer population, who were able to provide articulate information, based on their experiences and command of the English language. This intentional selection process was designed to ensure that specific characteristics and data were captured.

The inclusion and exclusion criteria for selecting participants are set out in Table 3.1 below.

These broad criteria were deliberately set, so that the greatest range of perspectives was likely to emerge from a relatively small sample. Thus, both healed and non-healed ulcer patients were eligible, providing their experience of ulceration and compression was within two years of the present.

Table 3.1: Inclusion and exclusion criteria

Inclusion	Exclusion
Capacity to give informed consent	No venous leg ulceration within the past two years
Adult, able to verbalise their experiences in English	Non-English speakers
Experience of venous leg ulcers within the last two years	Patients without the capacity to consent (e.g. through dementia, severe aphasia, severe stroke)
Healed ulcer or not healed	

Given the chronicity of the underlying pathology that causes venous leg ulcers, the simple requirement outlined above represents a large proportion of the venous leg ulcer population (McLafferty, 2014).

Recruitment was conducted by the tissue viability nursing teams, following a briefing meeting conducted by the researcher to ensure the nurses developed a thorough understanding of the research requirements. The patient was given a patient information sheet (PIS) with an invitation letter to explain the purpose and content of the research and to invite participation (Appendices D.1, D.2 and D.3). If the patients were willing to be interviewed their contact co-ordinates were released by the nursing team to the researcher and contact was made. The option to make contact themselves was also available. In this way, the anonymity of the patient was protected until the point when they agreed to participate, with the nursing teams who cared for these patients acting as gatekeepers.

It was hoped that recruitment on behalf of this study would not impinge too heavily on the workload of specialist tissue viability nurses, since research is seen as a key part of their work. Also, because these nurses would all have considerable research experience (unlike many district nurses, for example),

the researcher hoped that their cooperation with the research objectives would be with full understanding of exclusion and inclusion factors, and the objectives of the research. The briefing, therefore, was given using terms and concepts familiar to the specialist nursing audiences.

According to Lamb et al. (2016), however, there are a number of other factors that may influence the identification of potential participants for research. There is a risk of the recruiting nurse looking for the 'perfect patient' and thus possibly excluding the very frail, or those with complex or multiple needs. The level of rapport between the patient and the nurse was identified as another possible influencing factor: poor rapport was thought to work against patient recruitment or willingness to participate. Allied to this point, it was believed (Lamb et al., 2016) that most patients wanted to please their nurses by agreeing to participate and possibly also feared reprisal if they refused to participate.

Although this study employed purposive sampling in order to recruit the most relevant participants, with good ability to communicate, the factors identified by Lamb et al. (2016) as possibly influencing nurse recruiters imply a 'pre-screening element to the recruitment process'.

One of the purposes of a briefing meeting (Appendix C.2) with the nursing teams prior to recruitment was to underline the openness of the inclusion criteria. The meeting was scheduled to allow ample time for questions and discussions to clarify any matter that might arise. It was also an opportunity to make contact with all members of the teams and to motivate them to assist in the research process. The emphasis was at all times on the inclusion and exclusion criteria which were designed to offer broad recruitment scope and therefore be only a small time burden for the nurses (Cresswell, 2013).

There is no universal agreement to indicate optimal sample size of qualitative research. Some authors cite a requirement of four to 25 interviews, if thematic saturation is an objective, with lower requirements ascribed to studies with greater participant homogeneity – often the case with purposive sampling (Cresswell, 2013; Seale et al., 2005). In this current,

exploratory research, richness, depth and breadth of data was more important than saturation.

3.3.2 Ethical considerations

There are many facets to ethics in the research context, perhaps particularly when the participants are also patients within the NHS and the researcher does not work within the NHS. Great emphasis was placed on ensuring that this study tightly and thoughtfully adheres to the ethical outlines by Banister (2001). The most important of these are outlined in the following subsections.

3.3.2.1 Ethical approval

It is important to be aware of the ethical implications for participants and researchers throughout the research process. Participants must be protected from any harm: preserving and caring for their well-being, values and dignity. The ethical approval process within the NHS is extremely robust in order to ensure that the rights, safety, dignity and well-being of all involved are protected, as outlined by the Royal College of Nursing (RCN) in their guidelines (Institute, 2006). As mentioned above, ethical approval was granted to research on two NHS sites, after extensive assessments and security measures (REC no. 15.YH.0461). See Appendix C.3 for a copy of the favourable approval letter.

As this project involves persons under the care of the NHS who have a chronic illness and regularly receive care and attention from a healthcare professional, this research required full NHS Health Research Authority approval and, from each site researched, direct R&D authorisation. Guidance, indemnity and approval also had to be sought from the University of Leeds Ethical Governance department.

3.3.2.2 Importance of rapport

Good, ethical research is based on open and honest interaction to develop rapport. This involves psychological contact (Maslow, 1999; Rubin and Rubin, 2005), mutual respect and trust: truly informed consent is included here (Banister et al., 2001). The role of the researcher has been described in detail elsewhere (Section 3.2.4).

3.3.2.3 Interviewing in the patient's home

Entering a participant's home throws up a range of ethical considerations that require attention:

While it is hoped that being in their own home will add to the patient's ease and comfort in the interview situation, it is possible, however, that permitting a stranger into their home may feel challenging – especially as many of these patients may have limited mobility, which can add to their sense of vulnerability (Rubin and Rubin, 2005). The researcher was experienced and equipped to build rapport, promote safety and connect with participants in a sensitive and empathic manner. Humility and many years of research experience rendered the power differential less acute.

The researcher's risk must also be considered. The researcher enters a strange environment and, as a lone worker, must consider personal safety (Holloway and Wheeler, 2013). Thus, it was necessary to ensure that nothing lies between the researcher and the door that might impede the route out of the house, for example. Further, the researcher used telephone contact to check in with a colleague before entering the premises and agreed a time by which they must call back to report safe exit. In all such matters the University of Leeds Lone Working Policy was followed.

Safety is also a consideration in a clinic setting. In this case the researcher always ensured that a member of staff was in the building whilst an interview was in progress.

3.3.2.4 Accountability

The researcher felt accountable to the respondent, but accountability also extends to the funding or academic institution, and the NHS (Banister et al., 2001).

Above all, it is the researcher's responsibility to protect the well-being of the interviewee: humility, openness and respect are key attributes here. And these attributes must remain in the forefront of the researcher's consciousness, in order to ensure that they are offered in full measure (Rogers, 2000).

3.3.2.5 Informed consent

In this research study with patients who have a history of venous leg ulcers, only those potential participants who were deemed (by the nurses who know the individuals and their conditions) to be able to consent for themselves were included in the fieldwork. As well as providing a full explanation in an information sheet, the researcher discussed the study specification in some detail with the participants, in person, prior to interview commencing.

The issues of confidentiality and anonymity are closely related to the theme of participant protection. For example, according to the Data Protection Act, 1998, 'information obtained about a participant during an investigation is confidential unless otherwise agreed in advance' (Banister et al., 2001). Many provisions are in place to ensure participant anonymity in this study of patient perspective of compression therapy and textiles. A Covering Letter to respondents, a Patient Information Sheet and a Consent Form were prepared for respondents (Appendix D.1, D.2 and D.3). These set out the confidentiality the participant can expect.

All information collected, including electronic copies of transcripts, was anonymised and stored in encrypted protection on the University of Leeds computer system. Confidentiality extends to paper documents created in the course of this research (for example, consent forms and printouts). These were kept under lock and key until they were scanned onto the secure computer system. Paper documents were then destroyed in a confidential shredder at the University of Leeds.

3.3.2.6 Elements of well-being

As part of the management process of this project it is important to consider possible risks involved and take preventative steps where possible. In this context there was a possibility of the respondent becoming distressed in the course of the interview: living with a leg ulcer is often a challenging experience and impacts on many areas, from sleep to psychological distress. In discussing their condition, the enormity of their changed life may cause sadness/anger/grief (Biggerstaff and Thompson, 2008). While these emotions may be pre-existing psychological states for the participant, it is the discussion/interview that has evoked the experiencing of them. The

researcher is therefore accountable to the patient, at least in part. If empathic feedback, debriefing and time did not resolve the situation, the interview was to be terminated and the nursing team informed of the situation, thus signposting the participant to relevant sources of support. This had been discussed with the tissue viability teams during our briefing meetings. Advice was also sought from the researcher's supervisory team.

Time limitation for pursuing the fieldwork was another potential hazard: documentation and the necessary approvals took longer than anticipated, recruitment of one-to-one participants took time, especially as patients (or their nurses) were to contact me if they were willing or interested, rather than making direct contact with them to ask for their involvement. This is a further strategy to ensure their anonymity until such time as they are ready to assist with the research. In the event, the nursing teams proved to be excellent recruiters, and fieldwork was completed in good order and within schedule.

3.3.2.7 Debriefing

Considerable effort was made to ensure that participants had an accurate and clear understanding of the research. Moreover, the researcher undertook debriefing at the end of each interview and participants were given information regarding support services available to them – whether or not distress emerged during interview.

3.3.2.8 Research setting

Permission was sought and granted to conduct the research within two National Health Service (NHS) sites in the North of England. The tissue viability nursing teams within each NHS trust were asked to recruit potential participants, in consultation with research facilitators in each region.

While there is a trend towards treating venous leg ulceration in clinic, whenever practical, a good deal of care of venous leg ulcers still takes place in the patient's home (SIGN, 2010) and many such patients are elderly and physically limited (Ebbeskog and Ekman, 2001). It therefore seemed most acceptable for the patient to arrange most interviews at a time convenient to the participant, in their home. This might also allow greater privacy and a venue less affected by the power dynamics discussed earlier (Section 3.3.2.3). The option to be interviewed on clinic premises was also offered,

depending on the cooperation of the surgery or clinic, and some participants preferred this option.

3.4 Data collection

The research took the form of one-to-one interview or dialogue. The sessions lasted for approximately one hour and were audio recorded. Recordings were transcribed from an encrypted computer transcription facility.

No notes were taken during the interviews themselves. This was to facilitate a more conversational flow and to help put the participant at ease. Field notes, including the researcher's impressions and relevant non-verbal signals, were made immediately after leaving the interview venue. These notes included facial expression and elements of body language, description of the type of pause that occurred at any given point in interview: a pause laden with emotion as a participant struggled to hold back tears, or a pause caused by the inability to find the right word to convey precisely the right meaning.

Prior to commencing the interview, the researcher attempted to ensure that the participant was clear on the research objectives and parameters, to answer any questions posed by the potential participants, and to ensure that they fully understood their role in the research – and that of the researcher.

It was important that the researcher was confident, for the participant's sake and for the ethical conduct of the research, that a signed consent form from the participant was a true reflection of the patient's preparedness to consent. This is central to the ethical principle of respecting the participant's autonomy (Brown et al., 2004; Holloway and Wheeler, 2013). See 3.3.2: Ethical considerations. Time was also allowed after the end of the interview (and after recording had ceased) for a de-brief and potential questions from the participants.

Despite the invitation being for a one-to-one interview in a room where participant and researcher could talk uninterrupted, there were four occasions on which interviews took place with a spouse present. On two

occasions, the spouses had limited mobility themselves and could not have absented themselves without considerable effort or discomfort – or without the help of a carer. On the other two occasions, this was not the case. On these occasions, there appeared to be a slightly protective element to the spouses' presence. In all cases, the researcher underlined that it was the venous leg ulcer patient whose voice and views were being sought.

3.5 Data analysis

As already outlined (Section 3.1), the data analysis was conducted using IPA, utilising the phenomenological, hermeneutic and idiographic elements upon which it was designed. The current research followed the model proposed by Smith et al. (2009), chosen because it is an example put forward by one of the seminal designers of IPA, Jonathan Smith (1999). Whilst other writers on IPA (Colaizzi, 2002; Giorgi, 2000b; van Manen, 1990) may employ somewhat different descriptors and levels of prescriptive design for the stages of analysis they propose, they are not radically different from the ones illustrated here and most of them contain at least as much procedural latitude.

An example of one such set of stages (Table 3.2), providing a loose framework within which to work, serves as a description of the process.

Table 3.2: Framework to guide analysis procedure in IPA

Step no.	Analytic tasks
1	Unit by unit analysis of experiential data (a unit may be a word, phrase or sentence).
2	Identification of emergent patterns or themes.
3	A stage of to-ing and fro-ing between the researcher, her reflections (and bracketing), coded data and knowledge about what it might mean for the respondents to have these concerns and experiences. This, to lead to a more interpretive account of the patient's experiences
4	The development of a structure or frame with which to 'plot' relationships between themes

Step no.	Analytic tasks
5	Organisation of all the above material in a grid format to allow the analysed data to be traced from initial comments through the development process to a structure of themes
6	Review the process to test and develop further the coherence and plausibility of the interpretation (trustworthy, good fit, credibility)
7	Full narrative, detailed commentary – the writing – to describe the analytic process faithfully and as linguistically close to the original as possible, whilst being persuasive.
8	Point 7, with the addition of reflections, perceptions and phenomenology from the researcher

(adapted from Smith et al. (2009) pp. 79–80)

Analysis in the IPA traditions (and there are several) directs its analytic focus towards the person's attempt to make sense of their experiences. Analysis is an iterative and inductive cycle which includes a number of steps – each one of which may be revisited at any time (Smith et al., 1999). The prologue to these is full, verbatim transcription of each interview and immersion in the resulting text by the interviewer.

Giorgi (2011) takes issue with this procedure, as described by Smith et al. (2009). He believes phenomenological analysis should be descriptive and intuitive, and not inductive. But Pringle et al. (2011) questions whether it is possible to describe something without also interpreting it. IPA, by contrast, as described by Smith et al., (2009) stresses the interpretive and hermeneutic elements involved. Thus, there is no clear consensus of the key parameters so essential to IPA/phenomenological analysis. In this study, the focus was on the intuitive, phenomenological and hermeneutic aspects of the interview dialogue.

The challenge in the current project is to demonstrate the comparison and contrast between the strands of the different data streams, the breadth and depth of data, and to reach an understanding or 'truth' (a true reflection of the participants' views) about the data and language used (Kinsella, 2006; McCaffrey et al., 2012).

The interviews are generally analysed one-by-one in the first instance (the idiopathic focus), so that the researcher can reflect deeply and intuitively upon each respondent's experience and lifeworld meaning. The findings are then to be analysed across all participants.

Many authors have itemised what they perceive as the key stages and most then enter a caveat that declares these are not fixed in shape, order or form (Biggerstaff and Thompson, 2008; Cresswell, 2013; Smith et al., 2009). This stance is useful in exploratory research such as this, with patients who have venous leg ulcers, providing a loose framework to allow the patient freedom of expression and opportunity to lead the discussion to areas that they see as most pertinent.

The strategies for analytic process described above are broadly specified and allow considerable scope for individual creativity and insight (van Manen, 1990). Many authors agree that this breadth is necessary if any close approximation of a respondent's reality is to be achieved (Biggerstaff and Thompson, 2008; Cresswell, 2013; Sanders, 2003; Smith, 2011).

In the final steps of the process (although it can go on indefinitely), a full and iterative analysis of all data was undertaken, across cases and combining the different standpoints, ensuring all themes and ideas were captured and set in the context of a possible thematic structure (and any super-ordinate structures, should any emerge). The current research study followed the IPA analytic process as set out in Table 3.2. If this research has been conducted and written sufficiently clearly and in the spirit and principles of phenomenological methodology, something close to the patients' truth and experience will have been achieved (Brocki and Wearden, 2006; Crotty, 1998; van Manen, 1990).

The debate referred to previously, between Smith and Giorgi, on phenomenological analysis/IPA stems from the very different standpoints each researcher takes: Smith is attempting to devise a guide for the novice IPA researcher that allows the exploration in the security of a step-by-step guide; Giorgi, on the other hand, views the subject from the highly sophisticated and experienced position of someone whose phenomenological analysis has been expertly crafted over decades. He

shows little empathy with Smith et al.'s (2009) endeavour to guide the less experienced IPA researcher, when critiquing Smith et al.'s (2009) work. Such different standpoints cannot be expected to share a consensus.

As a novice IPA researcher, the framework was used to guide the steps taken in analysis, outlined in Table 3.2. It was, however, as detailed and thorough as possible, and great care was taken not to obscure the participant's values and attributions of meaning through over-interpretation or pre-assumption.

The pathways taken in this study are set out in Table 3.3 and 3.4.

Table 3.3: Analysis pathway taken for each transcript

Analysis Progress	Analysis Undertaken for Each Transcript
1	Accuracy check for transcript by audio recording
2	Immersion in transcript (minimum 3 iterations, average 5/6 iterations)
3	Addition of field notes, non-verbal signals and notes for clarity
4	Marking items of data
5	Highlighting elements of data with exploratory comments
6	Looking for the meaning behind the words – to identify, if possible, precisely what the patient meant
7	Listing emerging concepts
8	Noting language structure and linguistic formulation that might have special emphasis or significance
9	Describing context to amplify an individual's meaning
10	Noting elements of reflexivity e.g. empathic response
11	Overall check for individual frames of reference
12	Reading (several times) for comparisons and differences between transcripts

Table 3.3 shows the pathway followed on a transcript-by-transcript basis. On occasion, an extra iteration of any of these steps could take place in order to check for a point that had possibly been overlooked or to check closeness of fit, say, with another participant's narrative.

Table 3.4 Comparative analysis across transcripts

Analysis Progress	Action taken
1	Listing items of data and experimenting with meaningful groupings of data
2	Assessing volume of data, tallies and shared meaning
3	Examining emerging concepts, studying elements of homogeneity and heterogeneity of response
4	Assessing relevance of different life contexts overall and in individual experiences
5	Exclusion of data deemed less relevant to the research question
6	Developing themes and revising groupings to achieve greatest possible reflected meaning
7	Assessing themes vis a vis each individual's perceived lifeworld and the value attached to elements of their narrative
8	Developing and revising superordinate themes and subordinate themes
9	Structuring themes and subthemes to create a faithful picture of the perspectives of the sample

In the researcher's novice capacity, it was useful to follow the structure outlined by Smith et al. (2009). However, as the analysis proceeded and confidence in my knowledge of the data increased, the analysis seemed to develop a pathway of its own. It was clear which process was required next – whether it was yet another iteration of an element of analysis already undertaken or a step not specifically itemised by Smith et al. (2009) that appeared to be necessary for this research study. Item 5, above, regarding the exclusion of data is such a case (it may have been implicit in Smith et al.'s (2009) scheme but was not itemised). That said, the process of analysis undertaken in this study does, ultimately, resemble Smith's pathway, so the guide by Smith et al, (2009) works both at a practical level and an intuitive level – at least in the context of this current research.

3.5.1 Exclusion of data

In the course of analysis it became clear that the full range of information gathered, while fascinating, could not be encompassed in this thesis. It has already been highlighted (Section 2.4) that the factors affecting the

participants' perspectives of compression therapy are many, and are inter-related in a complex matrix. This made excluding data from the final analytic presentation extremely difficult. Considerable discipline was required and as strict as possible an adherence to answering the study question, with a focus on fulfilling the objectives of the research.

Thus, for example, the full detail and meaning of the participant/HCP relationship was not included as its central relevance to compression textiles and participant perspective could not always be demonstrated sufficiently strongly. Similarly, moral philosophical considerations of what can be expected of a patient in managing their condition, juxtaposed with the sometimes problematic style of nursing care offered (Katz, 2002) could not be given more than cursory exposure. Details of an individual's venous leg ulcer journey were not necessarily central factors in the individual's perception of compression products.

3.5.2 Quality measures

In this section some of the debate surrounding the issue of quality in qualitative research will be discussed, along with some of the markers of quality generally regarded as identifiers of good qualitative research and how these are evidenced in this research project.

3.5.3 Ensuring trustworthiness

Good research depends on being clear about where biases and other limitations lie and in making both procedure and interpretive reasoning as explicit and transparent as possible (Salmon, 2003). The quality of the research does not only depend on rigour, it depends on the skill of the researcher and the usefulness of the observations and interpretations made (Forshaw, 2007).

Seale (2002) agrees: he views qualitative research as a 'craft skill' and emphasises insightful thought. Both authors, however, adhere firmly to the concept of quality in qualitative research – though they are not convinced that anyone has yet established an appropriate protocol for assessing quality, despite the identification of a number of markers, such as credibility and transparency. What this attitude usefully does is remind us that good

research, qualitative or quantitative, is dependent on skill/craft/art as well as science and encourages the use of more liberal processes and procedures in the research endeavour. This may be sufficient for such experienced and skilled researchers, but it is not an attitude likely to find favour with decision-makers or those who do, indeed, adhere to a range of markers of good quality in qualitative research (Lewis et al., 2006; Malterud, 2001; Ritchie et al., 2013).

3.5.4 Markers of quality

Rather than try to force qualitative research to fit the quantitative definitions of assessment of rigour, it is suggested that 'reliability' is replaced with 'trustworthiness' and 'validity' is replaced with 'credibility' (Seale et al., 2005). These are achieved, not through statistical manipulation, but through thorough research procedures involving, for example, sufficient richness and relevance of data (Mays and Pope, 2000), inter-researcher analysis comparison, public and patient involvement (Boote et al., 2010; Mockford et al., 2012), use of an objective expert to assess method and analysis (Long and Godfrey, 2007), several passes through the analysis to check for accuracy or oversight (Mintz, 2010), and sometimes referring back to the respondents for their view on reporting accuracy (Charmaz, 2004). It may not be possible to include all these measures in every research project, however. The essential markers of quality are transparency, detailed description of process, and examination of potential bias (Malterud, 2001; Tong et al., 2007).

3.5.5 Measures taken in this research project

The objective is to understand the participants' world view and the meaning they attach to their experience, so a phenomenological methodology was chosen (Dowling, 2005; van Manen, 1990). Hermeneutic research is almost automatically included here, as the research focuses on the words, meaning and language construction of the participant. However, rather than leave this as an implicit inclusion, for the sake of transparency and to augment rigour and richness through having two analytical viewpoints (Hood, 2016), viz. phenomenology and hermeneutics, this inclusion has been made explicit (Bourgeault et al., 2010). See Section 3.1.

Interpretive phenomenological analysis was chosen as the most fitting analytical process with which to examine the data (Smith, 2011), despite the focus on subtlety and nuance that makes this analytical technique challenging. The findings from this analytic process were enriched by a hermeneutic view, as part of the phenomenological search for understanding and meaning: examining words, language construction and what implicit meaning may lie beneath the language, as well as that which is overt (Kinsella, 2006; McCaffrey et al., 2012; van Manen, 1990).

In this way, a thread of consistency (adherence to the principles and underpinnings of IPA) runs through the development of the research from initial design considerations and methodology to data handling and reporting.

3.6 Concluding thoughts

This chapter sought to describe the process by which the phenomenological methodology for the research project was chosen and to tie some of the many philosophical and scientific underpinnings together – both historical and current.

Considerable space has been devoted to the discussion of IPA: its origins, its content, its proponents and its detractors. This was necessary to unravel some of the differences in the use of language, as well as to try to do justice to complex concepts and thought processes that comprise IPA. On reflection, a well-defined nomenclature around phenomenology and IPA would advance understanding and resolution considerably, as a good deal of inconsistency in current writing emerged, upon critical examination.

The second half of the chapter was devoted to method and study design. Clear description and some thoughts on possible limitations of the design was the aim and are necessary to uphold transparency and clarity of process.

This chapter sets the scene for an examination of the participants and their worlds, set out in Chapter 4, Findings, using IPA as the 'best fit' analytic process.

Chapter 4

Findings

This chapter presents the findings from the research by foregrounding the themes and subordinate themes that emerged from the transcribed interviews in the course of analysis. Quotations from the interviews are used as appropriate to illustrate the data collected and to ensure that, as far as possible, the respondents' voices are clearly heard.

4.1 Participants

A total of 19 people was interviewed in this study, 10 from the NHS Trust A and nine from the NHS Trust B, both in the North of England. Of the 19, 11 participants were female and eight were male.

Age at time of interview ranged from 46 to 90, the mean age of the sample was 70 years. The median was 72 years. Two participants were under 60, while seven were 80 or older. Age at onset of first ulcer ranged from 15 to 88. Mean duration of living with venous leg ulceration was nearly seven and three-quarter years, the median was three and a half years. Three participants had lived with venous leg ulcers for over 25 years and at the other end of the scale, five participants had experienced venous leg ulcers for two years or less.

A short summary of this information can be found in Table 4.1.

All participants were recruited via the tissue viability nurses in each of the two NHS sites. As outlined in the previous chapter, this preserved the patient's anonymity from the principal investigator, until such time as the patient decided to help with the research.

Individual tables of potential themes and theoretical memos that were developed from the data sets (Appendix E) were collated. A master table of super-ordinate and sub-ordinate themes was developed (see Table 4.2).

Table 4.1: Participant Information

Participant	Gender		Age Range	Age	Age Range at onset of VLU	Length of time since onset of VLU
	M	F		Median Mean	Range Mean	Median Mean
n = 19	8	11	46–90	72 70.74	15–88 70	3.5 years 7.72 years

4.2 Findings

Three superordinate themes were identified:

1. Faith in Compression
2. Living with Compression
3. How Life with Compression Might be Better

The themes and subordinate themes are discussed in the sections that follow and are illustrated with the use of quotes, chosen to demonstrate the issues raised and the breadth of perspective reported by the sample. In some of these quotes square brackets are used to represent missing words from the participant or an interjection by the principal investigator. They are used to clarify meaning.

4.2.1 Theme 1: Faith in compression

This first over-arching theme and the inter-related sub-themes that follow, aim to provide a rich and illuminating insight into the lived and embodied experience of the participants. As seen in Table 4.2, Faith in Compression has a number of sub-themes and is the major phenomenon under investigation.

The concept of compression attracts both positive and negative comment from the sample. The response to the concept of compression is neither unilateral nor simple. While the sample had understood and accepted that compression therapy is the gold standard for treating their condition, their experience of compression and its attendant challenges was negative in almost all cases. The tension that these contrasting views create is

pervasive and is alluded to by participants throughout the interviews, implicitly and explicitly.

Table 4.2: Listing of superordinate and subordinate themes regarding perspectives of compression

Compression and Compression Products		
1. Faith in Compression	2. Living with Compression	3. How Life with Compression Might be Better
Compression: the paradox (beneficial but burdensome)	Footwear	Improvements to product range
Perspectives on bandages	Hygiene	Improvements to textiles
Perspectives on hosiery	Aesthetics/self-image	Autonomy vs dependence
	Social isolation/Pride/Dignity	Hope vs fear
	Emotional Response	
	Skin Quality	

The **tensions** in the participants' lives, reported throughout their narratives, seem to create an internal turbulence.

"I just used to shout all the time." R02, p34

"I get very frustrated and I have bouts of depression, which nobody really knows about. I do get very angry, very angry... very quick tempered, very sharp but... I don't want to be... it's a combination of all those things [in life]" R03, p10–p13

Like these participants, there were several references in these narratives to temper, frustration and anger. These feelings and outbursts were not necessarily aimed at anything in particular but represent evidence of that internal tension.

Many of these people alluded to attempts to reconcile the many dissonant elements associated with life under compression. The paradoxical nature of their difficulties, juxtaposed with their belief in compression caused stress

and anxiety in many and required energy to manage adequately. These are not just difficulties faced through receiving compression therapy, itself, but how to reconcile the corollaries of compression therapy with their daily lives. These are key findings in this research.

Few participants described any understanding of the **underlying pathology** which led to their venous leg ulcers (venous insufficiency). This lack of knowledge did not seem to have a negative effect on the participants' belief in, and perceived value of, compression as a necessary therapy – although unwelcome – and perhaps suggests a faith in what they have been told by medical personnel. Very few reported having 'read up' on their condition and those few who did, interestingly, had done so only when their ulcers had healed, or all but healed.

In this section, Faith in Compression, the participants' perceptions and reports have been grouped into a number of themes to cover the general conviction that compression is good for their condition and to describe the participants' relationship with compression: the benefit and the burden.

Reporting then continues with a more detailed view from participants of both compression bandaging and compression hosiery, respectively. These reports demonstrate the wide range of responses from the sample.

4.2.1.1 Compression paradoxically seen as beneficial and a burden

Belief in the benefit of compression could reasonably be supposed to bolster the participants' levels of endurance in the face of the many challenges associated with living with compression therapy. There is evidence in the data of considerable endurance, grit, determination and resilience. Whether these characteristics were pre-existing in this sample, however, or the result of faith over challenge is unknown.

Participants with venous leg ulceration reported facing many challenges. Perhaps the greatest of these was facing the treatment they received: compression therapy. They appeared to have faith in compression as the 'gold standard' treatment for their ulcers but alongside this were the many difficulties the participants associated with compression therapy.

It was acknowledged that venous leg ulcers took time to heal and that, therefore, **compression to healing** would also be a long and possibly daunting process. Finding the necessary resilience or endurance was a challenge. **Patience** was used as an example by a few. This is a learned rather than a natural asset (Reynolds and Schiffbauer, 2005; Stevens and Stephens, 2008). In this instance it represents an acceptance that healing through compression takes time and can be problematic, is just one quality seen as relevant for the individual, in order to cope:

“You’ve just got to be patient, because they’ve got to heal, but you’ve got to have the bandage on. It’s there for a reason” R07, p14

“No, it’s not problem-free [compression]... you’ve got to live with some problems, haven’t you?” R14, p23

There is little doubt expressed by the majority, as they explained the value they attached to compression. They have apparently developed belief or possibly absorbed the teaching of their HCPs that compression is the best treatment available for their venous leg ulcers. And they appear **to accept compression as necessary**:

“Yeah, yeah, I mean, obviously, that is the best. I do notice a difference, I have to say, when the bandages are on, compressing it, you know.” R17, p13–14

“It can be uncomfortable because they do have to put it on quite firm, as I say, because of the job it’s got to do.” R12, p14

“But this is, well, it’s still tight, it’s got to be, compression.” R20, p5

Thus, for these participants quoted above, compression was both a source of discomfort and pain as well as healing support and protection.

