

## **The lived experience of recurrence prevention in patients with venous leg ulcers: an interpretative phenomenological study**

### Highlight points:

- In this study, trauma either from an accident or compression was the cause of recurrence according to the patients.
- Patients use past experience of recurrence outcomes to develop their own strategies to prevent ulcer recurrence.
- Self-knowledge and education interventions are needed to optimise recurrence prevention.

### Abstract:

#### Aim of the study:

To explore patient understanding of why they develop a venous leg ulcer and how they can prevent recurrence.

#### Method:

The methodological framework of the hermeneutic phenomenological approach was used. Semi-structured interviews were conducted with seventeen participants living with a venous leg ulcer from May 2017 to November 2018. Data were analysed using Smith's interpretative hermeneutic analysis.

#### Results:

The results are categorised into three main themes: "Trauma due to accident" (initial venous leg ulcer) and "Prevention of ulcer recurrence" (compression); "Trauma due to compression therapy" (venous leg ulcer recurrence). The findings demonstrate active venous leg ulcers are often caused by acute incidents while carrying out an activity in people with underlying chronic venous insufficiency. After a complete healing, preventive measures, such as compression stockings are initiated by the patient or health care provider. Trauma due to adherence to compression stockings caused skin breakdown beneath compression that caused subsequent ulcer recurrence.

#### Conclusion:

This study contributes to understanding the lived experience of patients with venous leg ulcers who develop a venous leg ulcer and their understanding of how they can prevent recurrence. Patients with VLUs would benefit from early preventive strategies, such as such a compression stockings fitting and application, integrated into daily care plan of primary care and community settings.

## 1. Introduction

Venous leg ulcers (VLU) are slow healing wounds often caused by chronic venous insufficiency (CVI). VLU are defined as any skin breakdown present for at least six weeks or ulcers that occur in persons with a previous history of VLU (Norman, Westby et al. 2016). A cycle of repeated ulceration, healing and recurrence is common in people with CVI. The reported prevalence of VLU varies in literature, partly due to the heterogeneity in diagnostic methods and epidemiological characteristics of samples (Scotton, Miot et al. 2014). It is estimated approximately 1% of the population and 3% of people aged over 80 are affected (Franks, Barker et al. 2016).

Most (93%) VLU heal within 12 months when best practice compression is applied and patients adhere to compression therapy although seven percent remain unhealed after five years (Franks, Barker et al. 2016). Not only are VLU challenging to heal in a timely way, recurrence rates within three months of healing have been reported at approximately 70% (Finlayson, Wu et al. 2015).

Treatment of people with VLU is costly. Annual Ireland treatment expenditure of acute and chronic wound of €629,064,198, equivalent to 5% of the Irish health expenditure (Gillespie, Carter et al. 2019) (Gillespie, Carter et al. 2019). Data from Australia report annual healthcare costs for chronic wound management of more than AUD\$ 3 billion. These costs are predicted to rise dramatically in the upcoming years due to the ageing population and growing incidence of diabetes and obesity (Weller, Team et al. 2019).

Due to underlying aetiology and concurrent comorbidity conditions, such as obesity and diabetes, even after the first VLU has healed, VLU recurrence becomes a life-long health problem for patients (Saha, Wayne et al. 2011). Patients narrate these wounds are a burden and have an impact on quality of life (Kapp, Miller et al. 2018, Phillips, Lumley et al. 2018). Pain is reported as the most common symptom followed by exudate, odour, skin irritation, restricted mobility and sleep disturbances. Ulcers that are heavily exuding and odorous, are linked to embarrassment and shame, which affects patient's social activities and contributes to isolation (Phillips, Lumley et al. 2018). It is therefore important to prevent such wounds. Current VLU therapeutic approaches are multifaceted and focus on promoting wound healing as well as preventing ulcer recurrence by wearing compression hosiery, adhering to best practice recommendations of leg and ankle exercises and leg elevation when resting and to consume a protein-rich diet (Probst, Allet et al. 2019). Although patients report a number of challenges following these therapeutic approaches; a lack of patient knowledge of the importance of compression to facilitate healing and prevent recurrence and the adherence to treatment are some reasons for non-adherence (Weller, Buchbinder et al. 2013). Evidence shows that patients are unaware of the rationale for wearing compression bandages to prevent recurrence (Van Hecke, Beeckman et al. 2013). This is due to an unclear understanding of the underlying cause of VLU (Meulendijks, Welbie et al. 2019). A deficit of knowledge was also shown by Edwards and colleagues (2009) that VLU patients are not educated regarding self-care

activities, do not understand the importance of treatment, and do not have the ability to engage in self-care practices to prevent ulcer recurrence. Patient knowledge deficit may be due to lack of education by professionals during delivery of care, or lack of up-to-date best practice information or inadequate resources and time to provide education (Edwards, Courtney et al. 2009, O'Brien, Finlayson et al. 2014). Consequently, recurrence may occur. To better understand patients' experiences of why they develop an ulcer, an interpretative phenomenological study was undertaken to investigate VLU patients' experiences of how their ulcer recurred and how they prevented ulcer recurrence.

