



A qualitative study on the patient's narrative in the progression of chronic venous disease into a first venous leg ulcer: a series of events

A.M. Meulendijks ,^{1,2} M. Welbie ,¹ E.P.M. Tjin,¹ L. Schoonhoven² and H.A.M. Neumann³

¹University of Applied Sciences Utrecht, Research Group Healthy and Sustainable Living, Utrecht, the Netherlands

²Nursing Science, Julius Center for Health Sciences and Primary Care, University Medical Centre Utrecht, Utrecht University, Utrecht, the Netherlands

³Department of Dermatology, Erasmus University Medical Centre Rotterdam, Rotterdam, the Netherlands

Summary

Correspondence

Audrey Meulendijks.

E-mail: Audrey.meulendijks@hu.nl

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Conflicts of interest

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Background A venous leg ulcer (VLU) has a significant negative impact on quality of life. Prevention of a VLU is not yet imbedded in clinical practice because risk factors for developing a first VLU are not well known.

Objectives To explore further the progression of chronic venous disease (CVD) into a first VLU from the patient's perspective.

Methods A qualitative study using semistructured interviews was conducted among male and female patients with a VLU. Patients from primary and secondary care, under and over 50 years of age, and with first and recurrent VLUs were included. The interviews were transcribed and analysed using a narrative approach to a thematic analysis. Transcripts were organized in chronological order and an iterative process was used to code the transcripts.

Results Four key themes and the connections made between them emerged from the 11 narratives on the progression of CVD towards a first VLU: 'comorbidity', 'mobility', 'work and lifestyle' and 'acknowledgment of CVD'. Comorbidity was linked to reduced mobility and late acknowledgment of CVD. Comorbidity also affected work and lifestyle and vice versa. Work and lifestyle affected mobility and was linked to the acknowledgment of CVD.

Conclusions A reduction in mobility as a result of comorbidity and work and lifestyle occurred before the VLU developed. Patients did not recognize symptoms of CVD and did not acknowledge the chronicity of CVD. Healthcare professionals should be aware of reductions in mobility and the knowledge deficit in patients with CVD.

What's already known about this topic?

- Not all patients with chronic venous disease (CVD) develop a venous leg ulcer (VLU).
- A patient's quality of life decreases significantly when a VLU develops.
- Risk factors for the development of a first VLU in patients with CVD are not well known, unlike risk factors for other chronic wounds like diabetic foot ulcer and pressure ulcers.

What does this study add?

- The patient's narrative towards the development of a first VLU, a series of events.
- Insight into the events (comorbidity, mobility, work and lifestyle) that patients themselves link to the development of a VLU.
- Insight into the patients' acknowledgment of CVD in the progression of CVD towards a first VLU.

What are the clinical implications of this work?

- More awareness is needed of CVD symptoms among patients and healthcare providers, as well as more awareness for prevention of a VLU in clinical practice.
- New insights (for further studies) are needed into the concept of mobility and the development of a VLU.
- Improved patient education and follow-up are needed for patients with CVD.

A venous leg ulcer (VLU) as a result of chronic venous disease (CVD) occurs in approximately 0.3% of the Western adult population.¹ The incidence might seem low, but the impact of a VLU is high, as patients with a VLU have a significantly lower quality of life (both generic and disease specific) than patients with an earlier stage of CVD.^{2–5}

Patients with CVD have increased ambulatory venous pressure and decreased venous outflow due to obstruction in the veins, weakened vein walls or vein valves, or impaired function of the calf muscle pump. Symptoms of CVD start mild, with reticular veins and varicose veins; however, they can progress to more severe symptoms like oedema, skin changes and eventually a VLU.⁶ Progression of CVD takes years and a VLU develops mostly in patients over 50 years old, as age is an important risk factor for the progression of CVD. Yet not all patients with CVD will develop a VLU.⁷

Factors that have been associated with the development of a VLU are increased age and body mass index, hypertension, lower physical activity, deep vein reflux, deep vein thrombosis and a family history of VLU. However, these factors were identified from case–control studies in which causality could not be established.⁸ A prevention strategy for a VLU is therefore not yet imbedded in the current clinical practice of CVD.⁹

Not only CVD but also the risk factors for developing a VLU can be present some time before the VLU occurs. It remains unclear how these risk factors progress over time, as most studies use a cross-sectional design with mostly cross-sectional measurements.⁸ The patients' perspective on developing a first VLU could provide insight into the timeline of the progression of CVD into a first VLU. This information can be used to select valid and reliable measurements for a quantitative study into the risk factors for a VLU and would provide health services with more insight into when to start a prevention strategy. Timely prevention for patients with CVD at risk of a VLU should eventually lead to a reduction in the incidence of VLUs and subsequently prevent a decrease in quality of life.