Three participants, however, felt that the **individual variation** to be found between people could mean that not everyone with venous leg ulcers will benefit from compression therapy, despite a generalised belief in compression therapy. This view was held, quite apart from any other medical considerations or anything that might be considered ‘best practice’ for this patient group, and seemed to be more to do with a holistic perspective – treating the person, not the leg. Within the quotes below was also an

apparent sense that being seen as unique and individual was important to them. R11 expressed concern, for example, about being back in compression therapy because she did not feel that this was the best solution for her particular case – and the pain associated with compression, for this participant, was felt to be intolerable:

“But I’ve always felt you cannot go by a textbook because everybody’s different... what shouldn’t happen very often does, and everybody is different so you cannot treat everybody the same – and it does worry me [being back in compression bandages]” R11, p5–6

The others also expressed views that perhaps their cases merited greater scrutiny, before opting for compression therapy. Despite this, both had agreed to be treated with compression. R04 did not adhere to treatment for very long but acknowledged that compression had improved her circulation to the point of near-healing. However, she had found the deterioration of the skin beneath the compression and swelling around the ankle made compression too problematic and uncomfortable.

“But it... I thought it quite soon became obvious that that [compression] was not for me. And this older nurse said that. She said, ‘It’s the best answer, but it’s not for everybody.’ – that was her comment.” R04, p24

R21 indicated that compression might not be the correct treatment for him, but because of an earlier spinal injury. He felt his particular circumstance might reward closer examination of treatment options. Then he generalised; he seemed to think every patient should receive closer scrutiny on the basis of their unique individual condition and circumstances.

“Because I’m sure that all conditions are unique.” R21, p3

These participants may also be reflecting a concern held by some that the treatment received for their ulcers contained elements of ‘trial-and-error’ which was disquieting for them. Perhaps they hoped for a more effective treatment from the first and, in their view, a more carefully considered solution to their individual needs.

Whether they found compression intolerable or actually quite supportive there appears to be wide acceptance among the participants that **compression promotes healing** of their ulcer(s). Many of them had had previous experience of it doing so but what their belief was based on is not known. The implication in their narratives, although oblique, seemed to be that their belief was based on information from their nurses.

“Yeah, oh well, it [compression] did [help] at first because, obviously the circulation did improve. Because everyone, as they get older, their circulations isn’t what it might be.” R04, p32

“I know they’ve got to do it to get your... your ulcers to heal up.” R01, p12

“I know they’ve got to be tight, you know, because otherwise they won’t be effective.” R21, p8

Four participants alluded to a certain **dynamism** to venous leg ulceration, almost implying that ulceration has a life of its own - one which can be hard to control:

The reference to the ulceration still being ‘alive’ is an indicative notion from R14, as well as the suggestion that once ulceration starts, with one main ulcer, others just pop up, unbidden.

“Once you’ve got that ulcer, you seem to get a few, you know, I don’t know why... a few, all round my foot... and that’s what’s still alive. It’s here [points to Achilles tendon].” R14, p12

Again, the language used by R17 (who had a long history of venous leg ulceration) would suggest there is something autonomous happening, apart from her normal bodily function; something she can sense but not control.

“I can tell when an ulcer is starting. I can feel something happening under my skin, yeah, there’s little inklings...” R17, p24

And with R06 there is a sense that ulceration just happens to her body – and the venous leg ulcer journey starts again. The concept of control (or the lack of it) will be revisited in the relevant section of Desired Improvements, Autonomy versus Dependence on page 115. There was no indication within the views expressed regarding venous leg ulcers that the body could heal

itself – it seemed to have been taken for granted that an external compression agent was required to promote healing.

“When you can look down and they’re healed – and then the next few weeks you’re looking down again at bandages and you’re thinking, ‘Here we go again.’” R06, p40

This perception of ulceration having a certain ‘life’, independent of the patient’s volition, was matched by a level of detachment from the compression itself. Compression was a phenomenon seen as being performed on the patient, an external therapeutic agent. Its application to the individual’s leg might lead to a sense of dissociation: the compression therapy and the leg beneath the compression were seen, in a few cases, as not quite part of the rest of the body.

Participants discussed living with venous leg ulcers as a prolonged process that **prevented them from living life** as they would wish. And, as with the people quoted above, discussing the life of ulcers, these participants implied that the ulceration was out of their control, it was happening to their bodies, like an external entity that caused many problems:

Here, the participant referred to the disruptive element of being in compression therapy and the irritation it caused him, in his attempt to live and function normally. Participant R03 had a very long ulcer history and had rarely, if ever, been free of ulceration, despite dedication to his compression therapy

“I hadn’t got any ulcers on the right leg, but it didn’t take too long before I started developing ulcers in my right leg: all it takes is a knock or a break of the skin... once again, I went to the doctors, the nurses were dressing them [with compression bandages] and, in all honesty, I was getting sick – I was really sick of going backwards and forwards, backwards and forwards [swinging arms from side to side to demonstrate the repetitive motion].” R03, p4

The participant, R12, seemed quite worn down by both her ulcer history and by compression. The healing process had been accompanied by many setbacks. Despite being very tearful, however, she clearly accepted the

dissonance between her deep dislike of compression bandaging and the creed of compression being effective therapy.

“It is, it is awful, but then again it’s [compression bandaging] the whole point of it healing up. It’s the only thing they know, at the moment, that does the healing process...” R12, p44

Participant R17 had known little respite from venous leg ulceration in over 20 years and from the beginning of this long process had experienced significant problems with compression therapy.

“I did usually have that full bandaging, which was absolutely terrible because... I had three [children] under two... I’ve always had a problem with water retention... as soon as they used to put the bandages on, they were down... I was like Norah Batty walking around...I was young so I hated that.” R17, p2–3

Escaping from compression, even temporarily, was noted by five people as a great relief. This serves to underline how difficult they found it to endure.

R07 and R12 offer an image of relaxing, however briefly, when compression is removed. There is a great sense of release and freedom in their reports.

“The best part about it is when they take that off and put your foot in that bucket and wash it. It’s heaven! I could sit there all day.” R07, p25

“And it’s like when a woman takes her corsets off and you think , ‘Phew, let it all hang out!’” R07, p37

“I take it off to release my leg... so you can let your leg breathe... let it relax.” R12, p21–22

However, R13 reported feeling vulnerable without compression. Even the short hour of ‘release’ during a stocking change left him uneasy.

“T’other week, she, my wife, washes my legs and greases them up and my daughter comes and puts the stockings on. And they were off for about an hour and me wife said, ‘Do you feel better with them off?’ I said, ‘ No, I don’t, I feel vulnerable with them off’.” R13, p13

In contrast to those who catalogue the difficulties of wearing compression and describing their struggle to cope with compression on a daily basis, four participants described relatively **benign venous leg ulcer experiences**. These contrasting perspectives on compression serve to emphasise how differently individuals within the sample responded to compression. They seem to have gained some control of their condition with comparative ease. The treatment they received seemed to suit them well and one participant use the word 'comfortable' to describe their compression. This is a strong word to use in the context of compression where so many found it so difficult to tolerate.

"And when they took the bandages off it was dry. It was. It was really good, people couldn't believe..." R09, p3

"They feel quite comfortable, actually, underneath, aye. This is... when it's moist, so comfortable... it's lovely." R13, p6

"It's since I've been onto this Actico. It's been a lot more comfortable. The leg and the pain and everything about it has been a lot more controlled and not half as bothering." R22, p32

Although in one case this level of 'comfort' also indicated a short and uncomplicated ulcer journey, this was not so for the others. The reasons why some experienced so much less distress and inconvenience than the majority is not known.

Pain was generally associated with venous leg ulceration, even among those who seemed given to understatement and those who portrayed themselves as stoical. There are two main types of pain regarded as relevant in venous leg ulcers. The first is nociceptive pain, where the stimulus and response are directly related, for example, a venous leg ulcer and pain at the site of the ulcer. For the most part it was pain attributed to the ulcer that was described, although not everyone experienced this type of pain.

“... [long pause] the pain’s the worst thing. The pain’s the worst thing – drives you up the wall!... Yeah, it actually is that. You’re aching all the time. It’s like a toothache only it’s worse than a toothache... I’ve had toothache. It’s worse than toothache, if you get two or three ulcers on your leg.” R14, p22

The second type of pain is neuropathic pain, where there is no apparent, direct relationship between stimulus and response. However, in this instance, the participants quoted below were of the opinion that this pain was due to compression – and it is the patient’s ‘truth’ that is central here.. Five participants reported being unable to tolerate compression and this was often associated with what they called ‘nerve pain’. This was seen as quite distinct from ulcer pain or pain from tight bandaging (although this type of pain was also in evidence) or, indeed, pain from dressings, as in the experience of, for example, silver nitrate.

It appears to the participants to be compression that brings this nerve pain on. In addition, three of the five who made direct report of this nerve pain also described onset occurring when they were lying quietly, at rest.

As illustrated by the two quotes from R07, this ‘nerve pain’ was quite difficult to describe: it was pain (and excruciating) but it wasn’t pain; it was a stinging sensation yet it throbbed; it was described as intermittent:

“And the only other problem – and they can’t answer it – is when I... when you go to... it could be stinging. But when you go to bed you’re flat. Then it starts stinging, and you think, ‘Why is it like that?’ Why is the flow... sometimes you could feel it: push, push... And I think, ‘There’s something not ...’ I felt as though I wanted to hang it from the ceiling ‘cos I was in so much pain. Well, stinging more than pain; it’s not a pain that you get.” R07, p16

“It’s never been pain, it’s always been stinging. I would sit and it would [make me] jump and [nurse] used to say... well, other nurses too... she used to say, ‘It could be the nerve endings, that’s inside those.’ And I thought, ‘It’s stinging all the time!’” R07, p6

These quotes below underline that for these participants this pain was due to compression

“I’ve tried everything [therapy] that they’ve said – except the compression one... and it... I couldn’t stand it... it’s been very, very tender all the time... it’s like someone sticking a thousand needles in me,” R10, p2–6

Interestingly, the experience of this participant, R10, was that his right leg could not tolerate compression whilst his left leg could.

For participant R11, the re-introduction of compression therapy had renewed the pain she associated with such treatment. She found it intolerable and was hoping a different form of compression might suit her better – a product called JuxtaCure was the focus of her hopes.

“But the pressure [compression] bandage is now starting to cause problems again... I’ve been in awful nerve pain. It’s not a tolerable pain but it’s sporadic.” R11, p5

R16 always slept in his hosiery and it was clear to him that the hosiery was the source of his night pain.

“I had trouble with pain in my foot so it wasn’t a good night... Well, the other thing about it which I find surprising is when I’m moving about, it isn’t nearly as bad as when I’m stationary... when I’m stationary, I’ll get a shoot of pain that goes through it, every now and again.” R16, p37

The association of this type of pain with lying quietly, at rest, may possibly be explained by the gateway theory of pain, where pain is experienced more intensely because there are fewer distractions to mask the sensation.

Whether this was the case for these participants or not, their perception was that of pain generated by compression.

That so many participants referred to pain of some form or another could indicate that the pain experienced by people with venous leg ulcers is poorly controlled, no matter what the genesis of the pain might be. Their reported experiences also indicate that pain is an important contributor to loss of well-being (e.g. disrupted sleep, as described by R16). Great value is attached to the diminution or relief of pain. This is important because if the pain could be

better controlled, acceptance of and adherence to compression therapy might be greater yet.

4.2.1.2 Patient perspectives on bandages

A range of comments specific to compression bandaging were made, as distinct from compression hosiery. Because bandages and hosiery are experienced rather differently by people within the sample, these two product forms have been discussed separately.

Several of the participants talked about experiencing different types and layers of compression bandage. These were often incidental mentions as they described different time-points and stages in their venous leg ulcer journey. They may have started their venous leg ulcer journey with four-layer bandaging, like R02, and then gone on to other formulations of compression as their ulcers changed. There was also a reported tendency for the number of layers of compression to decrease as their ulcers improved.

“Well, apart from owt else you’ve got four lots of bandages to put on – you can imagine your foot [makes expanding gesture] I hated the four-layer bandages for that reason... So, when the three-layer bandages came out I thought, ‘Oh, thank God for that!’... they weren’t as bulky – but they were still quite bulky. It’s down to two layers now... and then you’ve got compression hosiery... and that’s very good...” R03, p19–20

However, in the case of R02, he regarded his change from four-layer to two-layer bandaging by the district nurses previously, as having been premature. This was prior to being seen at a Tissue Viability Clinic where four-layer compression was again instigated.

“Like, the two-layer, like, didn’t really make a difference but, like, the 4-layers have, like. Since I’ve been in four-layers they’re coming alright, aye.” R02, p7

Four participants explained that they had been in compression for so long (or had known compression long ago) that they could see improvements in the quality of bandages over the years. Despite their far-reaching, comparative memories of compression bandaging, and a certain gratitude

that products had improved over time, neither of the participants quoted above seemed to find their current place in the leg ulcer journey any easier or less disruptive as a result, than other participants with a less extensive ulcer history. R03 expressed anger on several occasions and this emotion was almost tangible in the room as the interview went on – his long experience of ulceration and compression had taxed him greatly. Participant R12, on the other hand, was very prone to tears and seemed to be exhausted by the venous leg ulcer journey she had been on, even though this episode of ulceration had been of relatively short duration. She had found the demands of wearing compression very difficult to accommodate whilst trying to live and function normally.

“At the time [30–40 years ago], the dressings [bandages] weren’t all that good because they were very heavy and very thick. It was a bandage called a blue-line bandage. And they used to bandage us right up to the top of me groin: from the foot right up to the top of the groin. And, obviously, what used to happen, as soon as you stood up, the bandages slid down. The material was that thick and heavy and bulky.” R03, p2

“They are different from when I had my ulcer on my ankle before [circa 20 years ago], because this top bandage is a blue line, it has a blue line on it. They have to do like a figure of eight for the compression in the leg...it’s not uncomfortable, but this top layer bandage – it used to be a brown, like a darky pink bandage... so there is a difference in what they’re using.” R12, p17–18

Issues with compression bandaging were reported as being numerous. There were quite marked emotional responses to compression bandaging; R01 provides a singular and extreme example (see below) as she described her sense of being ‘unclean’, perhaps contaminated in some way. These feelings were reported to focus on the compression bandaging for which she had experienced a deep aversion.

“I just felt unclean. I just felt as if I was like a leper. Yeah, it was just awful. And then having to go every two/three days to have them bandaged. And having them taken off... Alright, I know they had to do it – they were weeping and that, and that was the only way they could do it to get them to draw together but it’s... it’s...it’s... [lost for words].” R01, p5

In contrast, R09 described an ulcer journey and her compression therapy as both short and trouble-free. These two participants illustrate the wide range of response to their experiences with compression.

While problems related to skin will be covered in detail in Section 4.2.3, it is worth noting here that some of the problems were specific to compression bandaging. **Skin problems** caused by bandaging were reported, as illustrated by R07 and R11:

“And it stretches [the skin] – and there’s no stretch in it [the compression bandaging] – and that’s when you feel it pulling. And, I mean, this one hurts [leg with hosiery] but not as much as the one with compression bandaging on, cos it’s so tight.” R07, p12

“It’s the pressure [compression] bandages that cause me problems because they riffle and the ruffles go into the skin... make ridges and break the skin, you see... The doctor I saw about my leg at the hospital said, ‘If it was put on properly it wouldn’t riffle.’ But it has been on properly by five different nurses... it’s just my leg for some reason. And the ruffles go into the skin – which the skin is compromised anyway – and causes it to break out all over.” R11, p1–2

A sense of being **hampered by compression bandaging**, either physically, or in terms of mobility, or by way of apparel, was described by five people in the sample and similar numbers referred to the inconvenience of appointments for bandage change. These appointments were not easily obtained and not all nurses were permitted to undertake bandage change. If those nurses were unavailable, the appointment and journey were seen as wasted. In the quote below, compression bandaging is seen to hamper the participant in two different ways; it limits what she can wear and it causes

delays in getting appointments with a nurse because not all nurses have been trained to administer her particular compression product.

“Yeah, they’re so restrictive in what I can do and what I can wear and things. And, I mean, even getting appointments, it’s always been a problem getting appointments at the doctors and the nurse...” R17, p18

The need for regular bandage change by an HCP was also reported. Several participants reported that, at some stage in their ulcer journey, they had three bandage changes in a week. This bound the participants to their HCP and/or surgery, reduced their independence and was seen as a substantial disruption in everyday life. Planning events, appointments other than with the nurse and holidays became untenable. The issue of autonomy versus dependence will be addressed in more detail on page 115, however it is clear that such limitations on daily life, social life and recreational activities were seen as deleterious.

“Handicapped. Very much so. I mean, I was so independent... It is a handicap, after being so... you know, doing everything myself.” R20, p13

“It affects the whole family... the kids have missed out on holidays and things like that, you know, because we couldn’t get away. If you’ve got nurses coming in three times a week, where could you go on holiday?” R06, p40

4.2.1.3 Patient Perspectives on Hosiery

For most, coming out of bandaging and into hosiery was seen not just a **mark of healing progress**, but conveyed relief and, with it, a sense of release. Whether this sense of relief reflected a stage of physical near-healing (bringing with it less discomfort and mobility issues) or an emotional response to a different form of compression (perhaps seen as symbolic) is not known.

“All right, because I could wash my leg again properly. Aye, because they’re going all scabby and flaky, like, my legs, with being dry.” R02, p8

"I don't notice it so much now, but when I first started wearing these I did feel as though my legs felt lighter... or should I say just less heavy. So I was sort of walking around with a, you know, a new spring in my step." R05, p5

But there were a number who felt hosiery was also **restrictive and made daily function difficult**.

"They're awkward, like. You can't go swimming and owt like that, you have to keep your legs [in compression] dry. You're still wearing stockings on the beach, you know, this sort of thing. But you have to put up with things. But they're not bad." R14, p24

Making big efforts to live life fully and function normally, the participant below was alarmed at the notion of any new development that might move him out of hosiery and into something else. Changing the status quo did not seem to be acceptable. He spoke emphatically:

"I wouldn't want to try anything else apart from what I've got on now [hosiery], I'm happy with the way things are now." R03, p27

This participant expended a great deal of emotional and physical energy on maintaining a daily (and busy) function that was as close to normal as possible. The above response illustrates how precarious the balance of his control might be.

Even if hosiery was prescribed for a few before complete healing had taken place, **hosiery represented the 'forever change'** for the participants. Apparently, this was not an entirely pleasant thought:

"And that's why you have to keep wearing them. I just accept the fact now, that if I've got to wear them, I've got to wear them. I don't mind wearing the stocking. It's just the compression bandaging I don't want." R01, p18

"Well, I think when the skin has healed and that ulcer has gone... when the skin has healed, I think they will suggest elasticated stockings and I'll have to have that, probably, forever more. And they're very tight." R11, p22

But two participants reported that felt undressed and vulnerable without the support of their compression hosiery. They seemed undaunted by the idea of wearing compression hosiery ‘forever’:

“To be honest, now, if I don’t wear me stockings, I feel naked.” R01, p18

Hosiery was reported as **very difficult to manage** by seven participants – both putting them on and taking them off were seen as challenging activities. The very characteristic that makes compression hosiery effective, the strength of compression exerted, also represents one of the major drawbacks. Among the participants were those who had arthritic hands or diabetic neuropathy in their hands which made the task even more difficult. And even those without such co-morbidities admitted to needing help on occasion.

“And when I first went in to stockings, I mean, he [husband] used to help me to get them on... I presume people, when they’re older, have help to do it. ‘Cos you’ve got to be fairly... you’ve got to be able to do this that and the other... ‘cos they’re quite strong.” R01, p19

“They do come in the right size but as they’re new, when you first get them, as I say, they’re difficult to get on... Because I’ve got arthritis in my fingers now, and I can’t grip – sometimes I can’t grip – and I’m trying to pull it on round me... on me foot first, then pull it up to my lower ankle, lower leg, and then pull it up to here – because they still go from the toe to the knee as well ... [puffs and looks exasperated]. [Do you get very frustrated?] Yes, I do. Yeah! But it’s just one of those things I have to wear while I’m working.” R12, p21

Opinion on **aids to don compression hosiery** was divided. On the one hand, R11 reported that the product supplied made a difficult job easy:

“I’ve tried them and they’re very tight... They’ve given me a steel contraption which makes them easy – because they’re very difficult to get on – and they’re very simple with this contraption.” R11, p22

However, R16 was not so happy with the device provided for him, although he seemed to recognise that help with hosiery was useful (see quotes

below). Apparently, the product came with its own set of problems. In fact, when thinking of improvements he would like to see (Section 4.2.3.1: Desired Improvements), R16 wanted a donning device that was easier to use.

“There’s a device for putting them on, but it’s not easy... But it’s just one of those difficulties you’ve got to deal with. And so, I’m on compression stockings.” R16, p3–4

Looking ahead, R16 was dreading the day when he could not manage the stockings himself. Inconvenience, and the need to be available at set times, added to his distaste (and the threat to his dignity) for the possible future:

“...but so pulling this thing on can be a bit of a struggle. I dread the time when I might not be able to do it. ‘Cos if anybody has to come and do it, it’s going to be a real pain!” R16, p28

Most of the participants who had reported difficulties in managing to wear their hosiery claimed to have found their own solutions to this problem, rather than relying on the various pieces of equipment or advice supplied to help them. For one or two the solution seemed almost to represent a secret victory and the participants for whom this was the case did not appear to wish to share the precise nature of the solution:

“I’m OK, I have found a way [wry smile]...Yeah, there are certain ways to do it...I have my own way of doing it... but to fair, the nurses have shown me decent ways, and they’ve shown me things that might be helpful. But I found, because they’re tight, it is awkward – I’m not saying it isn’t awkward. It’s awkward but, because I’ve got quite a bit of upper body strength, I can really [makes vigorous pulling gesture]...” R21, p10

Among other solutions, talcum powder was reported to be useful, as was a long shoehorn:

“I thought, ‘I’m going to try a different way’, so now I put talcum powder on, talcum powder on my foot, all round me ankle and the bottom part of me leg and the stocking behaves very much better with that... It’s a learning curve with these things, you know, yeah.”
R16, p27–28

“It’s surprising what you can do with a long... a long shoehorn. It was getting that off that was the trouble, couldn’t get under the heel... but eventually, I learned – shoehorn it! Yeah. [Solutions] I know, but it’s finding the ways and how long it takes you to find those ways... No, it’s not always easy.” R22, p32

Finding these solutions was apparently not a simple matter, and it was implied that the solutions took time to discover and develop into useful coping strategies. They were valued as a source of satisfaction.

Four participants mentioned that **hosiery off-the-shelf** presented challenges and was seen as potentially damaging to what was regarded as already-fragile skin. Standardised sizing of stockings, even with an extensive range of different sizes and variations available, apparently did not provide a good fit for all. For example, R02 had a particularly wide foot and therefore the off-the-shelf stocking had a tendency to bunch up over his toes, creating ridges which dug into the skin:

“He [the Tissue Viability Nurse] thinks it’s because the stockings are made like that, like. They give us, like, a pre-packed one and, like, me foot’s, like, wide. So they’re going to try us on, like, specially made ones, or something, made-to-measure ones.” R02, p10

R21 experienced a similar problem:

“[Open-toed stocking] The only issue I have with it is that it can roll back and it sometimes rolls back in the night, and that’s a bit of an issue... it’s a bit painful there [top of foot]... it does, sometimes of a night, get uncomfortable, you know... I’ve taken it off.” R21, p5, p8

Despite being a recognised leg shape, this participant (below) reported problems with ill-fitting hosiery:

“And, of course, your leg goes a very funny shape. I mean, my legs are swollen at the moment because I do have arthritis, as well, which doesn’t help [rueful laughter]. So my ankles are really small, and then... it comes up like a table leg (I think they call them that) – but I have even had special ones made up and they’ve still not been any different.” R17, p8

Just below the knee was another reported problem area for fitting hosiery. Whether the stocking was too long or the area below the knee was unusually fleshy, the risk to the area was identified by a few as being sufficient to cause new ulcers due to the skin damage caused:

“The problem is when things start cutting in [at the top], That’s when you get another ulcer because it cuts and then maybe it’s like a normal cut for a week or something, but then it [ulcer] just pops up and that.” R06, p12

Even among those few who knew of the existence of made-to-measure compression and had **made-to-measure stockings**, hosiery was not necessarily trouble free – or even a perfect fit. As well as requiring a large number of measurements (and detailed precision was required in these measurements), made-to-measure hosiery did not always arrive as ordered. As well as being a source of frustration when such things happened, it also created a substantial lag-time for new hosiery to arrive:

“They were ordering the next lot of stockings – and I’m holding me... crossing me fingers that they’ll get it right... the last lot that were ordered... [laughs] the left hand one came up to here! [showing a point on the thigh] The other one was the right length... Now these things are made in Switzerland, it takes six working days... Well, I mean, I don’t want them to come up to here [thigh]. I mean, it’s far enough to come up to there [just below the knee] because they’re not easy to deal with, you know.” R16, p7

And even when no error was made in measuring, nor in filling the order for the bespoke hosiery, the resulting product was still not necessarily a good fit:

“When you get your stockings you do get measured up, I mean, these are some standard ones that they do, but they do measure you and then they have all different sizes, but I have even had special ones made up and they’ve still not been any different [cutting into leg below knee].” R17, p8

It would seem that the top of the bespoke stocking, just below the knee, was often the problem – as with the off-the shelf products. A fleshy or swollen leg around the knee area could cause the stocking top to bite into the leg or roll down slightly and thereby tighten at the top. This caused pain and in a few instances was blamed for degradation of the skin where a ridge was created or, at worst, the eruption of new ulceration.

Still with made-to-measure hosiery, one participant talked about the challenge presented by thigh-length hosiery, and this could be seen as an extension of the off-the-shelf problem identified with knee-highs. With apparently stocky thighs, this participant had experienced the hosiery rolling down the leg, becoming tighter as it did so. Ridges in the skin and considerable pain ensued:

“So these are the thigh-length and these were about £20. So this is Class 2 thigh length, but I’ve got to say they’re just like a tourniquet on my thigh... they were really tight. I mean, I have got quite chunky legs, but...and then they were rolling down a little bit. And the more they rolled down, the tighter it became, so it was almost unbearable.” R05, p9

This same participant reported that she had also been provided with bespoke compression tights. Some of the problems experienced echo those above regarding the extensive number of measurements required and the time taken to receive the bespoke garments.

“So these tights come from Sweden [label says Switzerland] and they’re made-to-measure, completely made-to-measure. What a right faff we had to get them! But I did get a prescription from my GP to get these because they cost £200 a pair.” R05, p11

She had also discovered that while putting the tights on was arduous, taking them off was a completely different level of difficulty and the method was

quite different from what she would employ with normal tights. Thus, her attempts ended with the tights getting 'stuck'. Had she not had a member of the family staying with her who was able to help, she reported that she would have panicked. With the knowledge acquired on this first attempt to wear compression tights, the participant had successfully worn them (and taken them off) on a few occasions since.

And, as well as the issues listed above, there were some other issues mentioned by one or two participants each. **Caring for compression hosiery** was seen as troublesome, as described by R07, and was regarded as adding to the many inconveniences to be dealt with in daily life.

"Well, your feet's sweating and you can only hand wash them – can't put them in the washer with softener, cos the softener take the elastic out of them...So I wash them by hand and drip them." R07, p25

Only one participant, R12, described hosiery as potentially tighter than compression bandaging.

"I don't... I must admit, I don't like wearing them, because they can be tighter than these actual dressings [compression bandages]." R12, p20

Her perspective demonstrates the range of opinion to be found in the sample from this current piece of research.

In contrast to the extensive range of problems reported with hosiery, above, about **half the sample offered no complaint** about compression stockings. The majority of the sample seemed to prefer hosiery to bandages; they regarded compression hosiery favourably and generally found them much more user-friendly than bandages, though not perfect, and still holding most participants back from full, normal function.

4.2.2 Theme 2: Impact of compression on everyday life

This is the second, overarching theme identified from the data and analytic process. It refers to the participants' struggle to function relatively normally. For some, normal function was seen as impossible; for one or two others, daily function was met at huge emotional or physical cost; for the majority a

compromise seems to have been reached – not a comfortable compromise, perhaps, but one seen as workable.

Attempts by the participants to comply with and take part in their venous leg ulcer therapy were apparently seen at one end of an important spectrum. Getting through day-to-day living was often seen as being at the other end of that spectrum; linked but often in opposition. There may be a pattern here: In the participants' perception, trying to live life and adhere to therapy were generally in marked contrast to one another.

For example, six participants reported **acts of non-adherence** to compression at some point in their venous leg ulcer journey. These acts were about reducing pain, promoting sleep, increasing mobility, going on holiday and so on. In other words, these acts of non-adherence were seen to promote getting on with life – and in most cases the participants seemed to be well aware that their actions ran counter to the objectives of compression therapy and ulcer healing. These behaviours might perhaps be viewed as mal-adaptive coping strategies.

Thinking about how it felt to listen to these participants as they described such instances in interview, this seemed to be more about making a difficult decision between two irreconcilable objectives at a specific moment in time than an act designed to be non-adherent, non-compliant or hostile to therapy in any way. These were occasions upon which the objective of healing was cast aside to facilitate comfort or the smoother running of everyday life.

“I went away on holiday again... It was nearly healed up before I went away. Nearly, not quite...I was changing the dressings every other day, myself, but with the heat... it just didn't heal. It was getting a bit worser, so I couldn't do anything about it while I was away.”

R12, p2

“I was in agony, but you see I got the scissors, didn't I? And I got into trouble, cos I cut that bit off – just that bit.” R07, p21

There are several sub-themes in this section on how the participants view their life with compression. These follow:

4.2.2.1 Footwear and compression therapy

One of the major inconveniences of compression therapy, particularly with bandages, as portrayed by the participants, was not being to wear ordinary shoes, difficulty in finding footwear that fits well and, in the participants' mind, was not too aesthetically displeasing.

As several participants indicated, the footwear challenges affect daily function as well as being an irritant.

