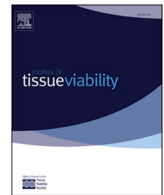
Journal of Tissue Viability 34 (2025) 100837

Contents lists available at ScienceDirect

Journal of Tissue Viability

journal homepage: www.elsevier.com/locate/jtv



"I was surprised that the veins were the cause" – The illness trajectory of people with venous leg ulcers: A qualitative study

Robin Schick [a,b,c,1], Caroline Staub-Buset [d], Gabriel Vujic [e], Sina Lachappelle [f,c,1], Eva-Maria Panfil [g,c,*,1]

[a] Department of Health Professionals, Bern University of Applied Science, Bern, Switzerland
[b] Department of Visceral Surgery and Medicine, University Hospital of Bern, Bern, Switzerland
[c] Institute of Nursing Science, Department Public Health, University of Basel, Basel, Switzerland
[d] IZZ Immunology Center, Zurich, Switzerland
[e] Department of Geriatric Medicine, FELIX PLATTER Hospital Basel, Basel, Switzerland
[f] Center for Musculoskeletal System (ZMSI), Department for Orthopedics and Trauma Surgery, University Hospital of Basel, Basel, Switzerland
[g] Practice Development and Research Department, University Hospital Basel, Basel, Switzerland

ARTICLE INFO

Keywords:
Illness trajectory
Education
Person-centered care
Qualitative study
Venous leg ulcer

ABSTRACT

Background: Patients with venous leg ulcers (VLUs) often carry out inadequate self-care. Person-centered care is recommended as effective support. Understanding the illness trajectory from the patient's perspective could be a way to better understand patients' needs.
Aim: The aim was to describe the illness trajectory experienced by patients with venous leg ulcers.
Methods: Using a qualitative approach, we conducted individual interviews with a purposive sample of 12 patients with venous leg ulcers in the wound outpatient department of a university hospital. Thematic analysis was carried out utilizing the Illness Trajectory Model as the theoretical framework.
Results: 8 women and 4 men with an average age of 74 years had different wound durations, recurrence rates and comorbidities. We identified six illness trajectory-relevant phases: (1) "Accident" or "mosquito bite"; (2) Experiential knowledge reaches its limits; (3) Seeking professional help; (4) Help from the wound clinic; (5) Saying goodbye to normality; (6) Managing VLU in everyday life. VLUs were often caused by accidents and initially treated by patients themselves, with medical help sought later. Over time, patients adapted to treatments like compression therapy, gained self-management (SM) skills to cope with daily life challenges.
Conclusion: All participants performed SM to varying degrees, but not always adequately. Insufficient awareness of the wound as a symptom and complication of a causative disease caused inadequate and ineffective wound management in many cases. Adequate SM developed primarily through learning from experience. The promotion of empirical knowledge and needs-oriented education can improve the SM of affected persons.

1. Introduction

Venous leg ulcers (VLUs) represent the final stage of chronic venous insufficiency (CVI) and are the most common type of chronic ulceration, accounting for around 70–90 % of cases [1]. CVI, a multifactorial disease of the superficial or deep venous system, is estimated to affect 20–30 % of adults in the community [2]. The prevalence of active venous ulcers in adult population is approximately 3 % and increases to 4–5% in people over 65 years of age [3,4]. In Europe, up to 2.2 million people are affected by VLU [5]. The treatment of VLU causes a significant financial and socioeconomic burden, accounting for up to 1–2% of national healthcare costs [6,7]. For example, the average annual treatment costs per patient in Germany amount to €9500 [8] and in the UK to £5488 [9]; the total cost of treatment in the UK in 2022 amounted to £300 million [10].

A VLU is a preventable complication of CVI. Treating the underlying disease and reducing risk factors are crucial for wound healing [11]. Around 50–60 % of VLUs can be cured with appropriate treatment [12].

* Corresponding author. Universitätsspital Basel, Programmleitung Dekubitus/Wunden, Abteilung Praxisentwicklung/Forschung, Hebelstrasse 2, CH-4031, Basel, Switzerland.

E-mail address: eva-maria.panfil@usb.ch (E.-M. Panfil).

[1] at the time the study was conducted.

https://doi.org/10.1016/j.jtv.2024.12.001
Received 30 September 2024; Received in revised form 7 November 2024; Accepted 3 December 2024
Available online 5 December 2024
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Nevertheless, almost 7 % of ulcers show no tendency to heal after five years and the recurrence rate three months after healing is around 70 % [13].

There are numerous treatment options, ranging from physical to medical and surgical measures [14]. Current guidelines and expert standards recommend a healthy lifestyle, lifelong compression therapy, measures to promote ankle mobility, elevation of the legs, avoidance of leg injuries, regular skin inspection and care, and avoidance of excessive heat and venous overload [15–22]. Compression therapy, which can be achieved through the use of bandages, compression stockings, mechanical systems or a combination of these methods, is considered the gold standard in the prevention and treatment of VLU [23,24].

