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ORIGINAL ARTICLE

Experiences of undergoing venous leg ulcer management: A reflective lifeworld research study

Marcus Rosenberg^{1,2}  | Gunilla Lindqvist¹  | Hanna Tuveusson¹  | Cecilia Fagerström^{3,4} 

¹Faculty of Health and Life Sciences, Department of Health and Caring Sciences, Linnaeus University, Växjö, Sweden

²School of Health and Welfare, Department of Health and Nursing, Halmstad University, Halmstad, Sweden

³The Research Section, Region Kalmar, Kalmar, Sweden

⁴Faculty of Health and Life Sciences, Department of Health and Caring Sciences, Linnaeus University, Kalmar, Sweden

Correspondence

Marcus Rosenberg, Linnaeus University, Faculty of Health and Life Sciences, Department of Health and Caring Sciences, 351 95 Växjö, Sweden.
Email: marcus.rosenberg@hh.se

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Abstract

Venous leg ulcers have multiple consequences for the patient. Ulcer management can be lengthy and recurrence is common. As the patient is the expert on their experiences and life, the aim of the present study was to describe patients' lived experiences of undergoing management for a venous leg ulcer. The study encompassed 16 phenomenological interviews. The analysis led to a description of the phenomenon's essence, further described by three constituents. The essential meaning of the phenomenon is described as being in an oscillation between hope and despair. Ulcer management is challenging for the patient, who feels unseen and lives with doubts during the management period. This study is considered enriching as it puts words to the patients' suffering during ulcer management and shows that reliable relationships and competence can reduce patient doubts. This knowledge should enable improvement of patient care and treatment during ulcer management.

KEYWORDS

lived experiences, qualitative research, ulcer management, venous leg ulcer

Key Message

- Long healing time are common, which affects the patient
- With the aim to describe patients' lived experiences of undergoing management for a venous leg ulcer, 16 patients were interviewed
- The patients oscillate between hope and despair when trust is absent, and no relationship has been built with staff. Setbacks include doubts about healing and staff being blamed for the slow healing

1 | INTRODUCTION

Venous leg ulcers (VLUs) are a group of ulcers that affects 0.8–2.2 persons out of 1000, or double that among those over 65 years.¹ VLUs commonly take a long time to

heal,² often in excess of 6 weeks, and thus might be referred to as chronic,³ although the term hard-to-heal⁴ more accurately reflects the potential to achieve healing. VLUs affect health care budgets worldwide. In the United Kingdom alone, treatment of VLUs costs GBP

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2 billion annually. The costs are expected to exceed 1% of the health care budget.^{5,6} Suffering from a VLU impacts life through pain,^{7,8} itching, odour,⁹ sleep disturbance¹⁰ and immobility.¹¹ Thus, VLUs are life-limiting.^{9,12} The daunting experience of having an ulcer also has an impact on life after healing: difficult memories remain and life is perceived as restricted.¹³

Although venous ulcers can affect anyone, persons of advanced age are at greater risk of developing VLUs. Venous symptoms such as varicose veins and oedemas are signs of venous interference.¹⁴ Deep venous thrombosis, deformities and damaged valves,¹⁵ as well as low physical activity and hereditary predisposition, contribute to ulcer development.¹⁴

Ulcer management begins with an assessment, taking account of comorbidities (eg, deep venous thrombosis, diabetes, hypertension, obesity and malnutrition) and including physical examination, focusing, for example, on varicose veins, atrophie blanche, oedema and mobility.¹⁶ Cleansing, debridement and dressing the wound are necessary. Another crucial part of treatment is compression. If healing takes a long time or does not occur, patient referral may be required.¹⁶ For the patient, there are barriers associated with non-adherence to compression, for example, knowledge, summer heat, fashion and memory failure have been reported.¹⁷ Involving a multi-disciplinary team is considered to be beneficial to optimise care¹⁸ and is recommended in guidelines.¹⁶ A review of guidelines revealed that the majority do not mention ulcer reassessment. One guideline does recommend reassessment after 12 weeks, in the absence of healing progress.¹⁶ Patient education may increase the use of compression. Franks et al.,¹⁹ and Protz et al.²⁰ found inconsistent recommendations regarding patient information on the underlying cause, compression therapy and physical activity. In the midst of all these medical doings and regimes, there is a patient whose experiences, expectations and personal circumstances should be considered.^{21,22} The benefits of distinct and genuine patient involvement are recognised because of their positive impact not only on the health care budget, but mainly at the individual level.²³