"It's difficult to a certain extent 'cos you've got these bandages on, so there's only certain footwear you can wear, 'cos your feet are too big for anything else – so you couldn't go out in your high heels and goodness knows what else." R01, p12

"I hated four-layer bandages for that reason; I couldn't wear shoes, I couldn't wear boots and for about three months at a time you were wearing bloody four-layer bandages and a slipper! [spoken in anger]." R03, p19

"[slipper on right foot] That's all I can get on. I've got the right one to that one [pointing to sandaled left foot], but I can't get that on. I can't wear it. I've tried it, it's too... it won't fasten." R20, p9–10

Four respondents spoke of the cost involved in footwear to accommodate compression bandages. These people seemed to imply that the cost of footwear needed when in compression should be met by the NHS. The reasoning seemed to be that since compression therapy created the need for different and differing footwear, this was, by extension, also part of the treatment.

In one case, a participant suggested that the NHS should have a ready-made selection of footwear where bulky compression or swelling of the leg/foot precluded the patient's own shoes or shoe being worn. It was implied that lack of provision of appropriate, well-fitted footwear should be addressed. If a range of alternative footwear was readily available – or at least if the facility for shoe-fitting was routinely available, one of the bigger problems associated with trying to function normally, in compression, would be solved.

“I’ve had to get new slip-ons, but the girl at the Tessa says, ‘Well, I don’t know whether you could ask at the health [NHS] for shoes.’ People do have big fat feet, don’t they, and they have to have proper boots and shoes made, don’t they? ‘There is a place where you can get these proper Cosy Feet. But, she says, they’re dear’, I says, ‘Oh, I cannot cope with that.’ ...But if it rained I was snookered because what they’d give us was one of them great big black boots. I couldn’t walk, I kept tripping over the toe... So I was putting a plastic bag on my foot before I put my sandal on, if it was raining... My feet were cold so I had to get slippers... different slippers, different shoes...”
R07, p10–11

By contrast to the large number complaining about difficulties with footwear, R09 reports having experienced none of these difficulties:

“I had a pair of sandals, believe it or not, and I wore them out, and that was that.” R09, p11

Her experience of compression, overall, was brief and unproblematic, and this experience serves to demonstrate the wide range of perspectives to be found in a sample of 19.

4.2.2.2 Difficulties with hygiene in compression

Hygiene was raised as a troublesome issue by about half the sample. They talked about not being able to have a bath, for example; not having the opportunity to relax into a good soak and not being able to enjoy the cleansing process: this was felt to be a considerable loss. The issue of hygiene was portrayed as being about more than the practical need for cleanliness. It was seen to be about well-being and the good feeling of being clean. The issue of hygiene seemed to be an added burden in the load most participants felt they carried in order to accommodate compression bandages and hosiery in their lives – although with hosiery there was, at least, the option of removing them, providing the respondent was able to put them on again, after washing their legs.

“But you couldn’t have a soak in the bath, you couldn’t sit back and you couldn’t do this [stretches out, leaning backwards expansively]. You could just have a quick shower and not get... cos you couldn’t get these bandages wet! Which was another thing that was a bit... [heavy sigh, long pause, seems lost for words].” R01, p21

“Yeah, getting in the bath, yeah, I will look forward to that, definitely.” R12, p23

The participant quoted below illustrates the degree of pleasure felt when a bath is possible and perhaps highlights the level of loss felt by R01 and R12.

“It’s a really good feeling when you’ve got everything nice and clean on your leg. And it’s lovely, because you go from a, from being in the bath, getting all the dead skin crap off and putting new crisp dressings on and everything’s nicey-nice, then I go to a nice comfy bed and that’s it.” R03, p23

Seven participants referred to products available to protect bandages and hosiery from becoming wet, albeit in the shower rather than a bath – or they described adapting ordinary plastic shopping bags for the purpose. Five reported using these protective products but they were not generally regarded as part of the well-being factor in getting clean. They may have had a practical purpose but they were apparently not much liked.

“Terrible! Because, like, you’ve got to, like, put plastic things over your legs to get washed and, like, you’re hurrying to get washed in case the plastic things leak in, so you cannot enjoy getting washed or nowt.” R02, p5–6

The other half of the sample made little or no mention of issues with hygiene and seemed not to feel the loss and inconvenience described by participants above. It cannot be assumed that there was no issue at all with this sub-sample, but it can be inferred, perhaps, that among all the other challenges they faced on a daily basis, practical issues with hygiene were not so noteworthy. Possibly there was a reticence about discussing such matters.

4.2.2.3 Aesthetics and self-image in compression

Alongside the inconvenience of compression and the difficulties of obtaining appropriate footwear, aesthetic concerns were highlighted by five participants. There is evidence in this research to suggest that the way people project themselves and the way they wish to be perceived by others is a subjective matter but involves practical, physical appearance to a marked degree. These projections may be influenced by altered body image. Poorly adapted footwear, bulky compression, matters of hygiene (possibly odour and exudate) could all contribute to and contaminate a person's attitude to social interaction. The aesthetics relate both to the social situation and to the personal image of self.

R02 felt the frustration of ill-fitting footwear, imposed by the bulk of his compression bandaging. And this became an added source of self-consciousness for the participant. It reportedly added to his self-imposed social isolation when his ulcers were at their worst.

"I've got trainers. That's what I've said, like, I've had to buy a bigger pair than what I am – just to get the bandages in... I just feel like Coco the Clown in them, aye. Like, I know that they're too big for us but wor lass [my wife] says, like, they look all right – but I know that they're too big for us." R02, p33

Satisfactory self-grooming, apparel and appearance, and an acceptable body image would appear to be inter-related among the participants in this study. This was discussed both by male and female participants. It is perhaps more the case with the female participants than the male, on the basis that a few female participants, who would wear skirts for preference, also mentioned feeling compelled to wear trousers whilst in compression, in addition to all the other issues reported. Participant R01 found the bulkiness of compression bandaging left her feeling less feminine and in some way contaminated. She also demonstrated the perception of cleanliness in a more metaphorical sense. The very presence of compression bandaging negatively altered her image of self (unclean and leprous) and she seems to have felt rather lonely. However, she later stated that despite feeling isolated and 'unclean' she continued with an active social life, work – which involved

being on her feet for eight hours a day – and care of two large dogs. Her feelings did not prevent her from leading a relatively normal daily function.

“I know they’ve got to do it [compression bandaging] to get your ulcers to heal up but, in my opinion, somebody must be able to invent something more woman-friendly [chuckles].” R01, p20

That said, the sense of yearning expressed by R01 during her interview was at least as strong as that portrayed by those referring to their desire for better hygiene and ‘a good soak’:

“I just felt unclean. I just felt as if I was like a leper. Yeah, it was just awful... you just felt like a leper, you just felt as if you’d been isolated from everything...” R01, p5

Although R01 directs her intense focus on compression bandages, it may be that she is, at least in part, reacting to the ulceration. Perhaps unconsciously, such negative focus on her ulcers would be too close to her person and therefore unacceptable in some way: she would be rejecting her own body. Safer then to direct her emotional response to an external object perhaps – the compression bandaging.

Appearance and apparel were reported to be relevant to hosiery products, too. While one or two female participants dismissed the notion of any concern with physical appearance at all, six others expressed dissatisfaction with the way in which compression stockings imposed on what they wore:

“The problem is when you are wearing these knee-highs [compression hosiery], when you’re wearing these you’re very limited in... I’m not a woman who wears trousers. I don’t suit them, so I always have skirts, so I have to wear a skirt that’s long enough to cover the gap.” R05, p4

“So for the funeral [husband’s], instead of putting a skirt on, they said to put trousers on, cos it covered my legs and my foot issues up [shakes head and looks mournful]. I’ve got them, but I’d rather have skirts. But I do wear trousers.” R08, p5

Among male respondents too, evidence of a shaken body image, plus a wish to disassociate themselves from their ulcers can be found:

"[I felt] that I was scruffy because I wasn't getting washed as, like, regular as I was used to... I knew, like, it wasn't me smelling, it was, like, the ulcers but there was nowt that I could do about it." R02, p33

Interesting language is used by R02: firstly he describes a self-conscious distaste for his 'scruffy' image; the second sentence in this quote demonstrates dissociation from his ulcerous leg, 'It wasn't me smelling'.

With R10 the dissociation is much clearer. He would rather like to amputate the offending leg, remove it altogether. Despite the moderate language used, the desire he expresses may be viewed as an extreme measure in an otherwise passive and sedentary life, and perhaps exposes the level of his depression/low mood. Also, a body image with half a leg removed would probably require some adjustment of self-image.

"[Problem with sensitivity of right leg to compression] Yes, other than take it off from here [indicates a cut just below the knee... [you desire this?] Yes, I am... [depressing?] It is a bit, yes." R10, p15

4.2.2.4 Social isolation/pride/dignity

Compression was reported by some participants to limit social activity – mostly through self-imposed isolation – based on fear, embarrassment or emotional exhaustion, for example. The change in behaviour described below, R02 attributes to the more effective compression therapy provided by the local Tissue Viability Team and the concomitant reduction in levels of pain experienced. He was put back into four-layer compression (from two-layer) and received more frequent review and bandage change. Dietary improvements were made, the participant was persuaded to give up drinking and he was asked to exercise more and more regularly. He was quickly less reliant on opiates for pain relief and became much more active and alert.

"[Social life?] Didn't have one; never went out... Normally, like, I'm up at the crack of dawn. And, like, when I was under the district nurses I was just lying in bed nearly all day – just couldn't be bothered. But, like, I'm out all the time now and cracking on." R02, p16/17

In order to prevent total self-isolation R07 fashioned two different thicknesses of shin pad to supplement the compression therapy she wore,

seemingly deeming her compression bandaging inadequate to protect her from a possible knock.

“But after that big ulcer I was frightened to go out.” R07, p12

To R12 the greatest embarrassment of the odorous compression bandaging was that her husband had felt impelled to mention it. And her reported response demonstrates both defiance and helplessness. This kind of paradox of opposing feelings was not uncommon among the sample in their juggling to make healing and daily function co-exist.

“It was very embarrassing for it to... even my husband said, ‘Ooooh, your dressing’s a bit odoury!’, you know. So it’s, ‘Well, I can’t help that until I’ve got it changed again!’.” R12, p2

For the participant below, as well as an element of social embarrassment, the main issue was a practical one – to be near his compression products at all times:

“I tend not to – parties – things like that. Now, I never stop over. I like to get home because that’s where all my stuff is... It will always be that way. I’ll never be free of that.” R03, p23

One or two individuals, however, did seem to manage to continue to function and to carry on with their social and familial roles despite the challenges of their condition and compression therapy.

“Oh, yeah. I managed. You just get on. You just coped... They do say to rest as much as possible, when you’ve got leg ulcers – but you’ve got no chance; not when you’ve got two dogs and you’re working, you know...” R01, p9

R01 habitually wore jeans and felt confident that the compression bandages were hidden from view – even though she mourned her high heels during her time in compression bandaging. This seems to have enabled her to function to near-normal capacity, despite her loathing of the compression therapy.

R22 was almost 80 and his walking was a little curtailed (by breathlessness) but he (and his wife) testified to his endurance and uncomplaining determination to get better, strengthened by his belief in the healing capacity of his current compression.

“I think you can tell by [the fact] that – it’s not often I complain. I don’t complain, I just get on with life.” R22, p28

This relatively normal functioning, while reported as achievable, usually came at a cost. In particular, two participants described a daily routine which was not just full and busy but, perhaps, reflected a marked self-sufficiency alongside the emotional burden they said compression inflicted on them. Participant R03, for example, pushed himself hard on a daily basis to maintain his patriarchal role. His self-image, pride and sense of dignity seemed to require it of him. He seemed much older than his years and admitted elsewhere to being extremely tired – these impressions from the interview session might be due to the large amount of energy he had to expend in his efforts to fulfil what he saw as his central, patriarchal role:

“A lot of people still depend on us, even though I mightn’t be in a workplace, sort of, like. It all comes through me. There’s still a lot of people depending on us: the grandbairns, the daughter, the son, the wife – because that’s what I do, I’m sort of like the main man within our family and everything sort of, like, comes through me. I organise things and that’s what I do, you know.” R03, p18

R01 was singular in her emotional perception that compression bandaging isolated her, set her apart, yet she also reported that her social life was rarely disrupted during her time in compression bandaging:

“You just felt like a leper, you just felt as if you’d been isolated from everything. Even though nobody knew you’d done it. In my opinion, that’s how I felt... Sort of, I was on my own; there was only me like that... I don’t suppose I stopped... I mean, I didn’t stop taking the dogs out. And we didn’t stop going to see friends.” R01, p5–6

Thus, the paradox of living life and ulcer healing, seen in many reports from this sample, was extended to the psychological sense of isolation for this

participant, while her reality was a fairly normal and active social life, even during compression bandaging.

Pride and dignity were expressed by four participants and implied by a few more (as seen in Section 4.2.2.4). This seemed to be linked to thinking about others as well as putting on a brave face.

“I’ve no regrets about owt, really... I would regret it if my wife couldn’t go anywhere because of me – that’d devastate me.” R13, p16

“But I’m still alive and kicking and here to help you, so I’m happy.” R03, p11

“Well, I mean, I’m more than happy to be helpful because I know, in the long run, it’s got to be helpful, not just for myself, down the line, but other people down the line.” R21, p22

Four expressed the opinion that they should not complain too much because other people had worse problems. This seemed to lend power to their dignified mien:

“But as bad as things might seem for me, it’s still a lot better than what a lot of poor souls put up with.” R03, p23

“There’s people worse off than me.” R07. p23

“I just, but I’m not trying to moan because I’ve been satisfied with my life and, whereas lots of me mates have gone, I’m still here.” R14, p23

And six participants expressed concern for those who were less physically capable than they were – particularly those older than them or more handicapped by co-morbidities:

“But they’re such a struggle for me. I have arthritis. I mean, I really don’t know how older people cope with the stockings, it’s really, really difficult to get them on. So I’ve tried all sorts of things that they give you to help... and the nurses struggle, putting them on, it’s really embarrassing, you know, watching them puffing and panting trying to get these stockings on.” R17, p3

“That’s another point, you know, if you had arthritis in your hands... I don’t think people could put them on, to be fair. I wouldn’t like to say to somebody old, ‘Look after yourself!’, you know... with an older person that was... had difficulties, you know. I would much prefer them to see a nurse, to have a nurse put them on, really.” R21, p10–11

The pride and dignity, the positive attitude to their situation in comparison to others and the consideration given to others (illustrated above) may provide a useful start in a search for markers of internalised locus of control in this patient population, when further investigated. This is beyond the scope of this exploratory study.

4.2.2.5 Emotional response

The range of emotional response to compression therapy varied widely: from expressions of discontent and frustration that seemed to directly relate to inconvenience or malfunction of elements of the participants’ condition and circumstance, to extreme expressions of psychological distress that might be seen as considerable cause for concern.

The language used to describe distress by participants in this sample illustrates that the compression bandaging (bandaging, in particular) could cause a symbolic, subjective sensation of being encased, trapped, set apart or contaminated – whatever the physical reality of the situation. This finding requires further research to develop a clearer understanding of this phenomenon and the symbolic values attached to compression bandaging.

Discontent and low mood was widespread. Very few escaped a negative emotional response to receiving compression therapy. The dissonance between participants’ feelings towards their compression therapy and their belief in compression, as the best means of healing their ulcers, is marked. The word ‘depression’ and descriptions illustrative of low mood were regular features of the dialogues with participants, as they discussed their difficulties of living with compression products during the period of venous leg ulceration. There is a sense in the quotes below of a certain need to show strength, perhaps generated by a sense of pride or the need to disguise the level of affect felt, even in recalling low points in their ulcer journeys.

“I got quite weepy at one time – not depressed – but weepy with, I think, thinking, ‘There’s no end to this’ and, ‘Does anybody understand?’ or, ‘Do they think I’m making this up?’” [the pain due to compression] R11, p14

“I get upset about it, as you can see [starts to cry]... because it’s taking such a long time to heal [note of desperation]... I’m OK with it now [voice wobbles] I know I’ve got to put up with it [compression] until it’s healed; maybe another couple of months.” R12, p5, p18

It is important to acknowledge here that it is unclear whether the emotions described above have their origins in the ulcer journey itself or their response to compression – or both. When prompted to clarify this, participants seemed unable to do so. What is clear is that the emotional response to their experiences is for some profound and for others less severe.

Others took a more robust view and acknowledged the times of low mood they had experienced in a matter-of-fact way, not showing distress but describing some parts of their journey as depressing. Three participants spoke of annoyance and anger rather than depression. Such energetic emotions can often disguise a sense of fear. However, in this sample, fear was an affect more often expressed when considering the future and the uncertainty of that future, rather than when looking back at the ulcer journey to date.

In Section 4.2.1.1 there are reports of pain of various kinds as a common feature in these participants’ lives. It has its effect on mood, also. They explained that they experienced discomfort and inconvenience of many kinds including: pain from compression, discomfort from skin being stretched by the bandage, enforced immobility from bulkiness of bandaging, poorly adapted footwear and frustration at the difficulty of trying to get on with life. In consequence, the participants’ mood was not generally one of cheerfulness and content. These more measured descriptions of mood tend to illustrate the situations and frustrations that characterise the participants’ perceptions of their lifeworld as they struggle with the functional difficulty of daily living.

“Because it’s so tight it affects your whole body... [Trapped?] yeah, it’s being stuck inside that... like being inside a box, that’s what it feels like.” R07, p38–39

“When everything’s rosy in the garden your body seems to heal, but as soon as you put yourself under stress or you’re in a stressful situation your body just deteriorates.” R03, p7

“Aah, there are worse things to have, I suppose, but it does get you down because it’s just going on and on and on and on.” R11, p25

The variation in the levels of discontent or depression naturally varied as individual differences between participants were illustrated and there were those who experienced an **extreme emotional response to compression**. The deeper levels of emotional response to leg ulcers and compression were clearly expressed by six participants. These appear to be qualitatively different from the less forceful descriptions of negative feelings set out above. Suicide ideation and the desire to remove the affected limb were described among this group. R01 was notable in the sample as the one who conceived a total loathing of bandaging. Hosiery was, on the other hand, quite acceptable.

“But it is one of the most degrading and depressing things to ever have had done to your legs, I think. It’s awful. If I had to wear [compression] bandages for ever and a day... I don’t know what I’d do. I’d probably have shot myself by now. They are awful!” R01, p5, p8

Restricted mobility from bandaging and the exhaustion of extreme pain (and opiates) had brought this participant, R02, to the point of wishing to remove the problem through amputation. He may never have got to that point but confessing to such thoughts indicates the depth of his distress.

“I wanted to get me legs took off an’ that. Like, I thought that it’d be better to get them took off... I felt like I couldn’t do nowt, at the beginning, but now I’m starting to get out.” R02, p18–19

This participant, R03, was not yet 60 but looked and sounded much older than his years – perhaps in testimony to how hard he had worked to maintain near-normal function and how emotionally drained he sometimes felt.

“And it’s the one thing people can’t take away from you is your pride. Eh, it was endless [voice slightly choked]... Just, I just felt sick of the same old thing [compression] and I couldn’t see my leg getting any better and I felt as though... It was horrible! I was sick of people doing things for us [bandage change]. I’m a proud man... [long pause]... [Maintain dignity somehow?] Well, that’s it! I felt as if I was losing all of that, you know, so I thought the world would be a better place if I’m not around. People would be able to get on better, they don’t have to look after me ...” R03, p28

Another example of a participant’s distress comes from R20 whose language was gentle and whose mode of expression was consistently moderate – on tape. Before recording had started, R20 exclaimed, by way of introduction to her theme, that her ulcer journey and particularly the compression bandaging was ‘a new form of torture’. By the standards of the rest of her interview, this was an extreme phrase for this participant to use. When reminded of this of this phrase, the slightly apologetic response was:

“Well, it’s just... you know... [voice wobbles] You can’t help it!” R20, p10–11

Dissociation with the ulcerous limb appeared occasionally and can be seen as another extreme expression of distress. While these particular dissociative reactions relate more to the ulcerations, they clearly illustrate levels of distress. The participants did not readily distinguish between their ulcers and their compression. In their lives it seemed that often ‘ulcers = compression’.

“... I don’t know, I just feel as if I’ve got a wooden leg.” R07, p40

“I feel like taking it off and throwing it away... [You said you wish the leg was not a part of you] That’s right, yes. From under the knee, downwards.” R10, p7–8

“I wanted it to be over there [far corner of the room] and not a part of me. But, err...” R01, p16

Notably, one of the 19 participants claimed to have experienced no pain and no problems and no social limitations – a marked contrast to the majority and a good illustration of the wide range of perspectives described within the sample. She acknowledged that she had been very lucky in her leg ulcer journey. The brief period of venous leg ulceration and compression therapy had troubled her remarkably little and seemed to leave no psychological scars:

“I’ve never had any pain.” R09, p10

“She said, ‘Just come back.’ So I never went, because I never did have any discomfort.” R09, p13

“I said, ‘I’m going out today. I’m going to play boules.’... It was fine. Yeah, I never, ever sat down.” R09, p14–15

Her husband reminded her, however, that on four occasions the compression bandaging had been too tight and he had been obliged to cut the bandage to ease the pressure. The reminder was a genuine surprise to the participant, albeit agreeing that this had indeed happened. It would seem that her particularly sunny and optimistic disposition had caused her to forget any discomfort and unpleasantness associated with her brief and successfully healed venous leg ulcer experience. This is perhaps an example of how influential mind set and attitude can be as a marker in the journey towards ulcer healing. Alternatively, perhaps the meticulous care she reported having received from the French medical system and the warm support she said she experienced from her holiday community during the first three to four weeks of her venous leg ulcer journey and the attentiveness of her spouse, throughout, had contributed in large measure to her general sense of well-being and thus promoted healing.

4.2.2.6 Skin quality

The negative effect of compression on the skin of the lower leg was perceived as, at once, an inevitable concomitant of compression and a

source of concern not always satisfactorily addressed or acknowledged by HCPs.

Seven participants avowed the importance of caring for their skin under compression. Many issues were talked about; from poor skin quality possibly leading to ulceration, through finding the emollient that best suited them and their allergies/sensitivities, to how these issues could be better addressed.

The quality of the skin of the lower leg, overall, occupied the minds of nine of the participants. The condition of their skin was a matter of concern:

“Because the leg was losing all of its moisture and it was very, very dry. And with the dryness and the swelling it was cracking – and that was creating places where more germs could get in and your ulcers could get worse.” R03, p6

The participants did not generally distinguish between changes in skin quality due to:

- the underlying pathology
- the formation of venous leg ulcers themselves
- skin changes as a result of compression bandaging/hosiery
- changes as a result of sensitivities or allergies (although sensitivities and allergies were mentioned by several).

There was little evidence to suggest that more than a few participants understood the underlying pathology of their venous ulceration. Their concern was with the evidence before them. Underlining the importance of looking after the skin beneath the bandage, R04, rather indignantly reported,

“The compression stayed on and my leg was scalded by the effluent.” R04, p2

So even when she was adhering to therapy and moisturising her leg, damage was still being done to her skin.

And respondent R07 reported a different, challenging concern relating to the sensation of pressure on the skin:

“When you’ve had an ulcer the... the skin on your leg, there’s no give in it, you know... Well, there’s no give, so when you’ve got this bandage on, it’s pulling all the time, when I bend over – even when I Hoover I can feel that pulling there [gestures to calf area] – more so when you’ve got the bandage on cos the bandage is so tight. It’s such a relief with a stocking.” R07, p8

Although not explicitly discussed, the interviewer was given the impression that these participants, despite routine moisturising by the HCP, in bandage change for example, felt it was up to them to take charge of their skin beneath the compression. This was not a task reported to have been laid on them by the HCP but one they had identified for themselves.

“So you end up doing everything yourself and you don’t bother with the nurses...but two days into that [four day space between bandage change] I had to take the dressings [compression bandages] off because it [exudate] had come through, go in the bath, wash me leg down, moisturise me leg with some Aqueous cream or something like that, and then go and see the nurse.” R03, p15–17

There was a certain unease about this element of care, and it is possible that this stems from reportedly experiencing ‘trial-and-error’ on the part of the HCP in finding the most effective dressing or emollient for a particular patient. It is also possible that they felt unheard when voicing their concerns related to the health of their skin.

The identification of sensitivities/allergies in compression may represent an issue that could benefit from further attention. As part of the sample’s preoccupation with skin quality, many reported allergic reactions which they perceived to be due to dressings and bandaging/hosiery products. These may have been allergies; they may also have been sensitivities to a variety of dressings and compression products. This issue had contributed to the element of ‘trial-and-error’ reported upon negatively by some participants. The participants tend not to distinguish between those reactions caused by compression and those caused by dressings – they all take place under the compression.

“Cos, I mean, you know, some people are like me, they’re allergic to different stuff, to whatever they use.” R07, p34

The search by nurses to find dressings and emollients to which patients showed no sensitivity was not believed to follow any set plan with regard to allergies and the like. The report from R17 seems to bear this out, talking about a long period of search to find an appropriate emollient. Perhaps further research might lead to guidelines in this regard, helping HCPs with guidance on what to avoid when faced with certain sensitivities or allergies.

“Yes, I’m allergic to a lot of things, I’ve had a lot of allergic reactions to dressings and stuff like that. I have the simplest things on and it’s took a long time to find the right cream, you know, for moisturising - because, obviously, your legs get very dry and stuff, and that doesn’t help.” R17, p5

Participant R04, below, indicated elsewhere in the interview that her nurses had never asked whether she had any pre-existing skin conditions and when the psoriasis came to light, there was no change in communication or prescribing as a result. The information was apparently scarcely marked, adding to the participant’s anger and frustration.

“Chunky bits, full layers [of skin falling off]... And I said sort of half way through all this... when I was getting a bit irate... ‘I have psoriasis, could that affect it?’ and the answer was, ‘Yes, it might’.” R04, p8

While this section describes reactions mostly to dressings and emollients rather than compression products themselves, the importance of the skin under the compression was at the heart of the matter. Anything that adversely affected the skin under compression was worrying to the participants and added to the fragility of the skin’s integrity.

Patient involvement in caring for skin under compression from this sample would appear to be universal. The majority of participants in this research were clear on the importance of skin care for the leg under compression – from both themselves and their nurses. Frequency of applying an emollient might be daily, if the patient was in charge of

moisturising the skin, to once or twice a week, when a nurse was to change bandages.

“It...[seems lost for words] if I can explain it: it looks crinkled, it looks old and decrepit...[dry?] I think so. But they do cream it.” R10, p18

“I think you’ll find the skin’s going to be delicate on it... I moisturise that every day... It’s just a moisturising cream” R22, p16, p18

Two participants were frustrated by the logistics: they would wish to moisturise daily but the need to wait for the HCP to have dressing and bandage changed made this impossible:

“When I used to go to the doctor’s surgery they never washed my leg down, they just used to get a saline solution, you know, wipe it down – and they never put cream on – that was down to me to put cream on. How am I going to put cream on when I’ve got a dressing [bandage] there?! So, obviously, the dressing had to come off, so I was having to re-dress [re-bandage] it myself!” R03, p17

R21 suggested that skin care products might be packaged together with bandages/hosiery to promote regular use of skin care, to underline the importance of moisturising and to ensure that appropriate moisturiser was made available.

Notably, again, participant R09 reported feeling no sense of burden or frustration during her three-month ulcer journey, including a short period of skin care:

“Oh yes! I rubbed a bit on – that’s just moisturising cream [on scar tissue]... and that was it.” R09, p13

This was another area of R09’s perception of compression therapy and venous leg ulceration where her experience seems to have been trouble-free. Again, this participant provides a useful illustration of the breadth of perspective, even though she, too, moisturised the leg under compression.

4.2.3 Theme 3: How life with compression might be better

It was important in this research to try to elicit participants' views on how compression and compression textiles might be improved. The wide-ranging responses are detailed in Section 4.2.3.1 Desired Improvements.

4.2.3.1 Desired improvements

There were suggestions for improvement, helpfully offered, that the patients felt might make living with a venous leg ulcer condition a little easier. However, not everyone interviewed felt able to think of improvements: it seems that for six participants, compression, as it had been presented to them, was the only form of therapy they could envisage and would always be necessary. Prompting and plenty of time to think did not elicit spontaneous ideas from these participants. Creative invention is perhaps not in everybody's repertoire.

"[Improvement?] Well, no, not if it's going to do its job. They have to be like that, don't they?" R08, p7

"Well, I think it is [the best they can do]. How else?" R22, p31

However, these participants did wish for improvements; they seemed to wish for those they regarded as more knowledgeable than they to develop something better:

"I just think... I just think if there is any research to be done, somebody needs to research on something nicer than that. Because it's just horrendous!" R01, p4

Later in the dialogue R01 did generate some ideas for improvements but, when the prompt for improvements was first made, she was almost tongue-tied and still focusing on the horror she had recalled feeling on her first encounter with compression bandaging.

There was a strong sense that **medical knowledge** should have advanced further than compression therapy in its current forms.

“Even though it is [the best we’ve got], we need some bright lads to think of something else... I don’t... I’ve no idea... but they’re not... you’d think – You think of something different! [turning on the interviewer with a command] – Some brain could think of something different than these... but that’s what it is – compression.” R20, p17, p24

Eleven participants did describe ideas for improvement. These were often offered tentatively, accompanied by a deprecating gesture, as if they did not expect their suggestion to be heeded.

“Oh, that’d be grand [zip closure]... I doubt they’re going to do it but it’d be wonderful.” R13, p20

In a couple of instances, the improvements suggested referred to items that already existed. This can perhaps be seen as a lack of information being communicated to the individual concerned about what is available. It may reflect on the quality of care being offered. Or perhaps the interview was the first occasion upon which the participant had ever discussed such concepts.

