



# Lived experiences of life with a leg ulcer - a life in hell

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## ABSTRACT

### Background

Little is known about patient lived experience with arterial or mixed leg ulcers. Due to the lack of knowledge and the increasing focus on implementation of patient perspectives, this study was conducted.

### Aim

This study investigates how patients suffering from arterial or mixed leg ulcers experience their everyday.

### Methods

Six qualitative life-interviews were conducted: one focus group interview and five semi structured interviews. Data was analysed with Pia Dreyer's Paul Ricoeur-inspired method, following three steps: naïve reading, structural analysis and critical analysis and discussion.

### Results

Following themes are discussed in the manuscript. The essence of the lived experience is captured in the overall theme: a life with a leg ulcer – a life in hell. This overall finding derived from four themes describing the influence on everyday life: constant pain – without the possibility of relief, an eternal battle against the ulcer – to survive, a state between despair and hope and the ulcer controlled everyday life.

### Conclusion

Patients consider living with an arterial or mixed leg ulcer as living a life in hell. Patients are in an existential crisis and would rather die than live the rest of their lives with a leg ulcer. Given their low quality of life and general unhappiness, more needs to be done to help these patients.

## INTRODUCTION

Chronic and slow-healing wounds are terms used for ulcers that do not heal within 8-12 weeks, assuming optimal local wound treatment<sup>1</sup>. The prevalence of chronic wounds is uncertain, but is estimated to be about 0.12 to 0.4 %. Early diagnosing and treatment of these patients is therefore of great importance, as chronic wounds have a great impact on patient quality of life<sup>2,3</sup>.

Patients with arterial insufficiency or mixed arterial and venous insufficiency are a special subgroup of leg ulcer patients, and little is known about their lived experience. These patients experience pain due to the compromised blood supply to the extremities, which negatively affects their quality of life. Patient experience of pain related to the wound is different depending on the aetiology<sup>4</sup>. As a consequence, it is important to focus in detail on these patients with respect to pain, quality of life, and the experience of living with painful wounds. Therefore, the aim of this article is to investigate how patients suffering from arterial or mixed leg ulcers experience their everyday life.

## METHODS

Through a qualitative study design and a phenomenological-hermeneutical approach<sup>5,6</sup>, we conducted five semi-structured interviews and one focus group interview to gain insight into patient lived experiences from their perspective. All ethical guidelines of nursing science and by the University of Aarhus were ensured.

## Research setting

All patients included in this study received wound treatment at The Wound Care Centre (WCC), a specialist patient facility within the Department of Dermatology and Venereology of

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Aarhus University Hospital in Denmark; the centre treats 65 patients per week.

The patients are involved as partners in their treatment and helped to gaining knowledge and insight about their condition, as well as how to cope with it. The WCC followed the patients within the clinic and worked with patients at home closely by telemedicine with homecare nurses.

### Patient selection

Two nurses from the WCC searched telemedicine, a photo-based information technology for wound-assessment and identified 11 patients that fulfilled the given inclusion and exclusion criteria.

FIGURE 1. PATIENT SELECTION

INCLUSION CRITERIA:
Patients with arterial or mixed leg ulcer with a known ABPI (Ankle-Brachial Pressure Index)- or toe pressure.
EXCLUSION CRITERIA:
Patients with venous leg ulcers, with diabetes, psychic or mentally unstable, with healed ulcers or patients who had had amputation.

FIGURE 2. PATIENT DEMOGRAPHICS

GENDER	AGE	DIAGNOSE	ABPI PRESSURE	TOE PRESSURE	WOUND LOCATION	DURATION OF WOUND
Female	65	Mixed leg ulcer	Right ankle = 0,57 Left ankle = 0,91	Right = 53 mmhg Left = 29 mmhg (may 2014) 53 mmhg (6/2-15 after blood vessel operation)	Lateral side of the left lower leg.	1 year and 3 months
Female	74	Mixed leg ulcer (Blood vessel operation not possible. Right leg was amputated)	Right ankle=0,39 Left ankle = 0,42	Not measured	Right lower leg. Small superficial ulcer on the left leg.	5 years
Male	61	Arterial leg ulcer	Right ankle = 0,22 Left ankle = 0,66	Right = 24 mmhg Left = 100 mmhg	Lateral side of right foot.	4 years
Male	69	Mixed leg ulcer	Left ankle = 0,59	Not measured	Lateral malleoli on the left foot.	1 year and 5 months
Male	69	Mixed leg ulcer	Right ankle= 0,70 Left ankle = 1,00	Right = 25 mmhg Left = 62 mmhg	Lateral malleoli on the right foot.	1 year and 9 months
Male	77	Mixed leg ulcer	Not found in the patients journal	Right = 127 mmhg Left = 80 mmhg	Lateral malleoli left foot and 1. toe on the left foot.	4 years