Evident elements of ulcer management are cleaning, debridement and dressing. Furthermore, patient education, pain management, psychosocial support and prevention are examples of measures considered beneficial for patients.²⁴ The importance of physical, psychological and social needs in ulcer management is known.²⁵ Despite recent medical advances in ulcer management, VLUs remain a major concern.²⁶ About half of patients still have an ulcer after 12 months of ulcer management^{27,28} and it is reasonable to assume that they are burdened. In one study, 55% of patients experienced

recurrence within 12 months.²⁹ It should be mentioned that the median healing time is more than 6 months.³⁰ Data from the Swedish Registry of Ulcer Treatment, which requires a diagnosis, show that resource use shortens healing times,³¹ which is assumed to have positive consequences for the patient suffering from a VLU.

Through a lifeworld perspective, it is possible to explore and describe patients' deeper understanding of their own situation.³² The lifeworld can be described as a venue where we share events and interact with others, but it is also a place for one's own understanding of and being in the world. With a lifeworld perspective, it is possible to gather individual experiences and perceived meanings from patients, which provide a deeper understanding of a phenomenon.^{32,33}

Lived experiences of ulcer management are valuable, not least because each patient is an expert on their own situation and experiences. When a person's lifeworld involves ulcer management, symptoms and a potentially uncertain future, this can be assumed to affect that person. With all this in mind, this study's aim was to describe patients' lived experiences of undergoing management for a venous leg ulcer.

2 | MATERIALS AND METHODS

2.1 | Study design

The phenomenon in the present study was 'lived experiences of undergoing management for a venous leg ulcer'. The study was carried out with a reflective lifeworld research (RLR) approach. The phenomenological view is that a phenomenon is described by an essence: the phenomenon's essential structure of meanings. The essence, in turn, is illuminated by its constituents.³³ The RLR has its roots in the Husserlian theories of the lifeworld and intentionality and Merleau-Ponty's theory of the lived body, offering a clear focus on individual experiences of a phenomenon.³³ The phenomenological focus here is on describing meanings from a patient's lived experiences of VLU. Use of methodological tools, such as the researcher's openness and 'bridling' to secure awareness of the researcher's inevitable pre-understanding, is advised.^{33–35}

2.2 | Participants

Sixteen patients, seven men and nine women in southern Sweden were interviewed on their lived experiences of venous ulcer management. Their age ranged from 58 to 86 years, with a mean of 71 years. The experiences of

ulcers ranged from having one ulcer, which healed in months, to having repeated ulcers over the course of several decades. The patients have lived experiences of ulcer management from various contexts and care in primary care, home care and specialised care (eg, ulcer management teams, infection care, dermatological care and surgical care). The inclusion criteria were undergoing management for a hard-to-heal VLU, ulcer duration more than 6 weeks, having the cognitive ability to convey experiences and having the ability to understand and speak Swedish. All patients lived in their own homes, with one of the men having home care. All participants in the present study provided written informed consent.

2.3 | Data collection

Suitable participants were first contacted and briefly informed about the study's aim by the health care personnel who treated the ulcer. One pilot interview was conducted; this was included in the results because of its richness of meanings. The interviews were carried out by the first author, between June and November 2020. Because of the COVID-19 pandemic, all interviews were conducted via telephone. All participants chose to take the call in their home. As advised by Dahlberg et al., interviews started with an open-ended question: 'Could you please describe your experiences of ulcer management?'. Follow-up questions such as 'What do you mean by...?' or 'How did you feel when...?' were used to gain in-depth answers.³³ Interviews were recorded and transcribed verbatim and lasted between 17 and 60 min (median 39 min). In the RLR approach, an openness and a curiosity towards the phenomenon under study means that interviews must be open, for example, constantly focusing on the phenomenon.