CVI or VLU represents a significant health problem for those affected [25]. Physical, psychological, social and economic effects impair patients' activities of daily living and severely limit their health-related quality of life (QoL) [4,26]. Pain, difficulty moving, sleep disturbances, body image disorder, lack of energy, wound fluid and odor as well as negative emotions lead to frustration, low self-esteem and can even cause depression [27–29]. In addition to organizational obstacles, many sufferers have difficulties integrating the treatment recommendations into their everyday lives [30,31]. The reasons for this are a lack of information about the treatment plan, a lack of understanding of the consequences, a lack of adherence to treatment and personal beliefs and values; often a combination of different factors that interact and influence the implementation of the measures [26,32,33].

Patients with VLU are insufficiently informed about self-care activities, do not sufficiently understand the importance of treatment and have difficulty applying appropriate therapeutic measures [34]. Professional support services are therefore increasingly focusing on the promotion of self-management (SM) [35]. However, there is a lack of evidence as to which patient education interventions are effective [36]. Multidimensional, holistic approaches that take into account the patient's understanding of the disease (including its causes, treatment and relapse prevention) as well as their physical, psychological and social experiences with the corresponding cultural context are considered useful [35,37,38].

The WHO prefers "person-centered care (PCC)" as a concept of healthcare for people with chronic diseases [39]. This approach is not based on the clinical picture, but on the health plans, expectations and beliefs of those affected and empowers them to make their own decisions [40]. PCC specifically takes into account the individual perspectives and needs of patients and their relatives [41]. Above all, patients want appropriate pain management and normalization of their lives [42]. Rosenburg et al. (2022) found that, contrary to the understanding of PCC, treatment focuses only on the wound and not on the person in their daily life [43]. A reliable, personalized therapeutic relationship can reduce hopelessness and despair in patients and increase their willingness to engage in their health [43].

However, the implementation of PCC in the acute sector is proving difficult [44]. Care for affected individuals is often provided from a disease- and symptom-oriented perspective, characterized by a cross-sectional perspective, i.e., the current state of health. However, living with CVI and VLU requires lifelong adaptation. Understanding the course of the disease from the patient's perspective could be a way of offering PCC in a more targeted way. The "Illness Trajectory" Model, developed by Corbin and Strauss, is particularly suitable as a theoretical basis. It represents a patient-centered approach that takes into account the experiences and perspectives of those affected from a longitudinal perspective [45]. Care and disease progression curves describe how patients and their relatives organize tasks in the disease process, what burdens arise and how they deal with them. Different stages and phases of a chronic illness are graphically represented in a curve, showing how the illness is managed and the degree of dependency. The aim is to offer phase-appropriate support to those affected and to help them cope with the disease with the best possible QoL [45]. Although the course of the disease is individual, people with the same disease can experience similar phases and comparable progression [45,46].

We do not know what the course of care and illness looks like for people with VLU. The research question is, therefore: How do people with VLU cope with their disease and its management during the course of care and illness? The aim of the study is to further develop the care of people with VLU in terms of PCC.

2. Materials and methods

The study was approved by the Cantonal Ethics Committee of Northwestern and Central Switzerland (Project ID 2021–01496). All participants gave their written consent to participate in the survey and allowed the interview to be recorded. For data protection reasons, names or places that could be used to identify a person were replaced with a pseudonym and all participants received a study code number.

2.1. Study design

To address the research question, we used a qualitative design with interviews based on the "Interpretive Description" [47]. This inductive-analytical research methodology aims to address complex and experience-related questions from the subjective perspective of those affected and at the same time generate practical results [48]. The interprofessional research team was composed as follows: RS and SL (nursing science students); CB (dermatology and venereology specialist; GV (wound expert); and EMP (nursing scientist).

2.2. Participants

We used purposive sampling. The aim was to generate a sample with maximum variation in terms of gender, age, comorbidities, wound duration, recurrence rate, self-care and QoL. We included adults aged 18 years and older with VLU who were treated in the outpatient wound clinic of a university hospital and spoke German. Patients with cognitive impairment and impaired general health were excluded.

The participants were recruited on an ongoing basis between October 2021 and April 2022 through a personal request in the outpatient wound consultation by the treating wound experts. The survey continued until satisfactory data saturation was achieved.

2.3. Data collection

Using an interview guide developed by our research group (Appendix 1), we conducted individual interviews with the patients. This included open questions on the course of care and illness, disease-specific QoL and self-care activities in VLU.

To ensure a heterogeneous sample, we collected data on self-care and QoL using standardized instruments. We surveyed self-care activities for VLU using the "Wittener Catalog of Self-Care Activities for VLUs" (WAS-VOB) [49]. The instrument, which consists of 59 items, uses a Likert scale ("yes, exactly true"; "rather yes"; "rather no"; "no, not true at all") to record patients' surgical self-care skills in dealing with compression, movement, warmth, venous overload, recurrence prevention and wound healing over the past 12 months on eight scales [50]. The questionnaire has sufficient to good psychometric properties [49]. A low total score (between 59 and 236 points) indicates adequate self-care behavior. We determined the health-related QoL with the "Questionnaire on quality of life with chronic wounds" (Wound-QoL) [51], a reliable and valid questionnaire [52,53]. It records the frequency of limitations in 17 items using a 5-point Likert scale ("not at all"; "somewhat"; "moderately"; "quite"; "very") in the categories body, psyche and everyday life [51]. The lower the total score (between 0 and 69 points), the better the QoL.