Patients' experiences were studied previously among patients with a (recurrent) VLU, focusing on the impact of the current VLU on quality of life. The negative impact on quality of life was caused by the pain, odour and exudate of the VLU.¹⁰ The patients' perspective on the recurrence of a VLU provided insight into factors that preceded the recurrence. Trauma on the lower extremities and nonadherence to compression therapy were factors that preceded the recurrence

of a VLU.¹¹ However, no studies were found that investigated the patients' perspectives towards their first VLU. Therefore, the objective of this study was to explore further the progression of CVD to a first VLU from the patient's perspective to provide insight into the factors that precede a first VLU.

Patients and methods

This study is reported according to the Standards for Reporting Qualitative Research.¹²

Design

We performed a qualitative study using a narrative research approach,¹³ as not all patients are aware of CVD as the underlying cause of a VLU.¹⁴ A narrative research approach with the oral history of the patients gives them the opportunity to tell their story and reflect on events and the causes and effects of these events from their perspective.¹⁵ The qualitative design is an efficient way to gain first insight into the events preceding a VLU. It provides a different perspective on the progression of CVD into a VLU and therefore might lead to new insights on risk factors.

Researcher characteristics and reflexivity

The first author (A.M.M., female, background in skin therapy and epidemiology) conducted all the interviews and performed the analysis. The second author (M.W., female, background in physiotherapy and health science) gave feedback on the recorded interviews and transcripts and partially performed the analysis. M.W. and A.M.M. had no relationship or prior contact with any of the patients. A.M.M. approached this study from the constructivism research philosophy to give insight into the individual reconstructions and understanding of the participants in the development of a VLU.

Sampling strategy

Male and female patients with an active VLU were recruited in the Netherlands. Patients were asked about participation by their healthcare professional (HCP) during a wound care visit. Patients were included when they spoke the Dutch language and were able to understand and sign the informed consent.

We used criterion sampling¹⁶ to include a heterogeneous group of patients with a variety of characteristics that might influence their narratives. The sampling criteria were as follows: patients under and over 50 years of age, patients with a first and recurrent VLU and patients from primary and secondary care. Saturation was considered to be reached when we included patients from all of the sampling criteria and reached inductive thematic saturation by not gaining new themes in two consecutive interviews.¹⁷

Data collection

We performed face-to-face, semistructured interviews among patients with a VLU to explore the patients' perspectives in depth. The patients were interviewed at their homes. Each interview started with the question, 'As mentioned before, I am interested in your experiences concerning the development of the VLU, can you start from the beginning?'. We used an interview guide with the following topics: advice to others at risk for developing a VLU, preventing the VLU, looking back: change of actions in the past with current knowledge, needs before the VLU developed, and self-management. The topics were compiled from the literature and revised by the coauthors. Interviews with a duration of 24–58 min were conducted and recorded digitally during the period of November 2016 to July 2017. After recording an interview A.M.M. transcribed the interviews verbatim using a transcription protocol¹⁸ and replaced all identifiable information.

Data analysis

We used the narrative approach to analyse thematically the key elements of the events the patients experienced in the development of their VLU. The narratives of the patients were rewritten into chronological order where we focused on what was said rather than how it was said.^{19,20} The thematic analysis was performed in five stages. (i) A.M.M. and M.W. summarized the interviews highlighting the tentative themes (and checked for saturation). (ii) A.M.M., M.W. and two research assistants used an inductive approach to code the first four transcripts. (iii) A.M.M. organized the codes and themes and M.W. checked the coding template. (iv) A.M.M. reconstructed all transcripts in chronological order, and for each patient a timeline of events was created using the patients' wording. (v) The coding template was continued using an iterative process²¹ of revising the data (individual narratives, themes and subthemes from all narratives) and discussing the themes and subthemes with M.W. from the perspective of the research objective. Finally, the themes and subthemes were discussed and revised with all authors. We used MAXQDA 12 (VERBI Software GmbH, Berlin, Germany) for qualitative data management.