2.4 | Data analysis

The description of the phenomenon followed the RLR approach, which includes curiosity, openness and bridling.³³ In this work, the approach guided us with a genuine interest in the phenomenon, a willingness to be surprised and an awareness about our influence during the whole process. Familiarisation with the interviews, gained through multiple readings, gave an insight into the entirety of the material. In order to gain a reflective attitude, the researchers continuously asked questions of the text: 'what does that mean?', 'what is really said about the phenomenon?' and 'are there any contradictions in this statement?'.³³ Meaning units related to the phenomenon 'undergoing management for a venous leg

ulcer' were retrieved from the transcripts and clustered together based on similarities and differences. The final goal, the essence, was reached by achieving an understanding of the material at a higher, abstracted level. According to Dahlberg et al.,³³ the analysis should be characterised by moving back and forth between the whole (transcripts) and the parts (meanings) of the interviews, towards a new whole (the essence). The analysis was carried out by the first and second authors, though the process was discussed with all co-authors. The results are first presented through the essence of the phenomenon, and then through its constituents. Some quotes from the interviews are presented to clarify the essential meaning.

2.5 | Ethical considerations

The principles outlined in the Declaration of Helsinki³⁶ were observed, protecting the rights and safety of all participants. The study was approved by the Swedish Ethical Review Authority (dnr 2020-00965). All patients were provided with written and verbal information. The researchers had no cognizance of the participants prior to this study and have not been involved in their care.

3 | RESULTS

3.1 | The essential meaning of the phenomenon

The phenomenon can be described as a situation characterised by a sense of being stuck, further aggravated by an ulcer that does not heal or even worsens. Even when the management was based on trust, this faltered over time. When healing fails, the staff is blamed and doubts about their knowledge arise.

The patient with an ulcer is in a situation with no end in sight. Meeting with different staff members, each working in their own way, causes confusion, increased by varying information. Ulcer management is experienced as neither encouraging nor healing and there is no possibility to influence the situation. Terminating ulcer management is not seen as an alternative; it is needed for healing. With things continuously happening around the own person, an invitation of involvement is conspicuous in its absence. As personalised care fails and no responsibility is taken, hopelessness appears and any former willingness to fight for one's own body lessens. A focus on the ulcer during treatment creates displeasure from the rest of the body. Pain is overlooked and the entirety is side-lined, which raises the feeling of being nothing but a

bearer of an ulcer. The person and their daily life are given minor importance in the management, which focuses on physical ulcer care. When a caring relationship emerges, it nourishes the lifeworld—being seen as a person is crucial in a difficult time. Functioning ulcer management teams are seen as a safe haven, where knowledge and confidence prevail. A clear focus not only on the ulcer, but on the whole person, is appreciated—especially when this differs from a previous situation. Genuine interest from staff is noticed and inspires confidence.

Damaged trust in staff leads to resignation, hopelessness and despair. When healing seems near, hope recurs, leading to an oscillation between hope and despair. A feeling of luck replaces that of being doomed to hopelessness. Luck is associated with adequate care and proficient, caring staff. The opposite is seen as a healing process that might in the worst-case scenario result in prolonged hopelessness.

The phenomenon means being in a situation of waiting for a healing that does not occur as soon as desired. When healing finally happens, the contact with health care ends abruptly and the joy of being healed competes with a sense of emptiness.

The following constituents further explain the essential meaning: 'A confidence scarred by doubts', 'A non-healing relationship', and 'An oscillation between hope and despair'.

4 | CONSTITUENTS

4.1 | A confidence scarred by doubts

Ulcer management is coloured by doubt. During management start-up, the patient is full of anticipation and trust in the expected healing. At the same time, there is an awareness of the dependence on staff—without their help there will be no healing. Soon, it becomes clear that ulcer management is something that takes place without continuity. Staff members provide dressing changes without sharing further plans or progress with the patient, as if a state of unpreparedness reigns. This creates insecurity, where doubts prevail regarding whether knowledge among staff is sufficient and also whether healing is actually possible. Different types of bandages or regimes are applied over time, which raises further questions regarding staff competence. Reliability is limited when someone advises something that is dismissed by the next person. Thoughts are awakened that pursue the patient constantly and cause uncertainty and concerns. As time passes, a future without an ulcer seems impossible.