The socio-demographic data we collected from patients using our own questionnaire included age, gender, origin, and clinical data such as wound duration and comorbidities.

The participants received all four data collection tools in preparation

for the upcoming interview so that they could familiarize themselves with and remember their care and illness history in advance. The aim of the preliminary survey was to enable better preparation of the participants, time efficiency in conducting the individual interviews, completeness of the information, increased accuracy and to avoid missing relevant information. These aspects should enhance the understanding of the qualitative findings.

RS conducted the interview using interview techniques he had learned. He also documented reflections and impressions to reconstruct the context immediately after the interview in the form of field notes. Ten of the twelve interviews took place in separate, quiet rooms at the university hospital, two interviews in the participants' private surroundings. The interviews lasted 36–104 min. They were recorded using an audio recorder. We did not have to repeat any interviews.

2.4. Data analysis

RS transcribed the interviews verbatim. We analyzed the data within the interprofessional research group using reflexive thematic analysis according to Braun and Clarke [54] and the computer software MAXQdA® [55]. A central feature of the iterative analysis process is the simultaneous collection and analysis of data [56]. This allowed us to consider and further explore findings already obtained in the further data collection. We carried out the inductive analysis according to the following six steps: Multiple readings of the transcripts and field notes (1); coding the empirical data, whereby similar content was assigned the same codes (2); forming initial potential themes, which we subsequently examined for internal homogeneity as well as external heterogeneity (3); recognizing coherent patterns and individual differences (4); refining and defining the themes until a consensus was reached (5); and describing related themes as findings in the form of a report, which was supported with relevant quotes (6).

The sample was calculated using statistical location parameters (minimum, 1st quartile, mean, median, 3rd quartile and maximum).

2.5. Rigor and trustworthiness

To ensure the study's rigor, we followed the Reporting Guideline Consolidated Criteria for Reporting Qualitative Research (COREQ) [57] and applied the trustworthiness criteria for qualitative research described by Lincoln and Guba [58]. The credibility of the results was increased by triangulating the data analysis by two independent research teams (an interprofessional research team and a university seminar group), regular peer discussions and a review of the structured research process. To maintain dependability, we kept detailed records of our research activities in order to continuously reflect on personal biases and assumptions and their potential influence on data collection and analysis. Transferability is supported by the targeted selection of participants who are as heterogeneous as possible. In addition, the study context was described in detail. The direct reproduction of statements by those affected in the results section, as well as the comparison and interpretation of the results with other research findings in the discussion section, increases the verifiability and confirmation of the results.

3. Results

The sample comprised 12 participants with an average age of 74 years (min. 52, max. 94) and different sociodemographic backgrounds (e.g., living situation, self-employment, education, and occupation). Four of those affected were single at the time of data collection.

According to their statements, those affected suffered from several various other illnesses, with cardiovascular diseases (n = 8) and accident-related orthopedic conditions (n = 5) being mentioned most frequently. Other illnesses were obesity (n = 2), allergies (n = 2), metabolic diseases (n = 2) and, with one mention each, chronic inflammatory diseases, kidney dysfunction, respiratory diseases, degenerative joint diseases, urological, rheumatological and mental illnesses.

The average course of care and illness was 10.5 years (min. 1 month, max. 38 years). Most respondents suffered from one to two recurrences or new wounds. The duration of the wounds ranged from one month to several years. Around half of those affected reported a psychological impairment, e.g. depression or exhaustion, due to the disease. The sociodemographic characteristics are shown in Table 1.

On average, the respondents performed rather adequate self-care (WAS-VOB medium 118.5 points, min. 87, max. 152, median 115.5). The results in the Wound QoL were 14.3 points on average (min. 0, max. 39, median 8.5), which indicated a higher health-related QoL.

3.1. Course of care and illness

We identified the following six phases in the course of care and illness: (1) Before the illness: "Accident" or "mosquito bite"; (2) Onset of the chronic illness: Experiential knowledge reaches its limits; (3) Acute: Seeking professional help; (4) Crisis: Help from the wound clinic; (5) Unstable: Saying goodbye to normality; (6) Stable: Managing VLU in everyday life. Different sub-subthemes could be identified for each phase. The six phases are shown in Fig. 1.

3.1.1. Phase 1: Before the illness: "Accident" or "mosquito bite"

VLU was often caused by accidents such as bumping and tearing the skin or friction from compression stockings and was not associated with CVI. Some described the wound as a "mosquito bite."

The unconscious CVI: As CVI typically presents with no initial symptoms, participants were unaware of it. One patient believed that only obese people get an "open leg." For most, the underlying disease was not present.

Table 1
Sociodemographic and wound characteristics; self-declaration (n = 12).