Ethics

The study was approved by the medical ethics committee of the University Medical Centre Utrecht, the Netherlands

(registration number 16-744/C). Patients were given written and verbal information about participating in the study before they signed informed consent. The patient names were replaced by pseudonyms to ensure anonymity of patient data.

Results

Thirteen patients with a VLU were approached to participate in this study. One participant was not able to participate due to hospitalization of the spouse, and another participant reported no reason. Eleven patients completed the interviews. Nine patients were over 65 years old. We recruited five male and six female volunteers. More patients had a first VLU and most were recruited in primary care. Table 1 shows an overview of the patient characteristics.

Key themes

Four key themes emerged from the narratives of the patients on the progression of CVD towards a first VLU. The key themes comorbidity, mobility, work and lifestyle, and acknowledgment of CVD and the connections the patients made between them are presented in Figure 1. To elaborate on the concepts of the key themes the coding tree is presented in Appendix S1 (see Supporting Information).

A series of events

The patients narrated on a series of events in which all themes came forward. Subsequently, patients connected the themes in their narratives to the progression of CVD towards a first VLU. To illustrate the patients' narrative as a whole we present one case that is representative of the cases included in this study. Table 2 shows that Leroy started the narrative with an event related to key theme 3, work and lifestyle, which started years ago and continued for at least 20 years. He also narrated on several comorbidities (theme 1) that led to reduced mobility (theme 2) prior to development of the VLU. Furthermore, he narrated on the acknowledgment of CVD (theme 4) in which he did not act upon recognizing the symptoms because he prioritized the comorbidity (theme 1). Finally, he had a late response to the actual development of the VLU because of events related to work and lifestyle (theme 3). After the VLU developed the acknowledgment of CVD (theme 4) also affected his work and lifestyle (theme 3). However, this last event is not within the scope of this study as it occurred after the VLU developed.

Theme 1: comorbidity

Patients narrated on their comorbidities and sometimes directly linked these comorbidities to the development of a VLU. In some patients the comorbidity was a recent event, like with Grace:

'No idea, I really have no idea. Because I thought I lived healthy and everything. I exercise and have

Table 1 Patient characteristics

Patient ^a	Age (years)	Sex	Recruited from	Ulcer	Time of the current ulcer in months	Index leg
Leroy	43	Male	Dermatologist	First	2	Right
Agnes	50	Female	Dermatologist	Recurrent	> 12	Both
Wilma	68	Female	General practitioner	First	3	Right
Jack	68	Male	Dermatologist	Recurrent	24	Both
Doris	70	Female	General practitioner	Recurrent	4 and > 12	Both
Irene	72	Female	Dermatologist	Recurrent	> 12	Both
Frank	71	Male	Homecare	First	> 12	Right
Earl	75	Male	Dermatologist	First	24	Right
Henry ^b	77	Male	General practitioner	Recurrent	6	Right
Grace	78	Female	Homecare	First	5	Right
Rose	89	Female	General practitioner	First	18	Left

^aThe patients' names have been replaced by pseudonyms to ensure anonymity of patient data.

^bThe recording device failed to record, so this interview does not contain quotes but notes from the researcher (A.M.M.).

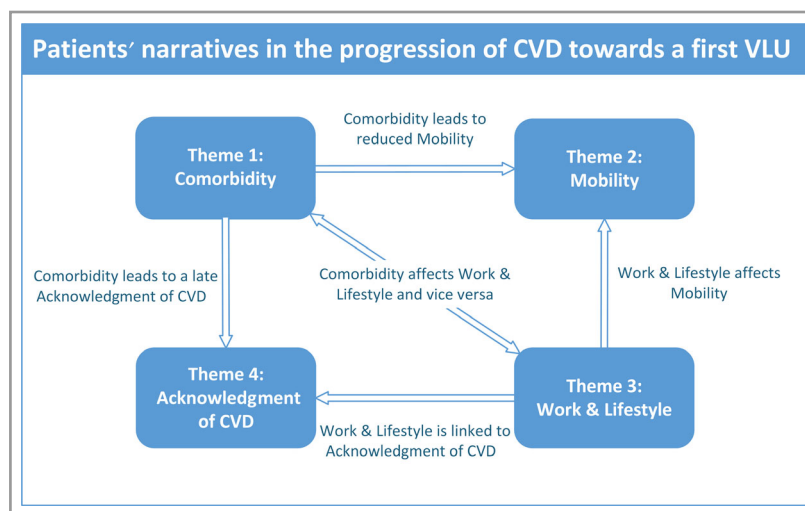


Fig 1. Key themes. CVD, chronic venous disease; VLU, venous leg ulcer.

enough fresh air. So I think it's the stress [few months]. That's the only thing I can explain, or eh what I think is the cause.'