Treatment is seen as something inadequate; the future is assumed to include an ulcer. This doubt

regarding whether the future will be marked by continued symptoms and endless suffering puts the patient in a state of hopelessness. The feeling that healing is not offered brings anger, worry and frustration to everyday life.

Well, I wasn't offered anything beyond walking around with wounds in my legs. That's how I felt. (Patient 1)

With doubts haunting the patient, confidence in the staff and the healing is affected. This might continue for a long time, causing resignation on the part of the patient, who is left alone in hopelessness. Some say it is not worth seeking treatment: nothing will happen anyway. Some are boosted in their belief that care does not occur automatically: it must be requested.

When they doubt others, the responsibility to request care falls on the patients themselves. Standing up for their own body is seen as one of the few ways to achieve healing. The sense of doubt might lead to increased strength in case of another ulcer; the patient would have knowledge of what to demand and where, with possible pitfalls having already been explored. When healing fails and doubts arise, inquisitiveness arises. Questioning leads to feelings of being nagging, which is the price you pay for taking responsibility.

4.2 | A non-healing relationship

When staff focuses only on the ulcer and does not take the whole patient into account, disinterest is experienced, with the patient feeling unseen. No relationship between the patient and staff is created, or at least it is not noticed. When the patient does not know which profession a staff member belongs to, there is no possibility of laying the foundation for a deeper relationship.

It all started really badly, and more than anything, it was like getting a bucket of water in the face when I didn't get to share my experiences. Because she couldn't know how I felt in my leg and my foot, and she told me, more or less, to shut up. (Patient 9)

An unwelcoming atmosphere, where staff does not ask about or request updates on the patient, or do not do enough, leads to the experience that they have no interest in the patient. The patient notes any unwillingness ahead of care. Any feeling of invisibility or sense of disinterest on the staff's part was increased by disregard of care tasks. Comments experienced as sarcastic or demeaning

were degrading to the patients, who already saw themselves as the weaker party.

The people who think that it's a hassle that I can't do this myself, I don't argue with them, I just give them my leg and wait for them to fix it. (Patient 7)

When the patient is not seen, there is a focus on the physical *doing* and little chance to consider the uniqueness of the patient. Recommendations that are physically impossible to comply with can be experienced as almost offensive. The understanding of advice given is then limited, as is its relevance for the own person, especially when asking questions makes the patient feel stupid. When the staff members do not follow up on their own actions or those of others, this leads to questions on the direction of the management and a feeling of being forgotten or unseen. Being one among many is seen as part of the management process.

In the beginning, it was like there was no time to read my records and stuff, so that was really bad. It was towards the end, when the same person was caring for everything, so to speak, that it all seemed more planned, so to speak. (Patient 7)

Despite advice regarding self-care and measures to avoid new ulcers being the default, it is often lacking. The desire to get rid of the ulcer may lead to an openness to and a reliance on staff. A feeling that the staff members do not take the patient's concerns seriously and do not invite the patient to discuss it creates the experience of not being seen and being in a non-healing relationship. The burdens of the ulcer, such as pain, are overlooked. Clear and directed information is seldom part of ulcer treatment. Knowledge on why an ulcer occurred in the first place and why it is hard to heal is lacking. Sometimes when advice is given, the patient does not feel that it is intended for them. One patient described waiting for 5 months for information on how to shower with their leg wrapped. Consideration of the person is not shown, which affects the possibility of person-centred management.

I was advised to go out, the weather was nice, and I was supposed to do calf raises. But, my God, I couldn't put my feet on the floor, I couldn't even stand up! (Patient 9)

When there is staff continuity, the relationship between patient and staff members improves, with the experience

of knowledge nourishing it. When a patient does not feel trust in staff knowledge, the situation becomes difficult for the patient. However, when they are offered care by ulcer management teams or staff with obvious knowledge, this is like a source of light in the dark.