	Quantity	Percent
Gender		
Female	8	66 %
Male	4	34 %
Age		
18-–29	–	–
30–65	3	25 %
>65	9	75 %
Nationality		
Switzerland	11	92 %
Abroad	1	8 %
Housing situation		
Living alone	5	42 %
Not living alone	5	42 %
Not specified	2	16 %
Gainful employment		
Employed	2	17 %
Retired	7	58 %
Disability insurance	1	8 %
Not specified	2	17 %
Comorbidities (excl. CVI[a])		
1	2	17 %
>1	10	83 %
Existing wound problems		
<3 months	2	17 %
3–6 months	2	17 %
>6 months	8	66 %
Frequency of consultations at the university hospital		
1x/week	3	25 %
2x/week	3	25 %
1x/month	1	8 %
2x/month	1	8 %
Not specified	4	34 %
	–	–

[a] *CVI - chronic venous insufficiency.

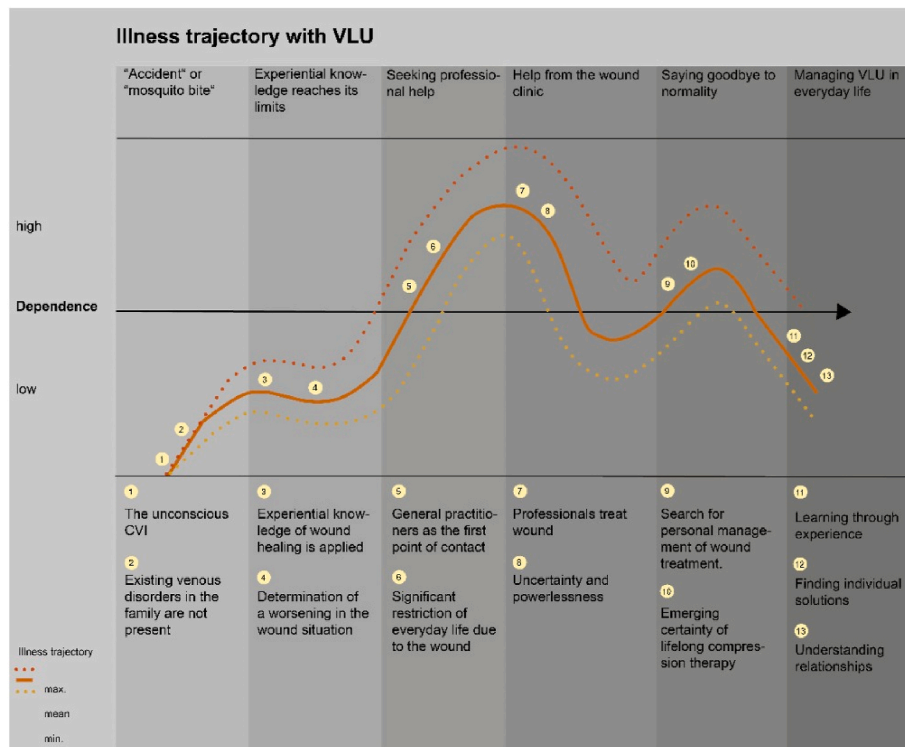

Fig. 1. Illness trajectory with VLU.

> *"I have a bit of varicose veins, don't I? […] I have no pain and nothing. […] It has nothing to do with the wound, it's independent of it."* (P11)

Existing venous disorders in the family are not present: While many patients reported a family history of "vein or leg problems," often in parents who underwent various therapies and suffered complications, most were unaware of CVI's relevance or impact. They remembered little or no information about the underlying condition and how to deal with preventative behaviors before the appearance of the first wound.

> *"Why do I get edema like this? Why does a wound open up afterwards?"* (P5)

3.1.2. *Phase 2: Onset of the chronic illness: Experiential knowledge reaches its limits*

Despite complaints, the majority of those affected initially treated the wound themselves or with the support of relatives. They only sought medical help when their health became impaired. Their views on the disease and wound development varied.

Experiential knowledge of wound healing is applied: Patients relied on prior experiences with wound care, mainly using simple plasters based on the success of past treatments. They believed that, like previous wounds, this one would heal on its own without professional intervention.

> *"I've never had anything wrong with the wounds. My wounds always heal very well. Yes, even after operations I've never had any problems, nothing."* (P7)

Determination of a worsening of the wound situation: The patients reported the following complaints in connection with the wound development: wound pain; feeling of tension (partly due to wound crusts); wound fluid; difficulty walking; burning; foot and leg edema; itchy, scaly, and dry skin; as well as sleep problems caused by pain. They sought medical help only after complications or health restrictions became severe, with delays of up to two years.

> *"I had the open wound for two years. It was a horror. But I was ashamed. I didn't want to go to the doctor."* (P9)

They became alert to signs of inflammation and infection, signs of sepsis (chills), hematoma, deterioration of the wound situation, skin changes, foot and leg edema, increase in symptoms, detachment of the wound crust and allergic reactions.

3.1.3. *Phase 3: Acute: Seeking professional help*

Although general practitioners (GPs) were often the first point of contact after the onset of VLU, patients were frequently referred to specialists. They reported numerous restrictions in their everyday lives, which significantly impacted their private and professional lives.

General practitioners as the first point of contact: For most of those affected, GPs were the first point of contact. They rarely took over wound care and were sometimes perceived as overwhelmed. Patients were referred to specialists, e.g., phlebology or the vein clinic, or to the emergency department at the university hospital. Some also went directly to the university hospital, often based on previous positive experiences or on the recommendation of their social environment.