Others mentioned comorbidities that happened many years ago, like Rose, who suspected the multiple erysipelas infections that happened over 20 years ago to be related to the development of oedema and the VLU. Jack and Wilma also mentioned stress and multiple erysipelas infections; however, they did not clearly link these comorbidities to the progression of CVD into a VLU.

Patients also narrated on the connection between comorbidity and the other key themes. Comorbidity was in some cases the cause of a change in work and lifestyle, mostly as a consequence of reduced mobility. However, none of the patients linked these events directly to the progression of CVD into a VLU, like Jack:

'I was a truck driver before yes. In, let's see, about 30 years ago I ended up in the wheelchair permanently.' (after surgery for comorbidity)

Furthermore, comorbidity was connected to reduced mobility, which Henry linked to the progression of CVD to a VLU. He told that after he developed peripheral arterial disease he became less active, but he knows walking is important for the veins and the oedema. Others also mentioned reduced mobility after comorbidity; however, they did not directly link the reduction in mobility to the development of the VLU. This varied from comorbidities that happened years ago, like the bicycle accident that caused Grace to shuffle instead of walking, to more recent events like Wilma's:

'Yes and the trouble with walking they [doctors] suspect it is because it [hip] is worn. ... So now since January [6 months ago] they placed the stair elevator.'

In addition, comorbidity was connected to acknowledgment of CVD. For Grace and Doris their comorbidity led to a possible incorrect interpretation of CVD symptoms, which led to disregarding the symptoms instead of acting upon them. Doris explained she had vitiligo on her arms and that she was unsure whether or not the white spots on her ankles were also

Table 2 The timeline of Leroy showing the different events and corresponding themes, and the connections he made between the themes

Year	Events	Theme
1992 to present	Assembly line job – standing all day	Work and lifestyle – mobility
2010	Varicose veins, oedema, advice on compression stockings – nonadherence to advice	Acknowledgment of CVD
2015–16	Arthritis in the knee – trouble walking	Comorbidity – mobility
2016	Gout in the ankle – trouble walking	Comorbidity – mobility
2016	Atrophie blanche – urgent advice take action but comorbidity had priority so no action taken	Comorbidity – acknowledgment of CVD
2017	VLU developed, no action, work had priority	Work and lifestyle – acknowledgment of CVD
2017	Incapacitated because of the VLU (outside of the scope of this study)	Acknowledgment of CVD – work and lifestyle

CVD, chronic venous disease; VLU, venous leg ulcer.

vitiligo (possible atrophie blanche). Grace connected the possible lipodermatosclerosis that she had on both lower legs to the haematomas she had on her left leg from the bicycle accident she had 9 years ago. Even when the VLU appeared patients did not always link this wound to CVD, like Frank, who had varicose veins and oedema:

‘The accident caused the large wound, and that wound did not heal because of the piece of bone sticking out. But now there are a few new smaller ones [wounds] that do not heal either, and those are just the skin. And that is eventually the problem that stayed.’

Theme 2: mobility

Mobility was mentioned by patients as events related to their physical activity (e.g. sports, work, walking aid) and events related to reduced body function (e.g. limping, shuffling, divergent foot position). Mobility was mentioned by all patients; however, they never linked it directly to the progression of CVD towards a first VLU. For example, Rose mentioned that she had become less active in the past 10 years because of her age; however, she did not link this reduced mobility to the development of a VLU. Grace and Frank mentioned their sports careers and how they had ended this over 20 years ago. However, they also did not link this active lifestyle or the subsequent reduction in physical activity to the progression of CVD towards a first VLU. When mobility was linked to the progression of CVD to a VLU the patients always connected mobility to either comorbidity or work and lifestyle.

Theme 3: work and lifestyle

Patients narrated on work and lifestyle and linked this directly to the progression of CVD towards a first VLU in some cases. When narrating on work and lifestyle events, patients always mentioned events that lasted for over 20 years. For example, Rose speculated on wearing heels all her life and the negative effects on her legs, whereas Earl guessed the long-term use of tobacco and alcohol did not have a positive effect.