## 2. Material and Method

We used an interpretative phenomenological analysis qualitative approach based on the hermeneutic version of phenomenology. This explored how human beings make sense of a major life experience on a personal level (Smith, Flowers et al. 2009). We used interpretative phenomenology analysis to explore and to capture the reflections of patient experiences. Our aim was to understand, in detail, what the patient experiences were and how patients made sense of what had happened to them during the experience. This explains why this study has a small number of participants, as the aim is to reveal something of the experience of each individual interviewee. Using a small number of participants for such a study is justified (Smith, Flowers et al. 2009).

### 2.1. Sample

We used purposive sampling to access the venous leg ulcer population from two outpatient wound clinics in Switzerland. Participants were recruited by wound care clinical nurse specialists who worked in the respective outpatient wound clinic. All participants received a study information sheet, and provided written consent to participate in this study (PB-2016-01780). Participants were included after the VLU was diagnosed by a specialist. The ulcer needed to present for at least 3 weeks, and patients had a history of at least one VLU in the past and were proficient in German or French. To protect the participant anonymity, fictional participant names have been used in this publication.

### 2.2. Data collection

Semi-structured face-to-face interviews were conducted from May 2017 to November 2018. Seventeen participants with a mean number of 3 VLU recurrences were included. 53% (n=9) were women with a mean age of 71 years. 82% (n= 14) were married. Socio-demographic characteristics are listed in table 1. Participants were able to choose where the interview would be conducted (home or wound clinic). The mean interview duration was 55 minutes (range between 40 to 75 minutes). Interviews were digitally audio-recorded and transcribed verbatim. Although the whole interview was conducted and transcribed in the respective language, French or German, key themes were translated

into English.

### 2.3. Analysis

Interpretative phenomenological analysis involves four steps (Smith, Flowers et al. 2009):

A verbatim transcription of the interview was made. Each transcript was read and re-read in an attempt to become immersed in the text and to become familiar with the narrative about the lived experience of VLU occurrence and recurrence. This process was guided by the research question. During this phase of the analysis, all phenomena were marked responding to the research question. This was how phenomenological reduction occurs, that was, pure phenomena are isolated compared to phenomena that are already known (Smith, Flowers et al. 2009). After reading and rereading the transcript, certain phenomena and themes were identified. These were eventually clustered into subthemes. The final step in analysis involved analysing how each phenomenon identified were categorised. This process enabled the researcher to identify and discover the essential qualities of the narrated experiences and how the VLU occurred. Field notes helped to reflect on the context of the data. MAXQDA (VERBI, 2019) was used to analyse the data.

### 3. Results

We identified three main themes related to participant experience of VLU occurrence or recurrence. Thirteen participants reported VLU originated from acute trauma. When their wound occurred all participants tried to medicate their wound according to their previous experiences of ulcer care. This worked for most of them well. But some participants reported that either after weeks living with such a wound or doing their self-medication, the wound pushed their skills and knowledge to a limit. Due to this they were forced to seek professional help. Ten participants attended a general practitioner, six participants attended a wound clinic and one person attended the pharmacist. After the wound completely healed all patients tried to prevent a recurrence. Eleven persons narrated preventive measures such as moisturising their skin or wearing, from time to time, their compression stockings were successful and prevented recurrence between 6 to 12 months.

In the following section, the themes “Trauma through an accident”, “Trauma from compression therapy” and “Preventing VLU recurrences” are outlined:

#### «Trauma through an accident»

Thirteen participants narrated that they were not concentrating and wanted to do something very quickly and as a result hit their leg «badly». In doing so the reason of the occurrence was an accident such as falling when walking up the stairs. Adam said:

*«I wanted to see the full moon and went in the garden, was climbing up the stairs out of stone. I went*

*too fast. I fell and it bleed heavily. It took me a while until I could stop the bleeding... yes and then I used a cream and put sterile gauzes on the wound. It acted really too fast ».*

Other participants narrated hitting the leg on furniture, falling over a cord of a fan, or falling over a branch that was lying on the street. Four male interviewees narrated that their wound appeared when doing some handicraft. Their legs developed a haematoma and an oedema. After 24 to 48 hours, they discovered a small skin-lesion.

Henri said:

*«I was in the basement working repairing an armrest of a garden chair. Then my wife called me to eat dinner. I wanted quickly finishing this work and got quickly the drill. In doing so the armrest fell on my lower right leg. It hurt a bit and later the evening I saw that my leg was swollen and I had three wounds. They didn't heal. I do not know why although I did everything.*

In summary for all participants, the occurrence of the wound was an acute incident caused by accident.

#### **«Trauma from compression therapy»**

The theme “trauma from compression therapy “ demonstrates the lived experiences of four participants or how the wound occurred even though they followed preventive measures as recommended by health care professionals. Participants illustrated the occurrence of the wound through excoriating because the stockings did not fit properly. Because the stocking did not fit the shape of the legs they started rub against the skin until the integrity of the skin broke. Alex narrated:

*“When it opened up again .... yes and this was because of these unpractical socks (stockings) .... I tried to follow my nurse’s advice to wear them.... Oh yes they are hot and then they are excoriating on my legs. Firstly, it (the skin) was red and in the evening, it was open again. This was catastrophic”.*

Georg shared similar experience:

*«I have to admit, I was wearing the prescribed stockings only from time to time. They didn’t fit properly and they were scratching. They are pretty rough. Through this scratching my skin got very thin and then it opened. Now I have this whole in my leg for about one month».*

In addition to non-fitting stockings, participants stated the stockings were anaesthetic. The colour was the main problem. Therefore, the interviewees tried to hide them by wearing long trousers.