Significant restriction of everyday life due to the wound: CVI and VLU brought different symptoms that disrupted daily activities, including personal hygiene, mobility, and wound exudation.

The majority of those affected had problems with personal hygiene, particularly showering, due to the need to keep dressings dry. Many adapted by using plastic bags or film, and some even reduced their showering frequency, which led to feelings of uncleanliness.

> *"I'm used to showering in the morning and evening and I also have to wash my hair. I do that once a week now and just hang my head over the bath and shower like that."* (P11)

Fatigue and difficulty walking also affected daily professional and private activities. One patient reported that he had to adopt a gentle gait (toe walking) due to the foot and leg edema, while others felt "constricted" by the compression therapy. Leisure activities like hiking, cycling and swimming were restricted. Wound care and/or compression

therapy took considerable time and forced personal compromises due to frequent specialist visits.

The participants often spoke about the experience of wound fluid, which sometimes occurred in considerable quantities and had to be controlled. They used unconventional materials like toilet paper or absorbent cotton, in addition to bandages and wound dressings. One interviewee laid newspapers on the floor to prevent carpet damage from aggressive wound secretion. Some patients reported that their professional activity and social life were severely affected by the wound fluid and the frequent dressing changes. The costs of wound material and compression stockings were discussed but are generally not a challenge.

3.1.4. Phase 4: Crisis: Help from the wound clinic

Wound care was initially the main focus in the outpatient wound clinic, with compression therapy recommended for CVI. Other measures like leg elevation, exercise or skin care were discussed less frequently. Adjustments to the various therapeutic interventions often led to uncertainty.

Professionals treat wound: Participants reported various treatment approaches in which the professionals carried out the wound care. They therefore had to hand over the care. Diagnostic measures like venous function diagnostics, laboratory tests, biopsies, or wound swabs were often unclear to patients. Compression therapy was the main treatment for CVI, typically in the form of bandaging. Other treatments included skin care, leg elevation, lymphatic drainage, and drug therapies like diuretics or antihypertensives, but the rationale for these was not always explained. Exercise was mentioned, but not in connection with CVI.

Uncertainty and powerlessness: Patients recalled various therapeutic interventions for wound care, which were often associated with pain. In addition to conventional wound care using wound dressings and ointments, they reported medical therapeutic interventions such as varicose vein surgery, laser treatment, skin grafting or negative pressure therapy. The treatment of VLU was adapted to the clinical situation but also to the individual preferences of the providers. This led to uncertainty and feelings of dependency.

Many patients felt shame and fear, particularly when justifying regular dressing changes to employers. Some required medical certificates for work incapacity, which led to reduced workloads, financial losses, or even being declared unfit for work by the disability insurance company.

> "*You're out of there, you're home, two hours later the bandage is soaked through. Once you've found time at work without your employer hitting the roof."* (P10)

3.1.5. Phase 5: Unstable: Saying goodbye to normality

Interviewees realized their "old life" was gone. Even though compression therapy was often perceived as restrictive, it was largely tolerated. Information needs regarding CVI and VLU varied. Background information helped to better understand and implement the therapeutic measures. Confidence and a positive attitude were important coping factors.

> *"Because it's a disability, the support stockings are a disability. You could say you walk like a robot. Because of course you're never that free."* (P2)

Search for personal management of wound treatment: Patients gradually began managing their condition by relying on professional information, though many received little about CVI and more about VLU. Misunderstandings arose due to technical language or conflicting information. Information needs and sources varied: some wanted little to no information, while others were overwhelmed. Many participants also received advice or recommendations through private exchanges. Some patients preferred to be informed by professionals, while others informed themselves independently on the Internet about the disease and its treatment options.

> *"Yes, there was information about the ulcer. I read it and accepted it. [...] I don't have to process it any further. I don't process what doesn't interest me. I don't burden myself with it."* (P3)

Emerging certainty of lifelong compression therapy: Acceptance of the disease and its treatments was a significant step for patients, many of whom recognized that compression therapy was a long-term necessity. The orthopedic specialist store, a partner of the outpatient wound clinic, fitted the compression stockings and provided instructions on how to use and care for them. All participants valued this support, especially the advice on using aids for putting on and taking off stockings.

> *"[...] I got all the help I needed to put this stump on, for pulling it up, a special glove and everything."* (P2)

3.1.6. Phase 6: Stable: Managing VLU in everyday life

As the care and illness progressed, patients gained more experience and SM skills. They developed individual coping strategies to organize their daily lives more independently of the professionals.

Learning through experience: Initially dependent on instructions, patients emphasized the importance of learning through experience to manage wound care and compression therapy independently. They gained necessary knowledge by observing professionals, who explained the reasons behind their actions. When explanations were lacking, patients actively sought clarification to avoid misunderstandings.

> *"He has already said that comfortable shoes are important and with regard to applying the cream, he has said that I must do that regularly [...] but he has not emphasized the importance enough [...] either I have to find out why myself or I am told that it is important and why."* (P1).