Well, it's like night and day. There's just no comparison. The most fundamental thing is that they don't have the same knowledge, they don't really know how to treat this. Down there, I immediately felt that 'they know what they are talking about'. (Patient 1)

Management differs between departments and regimes. Ulcer management teams do not see a patient only as a bearer of an ulcer, but as a person with experiences, a story to tell and a future without an ulcer. Here, the patients are not invisible, making the teams highly appreciated among those who have experiences from multiple departments.

4.3 | An oscillation between hope and despair

When healing fails, management is assumed to be inadequate; it is not expected to be a drawn-out process. A negative focus emerges for the patient, who no longer sees management as beneficial—life goes by alongside treatment, while the patient's focus is on healing. Shortcomings in the health care system are considered the reason for the slow healing. Dissatisfaction arises because of desperate situation, and because the future is uncertain, hopelessness takes over. When ulcer treatment is provided in different ways by different staff members, this leads to fading hope and the conclusion that time has been wasted.

Lack of continuity is experienced as an obstacle for healing. The patient experiences hopelessness when no relationship is built and sees no value in getting to know staff members when they seldom return more than once. A sense of safety arises when one or more staff members are designated as responsible for management, though this also increases vulnerability if knowledge is lacking. The patient is in an oscillation between hope and despair, depending on staff, but with no control over the staff's availability.

After a long period of management, healing may be a possibility, but is never certain. Management is associated with a need to stand up for one's own body, in a situation that is sometimes experienced as desperate. If the energy for this peter out, ulcer healing becomes more distant. Care meetings and treatment sessions characterised

by confidence in healing are seen as a contrast to what is actually being offered. New staff can be seen as a fresh start, which can be perceived as either good or bad.

You know, I had a damn good physician for several years, but he quit. I don't know where he went. I could call if there was any problem, but now I just get the cold shoulder.
(Patient 16)

In a situation characterised by despair, a new path might open up in the form of a referral to an ulcer management team. This is experienced as a turning point in management and hope might return because the situation has changed. Individual staff members might provide a glimmer of hope, or at least a chance of something that has not been experienced before: trust, continuity or transparency. Placing hope in specific individuals creates a sense of luck: not everyone can offer healing—some can just offer ulcer management. Getting the right care is associated with being in the right place. This experience ultimately stems from a comparison of units when referral was offered. Having multiple appointments with different staff members that are not considered beneficial creates a feeling of being stuck. Terminating treatment that is perceived as ineffectual is not a possibility, because one is reliant on treatment. One's control over the situation vanishes and the patient feels powerless. The insight that some things cannot be changed emerges. All the 'musts' associated with ulcer treatment—appointments, visits, referrals and telephone calls—become demanding features of everyday life. Hopelessness is close at hand when things do not go smoothly.

When staff members are seen as reliable and valuable, treatment is experienced as making a difference. If information had implied that nothing more could be done, progress and healing are a welcome surprise. After a long period of treatment and many ups and downs, the patient may gain hope that this will never happen again. However, as life is strongly impacted during ulcer management, an emptiness seems to appear as the ulcer is replaced by healing.

5 | DISCUSSION

A VLU creates suffering for the patient, in terms of symptoms and consequences in daily life. Patients also seem to be exposed to another suffering, springing from the varying care that they are dependent on. Not being believed, listened to, or seen in a situation of total dependency can be daunting for a patient. This has previously been described as suffering from care^{37,38} and is said to depend

on a lack of reflection in caring situations, which are often mainly guided by medical advances and technology. Staff need to be aware of the phenomenon of human suffering.³⁸ Patients who experience ulcer management in which they are nothing more than the bearer of an ulcer have not been seen or respected. Patients who are treated with compassion or commitment in health care feel treated as humans. Lacking care and indifference might lead to disappointment, which can be remedied if staff takes a genuine interest in the patient.³⁹ Dahlberg concludes that suffering from care has not been taken into account in health care. However, there must be time and the opportunity to sit down and listen to each patient.^{37,39} Without listening, there is no vigour or development, either in the relationship or in the care provided. A consequence of this is that the patient's ability to actively control their health is hampered.³⁷ Patients in VLU management do not feel seen or listened to, an experience highlighted in previous research.⁴⁰ However, a functional care relationship is known to provide a solid foundation, not only for management but also for its outcome. If communication fails, the staff risks losing sight of the patient, meaning that the lack of progress and healing will be in focus. The perception that communication between staff members also fails has been described before.⁴¹ Tollow and Ogden found that the treatment approach can differ between staff members, leading to decreased confidence on the part of the patient, another confirmation of this study's result.