Patients also narrated on the connection of work and lifestyle with mobility and the acknowledgment of CVD. Doris connected work and lifestyle to mobility in the progression of CVD to a VLU, where she mentioned working in a standing occupation for over 50 years and how this could not have been good for her legs. She also mentioned her colleagues having similar complaints. Henry narrated on his height as a possible cause for the progression of CVD towards a first VLU. From his perspective the veins got worse because of his knees being bent all the time when sitting because the chairs at work were never tall enough for him. Earl on the other hand mentioned the connection between work and lifestyle and mobility, but did not directly link this to the progression of CVD to a VLU:

‘I was never a fan of walking...and I sat a lot. Because in the weekends, making music, I would sit with my accordion two whole nights from 20:00 h till 02:00 h in the night. ... I always wore it [the accordion] on my right leg [index leg] and the pressure of it, now that annoys me, it hurts.’

Patients also narrated on how work and lifestyle was connected to the acknowledgment of CVD. Patients would reflect on why they were not compliant with compression therapy before the VLU developed, like Agnes:

‘I eh I sometimes skip the stockings when my legs are healed, when I wear pretty clothes you think no way I’m going to wear these stupid stockings.’

Patients also mentioned their body composition or related comorbidity, like type 2 diabetes, in the progression of CVD towards a VLU. Earl and Wilma narrated on how they knew their diabetes was a cause of the slow healing of wounds and therefore also the slow healing of their VLU. Henry also mentioned that his body mass index of 30 kg m⁻² was not helpful for his leg complaints.

Theme 4: acknowledgment of chronic venous disease

Acknowledgment of CVD was decreased in all patients in some way. However, Agnes and Irene did acknowledge CVD as the

underlying cause of the VLU, and Agnes acted upon the symptoms at an early stage.

- Irene 'Now we are with the two of us [Irene and Agnes]. So you can see that it [CVD, VLU] is hereditary.'
- Agnes 'Because of the bad circulation and the bad veins. That's what they [doctors] always told us [Irene and Agnes]. ... I was 15/16 when I got the stockings, that they [doctors] saw it wasn't going well with my legs. I went with my mother at that time.'

Other patients did not understand the underlying pathology of CVD, like Jack, who was permanently immobile. He was unaware of the importance of the calf muscle pump in venous function:

'I don't know, really I don't. Maybe the bacteria had always been in there? ... Other wounds heal just fine. Only on this leg [index leg] the wounds keep appearing on the same spot, it's very strange.'

Even when the pathology was explained not all patients were adherent to compression therapy, like Wilma, who told her doctor she was convinced the VLU would heal just fine without compression therapy. In addition, others had a late response to the symptoms of CVD or the VLU or did not act upon this at all, like Earl:

'I see them [varicose veins] now, but they don't bother me. ... And even if I needed surgery for it I would have never done it in the army. No, I'm not a fan of doctors in general.'

The lack of acknowledgment of the CVD as the underlying cause also led to a late response when the VLU occurred. Wilma and Earl treated the VLU like a regular wound and only consulted a doctor when it kept getting worse or after the advice of others.

- Earl 'And that's how it stayed. It had a crust and after I showered I rubbed it open again and it started bleeding again, hop, a bandage on it and done. And later I went to the pedicure and she said to me: "You have to see a doctor." I said what am I going to do there?'

Even when the VLU occurred and the underlying cause of CVD was known, not all patients understood the chronicity of CVD and the role of compression therapy in preventing the progression of CVD towards a VLU.

- Leroy 'Wish I had done it back then [stockings]. Maybe I wouldn't have needed the stockings now anymore, but now I do.'

Discussion

This study shows how patients narrate on the progression of CVD into a first VLU and why, in their opinion, the VLU developed. Each narrative was a series of events that patients directly or indirectly linked to the progression of CVD into a first VLU. In a narrative the conscious, subconscious and unconscious mind are involved, which could have led to providing information from the subconscious or unconscious mind without making a clear link between this information and the progression of CVD towards a first VLU. Patient narratives resulted in four key themes describing their perspectives on the progression of CVD into a first VLU: (i) comorbidity, (ii) mobility (iii), work and lifestyle and (iv) acknowledgment of CVD. Most patients started their narrative decades to several years before the VLU developed, with events related to the four key themes.