As can be seen from Table 4.3, a wide range of different suggestions were put forward, from a zip function and the use of Velcro:

“It’s a shame they can’t just pop you into something...’There you go... [gesturing an upwards zipping motion], you’re done!” R01, p25

“I suppose you could have Velcro, cos these bandages stick to each other like Velcro, anyhow – yeah, yeah, you have to invent something and then make a load of money.” R01, p25

...to the NHS providing a range of footwear at bandaging appointments in order to accommodate increased bulk around the foot (or feet) due to bandaging:

“I think they should find something else better than that, because, you see, they put the big bandage on and I didn’t have no shoes that would fit so she had to give us one of them to go home. And I thought they’re just horrible and clumsy and I thought, ‘Well, surely they’ve got something else at hand... have you seen them black boots before!?’” R07, p35

Table 4.3: Desired improvements

Desired Improvements	Tally
Compression products – not attributed to product type	
Something better – nothing concrete suggested	3
More 21 st century – in line with medical/technological advances in other fields	3
A zip-up version – for ease, comfort and autonomy	3
A Velcro version – to be done by the patient	1
Greater comfort – less tight	1
Better colour range – flesh colour not liked	1
Kinder to skin - no chafing/pulling	1
Provide an emollient with the compression product – a complete package	1
A product that senses change to diameter of leg – an ‘intelligent’ compression textile	1
Compression Hosiery	
Better applicators – less difficult to use	4
Tailor-made – the fit of hosiery seen as a problem	3
Machine washable – rather than having to hand wash	2
Can be dried in machine – not permitted	2
Retains compression strength – does not loosen	2
Non-snagging, does not ladder – does not lose power	2
Suitable for fabric conditioner – to soften	1
Many pairs supplied at a time – easier to keep clean	1
Better fabrics (e.g. no chafing) – new textiles	1
Compression Bandages	
Something that allows patient to apply bandage	3
NHS to provide appropriate footwear	2
More ‘woman-friendly’ – felt de-womaned	1
Better cotton wool layer – no chafing or sensitivity	1
Remove tough selvage – can dig in to flesh	1
Different combinations of bandages for greater comfort – too tight with full layers	1

Desired Improvements	Tally
Other Suggestions	
Leg coverings for showering – patient ignorant of these	1
Something to place on ulcer that cures – not compression, a panacea dressing or plaster	1
Provision of Care – spontaneously offered	
Continuity of care – highly valued	7
Better organisation – nurses liked but organisation derided	2
Improvement to level of care – more thought for person	2
Guidelines for nurses –appropriate compression for different patient types	1

Implied by the participants in many of these responses is the desire to be able to apply compression themselves, and to **become more independent**, to save them from relying on a nurse, or on a schedule, and providing greater opportunity, for example, to clean themselves regularly. The concept of autonomy will be discussed in more detail in on page 115.

“You need something the elderly or those with arthritic hands can manage to don and doff by themselves.” R05, p15

“That you could do the bandaging yourself ‘cos at least then you could do it yourself or learn your partner to do it. You could, like, get washed and that, regular. It’s just the fact that, like, you’re only, like, getting your leg washed twice a week.” R02, p39

“Could I do the dressings myself? (which I have done occasionally) Because that would help, not having to go down to the surgery twice a week – it used to be three times a week...” R11, p29

R21 was particularly engaged in thinking of improvements that might be useful; from the development of new treatment guidelines for HCPs to providing emollients in the same package as compression products. The notable element to his contributions was that his thinking encompassed ideas that might be of use to others. He wanted his considered ideas to benefit HCPs, those with co-morbidities other than his own, the cost of venous leg ulceration to the NHS and manufacturers – with an idea for a

new product formulation from manufacturers (which could extend the profitability of a certain product range). His thoughtful contributions were aimed at managing the condition and treatment better across many of the actors involved in the venous leg ulcer arena. These responses were of a different order to the other contributions, from other participants, in their range and depth. This is also the reason why they are presented in detail.

“Guidelines so they can be more certain of the treatments they’re giving – definite treatments – a definitive treatment, rather than try this, try that, try the other, you know. If you can say, ‘Right, we know this is what you want.’ Instead of the, ‘Oh, we’ll try this, see if it works, try that see if it works...’.” R21, p6

“...if they ever ladder, get rid of them because there’s no... the strength goes then [compression is compromised?] Yeah, exactly. So there’s that to look at: I’m sure there’s different fabrics that they can have, you know, different things to look at.” R21, p8

“[Made to measure] Yeah, I mean that would... that... you see, would be really good for me, Because I don’t walk, don’t use the legs like you normally would - I put weight on the toes. So the calf muscle, there’s a lot of wastage on the calf...” R21, p9

“So maybe there might be a fabric that you can just put in the washer... That would be quite nice because there’s bits of stocking all over. I know it’s not a big issue but, you know... It’s quite something if you can just...” R21, p11

“You might have to... use a cream with it, so that it can be sold along with the stockings: it’s not just a separate product... Yeah, job done, everything’s done in one packet.” R21, p24

In the text that follows, the issues raised by the sample, both explicitly and implicitly, regarding the management of their ulcers and compression therapy are explored. There were important indicators that **autonomy versus dependence and the locus of control** displayed by participants pointed to relationship issues between the individual and their context.

The participants' perspective varied widely, from those who had become expert in their venous leg ulcers and how best to manage the treatment of their condition to those who seemed to personify learned helplessness and a passive attitude to their ulcer management. The majority of people with venous leg ulcers in this research had a substantial venous ulcer journey to report and, over time, most of these participants had acquired expertise in their condition, for example, in helpful and harmful applications of their treatment and in the difference between holistic and perfunctory care.

A level of expertise, however, did not necessarily mean that a participant was also engaged in the treatment of their condition. A few respondents perceived the locus of control as residing with the nurses involved in their care. This participant (R20) displays vague understanding of some pathology in the leg but is unsure whether the pain she is suffering is indeed from an ulcer or the bandaging. Several times in the interview she suggested that her carers could provide information; she could not. There was no concern expressed about this lack of information and was happy to have the locus of control reside with 'the girls'.

"But all the troubles are still inside the leg... I'm not quite sure what it is. I think it's [the pain] more the – if it is an ulcer. I don't know exactly what it is..." R20, p1

The language used by this participant (R12) is telling: she is not 'allowed' to take the bandage off and if she does 'mess about with it' damage will be done. This latter excerpt conjures up a pejorative image of an inexperienced, botched attempt to adjust a bandage.

"I'm not allowed to take it off until – because it's all healing process, if I mess about with it and take it off, it's not going to, you know, it's not going to heal. I have to have it on two to three days until I have it changed again." R12, p16

Very often, though, the participant portrayed both knowledge and an engaged level of internalised locus of control. This quote below illustrates a patient who can feel whether bandages are being applied correctly and will say so to the HCP. This assertiveness suggests a confidence in her own knowledge and her willingness to manage her treatment with the HCP.

“There’s two or three that can do it properly... but then some of the other ones! ... I say ‘It’s too tight’ - and other times ‘It’s too slack’ – you can feel it slipping and it shouldn’t be doing that.” R06, p21

After decades of venous leg ulceration, this patient (R03) chose to take control of the application of the compression on his leg for the most part. Even when a district nurse was to apply the bandaging he is ‘getting the district nurse to do it’ – it was his decision.

“But all I know is that for, I’d say, most of the time, 75% of the time, I was dressing the wound myself, you know. The other 25%... 23% I was getting the district nurse to do it, and the other 2% was the Tissue Viability Nurses, you know.” R03, p16

R03 appeared quite philosophical about the advantage of being in control and behaving in a controlled and measured way. Perhaps this perception was part of a coping strategy:

“I think tidiness is part and parcel of doing your leg and your dressings, organising how you look after your body – and that seems to go on to your social and domestic life, you know. You run your life like that, you know... well, that’s me.” R03, p34

The effect of the knowledge and expertise acquired, among some, was often to adhere to advice and guidance from their nurse. Participant R12 had sufficient understanding of the reasons for advice given to her to follow it, because it made sense.

“I have to put my foot up on a cushion, to keep it a little bit high up, for the blood flow. That’s why the dressings [compression bandages] are on. It’s all to do with the blood flow in the leg... and, obviously, the healing of the ankle.” R12, p7

Thinking like an expert is essentially down to the patient’s attributes and when the patient describes a determined approach, the authority would seem to lie with the patient within the context of this sample:

“Erm, and, I mean, to be fair, they were being very careful [laughs slightly apologetically] because once I had gone... Well, actually, I’d sent for the nurse to do it again – because I’d said, ‘That’s awful’... And then after that they were very good.” R04, p17

It is perhaps useful to note that this participant (R04) was redoubtable and clearly used to being in command.

An internalised locus of control might, by contrast, lead to instances of non-adherence. For example, making the decision to remove parts or all of a compression bandage when its effect became unendurable to the individual:

[Taken it off?] “Sometimes, yeah. Sometimes I think, ‘Oh, it’s too sore round me ankle!’. And I’ve told the nurses, when I go to see them, that I’ve had to release it... excuse me [post tears gulp] – I just put it on [again] tight but not too tight...” R12, p15

...or rejecting compression bandaging on the objective basis that the ulcers are healing and on the subjective basis that the participant could not face bandaging at that time. This participant was virtually autonomous; she knew her body well, she had several co-morbidities to manage, in addition to many years of venous leg ulceration, and managed her body and her ulcers herself:

“I just thought I cannot face having them bandages on again. So I’ve put myself in stockings at the moment, you know, I would say... I’m not supposed to, but, I mean, they are healing... I’ve had them that long, so I know what to do with them myself, you know, I know what signs and stuff to look out for.” R17, p3

Or rejecting further compression altogether, despite having being fully aware of the risk of recurrence without continued compression:

“I have a pair of elastic [compression] stockings in the wardrobe somewhere for which I was measured – because apparently my leg was longer than the normal ... Well, I mean, no way, no way! And then a bit later they said, ‘Are you going to take these home?’ and I said, ‘Yes, I’ll take them home.’ But nobody ever suggested I had to put them on. I think they [laughs]... you know, they thought, ‘She’ll just shout at me if I say that’.” R04, p13

Only three participants displayed a lack of engagement with, interest in or knowledge of their ulceration and treatment.

“What else can you do? Nothing, really, is there? Just have to wait till they get better [slightly nervous laugh] – and pray it’s quick.” R08, p15

In the case of R06 this felt more like philosophical acceptance. This participant had lived with venous ulceration for over 25 years at the time of interview:

“But you’ve just got to put up with it, like, the ulcers. Nothing you can do unless you cut your leg off – and I wouldn’t do that.” R06, p38

One participant stood out as particularly helpless. The locus of control was, it seemed, entirely external and resided with the nurses. R10 seemed almost to be in stasis, just waiting, passively. The participant seemed rather vague about the cause of the underlying pathology and did not appear to participate in the management of the venous leg ulcers.

“I just have to bear it... until it improves itself... nothing I can do really, I’m in the hands of the nurses and that, so [shrugs]...” R10, p27–28

A number of other medical problems and the respondent’s age may have contributed to his exhaustion of hope and learned helplessness, however, other respondents with fairly similar physical profiles presented more positive attitudes to their condition and their future.

4.2.3.2 Hope vs fear

Hope, even among those displaying learned helplessness and passivity, was generally evident in some form. The hope generally centred around

compression therapy healing their legs. Hope might be accompanied by faith in compression, faith in the beneficence of their HCPs, determination to heal or acceptance of their lot and the belief that they were better placed than many other unfortunates.

“Because after a few weeks, when you keep going, they kept saying, ‘Yeah. That’s doing nicely and it’s definitely getting smaller and now you can see the granulation.’ And you start thinking, ‘Well, yes, it [compression] is working.” R01, p20

There was hope that they would come out of ‘heavy’ compression, even though many realised that venous ulceration indicated a forever change that would ideally see the participants in compression, probably hosiery, for the rest of their lives.

“Well, I hope that eventually the layers will decrease.” R10, p17

“Once it has healed though...I will have to carry on wearing compression stockings... Because, myself, I don’t want them breaking out again.” R12, p38

While hope was found to be a marker of venous leg ulcer patients in Reich-Schupke et al.’s (2009) sample – and was also frequently expressed by the participants in this current study – fear was also evident in the current research sample. This fear took a variety of forms. For example, fear of complaining lest they be ‘punished’ for doing so:

“Well, they’re very close, these nurses, you don’t want to go upsetting them.” R06, p20

I don’t want them to think I’m a grumpy old piece of work. You know, blacken me name... but there wasn’t just me complaining...” R07, p29

Fear of never healing was reported and this fear, for two participants, went very deep. For instance, R01 found the thought of never healing so upsetting that it seemed necessary to lighten the impact of her words with laughter:

“I had... I had visions of being stuck like this, of having to go and get my leg bandaged forever.” R01, p6

As she spoke her voice began to tremble, she laughed as if to lighten her own emotional response and then reddened. R06 shared a similar fear:

“I’ll still have them, because once I get on my feet, they will start and break down again... It’s a fear I’ll not get out again... Yeah, and that’s a horrible feeling.” R06, p22

4.3 Summing up

To conclude the chapter, many issues and challenges were faced by the participants with venous leg ulcers, to which they attached substantial meaning and importance. These have been drawn out of each individual narrative and collated in this chapter. They form the main findings of this research.

While several participants displayed behaviours indicative of competent self-management with a number of successful coping strategies, balancing everyday functioning and the objective of ulcer healing took its toll of the majority of participants.

Throughout this chapter the problems described by substantial numbers of people in the sample have also been balanced with evidence of participants who reported relatively problem-free leg ulcer journeys, who found compression tolerable and whose ulcers healed within a relatively short space of time. Perhaps the majority of these latter participants’ venous leg ulcer journeys were not as problem-free as participant R09 professed and would have registered at least one extreme moment, but they had coped well with the advent of venous leg ulcers and the ramifications of those ulcers. It was noticeable, as well, that when asked about what meaning they attached to the future, the sample responded with hope. Most expected their ulcer to heal and they looked forward to a much more normal and active life. A few had more modest aims but all responded positively.

The focus of this research is compression therapy and therefore much of the rich data from these respondents has not been covered because their narratives were often about the ulcer journey rather than compression per se. In these out-takes there is much that confirms previous research.

It appeared to be very difficult for the participants to confine their thinking to compression and there may have been a need to tell the researcher about the ulcer journey as well as their thoughts on compression. Certainly, despite repeated prompts to return the focus to compression, the conversation would regularly veer towards a totality of experience with venous leg ulcers.

Chapter 5

Discussion

The title for this research study is: The Patient's Perspective of Compression Textiles for Venous Leg Ulcer Treatment: an in-depth qualitative study. The research question was: What is the patient's experience and perspective of compression therapy?

5.1 Summary of main findings

1. There was widespread acceptance in the sample that compression therapy is beneficial in treating venous leg ulcers. Even those who were unsure that compression therapy was the best option for them and their specific case acknowledge that compression was the best available treatment for venous leg ulcers overall. From Theme 1, Table 4.2.
2. Many negative aspects of compression therapy were raised in the course of the interviews, regarding both bandages and hosiery. The participants raised such issues as bulky bandaging, the pain of compression, difficulty in applying hosiery and damage to skin caused by compression garments. From Theme 1, Table 4.2.
3. Negative emotional response to compression was a prominent issue. This ranged from expressions of low mood, experienced occasionally, to suicide ideation and a desire to mutilate the affected leg, reported by a few on particular occasions. The connection between negative emotional response and compression therapy was not universal and the venous leg ulceration also had an effect on mood – not least because of the pain caused. However, within this current sample there were individuals who responded with extreme distress to compression bandaging being applied to the leg. From Theme 2, Table 4.2.
4. Specific practical issues were of concern. Among them, finding acceptable, useable footwear was seen as a frustrating difficulty. Considerable irritation was expressed around issues of hygiene, and how these issues damaged self-image and well-being. Fitting daily living around appointments and bandage change was also seen as problematic – to the point where a few had not felt able to take holidays for some

years due to the need to be regularly re-banded. From Theme 2, Table 4.2.

5. The difficulty of coping with compression therapy in day to day life creates a tension, sometimes a paradox – where the objective of healing ulcers and coping with everyday life collide. This costs the patient time and energy. From Theme 2, Table 4.2.
6. Social interaction was seen as problematic: mostly, this was related to compression but physical issues such as odour and exudate also feature. Typically the compression issues were to do with reduced mobility with bandages, embarrassment over appearance (and for some the need to hide the compression) and needing to have equipment to hand at all times. From Theme 2, Table 4.2.

Pride and embarrassment feature here. There was a desire to maintain dignity, not to appear in public feeling like a clown in mismatched, ill-fitting footwear or clothes that were not to the person's taste - to disguise a bulky bandage, for example. There was also fear of sustaining a knock or injury to the ulcerous region, for example, when in a crowd or in the proximity of small children or dogs. From Theme 2, Table 4.2.

7. The quality of skin under compression was a source of concern. The participants were very aware of how fragile (easily damaged), dry and friable their skin could be under compression. A great deal of care was taken to ensure the leg was well moisturised (with something to which the skin was not sensitive) and some worry was expressed that the HCPs were perhaps not so assiduous in their care of the affected skin as the participants. Concerns were also expressed by some participants that a badly applied bandage could wrinkle, cause ridges in the skin, and that this could, in turn, cause new ulceration because of the fragility of the skin. This was in contrast to those few who felt bandaging was protective against new damage and supportive. From Theme 2, Table 4.2.
8. A range of improvements was offered by the participants to make compression therapy less challenging and more palatable. Some ideas were expressed vaguely, others with precision. They ranged from improved textiles (fabrics that do not ladder or chafe the skin) to finding improved formulations of compression to lessen distress (less bulk,

discomfort and inconvenience, less imprisoning, more compatible with regular ablutions). From Theme 3, Table 4.2.

9. It may be useful to employ a model to help to explore the person's relationship with their venous leg ulcer and with compression therapy. This relationship is a multi-faceted one and is not a simple matter to define, although the concept of a triad, which includes the HCP might help. Locus of control may provide a model for examining the person's relationship with their venous leg ulcers and with their compression therapy – or the concept of 'patient as expert' – or 'autonomy versus dependency'. In these relationships, the HCPs feature as a catalyst of sorts, affecting the relationship the patient holds with their ulcers and the compression therapy and they represent a possible focus of dependency or an external locus of control. The HCP is also a part of the relationship dynamic and a facilitator of the patient's perspective on both ulceration and compression. See Figure 5.1. From Theme 3, Table 4.2.

5.2 How this relates to earlier work/literature review

As noted in the previous chapter, much of the data from the participants in this study confirmed findings from previous research. In this section this data will be drawn on both to confirm previous work - and to add new insights – where the current study presents findings that are novel or not quite in line with what has been found previously.

5.2.1 Belief in compression

From the literature found through the searches conducted in preparation for this current study (in Chapter 2), the suggestion from some reports seemed to be that those venous leg ulcer patients who believed that compression would heal their ulcers, would endure more and longer than those who did not share this belief (Annells et al., 2008; Jull et al., 2004). Jull et al. (2004), for example, researched adherence to compression hosiery and found a meaningful relationship between belief in the value of compression and adherence to therapy. Annells et al. (2008), in their qualitative study, found the willingness of the patient to adhere to therapy was seen as central to the successful healing of a venous leg ulcer. Annells et al. (2008) also

mentioned that the patient trusting their nurse was a major contributor to adherence (though this point in support of adherence might also hint at greater dependency). They found that those who did not believe that compression would heal their ulcer (informed by contradictory advice or a previous, negative experience with compression) would either refuse compression altogether or discontinue compression therapy in a unilateral decision.

Further, in Brown (2010a), the nurse participants inferred that those lacking such faith were more likely to display non-adherent behaviour. In this research, lack of faith in compression was seen as one of the main causes of non-adherence.

In this current research, however, the situation reported by all the participants was a strong belief in compression (with very few caveats). No one reported a lack of belief that compression was indeed the best therapy available. Reasonable faith in their HCPs' ability was expressed by many and there was faith (held by most) that the future included healed ulcers. While such a finding might be expected from a sample recruited by Tissue Viability Nurses on the researcher's behalf, it was by no means the case that all the participants had a positive experience of compression and three participants were clear that compression therapy was not for their individual cases.

It appeared that the message about the benefits of compression in venous ulceration had been clearly received and understood. Non-adherence in this sample was more likely to be confined to an episode where the pain of compression had been intolerable, for example, or where the compression garment was cutting into the skin at some point and threatening the integrity of the skin, rather than a rejection of the concept of compression or evidence of a patient who might be labelled 'non-compliant'.

This belief co-existed with a paradoxical dislike of compression and the effects of compression, which created a tension within the participants. This tension might well lead to non-adherent behaviour, for example, when a participant had 'had enough' and had removed or reduced the compression

garment. Thus, in this research the non-adherent behaviour did not seem to relate to belief in compression or otherwise.

The dissonance between participants' belief in compression and the problems associated with compression can also be seen in the high level of frustration and sometimes anger expressed by some participants, despite evidence of considerable endurance and determination to continue with therapy to healing. When the mean length of venous leg ulcer history in this sample is more than 7.7 years, it seems likely that the attributes of endurance and determination are present.

5.2.2 Negative aspects of compression

The challenges faced by those with venous leg ulcers in compression have been reported widely in previous research (Brereton et al., 1997; Briggs and Closs, 2006; Briggs and Flemming, 2007; Persoon et al., 2004). These challenges were also found to be significant for the sample interviewed for this research project. This current research has as its focus patient perspectives of compression and will therefore highlight data that is pertinent to aspects of compression.

5.2.2.1 Pain

Pain was a major contributor to the participants' distress. This was most commonly pain from the ulcer. However, a number of participants attributed their pain to compression itself. Clearly, from the participant's perspective it is important to distinguish the two, as the response to pain may be different in each case. If the pain is from the ulcer, then the patient may call for stronger analgesia or, in extremis, wish to cut off the ulcerated limb; if the pain is thought to be derived from the compression garment, the person may decide to remove it or lessen the compression, in the short term, and may reject further compression as intolerable. Attributing pain to a specific, differentiated cause alters the significance of that pain to the participant, informs their actions and colours their experience of compression (Hider et al., 2015; Molton and Terrill, 2014) It may have an effect on a participant's tolerance of compression and the level of adherence to which they can commit.

'Nerve pain' was described by five participants and in most of these cases it was attributed to compression. While this pain was reported to be intermittent (and usually occurred when the patient was lying down and at rest), it was experienced as excruciating while it lasted. Previous work in this field (Closs et al., 2008) suggests that there may be one or two markers – such as time of most acute levels of pain – to help to differentiate the origin of pain experienced by the leg ulcer population. However, the breadth and range of descriptors Closs et al. (2008) recorded from patient narrative could not be so attributed. So, while the language used in patient reporting in this current research may not permit classification of the source of all pain, the participants themselves were clear in their attribution: compression. The concept of 'nerve pain' also appeared in the literature review conducted prior to the research being carried out. For example, Krasner (1998) quotes a patient describing their pain as 'sticking pins in you'.

Since pain is such a major feature of living with venous leg ulcers and compression, and would seem, from this research, to be poorly controlled. This facet of pain might reward further scrutiny. This is not a new recommendation yet, from this current research, adequate analgesic treatment for those in severe pain is still not being delivered (or perhaps does not exist).

5.2.2.2 Specific issues with bandaging and hosiery

The concept of compression evoked considerable negative response: not just in terms of the associated pain it could cause, but also in terms of inconvenience, bulk, disruption to life and 'depression'. There were also specific, differential issues reported by the participants regarding the two main forms of compression: bandaging and hosiery. The responses to these two forms of compression are discussed below.

5.2.2.2.1 Compression bandages

The bulkiness of compression bandaging meant that many felt the need to disguise the bandage. Females would wear trousers rather than their usual skirts (two older females within the sample were unhappy with the move to trousers and another, younger woman chose an ankle-length dress rather than resort to trousers); five females wore trousers habitually but this did not

prevent self-consciousness or a wish to hide the bandage from others. Males would perhaps wear looser clothing but disguising the bandages was of little concern to those few men who mentioned apparel. Issues with footwear, however, were widespread and caused frustration, anger and embarrassment. Most related to the bulk of compression bandaging and the resulting need to wear mismatching and ill-fitting footwear. Also, activity levels were reportedly reduced by the bulk - this could extend to restrictions in self-care and exercise.

Across the literature reviewed prior to field work, the points above regarding bandaging, namely footwear and bulk, have already been covered (Ebbeskog and Ekman, 2001; Flaherty, 2005; Hyde et al., 1999), but the main challenge raised by participants in the current research is not one found as a main focus by the literature review (although Fife et al. (2007) do touch on self-bandaging). It is that of requiring a nurse (at least in the UK), qualified in applying the specific bandage worn by the participant, to change the bandaging at regular intervals.

This had several implications: the participants' schedule (indeed, their life) was ruled by bandage change days where they either had to present at clinic/surgery or stay at home awaiting a visit from a nurse. Holidays were reported to be out of the question. Further, the nurse met with did not always have the specific training required for the compression bandaging in use. This wasted everyone's time and sometimes led to a different bandage being applied – not always with positive results. In one case, the same district nurse arrived twice in a row (of scheduled changes) even though on the first occasion she had declared she was not qualified to apply the required compression bandage and had left the home of the participant, with the old bandage still on his leg. This type of incident may be the result of the large number of bandaging systems in use. Perhaps a reduction in the number of such compression systems available would enable HCPs involved in venous leg ulcer care to undergo all the relevant training.

There were also occasional issues with the skill of nurses in applying the bandage described by participants. Particularly those who had a long ulcer history were quick to identify errors or poor technical skill. The dependency

on the nurse for their skill and their training, and the scheduling of bandage change was irksome and another source of deep frustration in this current research. For five participants, it had reached the point where they undertook their own bandage change, at least occasionally (and one participant estimated he self-banded 75% of the time) and were prepared to 'get into trouble' for doing so from whichever HCP they saw upon next scheduled bandage change.

As seen when desired improvements are discussed in Section 4.2.3.1 on page 115, this often unwelcome system of dependency was the driver behind many of the improvements sought: improvements that would lead to the person with venous leg ulcers taking back autonomy to manage/administer their own therapy. It is questionable whether such autonomy would be a practical, feasible or safe option for everyone.

This was not a universal desire however; there were eight who preferred the nurse to attend on them – a few were physically unable to self-bandage and a few were in dependent relationships with their nurses. In both circumstances, these participants took a more passive approach, trusting the HCP to deliver the best possible care.

This desire for greater independence did not mean that the participants had no regard for their nurses. Most spoke highly of the individual nurses with whom they had managed to build a relationship – and continuity of care was much valued. The sample, generally, was keen to develop some sort of relationship with the HCP and felt that lack of continuity prevented this. It was also seen as deleterious to ulcer healing.

5.2.2.2.2 Compression hosiery

The most common complaint about hosiery was the difficulty of putting it on and taking it off. This has been established by previous research too (Bentley, 2006; Chase et al., 1997; Mudge et al., 2006; Stephen-Haynes et al., 2006). However, the importance attached to this problem by the people affected with venous ulceration has not previously been evidenced in such detail. Many participants in the current research demonstrated considerable concern over this – not just for themselves but also for others less physically able than themselves.

Considerable time and thought had gone in to finding solutions to the problem and these tended to exclude 'contraptions' provided by the NHS. Solutions included liberal use of talcum powder and the dextrous use of a long shoe horn. But the need for help with hosiery was common and there was concern that someone older or less fit than the participants would find the task difficult, especially if afflicted with co-morbidities that impact on a patient's ability to use their hands, bend up or down or tolerate increased blood pressure. Given the generally older profile of those with venous leg ulcers, the sample (mean age >70) was very aware of the problematic nature of hosiery and expressed anxiety about coping in the future.

In contrast, there were four participants who described a good deal of comfort in their compression therapy. They acknowledged the occasional pain and the inconvenience of compression therapy but, once the pain of a new dressing and bandage or stocking had settled down, for example, there was calm acceptance of their condition. This did not seem to be dependent on their view of the future. One participant did not believe his leg would ever heal yet welcomed the support his compression therapy gave him. Another participant, whose ulcers had healed, was quite content to stay in compression hosiery forever and, indeed, felt naked without compression.

5.2.2.2.3 Skin under compression

Participants reported many concerns about the condition of the skin beneath their compression therapy. It was clearly important to most within this sample and it is an important element of this research because the participants regarded the compression, itself, as the major contributor to the degradation of the skin on their lower leg(s).

The quality of the skin beneath compression therapy and the need to care for the skin on the lower leg has been referred to in previous research papers (Briggs and Flemming, 2007; Moffatt et al., 2008). Again, what this current study offers is insight into the value attached by people with venous leg ulcers to the issue of skin quality. It would seem to be an important issue that takes the participants' time and attention.

While the ætiology of their friable skin was not of much note for the sample, addressing issues with the skin of the lower leg was taken seriously. This

concern encompassed both sensitivities to various dressings (e.g.: silver nitrate) and other products (such as Micropore, 3M), as well as what the participants saw as the inevitable effect of compression on the skin. In this, they echo the report from Reich-Schupke et al. (2009), which discovered frequently reported issues with skin quality under compression in the course of their study of patients at a phlebology clinic – 15 of whom presented with venous leg ulcers.

Friable, flaky, exceedingly dry skin was often described in this current research and care was taken by participants to moisturise the skin as often as possible. Frustration was expressed at the paradox of having, say, twice weekly re-bandaging which allowed the opportunity for only two opportunities for moisturising per week. There was fear of generating new ulcers, through damage to the skin, if care was not taken. This fear, related to the quality of the skin, went further: Compression led to the delicate skin being pulled and stretched. This was reported as painful and worrying. In addition, both bandages and hosiery could 'bunch', 'wrinkle', 'roll down', 'roll up' or 'riffle', which could also cause pain. The fear was greater than the pain, it seems: the fear that the ridges, marks or corrugation which resulted could, in their turn, cause new ulceration. This was another paradox found in the participants' experiences: while compression supported the skin it treated, there was a perceived danger that the compression could be the genesis of new ulcers. Two of those who had a venous leg ulcer history of long duration (over two decades) reported having experienced precisely this.

A point of interest is the language used to describe adverse skin reactions. Both 'allergy' and 'sensitivity' were used to describe these skin reactions. It was unclear whether these terms were being used with any precision by the participants. If accurate reporting is to be made of the patient's response to treatment options, it would seem that the development of a dedicated nomenclature to the topic could provide useful support for the HCP.

5.2.2.2.4 Practical Issues in living with compression

Two types of participant were present in the current sample: those who continued to try to function normally through their venous leg ulceration and compression, dealing with the practical difficulties that arose (n=8), and

those who had abandoned such attempts (n=11). Neither gender, age nor length of ulcer history seemed to have influenced this dichotomy. This then leads to the question: what characteristics of the participants lead to them falling into one type of response or another? Perhaps a model of locus of control, or a dependency/autonomy model, could be helpful in trying to understand the perspectives and motivations of these two groups.