Finding individual solutions: Patients varied in their experience with compression therapy, with many reporting that putting on and removing compression stockings was time-consuming, regardless of support. Compression stockings were preferred over bandages for comfort. Some used aids like rubber gloves, toe caps and special frames. In most cases, they needed support from relatives. Physical limitations, such a lack of strength in his arms due to a damaged shoulder, also impacted the process in a negative way.

> *"It's a disaster putting on the stockings. I'm glad I have the wife. She helps me in the morning ... "* (P4)

All patients aimed for maximum independence in everyday life with minimal restrictions. Due to the time-consuming nature of specialist consultations, most participants gradually took over wound care themselves or with family support, applying simpler dressings independently as their condition progressed.

Understanding relationships: With time, patients developed a better understanding of their condition, recognizing the links between the underlying condition, VLU, and appropriate therapeutic interventions. This growing experience enhanced their SM, enabling them to identify early signs of deterioration, like foot and leg edema, and understand when to use compression stockings or adjust wound care.

> *"If I realized that I had water in my left hand again, I would put on the support stocking."* (P8)

4. Discussion

In this qualitative study, we used twelve guided individual interviews to identify six phases during care and illness in which those affected perform different tasks to cope with their everyday life and their illness.

The number of patients recruited was sufficient to achieve data saturation. The sample is largely representative. Apart from a higher average age of 74 years and fewer wound recurrences (on average 1–2),

it is comparable (proportion of women/men, age, comorbidities, wound duration) to the systematic review by Gethin et al. [59]. We were unable to achieve the desired heterogeneity of the sample. Younger women and people with a migration background were underrepresented. Although the respondents also reported various limitations in everyday life, their QoL was higher than in other publications [60]. Patients with a severe symptom cluster (pain, fatigue, sleep disorders, depression) reported a lower QoL, regardless of gender, age, wound duration or comorbidities. Those affected also tended to show adequate self-care at the time of the interviews. This may be due to the context of the sample survey. The interviewees were all undergoing treatment.

Care and illness progression curves do not refer to a physiological course of a disease, but to the active role that patients and relatives play in the disease course – how they organize the work they perform and the associated burdens [45]. Due to wound recurrence, stable and unstable phases alternate, often resulting in emotions such as insecurity and powerlessness.

All participants performed SM to varying degrees, but not always adequately. Knowing that they had always been able to successfully treat previous wounds themselves, the participants initially applied their knowledge of wound care despite considerable symptoms and physical discomfort. For the most part, patients in our study only consulted specialists when a wound situation worsened, with 30 % of all VLUs being clinically infected by this point [61]. It is known that patients only consult specialists if SM is unsuccessful, if they are in unbearable pain or if their relatives ask them to do so [62]. In principle, it is important for those affected to retain control over their everyday life and to ensure "normality" through independence in wound care [62]. This is a typical need of people with chronic illnesses [63]. Insufficient awareness of the wound as a symptom and complication of a causative disease led to inadequate and ineffective wound management in many cases. Although many of those affected were aware of vein problems in their family, they did not make the connection with their own situation. CVI is associated with a positive family history [64–67]. Patients often mentioned dry, scaly and itchy skin on the lower extremities. As VLU is the most severe and visible form of CVI, early signs such as the typical eczematous changes were not recognized as signs of disease [68,69]. For prevention and effective treatment, however, it is crucial for those affected to recognize that the skin changes and wounds are not harmless injuries that heal by themselves [62].

The patients only recognized the importance of adequate compression therapy as their care and illness progressed. It was only through their own experiences that the interviewees became aware that symptom relief is only possible with consistent and long-term compression therapy. They found compression stockings restrictive and uncomfortable, which is why they often did not use them consistently and over a longer period. However, compression therapy is considered the therapeutic gold standard, as it promotes venous return and thus reduces fluid accumulation in the legs [70,71]. The success of the therapy depends largely on the patient's willingness to wear the compression stockings [72]. Studies describe that patients often do not understand the importance of compression therapy [73]. Due to the restrictions experienced as a result of compression, adherence to the therapy is rated as more important than choosing the highest possible compression class [74].

Inadequate SM leads to complaints, impairs the health-related QoL of those affected and their relatives in the long term and places a strain on many health resources [75]. It became clear that during the course of care and illness, adequate SM was developed primarily through learning by experience. Connections between the CVI and the wound could only be established by experiencing discomfort and alleviating it by managing compression therapy oneself. SM means not only implementing measures, but also registering and understanding symptoms and deciding on, implementing and adapting certain behaviors [75]. Therefore, it is not enough to "inform" patients. Many respondents did not recall receiving information from professionals. Respondents seemed to learn more by reflecting on the success and failure of therapeutic interventions and developing their own solutions.

Being affected by CVI requires a lifetime of work. People with VLU want their worries, fears and daily challenges with the disease and its management to be taken seriously. They want holistic and needs-oriented care and communication, social support, and continuity in the treatment process and, above all, normality in everyday life [42]. PCC means an approach to care that is based, among other things, on people's health needs and expectations and not on illnesses; it consciously takes the perspective of individuals and families, responds to their needs and preferences and empowers them to make decisions [39]. In the context of PCC, this would mean responding in principle to patients' health needs and offering support so they can actively participate in their care. Patients with VLU must find a balance between maintaining their daily lives and providing adequate treatment [37]. This requires a comprehensive person-centered history and specific assessments at the beginning of treatment to get an overall picture of the patient's situation and needs, rather than focusing only on the disease.