The same nurses phoned all patients, informed them about the study, and invited them to participate. Seven patients gave their consent. Four patients were excluded: two due to amputation, one to diabetes and one due to hospitalisation. The first author contacted the patients, and they were again given oral and written information about the project. One patient could not participate due to acute hospitalisation; therefore, six patients were enrolled in this study. (Figure 2)

### Data collection, setting and locations

One focus group interview was conducted at the WCC with four patients. Present at the interview were the first author and a nurse from another speciality to take notes and ask questions if the first author overlooked anything. Five semi-structured interviews were conducted after the focus group interview, two at the WCC and three in the patient's private homes, by the choice of the patient. The single interviews were conducted to give the patients a setting where they could speak more privately. The first author was present at all interviews. The same open-ended interview guide that had been pilot-tested was used at all interviews. All interviews were tape-recorded, lasted between 35-90 min and were then verbatim transcribed by the first author.

### Data analysis

The gathered data was analysed with Dreyer's Ricoeur-inspired method<sup>7</sup>. The analysis followed three steps: naïve reading, structural analysis and critical analysis and discussion. For naïve reading, the text is read as a whole.

FIGURE 3. STRUCTURAL ANALYSIS

MEANING-BEARING UNITS: WHAT IS SAID IN THE TEXT?	SIGNIFICANCE-BEARING UNITS: WHAT DO THE TEXT "TALK" ABOUT?	THEME:
<p>"Something more painful than a leg ulcer is hard to find", "It is terrible", These wounds, the pain is like hell. – I think we all can agree on that", "Because I had pain, it was so horrible, and I didn't get anything to ease it", ...because it has been so excruciating", "I can sometime come to tears, you saw it yourself before when I was telling you about it, the tears come, yes they do, because it's been so awful", "...and the pain was so bad that I was crying when I left the outpatient clinic. I went outside and I cried. I've been ..."</p>	<p>"Something more painful than a leg ulcer is hard to find". All patients live with terrible pain, it is there all the time, and it is so terrible that the patients have difficulties in the describing it fully. "Yes it's hard to describe, the pain, because it's something you have to try to really understand what it is". The wounds ache "like hell" and the pain is horrible, foul, terrible and excruciating at the same time. The leg ulcer is so painful, they would not wish it on anyone else. "I wouldn't wish it on my worst enemy. Not at all".</p> <p>Two patients explain how they sat crying after wound treatment ...</p>	<p><i>Constant pain</i> – <i>without the possibility of relief:</i></p>

The text was then read again, focusing on smaller parts of the text to gain a deeper understanding<sup>8</sup>, whereupon the first author wrote a summary of the overall meaning of the interviews. Structural analysis is a dialectic process consisting of three levels, where one looks at the meaning-bearing units and the significance-bearing units, and ends up with a number of themes. The structural analysis was conducted multiple times by the first and last authors, until changes became minimal<sup>7,9</sup>. (Figure 3)

Finally, we performed the critical analysis and discussion. The given themes were discussed with existing knowledge and there was a movement from the specific interpretation level to a more general interpretation, resulting in a superior overview over the comprehensive understanding of the text.

**RESULTS**

After the analyses, four themes emerged: constant pain – without the possibility of relief, an eternal battle against the ulcer – to survive, a state between despair and hope and the ulcer controlled everyday life. (Figure 4)


The four themes show how the leg ulcer inflicts on the patient's life. When describing life, the patients used words like dreadful, terrible, horrible, painful and expressions like "It's been like hell... like a living hell". These words combined with the four themes, create an overall finding: "A life with a leg ulcer is a living hell", which is the essence of the lived experience. One could argue that patients are in an existential crisis because they experience their lives with a leg ulcer as though a living hell. These words are the patients own very strong expressions.