Initial impressions from this study would suggest that self-image, pride and a sense of dignity seemed to influence the attitudes of those determined to carry on as normally as possible. Perhaps issues of identity and an unconscious refusal to adopt 'patient' status are active here. The emotional and physical cost of these attempts was felt by three of the individuals concerned to be particularly high. And the principal investigator found empathic response when talking with them, feeling concern for the level of anger being held, for example, or the level of endurance and resilience required of an individual. The remaining five in this group seemed to exert less effort and invest less emotional strain in their attempts at normal daily living. Perhaps they had adopted better coping strategies or maybe their roles within the family and wider network required a little less work – maybe their support network was stronger.

Those not expending effort on maintaining normal function seemed to have recognised the enormity of the task and maybe felt that their role, for the time being, was as a patient in a patient/professional dynamic, where their prime responsibility was to adhere to therapy (where possible) and work towards ulcer healing, in co-operation with the HCP. For many, there is a certain sense of abdication of responsibility in the label 'patient' (Katz, 2002) and it is possible that within the more passive group in the current research, this attitude was more prevalent. Also, by downgrading their expectations of themselves, they had reduced the self-imposed pressure to perform, possibly leaving them less discontented, more accepting of their situation and, most importantly, less stressed and anxious. In its turn, reducing stress and anxiety could aid healing (Rosenzweig et al., 2010; Sobel, 1995).

A number of day-to-day problems had considerable effect on the participants' ability to function normally to relate to others and themselves satisfactorily and on their sense of well-being (see below).

In most cases, the data gathered here confirms the findings from previous work, whilst adding more detail (Mudge et al., 2006; Rich and McLachlan, 2003; Walshe, 1995) However, in some cases the perspective taken by participants or the information offered is new and constitutes a novel finding.

5.2.2.2.5 Footwear

Access to well-fitting and appropriate footwear was rarely reported. This lack inhibited mobility and led to social isolation because of inconvenience and because the participant felt self-conscious wearing a shoe several sizes too large or non-matching footwear or a slipper slit open to accommodate a bandaged lower leg and foot. A few participants also mentioned being afraid of falling over because of ill-fitting footwear.

A call for the NHS to provide appropriate footwear at the time of bandaging was made and was expressed along with a feeling that the patient should not have to be responsible for the provision or cost of such apparel. Even those few who had access to NHS footwear were generally derisory of the aesthetics of such items.

Whilst footwear has been raised as an issue in already published work on venous leg ulcers (Briggs and Flemming, 2007; Hyde et al., 1999; Rich and McLachlan, 2003) and, for example, diabetes (Hellstrand Tang et al., 2017; Hurst et al., 2017), the size of impact of the problem (as described by these participants) was not highlighted. The inconvenience and frustration described underlines the importance of providing appropriate, aesthetically satisfactory, safe footwear where compression precludes the wearing of their ordinary shoes.

The issue also requires professional attention in relation to factors affecting healing. If the patient is less mobile and exercises less, the action of walking (pumping venous return) and flexing the ankle will also be reduced. This runs counter to optimal care solutions that should be taken to promote greater health and more rapid healing in the venous leg ulcer patient. Thus,

the situation reported by the sample in the present study regarding inadequate provision of appropriate and well-fitted footwear is important to the field.

5.2.2.2.6 Hygiene

The restrictions on hygiene caused by wearing compression therapy were a source of discontent. The process of getting clean was hurried for fear of getting bandages wet, a bath was too difficult for most to contemplate, although being able to luxuriate in a bath was something yearned for once out of compression bandages. In consequence, the act of getting clean was not regarded with pleasure – and the sense of well-being expected from thorough ablutions was absent. Self-image could also be affected (see Section 4.2.2.3: Aesthetics and self-image).

Discontent has been reported by previous research in relation to hygiene matters (Chase et al., 1997; Green et al., 2013; Walshe, 1995). Again, this current research adds new insight and understanding to previous findings by highlighting the well-being factor associated with good hygiene. The obstacles presented by compression therapy in this regard were yet another source of frustration for participants. Given the importance attributed to hygiene and the sense of well-being associated with it, this is an area where the HCP might work with the patient to develop logistics that allow easier access to regular ablutions (as suggested in the paragraph below).

Whilst two participants mentioned, with satisfaction, the procedure of removing bandages and bathing before attending a bandage change appointment, one participant sadly reported receiving advice not to do so before her appointments any more. She had no explanation for why this advice had been given. The practice of advising patients to remove bandaging in advance of a bandage change appointment (where advisable) would seem to provide at least a partial solution to increasing the well-being of the patient and perhaps saving nursing time.

5.2.2.2.7 Social isolation

As reported in previous research (Ebbeskog and Ekman, 2001), social isolation tended to be self-imposed by this current sample and, while some

of reasons given for this relate to self-consciousness, embarrassment and pride around their compression garments (particularly in terms of bulk), practical reasons also featured. These included the necessity for some to have dressing and bandaging materials always to hand, anxiety about having the leg knocked inadvertently and restricted mobility – whether due to bulky bandages that are cumbersome or painful to move around in or ill-fitting footwear.

One of the effects of this social isolation was to engender low mood (along with other inter-related factors) and this, in turn, might well have affected the desire to socialise, creating a negative circle (Cacioppo and Hawkley, 2003). Low mood and extreme negative responses to compression are covered more fully below.

5.2.2.2.8 Low mood and extreme psychological reaction

A wide range of previous research comments on low mood, reduced well-being and the often-inter-related nature of the factors contributing to a downturn in affect (Ebbeskog and Ekman, 2001; Lindholm et al., 1993; Parker, 2012). Very rarely is this attributed to any one cause (Brown., 2010a; Ebbeskog and Ekman, 2001). What is less evident in the literature is any distinction made between low mood/'depression' and extreme negative psychological response such as was found in three participants in the current study.

Many authors describe the low mood that may be commensurate with the difficulties faced by someone suffering with a painful, chronic illness such as venous leg ulceration. Suicide ideation is mentioned by Taverner (2014) and is presented as an extreme on the continuum of negative emotional response. From this current research, the investigator would argue that the two levels of distress are two different and distinct qualitative, emotional entities (O'Connor, 2011). The majority of the sample who report low mood/'depression' describe an emotional response that seems to be in line with the problems and discomfort they face; their reports confirmed the findings from previous research.

5.2.2.2.9 Extreme response

The admissions of suicide ideation in the past – due to compression bandaging, the length of the ulcer journey and the fear of being forever dependent upon others – and the desire to mutilate or remove the offending limb seem to indicate a response greater than that which might be expected; something of a different character, eloquent of desperation, a sense of degradation and horror. In these few cases, the effect on the individual participant seemed to have been severe. Three described suicide ideation and one participant, in particular, described a response that was at once acute and yet had lingered after compression had moved from bandaging to hosiery. She reported suffering acutely from the experience of compression bandaging. The impact upon her emotions was enormous. The words used to describe her feelings about compression and the meanings she attached to the act of applying compression bandages were marked in their intensity and illustrated a very strong sense of degradation and enforced isolation: ‘unclean’, ‘isolated’, ‘degrading’, ‘set apart’, ‘like a leper’, ‘horrendous’, ‘awful’.

In an empathic insight, the principal investigator found the word ‘trapped’ come to mind, as the participant struggled to find words to describe how she had felt. When ‘trapped’ was tentatively offered, the participant pounced on it, ‘Yes, exactly! ...’.

Despite her horror of compression bandaging, she had endured (as had many others) to the point of healing or, at least, to the point of moving to compression hosiery because the healing process was well under way. Hosiery provoked no angst-laden or extreme response from the participant. In fact, she found hosiery supportive and had come to feel naked without it. Apart from the intensity of her experience this person describes an almost archetypal story for the venous leg ulcer journey, with movement through a dreadful phase of bandages for healing, to hosiery for maintenance – which was found to be much more acceptable and less intrusive. It should be noted, however, that this is not the case for all people with venous leg ulcers. In venUS IV, research conducted by Ashby et al. (2014), they found that more participants decided to change from hosiery to bandages than

from bandages to hosiery. Thus, hosiery is not the preferred treatment for all.

These three participants in the current study reporting extreme emotional responses represent a minority. However, if the results of this research are found to be generalisable, they represent a sizeable minority of venous leg ulcer patients. This sub-population perhaps merits further research, partly because of the evident risk inherent in such extreme emotional reactions but mostly because of the human suffering implied by such negative reactions. Ideally, the aim of such study would be to find a psychological marker or emotional trigger that characterised such individuals so that the potential risk of a strong adverse reaction could be predicted and worked with in order to protect the patient better.

5.2.2.2.10 Low mood

Low mood in venous leg ulcer patients is created not just by compression and its many ramifications. A number of factors are involved here and they interlink with the effect of compression and each other.

Most of the sample in this research commented on the demands on their endurance – of pain and time; the difficulties, frustrations and challenges that had to be faced on an ulcer journey and the negative effects of disrupted sleep; inability to function normally, reduced mobility and social activity. These demands were sometimes related to the ulceration itself but mostly relate to compression and the consequences of a leg or legs under compression. They admitted to ‘feeling depressed’ at times. And a few wept as they described their most challenging periods.

Notably, very little was said about sleep disruption in this current study. It is known that sleep disruption is a factor which can contribute to low mood and low energy (Upton and Andrews, 2013). There were several mentions of disrupted sleep, mostly with reference to the pain of compression when at rest (‘nerve pain’), but as if in passing. A couple of participants referred to cramp and to exudate awakening them due to the wetness of the bedlinen. Overall, it seemed that disrupted sleep was taken as a given and the fact that so little emphasis was placed on problems with sleep seems to indicate that, among all the other challenges and frustrations, this was not one upon

which much emotional energy was focused. Perhaps the participants were not aware of the negative results, such as low mood and reduced energy levels, which could ensue from disrupted sleep.

A symbolic perspective that clearly denoted distress was that of somehow disowning the affected leg: wishing it into a corner of the room, away from the participant, talking of a desire to self-mutilate to get rid of the offending leg and describing the leg as being in a wooden box. This dissociation was also identified by previous research from Sweden (Ebbeskog and Ekman, 2001). While it may not be widespread, this dissociation would merit further study in order to reveal the drivers for such extreme urges.

In contrast, there was also one participant in the current research who recalled experiencing no pain, no angst and no problems of any kind. Pain and problems were simply not present in her narrative – and, indeed, she did report a singularly issue-free ulcer journey of short duration. Either her narrative offered the interviewer a mask rather than her true experience, or the excellent medical care she received in France before her return, and the support and attention she received both there and on her return to the UK contributed greatly to her problem-free healing.

5.2.2.2.11 The therapeutic triad

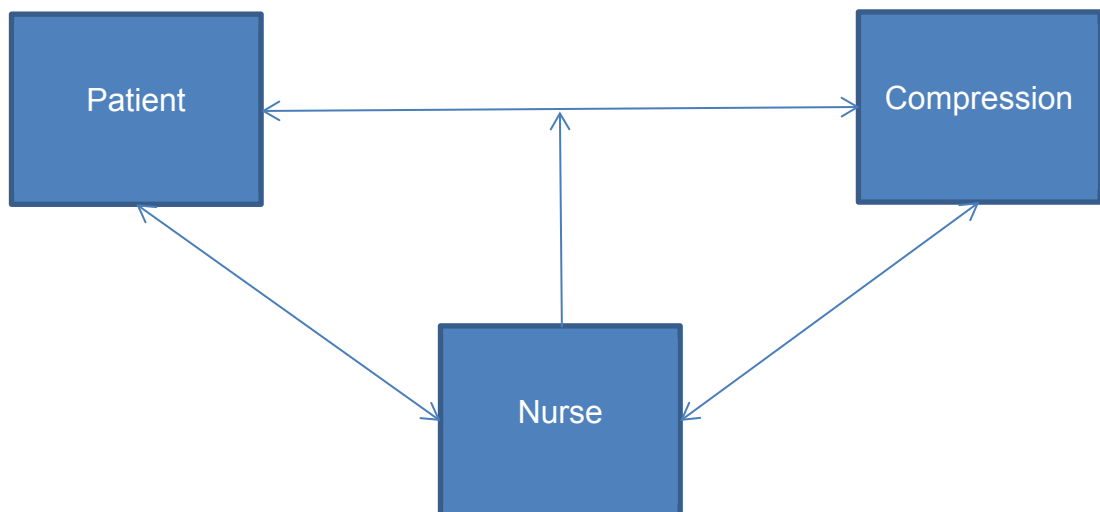
While the patient-nurse relationship is not the central focus of this research, it is clear that the HCP plays a critical role in the leg ulcer journey, in the acceptance and understanding of compression, and in the well-being of the patient. Critically the nurse has influence on the patient's relationship to compression. In terms of locus of control, it seems there is a **therapeutic triad** in place. The person with venous leg ulceration has a direct relationship with the compression therapy used to treat their condition. Within the equation of that relationship, however, is the nurse (or nurses) involved in prescribing and administering the compression therapy.

This is true whether the person with venous leg ulceration has an internalised locus of control and is an expert on their condition, or whether the power has been relinquished to the HCP. The balance of power/dependency will vary from individual to individual but the nurse remains in the equation as a kind of catalyst. See Figure 5.1.

Relating to the issue of dependency, and the wish, expressed in Desired Improvements (Section 4.2.3.1 on page 111), for some formulation that would allow the person to apply compression themselves; perhaps it can be inferred that some participants are keen to reduce or remove the level of dependency on the HCP that they perceive to exist. This would then change the balance within the therapeutic triad and lend weight to a greater internalised locus of control.

There is scope for more research in the field of venous leg ulceration to find useful ways of describing key relationships within the management of the patient's condition. The use of locus of control as a model and/or a marker for various facets of relationships could generate useful insights into the patients' experience. Dependency versus autonomy (Katz, 2002; Moffatt et al., 2009) and psychological theories of mind set are other possible models to work with (Annells et al., 2008; Cheng et al., 2016; Jull et al., 2004).

Figure 5.1 The therapeutic triad



5.2.2.2.12 Exclusion of data

The challenge in deciding which data to include, exclude or refer to only in passing is described in Section 3.5, Data analysis. The previous section, 5.2.2.2.11, describing a possible model of the therapeutic triad in venous leg ulcer management provides an illustrative example of this. The model, outlined above, represents a cursory look at the relevance of the relationship to the patient and potentially to the medical outcome and ulcer healing. It does have a relationship to compression textiles (if oblique), but is also

somewhat ancillary to the essence of the research title. So the decision was made to refer to the triadic relationship but briefly – to acknowledge its importance in the management of venous leg ulcers, without pursuing detail in the topic.

Humour frequently displayed by participants in the study is another such case. Humour (notably black humour) was evident in a number of narratives and the use of humour could be seen as an effective coping strategy of some potency. It can also mask more distressing emotions, particularly where the use of humour seems inappropriate (as evidenced by a few). Humour is a complex facet of human behaviour and to explore this facet of these findings within the context of this research report would take the analysis of data too far from the central focus of the research, even though its relevance and meaning to the individual participants is evident.

Because this was an exploratory study, there was always the possibility of excessive data richness. No *a priori* limit was set on amount of data collected or variables to be included. Data richness is a positive outcome, but one which required management and the disciplined ability to discard data if it was not of the most immediate relevance to the research question. Even with the exclusion of a good deal of data, the research yielded unique and valuable contributions to the field. See Section 5.3 below.

5.3 Unique contributions to knowledge in the field

As a qualitative, exploratory study, it is to be expected that this research would yield rich data on patients' perspectives of compression therapy (an area not previously researched in specific depth). It did. Further, the use of IPA has allowed the full range and meaning of the participants' views to be assessed and their 'truths' to be recorded. In a range of areas concerning compression therapy, this study offers new insights and adds to the information held in this field:

There was **universal acceptance of compression therapy** found in this sample. Previous research has found some who are not ready to believe in compression therapy as the gold standard treatment for leg ulcers.

Despite this belief in compression therapy there was strong evidence of **dislike of compression therapy**. In this way a paradox exists: the participants believe in compression but most dislike it intensely.

The inconvenience and unpleasantness of compression therapy set beside the desire to function normally creates **tension** and has negative emotional impact.

This study highlights the level of concern/patient involvement in the care of **the skin beneath compression**. Fragile skin beneath compression is not a new topic in this field but the level of attention professed by this sample is a new finding.

The level of importance attached to the issue of **footwear** by this sample has not been found in previous research. It is an issue which has great meaning for the patients, ranging from self-consciousness to anger at the potential risk inappropriate footwear represents.

Hygiene and the difficulties attached to regular and satisfactory ablutions were also of concern to this sample. This has been researched previously. But in this current work it is clear that the participants attach great store by the well-being factor associated with the cleansing process. This has not been found in previous research.

While much has been written on the patient-nurse relationship previously, the emphasis and value placed on finding ways to become less dependent on nursing appointments, seems to be a new facet of the relationship. The findings suggest that patients wish to find solutions to reduce the disruption to their lives that the nursing encounter involves and also to find product solutions to enable **greater autonomy** and self-management.

That the experience of living with venous leg ulceration usually evokes a negative emotional response does not represent a new finding. What is new, however, is the finding that a significant minority of this sample experienced an **extreme emotional response** that included suicide ideation. Further, this report contends that this minority represents a distinct group, qualitatively different from those suffering less extreme distress.

In view of the minority experiencing extreme emotional response, as well as other sub-groups identified (those struggling to function normally, those unable to manage their treatment alone), it is felt that **a model to explore these important differences** could usefully be employed. Such a model would look for markers that might identify patients with the relevant profile and begin the process of researching how best to help them. Such models exist but, to date, little evidence of their use in venous leg ulcers has been found.

The findings of this research also identify several areas where the **opportunity exists to improve practice** in the management and care of the venous leg ulcer patient.

5.4 Making use of the findings

As well as adding data of considerable detail to findings already established from previous research and confirming the participants' universal belief in compression as the best way to heal their venous leg ulcers, their ideas for improving compression therapy were wide ranging and serve to highlight areas of concern to those who live with venous leg ulceration. These ideas are the focus of this section.

The current research reports on 19 participants' views and was designed as an exploratory study. While this is a substantial number of people in terms of IPA and qualitative research, it cannot be regarded as representative of the population who have experienced compression to manage their venous ulceration in the North of England. Therefore, these results are far from conclusive and further research is needed to expand on numbers of participants and examine in more depth the various themes identified.

What this study **does** achieve is not just more detailed information about what is already known; it also adds new insights with important potential for improved practice, service provision, organisation and compression products.

What follows in this section (5.4) is derived from data in Theme 3, Table 4.2.

5.4.1 Greater autonomy

With many of the improvements suggested by the sample, such as compression with a zip, something easy to remove or bandages designed to be self-administered, the result would be greater autonomy for the patient, and less reliance or dependency on the nurse. While the participants themselves may not have been focusing on greater autonomy per se, when gathered together, the number of different suggestions that would lessen dependency on the HCP comprises an indication that greater autonomy is sought. However, despite the appeal such improvements might have for the participants, greater autonomy could potentially lead to harm from infection or ulcer deterioration. Autonomy carries with it no guarantee of good quality of care or adequate knowledge of wounds.

There was a call for a form of compression that could be removed to allow thorough cleansing of the whole body. This is possible with hosiery, of course, but in this instance the improvement desired referred to compression bandages. Such an improvement would allow the patient to bathe, for example, at a time chosen by them and not dependent on the timing of the next bandage change.

Some new formulation of compression bandages that would permit the patient to apply the compression themselves was also called for. Thus obviating the need to make appointments for the nurse to do so and freeing the patient to live a more normal life. Indeed, a few of the participants in this research already did most of the bandage changing they required themselves. These were people with a long venous leg ulcer history and considerable expertise in their condition, in their needs and in the bandages used to treat them. It is also possible, however, that the length of their ulcer history was in some part due to their self-bandaging, that the requisite technical skill, for example, was not present.

The advantage to the organisation to venous leg ulcer treatment in terms of time and cost are clear. If greater patient autonomy can be managed safely from a clinical perspective, the NHS would benefit and the patient would be able to function more normally.

Referring specifically to hosiery, it was felt that if there was some way of making such garments easier to put on and take off, this too, would make life easier and add to independence. If they could avoid the need for assistance either from a partner or carer or a nurse, this would be highly desirable. In the course of the interviews, there were many references to the plight of those older or less able than they themselves and how they were to manage without help. This consideration was clearly top-of-mind, being mentioned spontaneously, without any prompting. It was a topic that had been thought about in some detail, with compassion, and appeared to be informed by the participants' own difficulties in this regard.

This finding underlines the importance of addressing the unfortunate juxtaposition of a predominantly aged patient population and compression requiring dexterity and strength to manipulate successfully.

5.4.2 Improvements to textiles

There were calls for greater research into the textiles used in compression therapy:

Was it possible to develop a 'wool' layer that did not chafe the skin?

Could compression textiles be made so that they did not pull at the skin when the leg was moving? Thus implying the desire for more stretch in the compression bandaging? The complaint was that there was little or no 'give' in the bandaging – particularly, apparently, the top layer. This top layer was blamed for creating the extra pressure that made the bandaging so tight it limited movement by stretching the skin uncomfortably (e.g., when vacuuming).

While products exist that can automatically alter compression strength to match changes in leg diameter and shape, these participants were unaware of such technology. Such innovative products had not been offered to them. From the comments made in this research it would seem that such 'intelligent' compression products would be welcome.

With hosiery the desired improvements included the research and development of hosiery fabrics that did not ladder (and therefore did not lose compression efficacy); fabrics that were machine washable; fabrics that

would tolerate fabric softener without losing compression strength; hosiery that could be dried on a radiator without damage (if not in a drier) and some sort of textile design that would make the garment easier to put on and take off.

The fit of off-the-shelf garments was another issue of concern. The result was a call for made-to-measure hosiery. If the result could be wrinkle-free, close-fitting hosiery that correctly fitted the shape and length of the leg, this was thought to provide the best possible, most effective compression and that would, in turn, outweigh the time and expense of providing bespoke hosiery.

5.4.3 New closures

Participants were tentative in their suggestions, perhaps reflecting an anxiety that their lack of medical, technical or engineering knowledge would make them appear foolish. A few suggested that a zip or some sort of a Velcro closure would be ideal. How this would work was not explored, but it was felt that this solution would solve the difficulty in donning hosiery and revolutionise the process of applying compression bandages. It would also supplement the range of improvements that would contribute to greater autonomy. That these already exist, for example, within the product range of Jobst USA indicates that these participants have not been adequately informed of the full range of products and choices available. This may be an area where service delivery can be improved.

5.4.4 Research and development from manufacturers

With regard to the **application of hosiery**, there was a call for 'contraptions' that were easier to use, in applying compression garments. It was felt that a manufacturer could usefully devote some time to such a project. In particular, they should establish directly from people using compression with venous leg ulcers what the requirements were. This may already have taken place, however the participants in this research were not aware of such activity.

Manufacturers were also called on to research moisturising solutions to address the concerns with skin quality. Further, it would be helpful to provide

such moisturiser with the compression garment. This would be convenient for the patient and might help to avoid some of the 'trial and error' with moisturising products, described by the participants. Such a suggestion did not appear in the literature search undertaken prior to fieldwork.

One participant also felt there was work to be done in developing guidelines for HCPs to guide their practice (apparently unaware that guidelines already exist – although perhaps not in quite the form he envisaged). The 'trial and error' procedures that several people reported within the treatment of their venous leg ulcers might thereby be avoided. Whilst the detail for this was a little vague, it was thought possible by the participant to group venous leg ulcer patients into different profiles and to direct the HCP into one compression treatment (and dressing) path or another, depending on the individual's medical profile. Such specific guidelines may already exist, but this was outside the knowledge of this particular participant.

5.4.5 Organisational issues in the NHS

Although the topics below were not prompted by the researcher, a number of organisational issues were raised by the sample as areas where they would like to see improvement. They are all seen to contribute (or otherwise) to the perceived support of compression therapy.

Continuity of care was highly prized and many felt the lack of it. They found this lack unhelpful and unsettling at best, and a risk to the ulcerous leg at worst. A better organisation of care was sought. Continuity of care features in the literature review conducted for this research but more in terms of an exhortation to HCPs to consider its importance, rather than as a report of what meaning this has for the people with venous leg ulcers (Moffatt, 2014).

The research question here might be:

In the organisation of the management and care of patients with venous leg ulcers, where does the decision-making power lie to enable continuity of care?

Being sent nurses untrained in the specific compression in use and the experience of their patient notes not having been transferred between care units (or not read by the attending nurse) were only two examples of the

mishaps reported by participants. They give a flavour of the problems attributed to organisation.

So, a useful question to research might be:

Is it time to create a nation-wide armamentarium of compression products, in which all HCPs are trained?

This would mean that even if continuity of care failed and even if different agencies might present at the patient's home to offer care, the patient would receive the appropriate, agreed compression garment during bandage change or replacement of hosiery.

One participant felt the problem of finding appropriate footwear was an issue that should be addressed by the NHS. She felt that appropriate and properly fitted footwear should be provided at the time of applying compression to the leg. No detail was offered as to how this was to be managed, but living in mismatched footwear, often slipper and sandals, and especially bought, oversized shoes of which only one could be worn was not a burden she felt the patient should have to carry, given the many negative ramifications of inappropriate footwear. No similar suggestion has been found in the literature reviewed prior to research.

5.5 What questions does the research raise?

This current research raises many questions as evidenced in Section 5.4, above. It has begun to answer the question of how people with venous leg ulcers view their compression therapy and the textiles used in the application of compression. It has also contributed to the body of knowledge about people with venous leg ulcers and the meaning they attach to the many issues they face as part of their condition and their experience of compression. This is part of the phenomenological perspective of the study.

5.5.1 Compression as therapy

In this study, the participants demonstrate that they accept and value compression therapy, and believe that this is the best form of therapy available to them. This faith informs their relationship with compression, their ulcers and the HCPs responsible for their treatment. This is new information

in a number of ways. Such universal acceptance of the role of compression was not found in the literature search. Indeed there are mentions of those who do not appear to have faith in compression therapy.

Using a semi-structured qualitative format, the interviews have gathered detailed data on issues that confirm findings from previous studies and expand our knowledge of the patients' perspective. Specifically, the meaning and importance attached to matters of hygiene and footwear, the extreme emotional response experienced by a few, and specific attitudes to issues with compression hosiery and compression bandages.

A focus on such issues from the medical professions and the manufacturers could improve the patient's experience of compression therapy, potentially leading to greater adherence and commitment to therapy. This, in turn, could lead to less nursing time being required by this population, faster healing less, recurrence of ulceration, fewer resources required and saving to the NHS.

Thus, when nurses refer to a 'non-compliant' patient with venous leg ulceration, what do they actually mean? The research question might be:

If compression therapy is accepted as the optimal treatment for their venous leg ulcers, what factors/issues cause patients to refuse or defect from compression therapy?

The question in its general form is not new. But a different focus is required to achieve answers that can be worked with further. This study found a few who did not think compression therapy was for them, but this was not out of negativity. In this research, when there was evidence of non-adherence it was for specific reasons. A greater focus on these individual occasions and how to persuade the HCP to focus on those reasons rather than sitting in judgement of the individual patient is what is required.

Another question, regarding hygiene, might be:

How can care, over time, be adjusted to suit patients with venous leg ulcers so that they have the opportunity to perform ablutions more regularly and how do patients believe this will improve well-being?

Issues with footwear also need greater attention:

How can services be improved in order to provide well-fitting and appropriate footwear to patients with venous leg ulcers whose compression garment or oedema prevent the use of their existing, standard footwear?

5.5.2 Desired improvements

Improvements were called for which indicate the unmet needs experienced by the majority of the sample. They highlight the areas of compression therapy that were most important to the people with venous leg ulcers. Improvements such as compression products the patients could apply themselves, textiles that did not chafe or pull the skin, better textiles to increase the life and practicality of hosiery, made-to-measure hosiery, the provision of appropriate footwear and research in to better emollients. Clearly, these reported needs would require further research and quantification before appropriate ideas and prototypes could be developed.

5.5.3 Models for investigating patient attitude and perspective

There are a number of markers that might usefully be considered in the context of a person's attitude to and perspective of their role in their venous leg ulcer management. One such concept is that of greater autonomy. This has already featured in the reporting of findings from this research. Another might be the patient/professional partnership on which there is already a body of work, looking at managing many different conditions. Yet another might be the concept of locus of control. This latter has been usefully employed in psychology for many years and has entered the field of health psychology (Brincks et al., 2010; Nawafa'h and Hamdan-Mansour, 2015; Snyder and Hanft, 2009). The purpose in using such models is to find possible markers that might differentiate groups of people with venous leg ulcers, for example, in terms of psychological response to their experience of venous leg ulceration and around issues of independence/dependency. This may be helpful in further research, for example, on the relationship between nurse and patient and active involvement of the patient in the management of their condition – or not.

The research question might read:

Given the psychological profile of those patients who respond to compression bandaging with extreme distress, how can this inform the nurse/patient relationship to improve well-being and outcome, and protect the patient from the risk of enduring psychological distress?

5.6 Strengths and limitations

5.6.1 Strengths

The interview was loosely structured and permitted the dialogue to proceed much like a conversation where the participant led the discussion for the most part. This contributed to the richness of information gathered. As a result of the interview process, in almost all cases, the interviewer felt that a measure of psychological contact was achieved which facilitated disclosure and detail not often found in other research on venous leg ulcers. A couple of participants commented on how helpful and insightful the interview experience had been for them, although one was a little concerned with the level of disclosure she had permitted herself as a result of relaxing into the interview.

5.6.1.1 Methods

In an exploratory study, aiming to discover new perspective from people with venous leg ulcers, a qualitative approach was required in order to achieve the necessary depth of data. Further, the use of IPA as an analysis tool was designed to ensure that the report reflected the participant's voice faithfully, allowing the 'truth', as described by the participants was conveyed. The method of research and the analysis model provided a strong platform for this study.