Health policy strategies aim to ensure that patients take an active role in disease management and take care of their disease independently [75]. Not only early diagnosis and treatment are crucial for the success of therapy and the prevention of wound recurrence, but also patient adherence to therapeutic interventions [72]. Ineffective counseling and support services can interfere with proactive SM [32]. Therefore, the aim of effective therapeutic education is to support those affected through a systematic and individualized learning process, empowering them to take control of their own health, taking into account their own resources [41].

4.1. *Strengths and limitations*

The study was the first description of the course of care and illness in patients with VLU. The "Illness Trajectory" Model proved to be a suitable theoretical framework. The discussion of the results in the interprofessional team supported the validity of the results. A selection bias cannot be ruled out. Younger women and those affected with a migration background could not be included. Illness data are based on self-reporting, so their reliability cannot be assessed. Furthermore, the data were collected exclusively in the outpatient wound clinic, which limits the validity of the results and their transferability to other settings.

5. Conclusion

All participants performed SM to varying degrees, but not always adequately. Insufficient awareness of the wound as a symptom and complication of a causative disease resulted in inadequate and ineffective wound management in many cases. Patients only recognized the importance of adequate compression as their care and illness progressed. Adequate self-management SM primarily through learning from experience.

Knowledge of the identified phases of the care and disease course can sensitize healthcare professionals to care for people with VLU and their relatives attentively and to perceive their concerns and expectations in the respective phases. In practice, it is recommended that care strategies be geared towards the individual everyday needs of patients, their expectations, values, and beliefs. Promoting experiential knowledge and needs-oriented education can improve the SM of affected persons and encourage their personal concerns and goals. Professionals should consider the current level of knowledge of those affected and actively ask about family experiences.

Further qualitative research would be useful to evaluate the results of our study in other settings and with other samples to verify and further develop the phases found here.

Declaration of generative AI and AI-assisted technologies in the writing process

During the preparation of this work the authors used ChatGPT to rephrase and summarize individual passages. After using this tool/service, the authors reviewed and edited the content as needed and take full responsibility for the content of the publication.

Funding

This research did not receive any specific grant from funding agencies in the public, commercial or not-for-profit sectors.

Declaration of competing interests

None.

Acknowledgment

Our greatest thanks go to the participants for their trust and openness. We would also like to thank the interprofessional specialist staff of the department for recruiting the patients.

Appendix 1. How do people with VLU cope with their disease and its management during the course of care and illness?: A qualitative study

1. Introduction

To explore the experiences and views of the study participants in the form of stories about the course of care and illness experienced to date and the healthcare provided at the university hospital's outpatient wound clinic, primarily open questions are used during the interview. In order not to impede the flow of conversation, the interviewer only intervenes when the stories of those affected move outside the topic of the study. Specific follow-up questions can be used to go into more detail. To prepare for the interview, the study participants receive these guidelines in advance.

The following section contains both information and framework conditions to inform the study participants about the upcoming interview process.

1 Greeting
- Welcoming the study participants
- Introduction of the interviewer with name and function
- Acknowledgment of participation in the research project

2 General conditions: Study and interview
- Clarification of open questions about the study and ensuring that information in the study information was correctly understood
- Information about the rights of the study participant
  - The interview can be interrupted and/or canceled at any time
  - Questions do not have to be answered or can be omitted
  - All information is treated in strict confidence
  - Your answers will have no influence on further treatment at the USB
  - Your consent to participate in the study may be withdrawn at any time
- Interview details
  - The interview takes around 60 min
  - The conversation is recorded on an audio recorder
- Have the consent form signed in duplicate; one copy is given to the study participant

3 Procedure of the interview
- I will ask you questions and ask you to simply talk to me about them. I will follow your stories. If necessary, I will ask questions or ask you to tell me about an example you have experienced
- This interview guide is a support for me and serves to structure the interview.

4 Study objective
- We would like to use this study to find out how you have experienced the course of your chronic wound to date. At the same time, it is particularly important to us to understand your experiences with outpatient wound care at the University Hospital. In this way, outpatient wound care can be tailored to the individual needs of patients and the service can be improved.
- I will now switch on the audio recorder

2. Main part

	Question	Switching on the audio recorder	
		Maintenance issues	Inquiries
Course of the disease	Access The aim of this study is to describe how patients with venous leg ulcers have experienced the disease over time. In other words, from the beginning until today and everything that goes with it. This could be, for example, how they themselves deal with the condition and what healthcare professionals contribute. As this often covers a long period of time with different experiences, I would like to ask you to record the course of the illness you have experienced with the events or phases that are important to you. Here is an example of what this could look like. You see a "timeline": on the left-hand side would be the onset of the disease and/or the first appearance of the wound; on the right-hand side would be the present time. You have now told me about various situations that you experienced during your illness with the leg wound. Can you tell me why you remember these events in particular?	• Is there anything else? • And then/and then? • Can you describe this in more detail? • What exactly do you mean by that?	***Deepening*** • Can you tell me more about this? • Can you give us an example? • How was that exactly? • What happened next? • What happened then? ***Understanding/ clarification***