A systematic review¹⁰ on patients' experiences of living with a VLU showed that pain and compression therapy led to a reduction in mobility after the VLU developed. However, this study shows that the patients had a reduction in mobility before the VLU developed. Patients narrated on reduced or impaired mobility that lasted for at least a decade or happened within a few years before the first VLU developed. The reduced mobility was perceived to be a result of comorbidity or work and lifestyle. Most of the comorbidities affected the lower legs, like rheumatic arthritis in the knees, gout in the ankle, a divergent foot position, peripheral arterial disease, and trauma leading to a wound to the bone on the lower leg. Furthermore, events related to work and lifestyle, such as a standing occupation or not being a fan of walking, led to a sedentary lifestyle prior to the development of the first VLU. These comorbidities and events related to work and lifestyle that reduced the mobility can be related to a reduced range of ankle motion²² and/or impaired calf muscle function.²³ The latter leads to increased ambulatory venous pressure and is therefore a risk factor in the development of a VLU.

Obesity can also lead to increased ambulatory venous pressure, as people with obesity have a different gait and a reduced range of ankle motion compared with the non-obese.²⁴ In addition, obesity (body mass index > 30 kg m⁻²) is a known risk factor for the development of a VLU.²⁵⁻²⁸ However, patients in this study did not directly link obesity to reduced mobility. A quantitative study is necessary to investigate the exact association of reduced mobility with the development of a VLU in patients with CVD. This qualitative study shows that it is important to include changes in mobility in the past, as well as chronic comorbidities that impact the mobility of the lower legs, in future quantitative studies on risk factors for a VLU.

Patients in this study did not acknowledge the importance of the symptoms of CVD before the first VLU occurred and therefore did not seek medical attention. The low acknowledgment of symptoms in patients with CVD was also found in a study investigating knowledge deficits in patients with VLU.¹⁴

These patients perceived their VLU as an acute event and the knowledge on CVD as the underlying cause of the VLU was limited.¹⁴ The patients in the current study who did recognize their CVD symptoms before the VLU developed did not always follow up on these symptoms because they prioritized their comorbidity or work. However, the patients were also not followed up by their HCP, despite the regular visits to several HCPs for their comorbidities. This is in line with research by the National Institute for Health and Care Excellence (NICE) in the U.K. The publication of the U.K. NICE clinical guideline for referral of VLU to a vascular specialist did not lead to a significant change in referral from primary care to specialist care.²⁹

The current study illustrates that there is still a need for more awareness concerning CVD and its consequences. More awareness among the public, as well as among HCPs, should lead to an increase in early recognition, timely treatment and possible prevention of a VLU in patients with CVD, preserving their quality of life. A first step would be to provide easily accessible information on how to prevent progression of CVD into a VLU, similar to the information and prevention strategies for other chronic wounds like diabetic foot ulcers³⁰ and pressure ulcers,³¹ with medical follow-up and guidance on lifestyle interventions.

We included patients with different characteristics (purposive sampling) to enhance the generalizability of the results. The patients with recurrent VLUs narrated more on the periods between the recurrences and the health care they received in the past. This made it more difficult to create a timeline and to distinguish their own narratives in the development of the first VLU from the information they received from several HCPs over the years. In one case the recording device failed to record. This interview was analysed based on the notes of the researcher, which is less extensive than analysing the full transcript. However, notes were made during and directly after the interview, so most of the narrative of the patient was captured. The narrative approach in the interviews makes the interviewer coauthor of the story in the here and now.³² However, A.M.M. created a safe and nonjudgemental environment for patients to speak freely, and let the patients lead the conversation by asking open-ended questions. All patients were asked how they experienced the interview and they all reflected on the interview as being very pleasant. Finally, to reduce researcher bias, researchers and research assistants from different backgrounds were involved in all stages of the data analysis.

In conclusion, a reduction in mobility as a result of comorbidity and work and lifestyle occurred before the VLU developed. Patients in this study did not recognize symptoms of CVD and did not acknowledge the chronicity of CVD. Therefore, HCPs should be aware of reductions in mobility and the knowledge deficit in patients with CVD. Patient education and follow-up of patients should be imbedded in the care for patients with CVD to prevent or take early action on the development of a first VLU.

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Supporting Information

Additional Supporting Information may be found in the online version of this article at the publisher's website:

Appendix S1 Coding tree including key themes, subthemes and corresponding codes from the patients' narratives on the progression of chronic venous disease into a first venous leg ulcer.