5.6.1.2 Sample size

Nineteen participants is a large sample by IPA standards, but the wide range of response and the amount of data gathered has provided a wealth of material. This data confirms previous work and provides some novel insights into this patient population and their view of compression therapy. It also provides the basis for further research at many different levels.

5.6.1.3 Findings

The findings from this study are abundant and valuable. New information has been gathered and new insights into the patient's perspective of factors already studied – but not in such depth. The findings also provide implications for nursing practice.

5.6.1.4 The naïve researcher

There is an advantage to being a naïve researcher. In theory, there is less opportunity to make *a priori* assumptions because the research topic is unknown. Thus, bracketing previous experience and knowledge is more achievable. And in the case of this study, adhering to phenomenological principles, this was entirely consistent with the methodology and method of analysis employed. The researcher has no nursing training and had not worked with this patient group before.

5.6.1.5 Reflexivity

Elements of reflexivity have been interwoven with the main text. However, a note about its use appears here in summary. The researcher came to this field of therapy as naïve: no nursing training, no prior knowledge of either the pathology of venous insufficiency or the management of venous leg ulcers.

This does not mean, however, that the researcher was without pre-conceptions. As a doctor's daughter, the researcher has been around nursing staff of all kinds and levels throughout her life and has seen both total dedication to patient welfare and less optimal attitudes. Also, as a consumer of nursing care from time to time, the experience has been equally variable. By the time preliminary research had been initiated, scoping literature, talking to District Nurses and Tissue Viability Nurses, it seemed inevitable that fieldwork would yield some evidence of poor nursing care – often due to organisational constraints. This turned out to be the case, but how much of this was self-fulfilling prophecy?

That said, the researcher makes extensive use of the practice of bracketing in professional life outside of academic research and is well-experienced in this endeavour. It is hard work but very helpful in the interview situation.

Also, as a psychotherapist by profession, the researcher knew there would be a tendency to be drawn into the participants' narrative in an empathic response. By being aware that this could easily reach inappropriate levels, the 'supervisory eye' was put to work and was a constant reminder that in the research situation, while human feeling was acceptable, a professional distance was also required. It is self-awareness that is key here; it allows the researcher to check analyses and take measures against the pervasion of such biases into the reporting.

5.6.2 Limitations

5.6.2.1 Use of IPA

This is the first occasion on which the primary investigator has employed IPA as a form of analysis. Even for an experienced academic researcher it is regarded as a complex and challenging format to use. Whilst the choice of IPA seems to have been vindicated by the richness of the findings, a more experienced and skilled researcher might have been able to craft more refined analysis.

5.6.2.2 Lack of expertise in compression textiles

Being new to the field of venous leg ulcers and having no nursing background carried with it a scant knowledge of the range and breadth of compression technology. While literature research yielded information on the topic of compression and its manufacture, this is only a theoretical substitute for first-hand clinical knowledge. However, this exploratory study did not require researcher expertise in compression products or compression technology. The focus of this research was on the **patient's** perspective of compression textiles. The key was to 'hear' what value and meaning compression textiles and compression technology held for the sample in the treatment of their venous leg ulcers – and their perspectives did not include expert information about compression technology.

The comparative naivety of the researcher in this regard can be seen as an advantage rather than a limitation and, in the course of fieldwork, was not found to impede interview progress or flow in any way. Moreover, the knowledge held by the researcher was a theoretical understanding of

degressive compression and the way in which Laplace's law and Pascal's equation were principles which defined variable compression around the lower leg. Also, a summary of the different technologies used to manufacture the range of compression currently available.

5.6.2.3 Follow-up opportunities

While the interviews were successful in terms of engaging the participants, perhaps a different, more structured design, with less emphasis on the leg ulcer journey might have yielded even more rich data. Also, in the time allotted to the research design there was no latitude to return to the sample for further follow-up work, say, in the form of some group discussions to develop from the first phase, regarding perceptions of compression.

5.6.2.4 Insufficient probing

With hindsight, there were occasions where the investigator could usefully have probed further. That said, the investigator was keen to direct the course of interview as little as possible, to ensure as far as possible, that the interview genuinely reflected the participants' 'voice' and meaning. The weight of meaning the participants attached to the whole of their venous leg ulcer journey, including compression therapy is perhaps a finding in itself.

5.6.2.5 Researcher influence

Awareness that past experience and knowledge inevitably influence the way analysis is performed, leads to the reflection that, as a psychotherapist by training, the researcher is likely to have focused on psychological elements of the participants' narrative on occasion. Also, not being a nurse and not having worked with this patient group before, the interviewer may be unaware of certain medical or clinical or product facts that would be obvious to Tissue Viability Nurses.

5.6.3 Researcher influence and naivety

The challenges and dilemmas of a practicing clinician adopting the role of an academic researcher have been eloquently described and discussed from a nursing perspective (Colbourne, 2004; McGinnis, 2011). While those challenges and dilemmas remain relevant in principle, within the context of this study, they are somewhat altered when examining the shift from

counsellor and psychotherapist to academic researcher. The necessary practice of reflexivity remains the same.

As a counsellor, the principal investigator has received a great deal of training in **self-awareness** and it forms an important part of counselling practice. It is an exercise in identifying and removing (temporarily) personal issues. 'baggage', and distracting or discordant emotion. The purpose is to 'empty' the self in order to be open and receptive to the words and feelings brought by the client to a therapeutic session – the better to work with them on behalf of the client. Will this self-awareness exercise serve as well in a new context, however; that of academic researcher? Or will the counsellor side be led, unconsciously, by the narrative of the participants because of the different context; that of an exploratory research study pursuing academic knowledge? And if the researcher is thus led, is this a negative result or does it become a form of 'bracketing' performed by a naïve researcher – with all the advantages that naivety entails?

If such a lack of self-awareness was present and therefore had the potential to mask evidence (Colbourne, 2004), then this resembles the activity of the unconscious mind: one cannot know that which cannot, voluntarily, be brought to mind. What can be done is to present the evidence as faithfully as possible, with details of context, so the reader can form their own judgements or conclusions. As this was an exploratory study, there are few outright conclusions contained within this report. The greater purpose was to elicit a data-rich, descriptive narrative from the participants with which to work.

While a nurse clinician may be tempted, in interview, to put their knowledge and professional practice at a participant's disposal (McGinnis, 2011), where they see the need or the opportunity, so might a counsellor be tempted to enter into therapy with a participant where they see distress or cognitive dissonance. The risk was certainly present in this study; it would have been easy to slip into counsellor mode with these participants, the majority of whom had been through so much. While the researcher believes this risk was avoided in interview, thinking around some of the psychological issues that emerged in analysis the temptation to consider psychological aspects of

the data was not resisted. This was the case, for example, with the issue of extreme distress described by a few regarding their experiences of compression bandaging. Because the level of distress appeared to be of a different order from that experienced by the majority and because it felt disproportionate (to the researcher) to the general response described regarding compression bandaging, the interest in a possible explanation of the psychology behind such a response was born. In the case of counselling and psychotherapy (particularly perhaps person-centred counselling) the distinction between the role and that of academic researcher seems less clear cut:

- Listening skills are central to both roles
- Psychological contact greatly facilitates the dialogue in both roles
- Empathy creates an atmosphere of trust, confidence and safety for the interlocuter (client or participant)
- Empathy allows the counsellor/researcher to walk with the client/researcher on the path they choose to take in their narrative
- Reticence of speech is optimal, allowing the client/participant to speak freely, without ‘derailment’ and with least possible interruption.

Indeed, it is believed (Rogers, 1995) that without psychological contact, empathy and active listening skills, therapy will not take place, so central are these skills to the process.

In this reflexive exercise, the researcher has attempted to explore the influence of their presence in the interview and in the research dynamic. Because there are several similarities between the working relationship between counsellor/client and researcher/participant it is possible that the line between the two was transgressed on occasion. However, it is unlikely, in the researcher’s opinion, that this had a substantial effect. While any such transgression might run contrary to the ‘rules’ of academic research (Colbourne, 2004), it is likely, overall, to have produced a more comfortable experience for the participant and a more data-rich interview as a result.

5.6.4 Tissue viability nurse recruitment and influence

While the recruitment of participants via tissue viability nurses ensured a seamless and virtually trouble-free recruitment procedure, and while this also meant that the recruitment of participants with venous leg ulcers was undertaken by specialists in the field, this choice of recruitment procedure was accompanied by some concern. See Section 3.3.1, Participants and procedure for details. Given that it is human nature to wish to be seen to excel, it is likely that the recruiting specialist nurses will have wanted to recruit efficiently for this research project and will have looked for 'good' participants (Lamb et al., 2016). They are likely to have looked for participants who believed in and were adherent to compression therapy. The nurses may have selected their 'star' patients, patients who would perhaps tell a good story – who had a successful or particularly interesting venous leg ulcer history to tell. This is possible despite careful emphasis during the briefing meetings to make it clear that 'star' patients were not sought. It was, in fact, preferable to recruit cases that represented the majority of venous leg ulcer patients, rather than extraordinary cases.

There is another potential influence to consider from asking tissue viability nurses to recruit participants for the study, rather than, say, district nurses. Tissue viability nurses represent a secondary level of nursing care for venous leg ulcer patients and possess specialist expertise. Only a proportion of the venous leg ulcer population will have had access to their care (Lamb et al., 2016). The criteria for referring venous leg ulcer patients to tissue viability clinics is not known to the researcher, but longevity of the ulcer journey and a lack of healing would seem to be likely factors. In their turn, these factors or considerations may have influenced the characteristics of the participants interviewed in this study.

5.7 Further research

5.7.1 Improvements desired and background to perspectives

This study is exploratory in nature and wide-ranging in its objective. As suggested above, to extend the study into a second phase in the form of a

discussion group might well yield more ideas and greater creativity. The aim would be to explore the participants' perceptions in yet more depth and how they attach meaning to their life with compression and ask again how this might be improved. A short summary of the findings from the study might be supplied prior to the groups as prompts for the discussion and allow the researcher to guide the conversation into areas of specific interest. The stimulation of discussing a topic with others is appealing to some, needing the interaction and feedback from others to develop their ideas.

5.7.2 Emotional response

The different levels of emotional response to compression and especially compression bandaging represents a new finding in the field of venous leg ulceration and requires further elucidation. Verifying (or otherwise) the difference found in this study, perhaps with the use of psychological profiling, would be an important step in the assessment of psychological affect in those with venous leg ulcers and possibly shed light on factors affecting adherence to therapy in this patient group.

5.7.3 Locus of control or patient–professional partnership

Locus of control is not a new concept, but perhaps its application to the study of those with venous leg ulceration is uncommon. In terms of the patient's involvement with their condition and their relationship with the HCP caring for them, this could be a useful model to pursue in further work. It may be found to act as a foundation marker to differentiate patients who desire involvement in the management of their condition and those who do not. This concept could also be extended to incorporate the moral and philosophical issues inherent in the patient/HCP relationships and the management issues around chronic illness (Katz, 2002; Snyder and Hanft, 2009). Patient participation, patient responsibility and the essential asymmetry in the relationship between HCP and patient has been a topic for debate for decades and further work is needed to find a way forward that is patient led.

5.7.4 Tension in the relationship between patient and nurse

Often, because of organisational problems, there can be conflict and dependency issues as well as positive bonds between patient and nurse. If the NHS is to ask the patient for more involvement in the management of their compression therapy, venous leg ulcers and venous insufficiency, the factors affecting the relationship between patient and nurse(s) involved in their care would merit further scrutiny. The relationship can affect locus of control, willingness to adhere to therapy, the level of shared management and patient well-being (see Figure 5.1: Therapeutic Triad). Much has been written on this topic already but if the testimony from the participants in this study are representative, there is a great deal more to be done.

5.7.5 Textile research

A proportion of the improvements sought by the participants in this study centred on improvements to the textiles employed in compression therapy. Whether their ideas are possible and/or practical might require further research to clarify. This might have to take place in a number of arenas: in conversation with those with venous leg ulcers, with manufacturers with an interest in new formulations of compression and with textile designers possessed of the expertise to translate the patients' needs into suitable products.

5.7.6 Nomenclature/listing/guidelines around 'sensitivities/allergies'

From existing research, it seems that accurate diagnosis of venous leg ulceration is not straightforward and quite often not undertaken at all (Guest et al., 2015). If that uncertainty extends even to the language used to describe skin reaction or skin condition in venous leg ulcer patients, then this seems unhelpful. A great many of the participants in the current research reported sensitivities or allergies to a variety of treatments and textiles used in their therapy. While it is acknowledged that these participants are patients and not HCPs, it might yet be useful to research and document the skin issues in this group of patients in order to develop a nomenclature. This

would provide consistent, accurate description and understanding of the skin reactions described.

5.8 Conclusion

This study has achieved its objective in exploring the patient's perspective of compression and compression textiles for venous leg ulcer treatment. It has added detailed data to work already published in the field but, more importantly, has identified new evidence, not known to have been covered before.

Prime new evidence relates to the overarching acceptance and recognition of compression therapy as the best treatment option available to this group of patients. The findings also offer preliminary evidence of areas where changes to current practice might yield positive results.

The study has highlighted the importance to venous leg ulcer patients of certain issues they face both with compression per se, their day-to-day lives and the textiles used in their compression garments. It has identified two very different levels of emotional response to being in compression, and it explores the possible importance of locus of control (and/or health locus of control) as a concept for describing the status of venous leg ulcer patients and as a potential marker for their orientation to compression, compression garments and the HCPs involved in their care.

It raises many questions and identifies many opportunities to broaden knowledge still further with more research. It is a step forward.

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Appendices

Appendix A

Classification System

A.1 Classification of compression bandages and hosiery

Taken from Clark (2003)

Table A.1: Classification of bandages

Class 1	retention bandages, used to retain dressings
Class 2	support bandages, used to support strains and sprains, e.g.: crepe Other bandages in this category can apply mild to moderate compression when particular application techniques are used and the bandages re-applied frequently
Class 3a	light compression, 14–17 mmHg at the ankle when applied in a simple spiral
Class 3b	moderate compression, 18–24 mmHg at the ankle when applied in a simple spiral
Class 3c	high compression, 25–35 mmHg at the ankle when applied in a simple spiral
Class 3d	extra high compression, up to 60 mmHg at the ankle when applied in a simple spiral

Table A.2: Classification of compression stockings

Class 1	light support, 14–17 mmHg at the ankle, used to treat varicose veins
Class 2	medium support, 18–24 mmHg at the ankle, used to treat more severe varicosities and to prevent VLUs
Class 3	strong support, 25–35 mmHg at the ankle, used to treat severe chronic hypertension, severe varicose veins, and to prevent VLUs

A.2 Compression systems

Taken from Cullum (2001)

Table A.3: Compression systems

Short stretch/inelastic	wool, plus 1–3 rolls of short stretch bandage
Inelastic paste system	paste bandage plus support bandage
Unna's boot	non-compliant paste bandage
3-layer elastic multi-layer	orthopaedic wool, plus class 3c bandage (crepe), plus shaped tubular bandage
4-layer elastic multi-layer	orthopaedic wool, plus support bandage (crepe), plus class 3a bandage, plus cohesive bandage

Appendix B

Search Strategies

B.1 Details of search strategy for focused search

B.1.1 Search terms used

Compression stocking OR compression bandage OR leg compression OR
exp compression OR compression therapy OR compression garment

AND

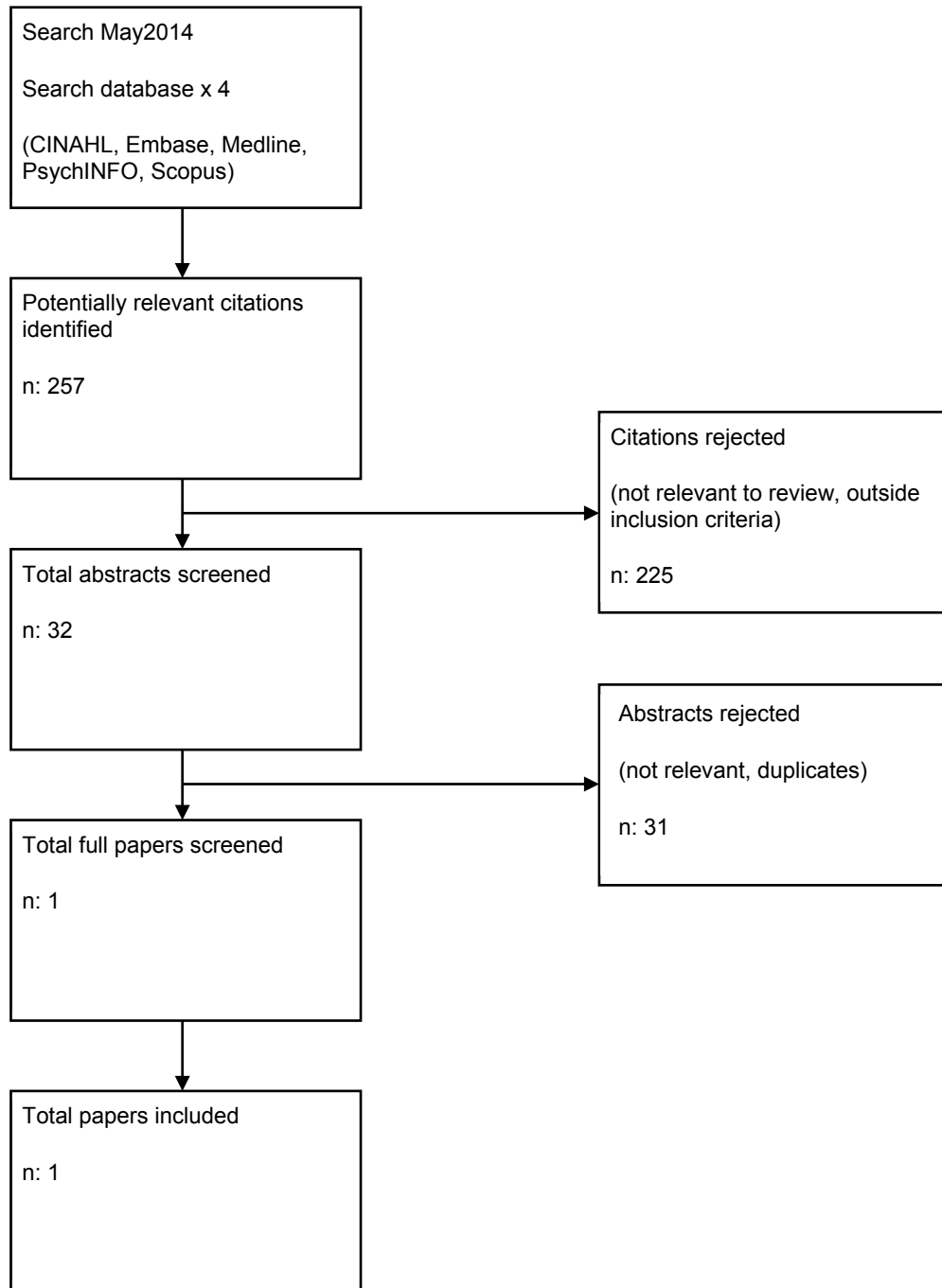
Patient* adj2 experience* OR attitude* OR perception* OR view* OR feeling*
OR well* OR psychol* OR subje* OR quality*

AND

Leg ulcer*

B.1.2 PRISMA diagram

Figure B.1: Summary flowchart of literature review



B.2 Details of search strategy for broad-based search (strings employed)

B.2.1 Search terms used

(lived experience OR living with)

AND

MH (MH leg ulcer or TI (varicose ulcer* OR venous ulcer OR leg ulcer OR stasis ulcer OR crural ulcer) OR AB (varicose ulcer OR venous ulcer OR leg ulcer OR stasis ulcer OR crural ulcer)) OR (lower extremity n3 ulcer OR AB lower extremity n3 ulcer)

AND

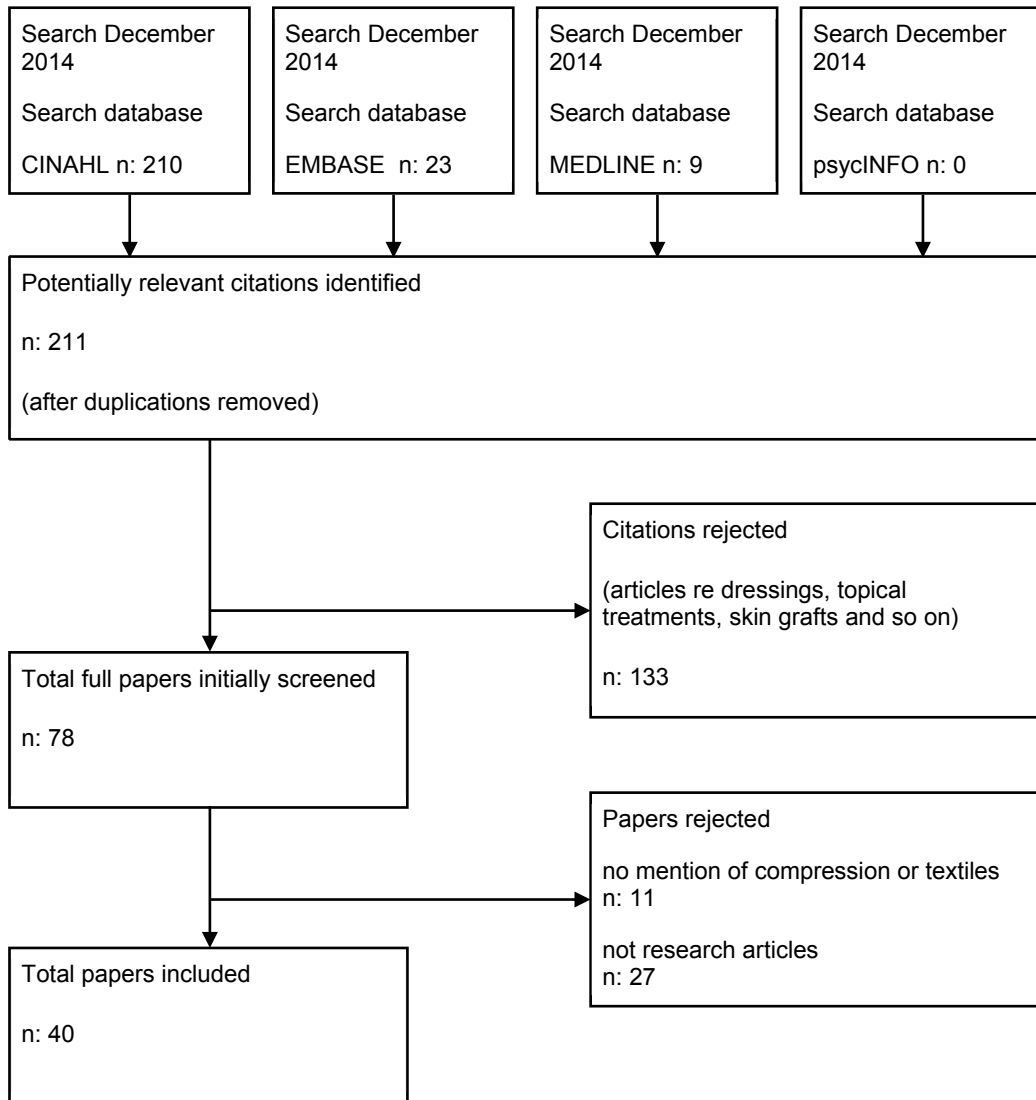
MH (MH compression therapy or MH bandaging techniques) or (TI compression or AB compression) or TI (stocking or hosiery) or AB (stocking or hosiery) or (TI bandage or AB bandage) or (TI wrap or AB wrapp)

AND

research

B.2.2 PRISMA flowchart of broad-based literature review

Figure B.2: Flowchart of broad-based literature review



B.3 Papers derived from broad based search

Table B.1: Comments and lived experience relating to compression therapy and the textiles used:

Quantitative. 12 papers

Study, year country	Type of study	Main topic	Sample size	Replicability	Compression data
Brereton et al., 1997, UK	Experimental arm with control	Tolerance of leg ulcer treatments	301	Yes	Attributed four-layer discomfort “ leakage “ odour “ appearance/self-consciousness “ fits well
Collins et al., 1997, UK	Experimental arm with control	Problems associated with patient satisfaction surveys in venous leg ulcers	233	Yes – except that this is part of a larger, RCT	Attributed Comfort of bandage (+ve)

Study, year country	Type of study	Main topic	Sample size	Replicability	Compression data
Fife et al., 2007, USA	Database query language for a research consortium agreement (Intellicure Inc)	Problems with self-bandaging	547	Not unless I belong to the research consortium	Not Attributed Limited mobility Problems w bathing Problems with dressing Problems with going to the loo
Franks et al., 1995, UK	Randomised trial of two hosiery products	Risk factors for leg ulcer recurrence	188	Yes – if sponsorship from Medi (UK) Ltd was available again	Attributed Hosiery ease of donning and doffing Discomfort Skin irritation Redness/itching Rash Swelling

Study, year country	Type of study	Main topic	Sample size	Replicability	Compression data
Jones, 2009, USA	Data extraction from medical records on four sites imported into SPSS	Why VLUs do not heal	183	No – Similar sites and access in the UK would not exist Nor is healthcare structured in the same way	Not Attributed Discomfort Exudate Poor application of bandage Pain
Lindholm et al., 1993, Sweden	Quantitative assessment using Nottingham Health Profile	Quality of Life	125	Yes – clear description and standardised assessment tool	Not Attributed Lack of energy Pain Sleep disturbance Emotional reaction Social isolation Physical mobility
Miller et al., 2011, Australia	Part of an RCT	Predicting concordance	209	Not easy – the paper is based on data from an RCT that omits several possibly relevant variables	Not Attributed Pain

Study, year country	Type of study	Main topic	Sample size	Replicability	Compression data
Moffat et al., 2008, UK, USA, Canada	Randomised controlled cross-over evaluation	Comparison of a two-layer and a four-layer compression product	81	<p>No – Exclusion criteria fluid and not clearly defined</p> <p>Previous treatment and history not defined</p> <p>One of the outcome measures not appropriately discussed.</p> <p>Otherwise very clear</p>	<p>Attributed</p> <p>72% preference for two-layer system</p> <p>Not attributed</p> <p>Redness</p> <p>Eczema</p> <p>Folliculitis</p> <p>Wound infection</p> <p>Pain at wound site</p>
Pieper, 1996, USA	Retrospective analysis	Venous ulcer healing in current and former users of injected drugs	172	<p>Possibly – it would depend on record-keeping re drug users in UK.</p> <p>Clear description of procedures</p>	<p>Attributed</p> <p>Cost of compression stockings</p>

Study, year country	Type of study	Main topic	Sample size	Replicability	Compression data
Price et al., 2008, International (15 country study)	Cross-sectional descriptive questionnaire design	Dressing related pain in patients with chronic wounds	2018	<p>Yes – although the words listed for pain might lose something in translation despite the back-translation reported.</p> <p>Cultural differences mentioned but not sufficiently discussed</p> <p>The size of the study would be a challenge.</p>	<p>Attributed</p> <p>Slippage</p> <p>Not Attributed</p> <p>Pain</p> <p>Impaired mobility</p> <p>Difficulty bathing</p> <p>Leakage</p> <p>Odour</p> <p>Specific product make dressing change less painful</p> <p>Locus of control</p>
Roe et al., 1993 UK,	Quant: Interview	Assessment of community nurses practice	146	Possibly - but because of changes in recommended practice the questionnaire might require updating and revalidation	<p>Not Attributed</p> <p>Pain</p>

Study, year country	Type of study	Main topic	Sample size	Replicability	Compression data
Wissing & Unosson, 1999, Sweden	Quantitative: assessment scale and interview	Impact of nutritional status	70	Yes– providing a validated translation of the questionnaire could be made available	Not Attributed Pain Discomfort Problems with mobility

Table B.2: Comments and lived experience relating to compression therapy and the textiles used:

Mixed Method Research: 3 papers

Study, year, country	Type of study	Main topic	Sample size	Replicability	Compression data
van Hecke et al., 2011, Belgium	Mixed method	Adherence to leg ulcer lifestyle advice	26	Yes – if translation of materials validated and cultural differences accounted for	Attributed Greater acceptance of compression therapy

Study, year, country	Type of study	Main topic	Sample size	Replicability	Compression data
Jones et al., 2008, UK	Mixed method (qualitative phase purports to follow van Manen – essentially Hermeneutic phenomenology)	Impact of exudate and odour from chronic venous ulceration	196 and 20	Difficult – as the article draws on a wider study reported on earlier Description of procedure a little to sparse	Attributed Increased exudate from inadequate compression Discomfort of wet smelly bandage Shame of wet smelly bandage Not Attributed Leaking Odour Anxiety and depression

Study, year, country	Type of study	Main topic	Sample size	Replicability	Compression data
Price & Harding, 2004, UK	Mixed method	HRQoL in patients with chronic leg wounds	23 and 124	Yes – theoretically. But the work on HRQoL in venous leg ulcers has moved on since 2004	Attributed Discomfort with bandages Not Attributed Pain Mobility Problems w footwear Difficulty bathing Odour Leakage/exudate

Table B.3: Comments and lived experience relating to compression therapy and the textiles used:

Literature Reviews: 4 papers

Study, year, country	Type of Study	Main topic	Number of articles included in review	Replicability	Compression data
Briggs and Flemming, 2007, UK	Systematic literature review (synthesis of qualitative research))	Living with leg ulceration	12	Yes – transparent descriptions	Attributed Wet bandages (shame) Problems w footwear Having to wear trousers Not Attributed Pain Odour Leakage Itch Infection
Briggs and Flemming, 2007, UK continued	Systematic literature review (synthesis of qualitative research))	Living with leg ulceration	12	Yes – transparent descriptions	Life change Problems w bathing Embarrassment Altered body image Poor self-esteem

Study, year, country	Type of Study	Main topic	Number of articles included in review	Replicability	Compression data
McMullen, 2004, UK	Literature review	Relationship between pain and leg ulcers	Not stated – or at least, not made clear Maybe 8	No	Attributed Leakage Odour Pain from ill-fitting bandages Slippage Having to wear trousers Psychological impact Not Attributed Odour Leakage Hope vs experience Mobility dependent on levels of pain