Martha said:

*«The physician prescribed such unaesthetically socks. I went to the pharmacy and picked them up. From time to time, I was wearing them. You know it is difficult to put them on and then you have to wear all the time trousers to hide them....and then they do not properly fit. Yes, when I was walking they were rubbing on my skin. One day I was walking with these socks to the grocery store and then I felt it. Yes I felt it. It was rubbing. I was walking very carefully and when I got home, yes and when I got home, it was open again. Yes I blame these socks ».*

Summarising, the prescribed stockings are visually unappealing and they do not fit properly, rubbing on the underlying skin and cause ulcer recurrence.

#### **«Preventing VLU recurrences»**

After a complete VLU healing, all participants tried to prevent a recurrence. All participants were worried that a recurrence could become chronic. Therefore, they tried to use preventive

measures such as wearing prescribed stockings or to moisture the skin. Putting the stockings on was often a challenge, as many did not have enough strength to apply the elastic stocking. To accept professional help was also a challenge for all participants, as they did not want to lose their autonomy. Additionally, the colour of the prescribed stockings were mainly an issue for female interviewees. Angelika said:

*«I do not want that this leg will open up again. The nurse told me to wear special socks. This might be very good but I am not the youngest anymore. I do not have the force to put them on. She (the wound care nurse) suggested organising the community nurse. But I don't want this. I am independent person and I do not want to wait for them ... But you know the most important thing is that I take care of my skin. Yes I always moister my skin. Through this, I do something good for my legs. But, one morning, even I prevented sufficiently my leg was open again».*

Other participants said that wearing stocking was comfortable during the cold season because they are too warm. Others put them on when their legs swell with oedema For Magdalena, Martha and Georg, swollen legs meant that they had to start prevention measures by wearing stockings and/or moisturising their skin.

Frank and Nick developed their own prevention intervention by taking hot and cold showers and not wearing stockings as they believe stockings are used only by women. They. If this does not help, they were putting their legs up. Nick said:

*«Wearing stocking is something for women and not for men. I developed a technique how I can prevent a recurrence. Yes, this works nearly all the time. During the wintertime I shower my legs with hot and then cold water. During the summer I only use cold water..... and you know if they get too swollen then I put them up on the chair and watch TV until it is better. But, this summer is too hot and I couldn't keep up with cooling my legs. Therefore I have it (the wound) again ».*

Wilma, Nicole and Martha tried to change their eating habits and eat more vegetables and fruit. And, they tried to decrease their risk of trauma, so they do not fall and nobody will hurt their legs. Each patient we interviewed had developed their own strategies to avoid developing a recurrence.

#### 4. Discussion

This interpretative phenomenological study identified why patients' believe they developed an ulcer and how they prevented ulcer recurrence. Our findings illustrate that for these patients VLU recurrence was due to trauma from lower limb injury; application and/or wearing unfitted stockings or due to non-adapted prevention measures. All participants were unaware they had limited knowledge about ulcer aetiology.

Our study findings confirm that some patients with VLU do not have sufficient knowledge of the pathophysiology of their condition or of preventive therapeutic measures to perform effective self-management (Van Hecke, Grypdonck et al. 2008, Finlayson, Wu et al. 2015).

Additionally, our findings show that compression stockings are worn although ill-fitting stockings caused skin-trauma through rubbing. Wearing stockings that do not fit was also demonstrated in Nørregaard's and colleagues work show that ready-made compression stockings presently prescribed will not properly fit the majority of patients to prevent oedema and ulcer recurrence (Norregaard, Bermark et al. 2014). The authors concluded that there is a need to standardise measuring methods for ready-made below-knee compression stockings as not all patients have the same anatomy. Prevention of VLU recurrence is a challenge not only for patients with VLUs but also for health care professionals. To reduce risk factors associated with peripheral vascular disease strategies such as wearing stockings, lifestyle modifications, increased physical activity, limb elevation, high protein nutrition intake and skin care have to be followed (Probst, Allet et al. 2019, Weller, Team et al. 2019). Participants in our study endeavoured to wear compression stockings and or to moisture the skin. Application compression stockings was often reported as challenging. To accept professional help was difficult for all participants, as they did not want to lose their autonomy.

## 5. Conclusion

For participants of this study, initial ulcer occurrence was primarily caused due to trauma to their leg. Wearing ill-fitting compression stockings or engaging in ineffective preventive measures were two reasons identified by participants for VLU recurrence. Some participants used self-care skills and knowledge to prevent ulcer recurrence. Future work could explore if health literacy awareness in people with VLUs could help optimise recurrence prevention. There is a need to develop effective educational interventions that focus on patient-perceptions and understanding.

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