(*continued on next page*)

(*continued*)

	Question	Switching on the audio recorder	
		Maintenance issues	Inquiries
	Can you think back to the situation when the wound first appeared and tell me about it? What happened next? When you think about changes in the course of the disease, what exactly comes to mind? • What positive experiences have you had? • What do you remember negatively?		• Can you describe/explain this again? • What exactly did you mean by that? ***Emotions*** • How did that make you feel? • What was it like for you? • What did this situation trigger in you? • How did you react to this?

	Question	Maintenance issues	Inquiries
Health-related quality of life	*"Body"* You may have experienced physical discomfort from the leg wound over time, such as pain, wetness from wound fluid or an unpleasant wound odor. • What impact did this have on your life? • Can you describe how you dealt with the physical complaints? How did you experience the physical complaints retrospectively over time? *"Psyche"* Can you tell me what impact the wound has had on your mental well-being so far? How do you feel about it? Has your mental well-being changed over time? Why? *"Everyday life"* The open leg can affect everyday life in different ways, such as getting around, leisure activities or the financial situation. • Can you remember a time when the wound affected your everyday life and tell me about it? • What challenges did you have to deal with? • Have the effects of the open leg on everyday life changed over time? What have you done to cope with your everyday life?	• Is there anything else? • And then/and then? • Can you describe this in more detail? • What exactly do you mean by that?	***Chronological classification*** • When was that approximately in the course of the illness? ***Deepening*** • Can you tell me more about this? • Can you give us an example? • How was that exactly? • What happened next? • What happened then? ***Understanding/clarification*** • Can you describe/explain this again? • What exactly did you mean by that? ***Emotions*** • How did that make you feel? • What was it like for you? • What did this situation trigger in you? • How did you react to this?

	Question	Maintenance issues	Inquiries
Self-care activities	You may have received information about the open leg or the disease during the previous treatment(s). How did you experience the handling of the information? • What was important to you? • What was difficult? • Can you tell me what you were missing or what you would have liked? Various measures are available for the treatment of leg wounds. When you think back to your previous treatment(s), how did you find the implementation of the recommended therapeutic measures in your everyday life? • What was helpful? • In which situations was the implementation possible? • Can you describe to me when the implementation was rather difficult? • What do you think is helpful for implementing the measures at home? Can you tell me to what extent you were/are dependent on external support? ***→ Possible self-care activities (over time); if not yet discussed*** • *"Wound care":* When you think about dressing the wound. What experiences have you had? • *"Compression therapy":* Can you tell me how you deal with compression (e.g., bandages or stockings)? • *"Movement exercises":* What thoughts come to mind when you think of movement exercises in connection with the leg wound?	• Is there anything else? • And then/and then? • Can you describe this in more detail? • What exactly do you mean by that?	***Chronological classification*** • When was that approximately in the course of the illness? ***Deepening*** • Can you tell me more about this? • Can you give us an example? • How was that exactly? • What happened next? • What happened then? ***Understanding/clarification*** • Can you describe/explain this again? • What exactly did you mean by that? ***Emotions*** • How did that make you feel? • What was it like for you? • What did this situation trigger in you? • How did you react to this?

	Question	Maintenance issues	Inquiries
Interface management	Can you tell me how you have experienced the care here in outpatient wound care so far? What is your experience of the support from the outpatient wound clinic? • What do you find helpful? • What is less useful? Can you describe how you experienced the cooperation between the outpatient wound clinic and other specialists (e.g., Spitex, family doctor, other institution, etc.)? • What struck you as positive? • Where do you see room for improvement? How do you perceive the exchange between the professional groups involved in your care? • What struck you as positive?	• Is there anything else? • And then/and then? • Can you describe this in more detail? • What exactly do you mean by that?	***Chronological classification*** • When was that approximately in the course of the illness? ***Deepening*** • Can you tell me more about this? • Can you give us an example? • How was that exactly? • What happened next? • What happened then?

(*continued on next page*)

(*continued*)

	Question	Maintenance issues	Inquiries
Conclusion	• What struck you as negative? If there has been an interruption in the treatment of your wound so far, what do you think has led to this? Can you think of anything else we haven't mentioned so far that you would like to mention?		***Understanding/clarification*** • Can you describe/explain this again? • What exactly did you mean by that? ***Emotions*** • How did that make you feel? • What was it like for you? • What did this situation trigger in you? • How did you react to this?

3. Conclusion

Following the interview, the interview is concluded as follows:

- **Switching off the audio recorder**
- I would like to thank you very much for your participation in the research project as well as for your openness and trust
- I will pass on technical questions and concerns to the treating wound expert and/or the medical profession
- I will analyze the tape recordings of the interview anonymously with the support of the research group
- The study is now officially closed for you
- Thank you again for taking the time to participate
- I wish you all the best for the future. Goodbye

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