Study, year, country	Type of Study	Main topic	Number of articles included in review	Replicability	Compression data
Parker, 2012, UK	Literature review	Psychosocial effects of living with a leg ulcer	11	No – insufficient detail on inclusion/exclusion	Attributed Reduced mobility Poor bandaging technique Having to wear trousers Not Attributed Pain Odour Leakage Healing process Social isolation Altered body image

Study, year, country	Type of Study	Main topic	Number of articles included in review	Replicability	Compression data
Persoon, 2004, Netherlands	Systematic literature review Qualitative and quantitative	The impact of leg ulcers on daily life	37	No – do not think searching two databases would be sufficient BUT procedure very clearly set out so in principle, possible	Attributed Problems w footwear Problems w bathing Not Attributed Pain Disturbed sleep Reduced mobility Regret/anger Depression Loss of will power Loss of control Helplessness Hopelessness Loss of femininity Itching Odour Leakage Low self-esteem Less energy

Table B.4: Comments and lived experience relating to compression therapy and the textiles used:

Qualitative Research: 21 papers

Study, year, country	Type of study	Main themes	Sample size	Replicability	Compression data
Bentley, 2006, UK	Case study	Improving QoL in venous leg ulceration	1	Yes	Attributed Patient reluctance to comply with optimal compression device Discomfort from compression device (off the shelf)
Brown, 2001, UK	Grounded theory Focus groups of 20 per group?	Self-efficacy theory (Bandura) and coping strategies	18 Nurses 28 pts in 4 groups 80 pts and carers in 4 groups	No – this study is part of a larger piece of research and the description of the research focus in this paper is not clear	Attributed Negative impact on body image Having to wear trousers Difficulties donning and doffing stockings Poor bandaging skills Not Attributed Denial of condition Problems w bathing Locus of control

Study, year, country	Type of study	Main themes	Sample size	Replicability	Compression data
Chase, Melloni & Savage, 1997, USA	Phenomenology van Manen	The lived experience of venous ulcer disease	37	No – No description of recruitment strategy. An ad hoc study: some kept a diary for 12 weeks, others didn't. Weekly observations and field notes Seven interviews	Attributed Slows you down (Unna's boot) Difficulty with bathing Difficulty with clothes Unna's boot aids objectifying the ulcer/leg Compression hose irritate skin Compression hose uncomfortable Compression hose hot
Douglas, 2001, UK	Grounded theory – yet there is no mention of theory generation	Living with a chronic leg ulcer	8	Probably	Attributed Pain Leakage Odour Sleep disturbance Embarrassment Loss of control

Study, year, country	Type of study	Main themes	Sample size	Replicability	Compression data
Ebbeskog & Ekman, 2001, Sweden	Hermeneutic phenomenology Ricœur	Elderly peoples' lived experience of venous leg ulcer (age 74-89) Freedom and imprisonment	15	Possibly – Sweden has different healthcare system and bureaucracy Clear procedurally	Attributed Discomfort Feeling trapped/loss of freedom Having to wear trousers Shame in social context Difficulties with footwear Difficulties with bathing Impaired mobility Wound irritation Slippage Leaking exudate thro bandage (shame) Symbol of vulnerability Symbol of 'broken' body

Study, year, country	Type of study	Main themes	Sample size	Replicability	Compression data
Ebbeskog & Emami, 2005, Sweden	Phenomenology IPA	Patient expert on dressing changes	15	Possibly – Sweden has different healthcare system and bureaucracy Clear procedurally	Attributed Feeling bad with one bandage (Comprilan single layer but OK w another) Compression causing pain Recommended bandage Not always available Use of incorrect bandage Not Attributed Locus of control

Study, year, country	Type of study	Main themes	Sample size	Replicability	Compression data
Edwards, 2003, UK	Hermeneutic phenomenology	Non-compliance	14	Possibly, No explanation of how demographics were collected.	Attributed Pain of compression bandaging Poor application technique of compression Poor exudate control from bandage Bulky bandaging prevents ordinary footwear Irritating the ulcer Poor relationship with HCP re compression therapy
Flaherty, 2005, UK	Semi-structured interviews Refers to 'immersion' but does not mention any methodology	The views of patients living with healed venous leg ulcers	10	No	Attributed Discomfort from stocking Denial/refusal to rely on stocking Positive attitude to continuing use of stocking Stockings more socially acceptable than bandages

Study, year, country	Type of study	Main themes	Sample size	Replicability	Compression data
Green et al. 2013, UK & Australia	Phenomenology Unstructured interview	Patient perspectives of their leg ulcer journey	8	Possible – different healthcare system in Australia	Attributed Difficulty with bathing Difficulty with footwear Having to hide bandages (trousers) Not Attributed Pain Shame/embarrassment Odour Leakage Difficulty with travel after dressing change Reduced mobility Depression Poor self esteem Disturbed sleep

Study, year, country	Type of study	Main themes	Sample size	Replicability	Compression data
Haram & Dagfinn, 2003, Norway	Descriptive, exploratory Martinsen's theoretical framework (care as an analytical and philosophical entity)	Patient as expert on leg ulcer treatment by visiting nurse	9	Would require study of relevant theory before an answer on replicability was possible	Attributed Incorrect bandaging causing new ulcers Use of salve/ointment to sooth irritation Moving about before compression applied/reapplied – pain
Hopkins, 2004, UK	Hermeneutic phenomenology Heidegger Interviews and patient diary	Patients' coping strategies for coping with non-healing ulcers	5 (all known to the author)	Yes – clear and transparent, all but discussion on ethics	Attributed Constant vigilance required re bandage (shame) Not Attributed Pain Leakage seen through bandage Odour

Study, year, country	Type of study	Main themes	Sample size	Replicability	Compression data
Hyde et al., 1999, Australia	Phenomenology Diekelman	Older women's experience of living with chronic leg ulceration	12	Yes	Attributed Odour (at night) requiring extra bandage to prevent Difficulties w footwear Not Attributed Locus of control Life changing Patient expert Pain Leakage Feelings of helplessness Having to wear trousers Embarrassment Loneliness

Study, year, country	Type of study	Main themes	Sample size	Replicability	Compression data
Kapp et al., 2014, Australia	Case study	Living with and self-treating	1	Yes – but why would you? Consists mostly of verbatim chunks from pt.	Attributed Bandage slippage Not Attributed Ulcer journey Independence in self-care Loss of independence upsetting Pain Cost of materials Vigilance Need for education/information
Krasner, 1998, USA,	Hermeneutic phenomenology Heidegger Diekelman	Living with the pain and suffering	14 patients 6 nurses	20 month fieldwork period might be difficult but the process is clearly described	Not Attributed Pain: Nociceptive Neuropathic New vs old Frustration Swelling Life changes

Study, year, country	Type of study	Main themes	Sample size	Replicability	Compression data
Mudge et al. 2006, UK	Phenomenological approach 1 focus group 'Content analysis' not elaborated. Question congruence with the claimed phenom approach	Adherence	6	No – insufficient detail. Would not choose focus group for this topic	Attributed Discomfort from poorly applied compression Sleep disruption Difficulties w footwear Embarrassment Difficulty w bathing Not Attributed Leakage Odour

Study, year, country	Type of study	Main themes	Sample size	Replicability	Compression data
Rich & McLachlan, 2003, UK	Descriptive phenomenology Semi-structured interview	Effect of leg ulcer on daily life	8	No – insufficient detail and clarity re processes	Attributed Shame re bandages (says to others for a sprained ankle) Discomfort Compression applied under duress Not Attributed High levels of exudate Having to wear trousers Problems with footwear
da Silva et al. 2014, Brazil	Semi structured interviews, content analysis	Influence of social networks on therapeutic itineraries	14	Difficult - The social networks of Brazil do not appear to resemble those in the UK	Not Attributed Anxiety Vigilance Lost independence Shame/embarrassment Help from carers and neighbours Emotional response

Study, year, country	Type of study	Main themes	Sample size	Replicability	Compression data
Stevens, 2006, UK	One interview and literature review (case study)	Impact of venous leg ulcer pain	1	Yes	Attributed Pain from compression due to poor technique Not Attributed Pain Reduced mobility Sleep disturbance Anxiety Hopelessness Depression Embarrassment Self-efficacy Life change Locus of control

Study, year, country	Type of study	Main themes	Sample size	Replicability	Compression data
Tobón, 2010, USA	Case study	Complementary and Alternative medicine for VLU in elderly	1	Yes – if all alternative treatments available in UK	Attributed Dislike tight ‘things’ on legs Not Attributed Reduced mobility Heaviness in legs Pain Discomfort Anxiety
Walshe, 1995, UK	Claims phenomenology but actually pragmatic	Patients’ experience of living with a venous leg ulcer	13	Probably not – incongruences and lack of clarity about processes	Attributed Difficulty with bathing Too tight (bandages) discomfort Difficulty with clothes Not Attributed Self-consciousness
Wellborn and Maceri, 2014, USA	Semi- structured focus groups & interviews ‘Phenomenology’?	Lived experience of venous leg ulcers and venous insufficiency	10	No – method and analysis insufficiently described	Attributed Discomfort

B.4 Key to studies listed in Figure 2.1: Network of factors drawn from literature review

Quantitative studies

1. BRERETON, L. et al. 1997. Patients' tolerance of leg ulcer treatments
2. COLLINS, K. et al. 1997. Problems associated with patient satisfaction surveys.
3. FIFE, C., WALKER, D., THOMSON, B. and CARTER, M. 2007. Limitations of daily living activities in patients with venous stasis ulcers undergoing compression bandaging: problems with the concept of self-bandaging.
4. FRANKS, P. J. et al. 1995. Risk factors for leg ulcer recurrence: a randomised trial of two types of compression stocking.
5. JONES, K. R. 2009. Why do chronic venous leg ulcers not heal?
6. LINDHOLM, C., BJELLERUP, M., CHRISTENSEN, O. B. & ZEDERFELDT, B. 1993. Quality of life in chronic leg ulcer patients.
7. MILLER, C. 2011. Predicting concordance with multilayer compression bandaging.
8. MOFFATT, C. et al. 2008. A randomised controlled 8-week cross-over clinical evaluation of the 3M Coban 2 layer Compression System versus Profore to evaluate the product performance in patients with venous leg ulcers.
9. PIEPER, B. 1996. A retrospective analysis of venous ulcer healing in current and former users of injected drugs.
10. PRICE, P. E. et al. 2008. Dressing-related pain in patients with chronic wounds: an international perspective.
11. ROE, B. H. et al. 1993. Assessment, prevention and monitoring of chronic leg ulcers in the community.
12. WISSING, U. and UNOSSON, M. 1999. The relationship between nutritional status and physical activity, ulcer history and ulcer-related Problems in patients with leg and foot ulcers.

Mixed Method Studies

13. VAN HECKE, A. et al. 2011. Adherence to leg ulcer lifestyle advice: qualitative and quantitative outcomes associated with a nurse-led intervention.
14. JONES, J. E., ROBINSON, J., BARR, W. and CARLISLE, C. 2008. Impact of exudate and odour from chronic venous leg ulceration.
15. PRICE, P. and HARDING, K. 2004. Cardiff wound impact schedule: the development of a condition-specific questionnaire to assess health-related quality of life in patients with chronic wounds of the lower limb.

Systematic and Literature reviews

16. BRIGGS, M. and FLEMMING, K. 2007. Living with Leg Ulceration: a synthesis of qualitative research.
17. MCMULLEN, M. 2004. The relationship between pain and leg ulcers: a critical review.
18. PARKER, K. 2012. Psychosocial effects of living with a leg ulcer. *Nursing Standard*, 26, 52-62.
19. PERSOON, A. et al. 2004. Leg ulcers: a review of their impact on daily life.

Qualitative Studies

20. BENTLEY, J. 2006. Improving Quality of Life in Venous Leg Ulceration: a case study.
21. BROWN, A. 2010. Managing chronic venous leg ulcers part 2: time for a new pragmatic approach.
22. CHASE, S.K. et al. 1997. A forever healing, the lived experience of venous ulcer disease.
23. DOUGLAS, V. 2001. Living with a chronic leg ulcer: an insight into patients' experiences and feelings.
24. EBBESKOG, B. and EKMAN, S.-L. 2001. Elderly persons' experiences of living with venous leg ulcer: living in a dialectical relationship between freedom and imprisonment.
25. EBBESKOG, B. and EMAMI, A. 2005. Older patients' experience of dressing changes on venous leg ulcers: more than just a docile patient.

26. EDWARDS, L. 2003. Why patients do not comply with compression bandaging.
27. FLAHERTY, E. 2005. The view of patients living with healed venous leg ulcers.
28. GREEN, J. et al. 2013. Patient perspectives of their leg ulcer journey.
29. HARAM, R.B. and DAGFINN, N. 2003. Errors and discrepancies: a patient perspective on leg ulcer treatment at home.
30. HOPKINS, A. 2004. Disrupted Lives: investigating coping strategies for non-healing leg ulcers.
31. HYDE, C. et al. 1999. Older women's experience of living with chronic leg ulceration.
32. KAPP, S. et al. 2014. Perspectives on living with and self-treating venous leg ulcers: a person's story and health care perspective.
33. KRASNER, D. 1998. Painful venous ulcers: themes and stories about living with the pain and suffering.
34. MUDGE, E. et al. 2006. Living with venous leg ulceration: issues concerning adherence.
35. RICH, A. and MCLACHLAN, L. 2003. How living with a leg ulcer affects people's daily life: a nurse-led study.
36. DA SILVA, D.C. et al. 2014. Influence of social networks on the therapeutic itineraries of people with venous ulcer.
37. STEVENS, H. 2006. The impact of venous leg ulcer pain: what can the patient teach us?
38. TOBÓN, J. 2010. Complementary and alternative medicine for older adults with venous leg ulcer pain.
39. WALSH, C. 1995. Living with a venous leg ulcer: a descriptive study of patients' experiences.
40. WELLBORN, J. and MOCERI, J.T. 2014. The lived experiences of persons with chronic venous insufficiency and lower extremity ulcers.

Appendix C

Interview and Briefing Guides

C.1 Interview guide

Thank you very much for agreeing to help me.

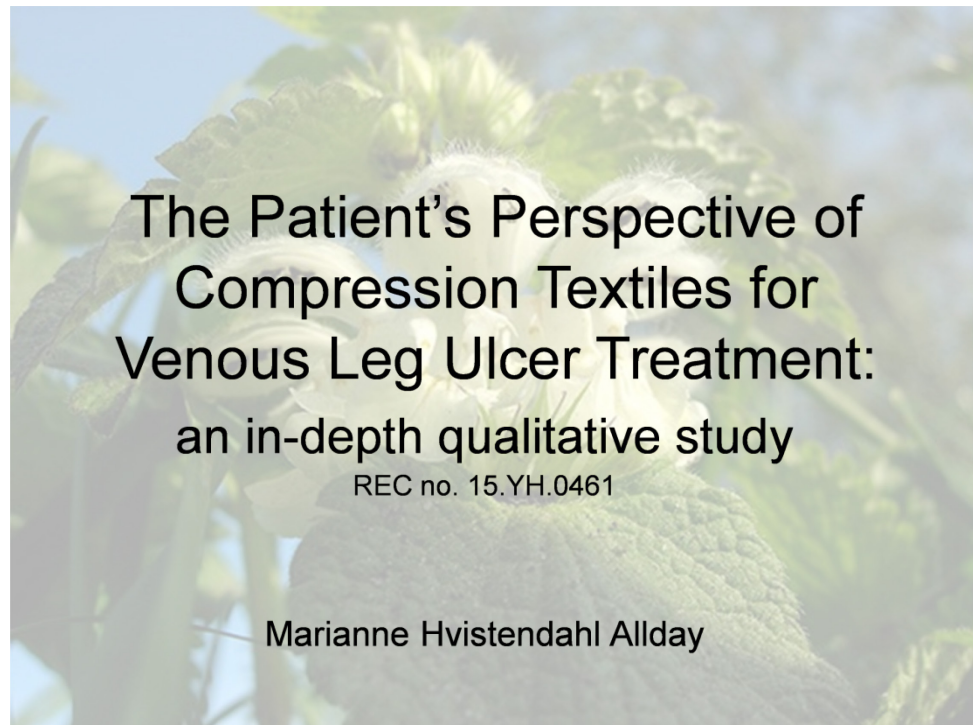
1. Can you tell me about your leg ulcer(s)?
How did they start?
What has it been like?
2. I wonder if you could tell me about your experiences with compression therapy, (you know, tight bandages and stockings)?
3. How do you feel about the recovery/healing process?
4. How do you feel in your body or about your body?
5. Tell me how physical activity affects you.
6. How mobile are you?
7. What changes have occurred to your identity as an individual?
8. Has your body image or self-image changed?
9. What are your thoughts about the future?

C.2 Briefing for tissue viability nurses

Presentation for nursing teams

Slide

1



Slide

2



Slide
3

Gaps in Published Research

- There is some research in this area exists
BUT
- Nothing that **focuses**, in-depth, on what the patient thinks and feels about their compression bandages and hosiery
- Lots of scraps of information, as incidental data
 - Stray comments not followed up in detail by researchers

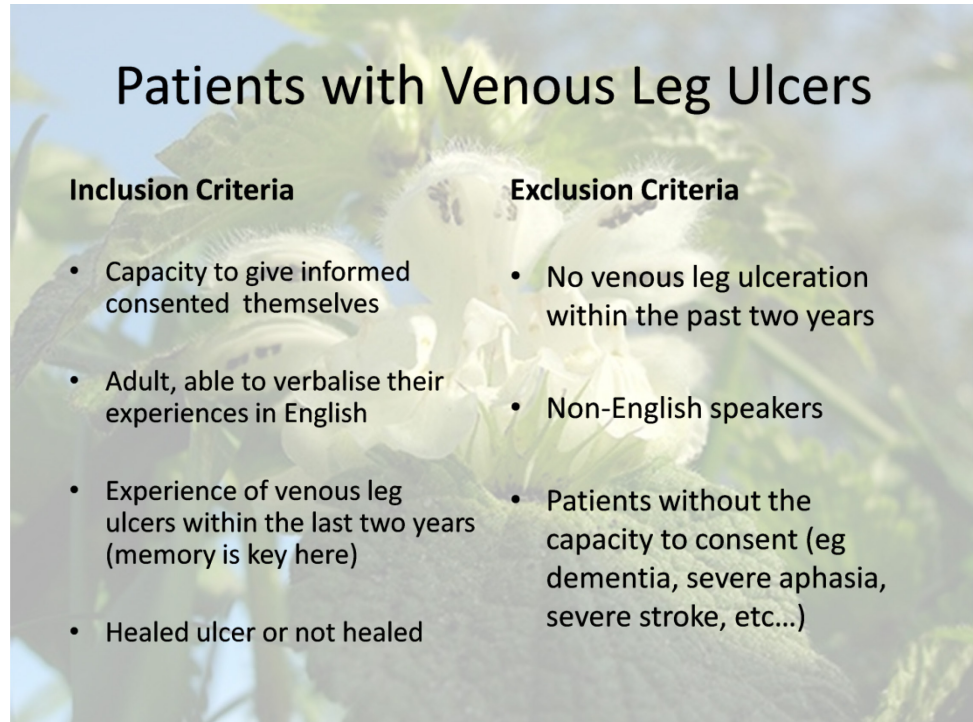
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An example: reports of pain

Is it due to the ulcer or the bandaging?



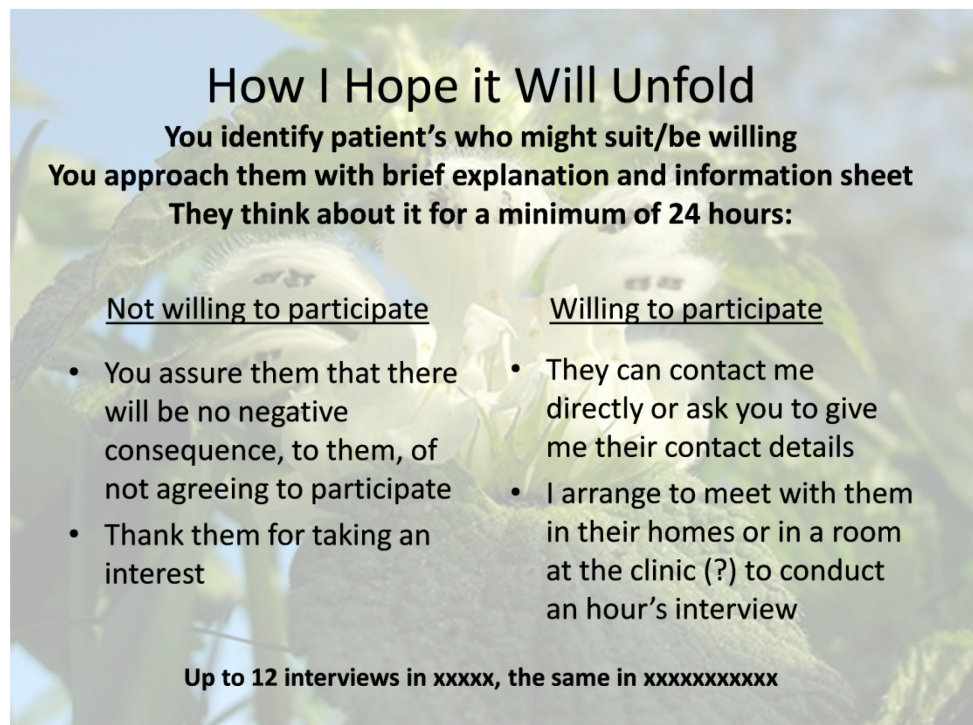
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Patients with Venous Leg Ulcers

Inclusion Criteria	Exclusion Criteria
<ul style="list-style-type: none">• Capacity to give informed consented themselves• Adult, able to verbalise their experiences in English• Experience of venous leg ulcers within the last two years (memory is key here)• Healed ulcer or not healed	<ul style="list-style-type: none">• No venous leg ulceration within the past two years• Non-English speakers• Patients without the capacity to consent (eg dementia, severe aphasia, severe stroke, etc...)

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6



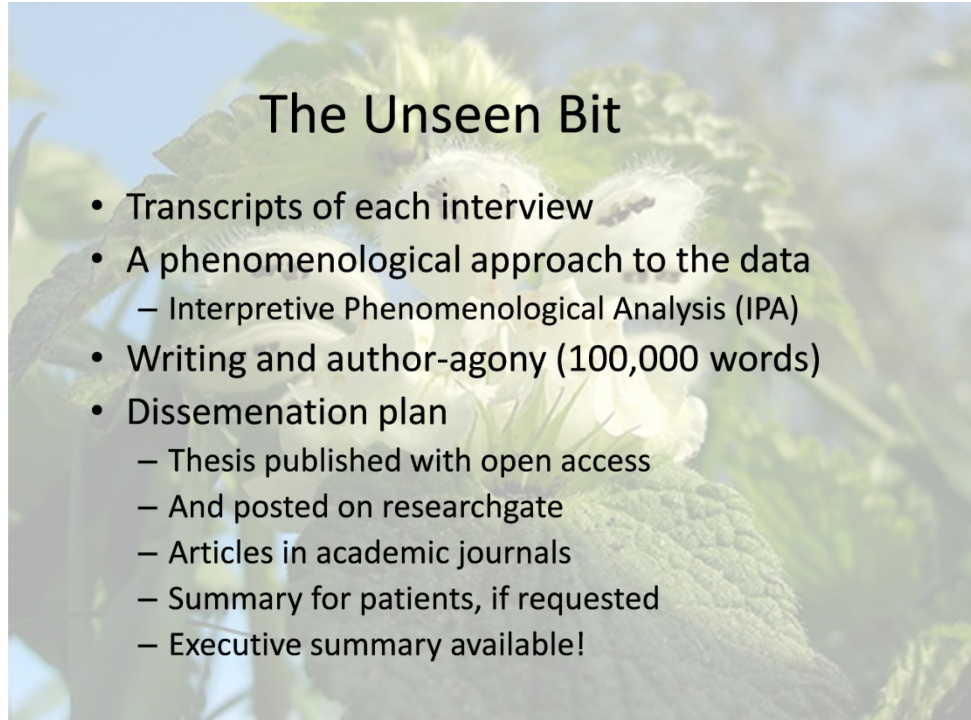
How I Hope it Will Unfold

You identify patient's who might suit/be willing
You approach them with brief explanation and information sheet
They think about it for a minimum of 24 hours:

<u>Not willing to participate</u>	<u>Willing to participate</u>
<ul style="list-style-type: none">• You assure them that there will be no negative consequence, to them, of not agreeing to participate• Thank them for taking an interest	<ul style="list-style-type: none">• They can contact me directly or ask you to give me their contact details• I arrange to meet with them in their homes or in a room at the clinic (?) to conduct an hour's interview

Up to 12 interviews in xxxxx, the same in xxxxxxxxxxxx

Slide
7



The Unseen Bit

- Transcripts of each interview
- A phenomenological approach to the data
 - Interpretive Phenomenological Analysis (IPA)
- Writing and author-agony (100,000 words)
- Dissemination plan
 - Thesis published with open access
 - And posted on researchgate
 - Articles in academic journals
 - Summary for patients, if requested
 - Executive summary available!

Slide
8



With enormous gratitude...

To you, especially, for helping me to make this happen – can't do it without you !

For any constructive criticism, questions, suggestions, guidance

To my illustrious sponsors, the Worshipful Company of Clothworkers

To my amazing supervisors:

- Prof. Andrea Nelson
- Dr Elaine McNichol
- Dr Jo Gilmartin
- Dr Una Adderley

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C.3 Ethics approval letter



Health Research Authority

A Research Ethics Committee established by the Health Research Authority

Yorkshire & The Humber - Bradford Leeds Research Ethics Committee
Room 001
Jarrow Business Centre
Viking Industrial Park
Rolling Mill Road
Jarrow
NE32 3DT

Telephone: 0191 428 3566

12 October 2015

Mrs Marianne Hvistendahl Allday
Room 3.35, Baines Wing
School of Healthcare, Faculty of Medicine and Health
University of Leeds
LS2 9JT

Dear Mrs Hvistendahl Allday

Study title:	The Patient's Perspective of Compression Textiles for Venous Leg Ulcer Treatment: an in-depth qualitative study
REC reference:	15/YH/0461
IRAS project ID:	156535

The Proportionate Review Sub-committee of the Yorkshire & The Humber - Bradford Leeds Research Ethics Committee reviewed the above application by email correspondence.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager, Katy Cassidy, nrescommittee.yorkandhumber-bradfordleeds@nhs.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Ethical opinion: Favourable Opinion

On behalf of the Committee, the sub-committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission (“R&D approval”) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research

A Research Ethics Committee established by the Health Research Authority Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation’s role in the study is limited to identifying and referring potential participants to research sites (“participant identification centre”), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see “Conditions of the favourable opinion”).

Summary of discussion at the meeting

Ethical issues raised, noted and resolved in discussion:

Informed consent process and the adequacy and completeness of participant information

The Committee reviewed the application and supporting information and raised the following queries:

- The Committee noted that the Participant Information Sheet - needs the word audio added to page 2, line 3 ‘The interview will be audio recorded...’

You informed the Committee that the word ‘audio-‘ has been added to the participant information sheet wherever the words ‘recorded’ or ‘recordings’ appear (twice on page 2 and twice on page 3).

- The Committee agreed that the Consent Form needs a sentence saying the interview will be audio recorded and add this to the first box/part of the form.

You confirmed that the first box on the consent form now reads ‘I confirm that I have read and understood the information sheet and covering letter, Version 1, explaining the above research project, that our conversation will be audio-recorded, and that I have had the opportunity to ask questions about the project.’

- The Committee agreed that the Consent Form needs to include the regulatory authorities paragraph: The consent form should include that standard text about review by regulatory authorities - The consent form to include the standard paragraph - ‘I understand that relevant sections of my medical notes and data collected during the study may be looked at by responsible individuals from regulatory authorities or from the NHS Trust where it is relevant to this research study. I give permission for these individuals to have access to my records’. (If applicable).

You confirmed that the consent form was revised to include the standard regulatory authorities paragraph.

The Committee was satisfied with the responses and the revised documentation.

The PR Sub-Committee agreed that this was a well presented study with no material ethical issues.

Approved documents

The documents reviewed and approved were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering letter on headed paper [Covering letter]	1	12 August 2015
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [U of Leeds Indemnity]		
Interview schedules or topic guides for participants [Discussion guide]	version 1	12 August 2015
IRAS Checklist XML [Checklist_07102015]		07 October 2015
Other [CV of supervisor, Dr McNichol]	1	12 August 2015
Other [CV of supervisor, Dr Gilmartin]	1	12 August 2015
Other [CV of supervisor, Mrs Adderley]	1	12 August 2015
Other [Information Sheet]	2	07 October 2015
Other [Consent form]	2	07 October 2015
REC Application Form [REC_Form_01102015]		01 October 2015
Research protocol or project proposal [Protocol]	1	12 August 2015
Summary CV for Chief Investigator (CI) [Mrs Hvistendahl Allday]	version 1	12 August 2015
Summary CV for supervisor (student research) [CV of primary supervisor]	Prof. Nelson	

Membership of the Proportionate Review Sub-Committee

The members of the Sub-Committee who took part in the review are listed on the attached sheet.

There were no declarations of interest.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

A Research Ethics Committee established by the Health Research Authority

After ethical review

Reporting requirements

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project.

15/YH/0461	Please quote this number on all correspondence
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Yours sincerely

pp

Dr Janet Holt

Chair

Email: nrescommittee.yorkandhumber-bradfordleeds@nhs.net

Enclosures: List of names and professions of members who took part in the review

"After ethical review – guidance for researchers" [SL-AR2]

Yorkshire & The Humber - Bradford Leeds Research Ethics Committee

**Attendance at PRS Sub-Committee of the REC meeting via email
correspondence**

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Dr Rhona Bratt	Retired Multi-media Project Manager	Yes	
Dr Janet Holt (Chair)	Senior Lecturer	Yes	
Mr. Andy Scally	Senior Lecturer	Yes	

Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>
Mr Neil McCaffery	Deputy Regional Manager

Appendix D

Documents for Participant Recruitment

D.1 Covering letter

Date

Dear service user,

My name is Marianne and I am a student at the University of Leeds, at the School of Healthcare.