**Constant pain**  
– **without the possibility of relief**

All patients lived with a constant and horrible pain and would not wish it on their worst enemy, stating, "It's hard to find something more painful than a leg ulcer". The leg ulcer pain made it difficult to walk, and the patients were forced to use crutches, walkers or swivel chairs, making it close to impossible to move around. Sitting down a whole evening was also difficult, and during the night, the leg ulcer pain was at its worst. Every patient complained about lack of sleep: "I never sleep more than two hours in a row."

FIGURE 4. ILLUSTRATION OF THE RESULTS

**A LIFE WITH A LEG ULCER**



- Constant pain – without the possibility of relief
- An eternal battle against the ulcer – to survive
- A state between despair and hope
- The ulcer controlled everyday life

**IS A LIFE IN HELL**

It's every night". Despite taking painkillers before bedtime, they could not find total relief, and were happy when they got two hours of coherent sleep. Analgesics did not have any significant effect. The only thing that could ease the pain a little was to move the leg in a vertical position. Every night, the patients wished to sleep a whole night. The patients could not escape the pain completely, and they were stuck in the present, because the ulcer was hurting all the time. The ulcer was even painful when it was healing. Together, the patients' statements showed how they lived life in constant pain without the possibility of total relief.

### **An eternal battle against the ulcer – to survive**

If their leg ulcer would not heal, the leg had to be amputated. That was their biggest fear for patients, and they would rather die than let it happen. One said, "I will not accept it! Then I wouldn't like to be here anymore. It's what I fear the most". The patients fought hard to keep their legs. The patients always talked about their leg ulcer in third person, as "it" instead of "my (leg) ulcer": "It's become a strange thing for me, and it's hurting me". This indicated that they distanced themselves, making it something that was outside their body, something they fought against.

When the leg ulcer progressed unrestrained without healing, the patients' attitude towards amputation changed. The patients had a feeling of rotting; they were disgusted, shuddered and shaken by the sight and smell of the ulcer. Their lives were threatened, and the earlier fear for amputation changed for a fear of death. All patients said that there was nothing positive in having a leg ulcer, that life with a leg ulcer was not a life worth living. For one patient amputation was a reality, because "there is no chance that it'll get better at all"! The fight against the leg ulcers began to be lost and the earlier hope for healing turned to a hope for a quick amputation, for peace and absence from the pain.

The other patients had successful blood vessel operations, and that, together with the consistent wound treatment, made the ulcer starting to heal. Seeing the ulcers decreasing in size, they started to believe in victory against the leg ulcer, that it would eventually heal and allowing them a new life. Living with a leg ulcer was a point of no return and changed everything. Patients would live in fear for re-occurring ulcers and be marked by their experience for the rest of their lives: "It'll always be a part of you. It'll always be there". The fight against the leg ulcer could only end with a healed ulcer or an amputation. No matter the outcome, there was a battle against the leg ulcer – to survive.

### **A state between despair and hope**

When first developing a leg ulcer, patients immediately had some negative thoughts, stating, "...you think gangrene, you think cancer, you think a lot of things. Why

won't it heal"? After four months without healing, it was not possible for them to be positive, and they became scared and vulnerable, and doubted that they would survive. The wound dressings and bandaged reminded them of their situation and they felt sick to death.

The patients all blamed themselves for their leg ulcer, because of smoking, alcohol, unhealthy food habits, and stressful jobs: "It's my own fault that I've calcified". They had all seen their ulcer progress in size, even though specialists treated them. This made them depressed and fearful, and they lost hope. Experiencing this, the patients grew sceptical of health professionals, a feeling that would only truly disappear when the ulcer was almost healed, or healing was not possible at all. Despite the distrust, they needed the support from the nurses, which they got throughout the treatment. The nurses never gave up on hope for healing: "The nurses always say, "It's going the right way", and they're optimistic. They are like that for years". This encouragement and support was described as priceless and vital to the patients. One stated, "Without them I don't think I would be here today". The nurses awakened a little hope that the despair could not destroy, causing the patients to live in a state between despair and hope.