I am writing to you because (community nurse) says she helps a number of people with venous leg ulcers who live at home – of whom you are one. She/he has kindly agreed to give you some written information about the study I am doing as part of my course, in the hope that you will agree to help me.

I do not know who you are or where you live and that is how it will remain, unless you say you would be prepared to help me. I do not wish you to feel under any pressure from me or anyone else to help me with my research and it is important that you feel free to choose what suits you best. If you do agree to help me, your name and contact details will be passed to me so that I can make contact with you, directly. Or you can call me yourself to make a date to meet.

My research project is all about the thoughts and feelings of people with venous leg ulcers and what their experience is/has been of living with these leg wounds. In order to gather the information, I propose to come to your house and ask you to tell me all about your experience of venous leg ulcers.

Attached are a few pages that tell you all about the study in more detail and explain why this research is important. Please read them before you decide whether or not to help me.

I hope you will feel able to take part in this research but, if not, I respect your decision.

Thank you for reading this letter.

Yours,

Marianne Hvistendahl Allday

Tel: 0113 343 3058

Email: hcmha@leeds.ac.uk

D.2 Patient information sheet

Research Project Title: The Patient's Perspective of Compression Textiles for Venous Leg Ulcer Treatment: an in-depth qualitative study

Information Sheet for Participants

Interviews about what you think and feel about having compression therapy

I would like to invite you to take part in a research study. Please read this information sheet before you decide to take part. It will explain why the research is being done and what it will involve. If there is anything you are unclear about after you have read this information, please feel free to ask questions. I can be contacted by email or by phone using the contact details at the end of this document.

Purpose of study

Although there has been a bit of research about people with venous leg ulcers and how they cope, there hasn't yet been enough information-gathering for us to understand fully how patients feel about the ulcer(s) they suffer with and what they think about the compression therapy that is prescribed for them. This study, therefore, aims to look more deeply into this important subject and collect more information to help us to understand better how you view compression therapy and how it affects you. We hope, with your help, to come up with new, different ways of assisting those who live with venous leg ulcers.

Who are the researchers?

My name is Marianne and I am a research student at the University of Leeds. I will be the one conducting all the interviews and collating all the information (I need to find up to 24 people like you to help me). My work follows on from a small body of research already done in the area of venous leg ulcer patients perspectives on compression therapy and the textiles used for the bandages and stockings.

Why am I asking you to take part?

As you have, or have had, a venous leg ulcer, you are the type of person I need to speak with. I want to hear about how you experience your venous leg ulcer, the compression products used and how your life and well-being is affected – the good, the bad and the indifferent. It's your views and feelings I am interested in – things you are expert on.

What will the study involve?

It will involve meeting with me for about an hour to tell me about your situation, in your own words. The interview will be audio-recorded so that I can listen to you properly and not take notes all the time we are talking. We will need to decide whether to talk at the clinic or in your home – whatever suits you best; a place where we won't be interrupted for an hour or so. Back at the university, I will listen to the audio-recordings and make full notes so that I can write up the summary of what everyone said. You will remain anonymous and nothing you say will be attributable to you.

What are the benefits of taking part in the study?

There are no direct benefits from participating in this study, although many people find it interesting to tell their story and often gain new insights into their situation as a result of such a discussion. Indirectly, I hope that the additional information you give me will help to benefit you and others with venous leg ulcers by providing a wider and deeper understanding among the health care professionals, based on the voices of their patients, in this field of treating and managing venous leg ulcers.

I cannot predict the results but the findings will offer us more knowledge about how patients like you experience and cope with their ulcers and the compression therapy.

What are the disadvantages of taking part in the study?

There will be no disadvantages to taking part in this study, other than giving up a little of your time. The study involves you and me sitting down to talk about your experiences and views for about an hour.

Do I have to take part in the study?

No, you do not have to take part in this study. Participation is on a voluntary basis. You will not suffer any consequence if you decide not to take part. Also, you can withdraw from the study at any time, without giving an explanation, until I begin to analyse the recorded interviews. If you choose to withdraw before that point, you can let me know or you can contact Clare Skinner, Faculty Head of Research and Innovation Support at the University of Leeds, on governance-ethics@leeds.ac.uk.

If you do decide to take part, please keep this information sheet for reference.

Before we start the actual discussion, I will run through the points of the study again, just to make sure you have all the information you require and to answer any outstanding questions.

I will ask you to sign a consent form – a copy of which you can also keep. This confirms that you understand the purpose of the research and that you give me permission to talk with you.

What will happen to the data?

All the information you give me will be kept confidential (under lock and key and on a coded computer at the university). Your name and personal details are used for making contact with you. No-one but me and the nursing team at the leg ulcer clinic will have access to your contact details. Your contact details are kept separate from the interview notes.

Once an interview is completed, it will be given a code number so that your name and any personal details are not recorded along with your interview.

This ensures that the notes from your interview cannot be identified as coming from you. When I have scanned your details onto the computer, any pen and paper documents will be destroyed.

Once I have full notes (transcripts) on all the interviews, I will start the analysis of the items of information you and the others have given me in your interviews. I then write a report on all the information (data) I have collected.

After the report is written, the audio-recordings of our interview and the transcripts will be destroyed. The analysis of the data will be kept for three years, so that if there are any queries or if I need to rewrite bits of the report or write a new report, the information is to hand. It will be kept on a coded programme on the computer – only I will have access to it.

What will happen to the results?

The results of this study will be written up as a report, as mentioned in the paragraph above. It will not be possible to identify participants from this report. A summary of the report will be available on request.

The results may also help me to look at what further research is needed in the attempt to develop different and better ways of assisting people with venous leg ulcers.

Any further questions?

When you take this away with you, you may have further questions. I am always happy to talk with you. You can contact me using the details below:

Marianne Hvistendahl Allday hcmha@leeds.ac.uk

Room 3.35

School of Healthcare

Baines Wing

University of Leeds

LS2 9GT

Tel: 0113 343 3038

D.3 Consent form

Consent to take part in The Patient’s Perspective of Compression Textiles for Venous Leg Ulcer Treatment: an in-depth qualitative study

Add your initials next to the statement if you agree

I confirm that I have read and understand the information sheet and covering letter, Version 1, explaining the above research project, that our conversation will be audio-recorded and that I have had the opportunity to ask questions about the project.	
I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline.	
I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research. I understand that my responses will be kept strictly confidential	
I agree for the data collected from me to be stored and used in relevant future research in an anonymised form.	
I understand that other researchers may use my words in publications, reports, web pages, and other research outputs, only if they agree to preserve the confidentiality of the information as requested in this form.	
I understand that relevant sections of the data collected during the study, may be looked at by auditors from the University of Leeds or from regulatory authorities where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	
I agree to take part in the above research project.	

Name of participant	
Participant’s signature	
Date	
Signature	
Date*	

*To be signed and dated in the presence of the participant.

Once this has been signed by all parties the participant should receive a copy of the signed and dated participant consent form, the letter/ pre-written script/ information sheet and any other written information provided to the participants. A copy of the signed and dated consent form should be kept with the project's main documents which must be kept in a secure location.

Appendix E

Preparatory Analysis

E.1 Preparatory concepts and notes

Concepts Linguistics/language used	Transcript (items of data highlighted)	Exploratory Comments Context
<p>Hereditary predisposition</p> <p>'Bad' as only descriptor</p> <p>Outdated surgical procedure</p>	<p>R.01 Well, I think it started with varicose veins, you know.</p> <p>I think they are hereditary because my Dad's got them and his are terrible. Mine are quite bad.</p> <p>MHA But not your Mum...</p> <p>R.01 My Mum's got some but not as bad as my Dad. Me Dads're bad. And mine are quite bad.</p> <p>I did have them stripped at one time, when they did strip them, you know, going back... [Makes gesture with both hands around lower leg area]</p> <p>MHA Oh right, how long ago...</p>	<p>A family problem A long history</p> <p>Family history Hereditary predisposition</p> <p>Related medical problem</p> <p>The phrasing seems to indicate that this is an outdated process</p>

Concepts Linguistics/language used	Transcript (items of data highlighted)	Exploratory Comments Context
<p>Little sound bites of thought to illustrate events</p> <p>Ulcer development</p> <p>'Just' used repetitively to signify lack of perceived importance</p> <p>The narrative speeds up as the story reaches its crescendo. She becomes more and more animated as the story peaks and the panic is re-lived</p> <p>Very coherent story-telling</p> <p>Fluent, little hesitation</p> <p>Physical accident</p>	<p>R.01 [Looks into middle distance] Ooooooh, about 25 years ago when you... you know, you had them stripped and then you had to have them bandages - and then they did go away for a while, but what you do get are these little, sort of like purpley veins, all round your ankle, and stuff like that.</p> <p>And then... not last Summer but the Summer before, I had a little cut on one of my legs. Only a little tiny cut, like that [shows circa 1 cm between finger and thumb]. And, obviously, I scratched it, because it itched, and instead of growing [together] it just got bigger and bigger. And I thought, 'This isn't right.' And you know, you just think, 'Oh, it's not too much.' I just kept going, I kept covering it up and thinking it's just taking a long time healing...</p> <p>And it's only because last April; I was upstairs dusting and I was reaching up to do the tops of the wardrobes – well, you do now and then, don't you [ironic smile]. And I was climbing down the step ladder and I LOOKED [eyes wide open] and I thought,</p>	<p>Her body language suggests distaste with this process</p> <p>An effort of memory to place the event along a time line</p> <p>After-effect of surgery</p> <p>Lasting marks of the process</p> <p>The tone of her voice suggested that this an unpleasant by-product, but a measure of acceptance had been achieved</p> <p>Placing event on time line</p> <p>Symptom of wound</p> <p>A fleeting awareness that the wound was not progressing normally but largely ignored</p> <p>'Kept going' illustrative of her strength and resilience</p> <p>No effort of memory: prompt placing on timeline</p> <p>Humour</p> <p>An expression of horror on her face</p>

Concepts Linguistics/language used	Transcript (items of data highlighted)	Exploratory Comments Context
<p>Burst varicose vein – rare</p> <p>Known phenomenon</p> <p>Panic</p> <p>Seeking help</p>	<p>‘What’s that?!’ And all I could see was this stuff coming from underneath me jeans and it was blood and I thought, ‘Oh, my God, its blood!’</p> <p>I knew what had happened as soon as I saw it because me Dad had a burst varicose vein at one time. And I thought, ‘Oh, God, it’s a vein that’s burst!’ It was shooting out all over the place. Honestly, it was horrendous. [animated and a little breathless] and I was getting panicky cos I couldn’t stop it. And I thought, ‘What am I going to do here?’</p> <p>And it really was shooting out. It was like... well, when you get a vein, you know how it shoots out! And I was on my own and I thought, Well, what do I do – I can’t stop this blood!’</p> <p>MHA Hhm</p> <p>R.01 So dashing about, I got in the bath because that was the only thing I could think of, you know, that I could do – and I still couldn’t stop it - and I tried to put compression on it – and I still couldn’t stop it. And I was starting to feel weak at this time [one of the dogs</p>	<p>Previous experience of being present with Father</p> <p>Shaken by the realisation of blood</p> <p>Instant recognition and understanding of the event – had witnessed it in her Father’s case</p> <p>Large quantity of blood – extreme</p> <p>Alone and frightened</p> <p>Admission of panic, the sense that this is not like her, not how she sees herself</p> <p>Large quantity of blood</p> <p>On her own: feeling alone, feeling vulnerable, without support</p> <p>Corrective action in an emergency: resourceful</p> <p>Noticing the effect on her body, aware of bodily changes</p> <p>First thought Husband Second thought Son</p> <p>Decisive action</p> <p>Call for support: first thought Husband, second thought Son</p> <p>Need for emergency services</p> <p>Emergency services called: measure of the gravity of the situation</p>

Concepts Linguistics/language used	Transcript (items of data highlighted)	Exploratory Comments Context
<p>Mimics male voice Emergency services</p> <p>'Started to stop' curious construction</p> <p>Composure/public face</p> <p>Substantial blood loss</p>	<p>panting at her]. And I thought, 'Well I'm going to have to ring somebody, it's no good.' So, my husband was working; he works on the trains as well, he's a driver. So I rang my son, 'Can you come home?' I says, 'I feel really faint at the moment.' I says, 'I've got this burst varicose vein and it won't stop bleeding.' And he says, 'Well, do you think I should call the paramedics?' and I says, 'Oh, I don't know.' And he says, 'Well, I think I better do.' So he calls an ambulance and then I managed to come downstairs and I managed to sort of prop my leg up – and I prop it up and eventually it started to stop and so by the time the paramedic came, I managed to open the door</p> <p>So by the time the paramedic came she says, 'Well, you've done the right thing, you propped it up.' So she just bandaged it up. But she said, 'Well, you'll have to go to your doctor's.'</p> <p>So I went to the doctor's the following day, mainly because I felt weak, you know faint. You know, I took the dogs for a walk and I</p>	<p>A certain satisfaction that the paramedic was presented with a calm woman who, through her own management, had stopped the bleeding and was able to open her own front door</p> <p>Arrival of paramedic seems to reassert self-containment: things in control</p> <p>Referred to GP, once safely bandaged Aware of own body: felt weak – uncharacteristic? Clear observation of self: description creates context Dialogue/communication with HCP – open, informative</p> <p>Identified moment when two ulcers are diagnosed. Introduction of VLU's to narrative – not one but two</p>

Concepts Linguistics/language used	Transcript (items of data highlighted)	Exploratory Comments Context
<p>Hesitation through effort of memory</p> <p>Healing vs non-healing</p> <p>Referral</p>	<p>thought, 'I don't feel right.' And she says, 'Well, it's because you're anæmic because you've lost blood.' And she looked at me ankle and she said, 'It doesn't look right to me.' She says, 'We better keep an eye on it, it looks like you might have an infection in it or something.'</p> <p>Anyway, they kept keeping an eye on it but by this time it had ulcerated – and then I showed her my other leg and she said, 'Yeah, that's an ulcer, as well.' Well, you know, I didn't know [shrug of shoulders].</p> <p>So they started... em, what did they do first?... they put some sort of bandage on and they put some... cream, was it? [looks at her dogs for the answer] Do you know, I can't for the life of me remember what they put on to start with. But I had to go just about every day to have them dressed – because, you know, they were weep... they were weeping and bleeding.</p> <p>MHA How long ago was this, then?</p> <p>R.01 That'll be about a year ago.</p>	<p>A dismissive shrug to indicate that she had not taken her non-healing cut seriously</p> <p>Dressing and bandaging but no compression</p> <p>Effort of memory</p> <p>Dogs were still attentive to her, watching her, after her animation in describing the burst varicose vein</p> <p>Daily dressing change</p> <p>Daily dressing – interrupting the pattern of her life</p> <p>Corollary of VLU in her experience</p> <p>No effort of memory</p> <p>Infection</p> <p>Swabs vs biopsy – suspected infection</p> <p>Referral to leg clinic</p> <p>Referral to secondary care – leg ulcer clinic</p> <p>Non-healing ulcers is the patients lived experience vs others who may heal without treatment/spontaneously</p> <p>Further to travel, further impact daily pattern of life</p>

Concepts Linguistics/language used	Transcript (items of data highlighted)	Exploratory Comments Context
<p>Act of bandaging inflicted upon R. Negative experience Extreme psychological/visceral reaction</p> <p>In my opinion...’ emphasis on the subjective nature of her response Inversion: ‘it’s so degrading, is that’</p>	<p>MHA OK.</p> <p>R.01 The doctor came and had a look because they thought there might be an infection in them. But they took... they took loads of swabs and they says, ‘No, they’ve come back alright. Oh, they did come back with something but nothing to worry about, nothing to treat with antibiotics. But obviously, these were not healing up so she decided that she’d refer me to the leg clinic.</p> <p>MHA She? GP?</p> <p>R.01 Well, yes, but it was the practice nurse that did it. They do all the, they see to all the bandaging and stuff like that. She said, ‘Sometimes it does get better but it’s not, so we need to send you to the leg ulcer clinic, just to have a look at you.’</p> <p>So I started going up to Yeadon [?], to the leg ulcer clinic, up there, to see... she had an Irish accent, I can’t remember her name, a lovely lady...</p> <p>MHA They’re all lovely.</p>	<p>Compression bandages introduced Introduction of compression bandaging Immediate and profound negative, psychological reaction Emotive response, emphatically expressed, creates a new, visceral context to work with</p> <p>Her face a picture of sorrow, her words expressing a depth of feeling – a sense of degradation Metaphor of a Mummy: dead human, all wrapped up incarcerated in a tomb, dead but preserved, much used in horror films</p> <p>No effort of memory Degradation of the respondent’s person Repetition of sense of degradation – making her a lesser person? Degrading her body? Violation? Depression – profound effect on mood Emphatic</p>

Concepts Linguistics/language used	Transcript (items of data highlighted)	Exploratory Comments Context
<p>Degradation Mummy theme Horror</p> <p>'Mummy' object of horror films, entirely wrapped up, bandaged in death, de-personified, externally altered Degrading and depressing repeated several times throughout. Repetition lend weight but may also be indicative of inability to find other descriptors</p> <p>Depression Choice Need for innovation and change</p>	<p>R.01 And she said, 'Well, yeah, I think we'll have to put you into these compression bandages. And, in my opinion, that's the worst thing that could have happened to me. It's so degrading, is that. [meets my gaze with sad eyes] It's horrible; it really, really is. It's awful. You know, sort of, you have layers of cotton wool and then these bandages over the top so you're coming out like a mummy. I just think, I just think if there is any research to be done somebody needs to research on something that's nicer than that. Because it's just horrendous.</p> <p>MHA Do you remember how many layers of bandage that was?</p> <p>R.01 Two layer. There were two layers of this like... sort of cottony wool stuff. And then two layers of this adhesive bandage stuff. And it's just so completely degrading, so depressing, it really is.</p> <p>MHA You obviously hated it. [laughs softly]</p> <p>R.01 I hated it. I absolutely hated it.</p>	<p>Communication with HCP: admission of emotional reaction Sympathetic response from an HCP who is listening Switch from visceral response to cognitive assessment Placing the experience of being bandaged with compression bandages as one of the worst in her life experience Response from HCP that R can choose whether or not to adhere to compression bandaging R chooses to adhere: cognitive processes come to the fore NB is the emotional response even stronger because she chooses to adhere Recognition that compression bandaging is a product: A context of design, innovation and manufacturing Calling for research and innovation to find an alternative First mention of compression hosiery: compression hosiery vs compression bandaging Comparison of self to older person who might be less able</p>

Concepts Linguistics/language used	Transcript (items of data highlighted)	Exploratory Comments Context
<p>Compression hosiery represents advance</p> <p>Leprous theme Leprous theme: unclean, marked as separate from mainstream society, at risk of losing body parts, segregated, stigmatised, visible and degrading illness, isolated from others, alone with the problem</p> <p>Age vs youth</p> <p>Hidden shame/affliction Inconvenience</p> <p>Isolation/alone/ only her with</p>	<p>And, you know, I had to keep going to the practice nurse to have them dressed. And I said, 'I don't like this. It's awful.' And she said, 'well, we don't have to do it, if you don't want... she says, 'We can do without it.' And I says, 'yeah, but how are they going to get better, without having them done?' But it is one of the most degrading and depressing things to ever have had done to your legs, I think. It's awful. if ever there is any research to be done, somebody should find a better way, rather than that.</p> <p>I mean, I wear compression stocking now. And when I got into them, I was fine, I can cope with them. That doesn't bother me one little bit. But these bandages: horrendous.</p> <p>MHA Can you give me any examples?</p> <p>R.01 I just felt unclean. I just felt as if I was like a leper. Yeah, it was just awful. And then having to go every two/three days to have them bandaged. And having them taken off... alright, I know they had to do it, they were weeping and that, and that was the</p>	<p>The leprous/unclean metaphor is introduced: marked as being a thing apart from mainstream society? Isolated? Unclean meaning her body was defiled by the ulcers? Leprous as in at risk of losing part of her body?</p> <p>Onerous and time consuming to leg dressed frequently AND repeated horror of that act of compression bandaging, applied to her, impinging on her soma and psyche</p> <p>Further description of possible stigmatisation and being 'marked' as something apart: greater depth of context</p> <p>Age vs youth Fellow feeling for those less fit and able Corollaries of wearing compression bandaging Sense of isolation</p> <p>Pride bruised by compression bandaging and the symbolic act of being bandaged Compression bandaging hidden from others: shame? Footwear problem: effect of compression bandaging Leprous theme repeated Cognitive side re-emerges, separating feeling</p>

Concepts Linguistics/language used	Transcript (items of data highlighted)	Exploratory Comments Context
<p>the problem</p> <p>Lonely? in her affliction</p> <p>Bleak future Deep emotional effect</p> <p>'Forever' a strong impactful word</p>	<p>only way they could do it to get them to draw together but it's... it's... it's...</p> <p>I suppose it's not too bad if you're elderly (this sounds awful) and you're not too active and you're sat in a chair all the time and you've got bandages on... ooh, sorry one of the dogs has a touch of flatulence... but, you know, when you're up and about and walking... I mean, alright, I had my jeans on so nobody knew ... apart from the fact that I could only get one pair of shoes on [laughs and shakes head]...</p> <p>But it just was really, really... you just felt like a leper, you just felt as if you'd been isolated from everything. Even though nobody knew you'd done it. In my opinion, that's how I felt.</p> <p>MHA Isolated in what way?</p> <p>R.01 Sort of... I was on me own; there was only me like that. For the first months, obviously, it didn't seem to be getting any better – even though she kept saying it was getting better. She kept saying, 'This piece is granulating, it's getting better', and so on. And it was</p>	<p>from an acknowledgement that this was internal and not reflected in her social interactions</p> <p>Alone with the effect of ulceration/compression: lonely</p> <p>Communication with HCPs: positive, informative</p> <p>Envisioned a bleak future</p> <p>A forever change to her life</p> <p>Tries to keep the tone light but is much moved by the thought</p> <p>Feedback from HCPs: the context of communication</p> <p>Looking ahead to a life in compression bandaging</p> <p>No effort of memory</p> <p>Timeframe</p> <p>Strength, force of character</p> <p>Logistics of holiday with VLU</p> <p>Logistics on holiday</p> <p>Recalling the thread of her narrative</p> <p>Decision made: non-negotiable stand</p> <p>Locus of control</p>

Concepts Linguistics/language used	Transcript (items of data highlighted)	Exploratory Comments Context
<p>Locus of control Decision-making Prefix says she doesn't care what they say, it lends weight to her determination to stay out of bandaging. Yet the statement, in absolute terms is false, she is diligently adherent to therapy and advice</p>	<p>only when it started to start looking better that I started feeling that I was getting somewhere. I had, I had visions of being stuck like this, of having to go and get my leg bandaged forever [voice trembles slightly, laughs, reddens slightly].</p> <p>MHA How long did it take?</p> <p>R.01 Well, I went on holiday in the September... The ankle one wasn't too bad. As soon as the... that didn't have to be bandaged for too long. Because the nurse at the therapy clinic said that as soon as me stockings came I could use a stocking on that. But this one [pointing] well, April... and I was going on holiday in September. And I said, 'I aren't going on holiday like this; cos I can't do...' I said, 'I can't bandage up my leg myself, to start off with.' So they said Well, we'll try you with stockings.'</p> <p>MHA So a good six months in bandages then?</p> <p>R.01 Yeah, that leg [pointing again]. Er... and then I went on to the support stockings. And when I came back, I said, 'Well, I don't care what you say, I aren't going back into</p>	<p>Effort of memory</p> <p>Compression hosiery acceptable Acceptance</p> <p>Makes little of difficulty in donning and doffing hosiery Some early problems highlighted with donning and doffing. Impression of a past problem. Historical context</p> <p>Locus of control</p>

Concepts Linguistics/language used	Transcript (items of data highlighted)	Exploratory Comments Context
<p>Coping attitude Soldiering on Humour</p> <p>'This, that and the other' used a few times and seems to mark her ability to say more on the subject if required, rather than a throw-away phrase</p>	<p>compression.' And they said, 'No, it's fine. Your leg's fine now.' But it took till... oh, until, sort of, like November to heal up.</p> <p>MHA So that one, the varicose vein one healed first?</p> <p>R.01 That healed before I went on holiday. So April, May, June, July, August. ..That only went into a compression bandage short term and then went into a stocking. So I wear compression stockings on both legs at the moment</p> <p>MHA Same strength compression [on both legs]?</p> <p>R.01 Yeah</p> <p>MHA And how is that?</p> <p>R.01 I don't mind them; I've got used to them – yeah.</p> <p>MHA And you can get them on all right?</p> <p>R.01 Yeah, once you get used to it [laughs at the thought]</p> <p>MHA s it a faff?</p>	<p>Six monthly follow up and supply Six month review, check up and fresh supply</p> <p>Has perceived no lessening of compression over time, with hosiery Demonstrates hosiery to me, with a certain satisfaction</p>

Concepts Linguistics/language used	Transcript (items of data highlighted)	Exploratory Comments Context
	<p>R.01 It is... to start off with, you know, you're getting the heel the wrong way round, this that and the other. And you're just 'do I have to get these on?' But after a while... you just accept it and you get on. But, yeah, it's fine.</p> <p>MHA Do they just leave you to it, then, with the compression stockings</p> <p>R.01 Yes, I have to go for a Doppler test every six months and so I can get a fresh pair of compression stockings. I should have gone yesterday... no, Tuesday. I wasn't feeling very well. I'd been looking after my granddaughter because she was poorly and I think I just picked up what she had. So I had to ring up and cancel it. I'll have to ring again and make another appointment. I've had this lot for six months and every six months you're due a new lot of stockings</p> <p>MHA Can you feel that they get looser?</p> <p>R.01 No, they don't seem to get looser. [pulls up trouser leg to show me] You wear like a stocking underneath and then you wear this black pull-on compression thing over the top</p>	

Concepts Linguistics/language used	Transcript (items of data highlighted)	Exploratory Comments Context
	– which doesn't get looser. An ordinary pop-sock underneath and then you have a black, no-toe thing on top and that comes out to there, like that [points to just below the knee].	

E.2 Example collation of data: Thematic exploration

The purpose of this document is to provide an illustration of the collation of data from interviews to form potential thematic consensus.

This data is taken from the first 10 interviews undergoing analysis. It should be noted, however, that evidence from other interviews can be added to that set out below (as established when checking through all transcripts, previously). Because the remainder have not yet been studied with the same intensity, they are not included in the data set, at this point.

I expect to be able to create super-ordinate themes when full analysis has been completed and, at this stage, that is not the objective. The objective is to explore possibilities and ways of gathering data into meaningful units that reflect the respondents' views.

Theme: Faith in Compression

"I had to keep going to the practice nurse to have them dressed [changed]. And I said, 'I don't like this. It's awful... She says, 'We can do without it.'. And I says, Yeah, but how are they going to get better without having them done [compressed]?" R01

"Since I've been in four-layer they're coming alright, aye" R02

MHA So, looking forward, what are you thinking? "That they're going to heal." MHA Yeah, and then what? "Get a pair of shorts on!" R02

MHA Looking ahead? "That I hope to be better – but I just hope I could be free of the bandage." R07

MHA And in the future? "And then I'll be able to go back to work. Oh, I know it will get better." R12

" It has to be on me leg because it's the only form of healing they know of, that works, you know." R12

"They heal up better in bandages." R17

"At some point it will heal up – and I'm trying everything I can do that the professionals have told me to do i.e. Taking weight off the leg, you know, when I'm in bed, wearing the compression, having a suitable dressing." R21

MHA So you expect to be healed in a few months? “Oh yeah! ...Yeah, I just have to be patient. I’m walking alright...” R22

Low mood/Depression

“I think I just got more depressed than anything else.” R01

“I kept bursting into tears.” R01

“Terrible!... you cannot enjoy getting washed or owt!” R02

MHA What sorts of thoughts went through your head? “Loads, like. I wanted to get me legs took off, and that. I thought that it’d be better to get them took off.” R02

“Sometimes I do [get depressed]; drives me round the twist sometimes... I’m stressed up to there!... I just want to sit in a corner and cry ‘cos I’m sad.” R07

[Weeping throughout] “I get upset about it, as you can see, because its taking such a long time to heal. [note of desperation]” R12

“It was painful and sore. I couldn’t put my foot on the floor; I was hobbling about on me toes or me heel... I didn’t go out – and with not going out, just sitting in the house, it drives you barmy.” R12

“I got quite weepy – not depressed, but weepy – thinking, ‘There’s no end to this!’ and, ‘Does anyone understand or do they think I’m making this up?’” R11

“Well, I got very down and stuff, but it’s difficult to tell whether that was the ulcers or my other problems [co-morbidities] so... The ulcers are the ones that have caused me the most – that much pain and inconvenience!” R17

I wouldn’t say it’s depressing; it was bloody annoying. That’s the way I’ve looked at it – more of an annoyance than anything. I’m... I think I’m fairly lucky, I have a fairly good pain tolerance. I think you can tell by... that... it’s not often I complain. R22

E.3 The patient's perspective of compression textiles for venous leg ulcer treatment: an in-depth study: Code key

Code	Concept
AC	Age comparison
AI	Adherence issues
APR	Adverse psychological reaction
AS	Allergy/sensitivity
BA	Perspectives on bandages
BI	Body image
BS	Blue sky thinking
CC	Continuity of care
CD	Connection/Disconnection
CM	Co-morbidity
CT	Compression/Compression Textiles
EO	Effect on others
FA	Fear/Anxiety
FC	A forever change
HD	Hope/Despair
HO	Perspectives on hosiery
HS	Help sought
HU	Humour
IA	Isolation/Aloneness
LC	Locus of control
LMD	Low mood/Depression
MS	Mind set
PA	Pain
PD	Pride/dignity
PE	Patient expertise/Knowledge
PI	Prominent Issues
RE	Resilience
RHCP	Relationship with HCP
RS	Restrictive

Code	Concept
SB	Self-blame
SC	Social self-consciousness
SH	Shame/Embarrassment
SI	Suicide Ideation
SK	Skin Issues
SP	Specific trigger
UN	Unclean/set apart
UP	Understanding of Pathology
VF	View of future