### **The ulcer controlled everyday life**

The leg ulcer affected them in every possible way. Daily activities like taking a shower, getting dressed, grocery shopping, and gardening were complicated by the leg ulcer. The patients used to be active with hobbies, but stopped with the leg ulcer. "It stops my swimming, it stops my bowling and it stops our travelling. I can't ride a bike anymore and things like that". The patients grew inactive and lost mobility and fitness, which affected them negatively.

The ulcers were treated regularly, some on a daily basis, twice/trice a week and some weekly. The strict treatment schedule made them feel trapped and imprisoned.

The process of healing the leg ulcer was very slow, and they needed to be patient. One stated, "I thought it'd take 14 days, but now it's been three years". One patient was particularly tired of waiting, "This little one, it's been 18 months now. It isn't bigger than the tip of that ballpoint pen. It won't close..... But what am I to do? Wait! I'm waiting for Godot".

The ulcers even controlled the purchase of shoes, due to the many layers of compression bandage on the foot and leg, which enlarged the foot. All patients found they needed bigger shoes, and had difficulty finding some that would fit and that they liked. They solved the problem by not wearing shoes or wearing sandals, no matter the season. The patients were offered special footwear from

the WCC, but they refused to use them and put them in the closet. The look of the shoes was a daily irritation and had a huge impact on how the patients saw themselves. One stated, "I can't come like the fine gentleman, I used to be". Therefore, the leg ulcer overtook their life, options and doings, in other words; the leg ulcers controlled everyday life.

## DISCUSSION

### Constant pain – without the possibility of relief

Pain caused by the leg ulcer affected the patients' everyday life and existence, which is also mentioned in other articles as the worst symptom when living with a leg ulcer<sup>10-20</sup>. As found in many studies, patients are so severely affected by the pain that their sleep is reduced for many years<sup>4,10,13,15,18,19,21-24</sup>. Is constant pain – without the possibility of relief a consequence to the arterial disease or the ulcer? It is known that great pain is associated with arterial disease in the legs<sup>4</sup>. For patients with an arterial component in their leg ulcer, the pain is connected to both the ulcer and minimized blood supply, making it even more painful.

Analgesic medication is known to have a poor impact on leg pain where intermittent claudication (claudicatio intermittens) occurs<sup>25</sup>. Insufficient pain-regulated patients are a known problem<sup>14,15,18,22,24</sup>, and despite taking analgesic medication, the patients from this study found incomplete relief from the pain. These patients continue to have pain, despite medications and the existing knowledge of the phenomenon. Could ultrasound-applied nerve block against pain be an option in the future, or is it too expensive? Should the healthcare system aim at helping through therapy, where total pain relief is not promised as the goal, for instance, through acceptance and commitment therapy<sup>26</sup>. We need some new ways to pain-regulate these patients, or we need to change our promises of complete pain elimination.

### An eternal battle against the ulcer – to survive

The patients fought to keep their leg, which is also found in three other studies<sup>13,15,17</sup>. The patients interviewed were disgusted with their leg and rejected it, which has not been described earlier for these types of wounds. For one patient, amputation was a reality, and the earlier fear for amputation changed to a hope for a life after amputation without pain. Therefore, as describes earlier<sup>18,23,24</sup> amputation can be the patients' biggest fear, but also a relief when healing is not possible.

When dealing with these types of wounds, blood vessel operation should always be conducted when possible. However, if the wound is progressing from bad to

worse, despite operation, when is then the right time for amputation? The patients depend on support from the health professionals and if healing is not possible, when should the support change from healing to amputation? And should amputation be executed much earlier? These questions need to be further studied to help bring better care to these patients.

### A state between despair and hope

Self-reproach and guilt were central feelings and affected the patients, but were also a way to comprehend their situation. These feelings have not been described previously. Furthermore, the patients had all been smokers, and some still were. As smoking is one of the biggest factors that contribute to reduced wound healing<sup>27</sup>, the guilt and the negative thoughts the patients have may give them psychological stress. This was found to cause significant delayed wound healing, a weakened immune system, increase anxiety and depression, and lower quality of sleep<sup>28</sup>. Having a low mood is reported in other studies<sup>10,12,14,15,17-20</sup>; therefore, it is of great importance that the health professionals detect how the patients are affected mentally. Wound treatment is not only the physical treatment, but also a holistic treatment, involving the physical, psychological, social and existential state of the patient, and therefore, nurses need to apply holistic need-orienting nurse intervention.

### The ulcer controlled everyday life

We found that the patients' world become smaller, they cannot move around, attend their hobbies, or live their normal everyday life – the leg ulcers take over and control everything. Other studies have even reported on decreased activity<sup>10,13-20</sup>. The patients feel punished and imprisoned because they cannot be away from their home for too long, due to scheduled wound treatments. This situation can be compared to criminals wearing an ankle bracelet with electronic tracking. The difference between the patients and the criminals is that the patients do not know when or if the leg ulcer will heal, whereas the criminals only have to wear the ankle bracelet for maximum six month before they are free.

The patients wait to heal, and one patient describe it as waiting on Godot, making a parallel to the French play, *En attendant Godot*, by Samuel Beckett from 1953<sup>29</sup>, where to characters are waiting endlessly and in vain for the person Godot. Are we doing enough to help these patients? In England, there are Lindsay's leg ulcer clubs<sup>30</sup> that offer leg ulcer treatment and social activities. Instead of being isolated at home, the patients go out to get their treatment and meet others in the same situation. In Denmark, there are no associations for these patients, so maybe the concept in England needs to be adopted by other countries. ►

The leg ulcer takes over everything, including the choice of buying shoes, which is also reported in other studies<sup>13,15,17-19</sup>. This has been reported since 1999, and is still a problem today, indicating that the optimal solution is still out there somewhere to be discovered.

### Limitations of the study

There were only six patients – one with arterial leg ulcer and five with mixed leg ulcers. If there had been the same number of patients with one of the two diagnoses, statements could have been analysed against each other. It is uncertain if interviewing more patients would have created other themes.

### CONCLUSIONS

The findings from this study give a deeper understanding into how arterial or mixed leg ulcers affect the everyday life of the patients, which is felt like living in a living hell. Patients experience an existential crisis and would rather die than live the rest of their lives with a leg ulcer. These patients are in great pain, feel guilt or self-reproach in relation to how they got their wounds, and they are fighting to keep their leg and to maintain hope. Therefore, it will not be sufficient only to treat the wound. Health professionals need to give individual holistic treatment to each patient, involving the physical, psychological, social and existential state of the patient. We need to treat the wound and the person living with the wound. Even though many interventions have been developed to help these patients (e.g. pain management and specialised wound dressings), this study indicates that there is more to be done.

### Further research:

- These patients have problems with footwear. A new study could look at the special needs of the patients and work closely with shoe manufacturers to develop new shoe models.
- Further research could enlighten the patient perspective before and after amputation. Had they preferred it earlier or later?
- When and what makes a patient change thoughts and attitude towards leg amputation?
- Living with a leg ulcer is a life-changing event, and further studies could look at life after healing or amputation in relation to the patients becoming themselves again.

### Author contributions

L. Lernevall performed this study; it is a presentation of her Danish master thesis (June 2015). She was in charge of the design, data collection, data analyses, and drafting and writing of the manuscript. K. Fogh, W. Dam and C. B. Nielsen enabled the recruitment of the patients for this study and gave substantial input to the writing. P. Dreyer was the supervisor, gave substantial input to the design, supervised the creation of this article and commented on and made critical revisions of the manuscript.

### Implications for clinical practice

- Healthcare systems need to apply a holistic need orienting nurse intervention for these patients.
- Healthcare professionals should aim at helping patients live with the pain, for instance through therapy, instead of promising total absence of pain during the ulcer period.
- Healthcare professionals should discuss the possibility of amputation sooner. If blood vessel operation is not possible and healing is not progressing, one should consider amputation. We cannot let the patients live in living hell for many years.
- In many countries, there are no organisations dedicated to help these patients, no places these patients can meet. Could the successful Lindsay's Leg Club organisation from England be adopted<sup>31</sup>?

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