Phillips et al., write that when a patient does not understand the importance of compression, this part of management is terminated. The worst possible consequence of that is ulcer recurrence. An Australian study shows knowledge gaps among nurses caring for ulcer patients (Weller & Evans).⁴² Increased knowledge among those caring for patients with VLUs should strengthen care. This should extend to ongoing evaluation of the patient's situation, including the patient's mood, ability to perform physical activity in daily life and whether there is a capacity for self-care, as well as evaluation of physical symptoms.⁴³ Well-known problems for patients, such as reduced psychological and social well-being, pain, affected body image and reduced mobility,⁴⁴ must be curbed.

Eriksson refers to Florence Nightingale's view of unnecessary suffering, which is explained as a 'response to insufficient care'. Eriksson goes so far as to call it a violation of dignity when a patient is not seen or given space. Inevitably, not being taken seriously or having one's experiences questioned is associated with suffering. Suffering from care can also occur in situations where care is absent, because of either conscious choices or negligence.^{37,38} Eriksson describes suffering from illness and

suffering in life—and it is evident that pain, odour and insomnia would have an impact on daily life, which would be changed in many ways. In summary, while the requirements of ulcer management health care are unambiguous, there is ambiguity in how to achieve a view of the patient as a person.

6 | METHODOLOGICAL CONSIDERATIONS

The present study's phenomenological foundation involves certain methodological aspects, namely intentionality, openness and bridling.³⁵ The goal is always to get deep, lively and rich descriptions of the phenomenon, through an openness and a clear focus on it. In the understanding and analysis of the material, openness was guided by a constant desire to be surprised by the material: nothing was taken for granted. A bridled (pre)understanding and lingering create the chance to really see things that are not expected. This is strongly linked to intentionality and a fundamental understanding of the world around ourselves.³³ Intentionality is also associated with a directedness towards the phenomenon at hand and an awareness that one's own involvement is ever-present. Discussions within the research team act as an eye-opener, allowing different perspectives to emerge. Moving back and forth between the whole and the parts also require openness. This movement means seeing (new) things from several angles: seeing one interview in the light of the rest and seeing all interviews in the light of each one. Seeing the essence in the light of the constituents and vice versa requires an openness to seeing something else or something more than what an initial glance reveals.

According to van Wijngaarden et al., validity is associated with meaning, and thus what participants consider to be meaningful in life. Studies focusing on the essence of a phenomenon are generalisable, as it lies in the very concept of the essence that it is generalisable. It is also in the nature of the matter that a generalisation is associated with transferability, how the results can be used and their impact, taking into account the limitations of each study.³⁵ The present study includes lived experiences from care in primary care, home care and specialised care (eg, ulcer management teams, infection care, dermatological care and surgical care). Because of the organisational structure, all patients had first received care at a primary care centre, while referrals led to encounters with more specialised care during treatment. This is not likely to skew the results of the present study, because it reflects the patients' trajectory through the care system.

Interviews were carried out by telephone, because of the COVID-19 pandemic. However, we argue that the descriptions of the phenomenon were rich with meaning. Interviews by telephone have been used previously¹³ and have been shown to increase the readiness to speak openheartedly⁴⁵ without interfering with the depth of the material.⁴⁶ We all contributed with our own lifeworlds, and previous experiences as nurses, and researchers. The first author is a novice in research, but supported by the senior researchers in the team. CF and HT have earlier published material within the field. Furthermore, all four authors have a wish to improve the care for these patients, with one previously published work.¹³

This study has provided the field with important findings—not only for researchers but also for healthcare staff, students within nursing and patients with ulcers.

7 | CONCLUSIONS

This study shows that VLU patients experience ulcer management as time-consuming and lined with doubts. Ulcer management takes place in an oscillation between hope and despair, with patients experiencing various types of suffering. Healing is challenged by lacking relationships with staff, where the patient feels unseen, and care is not explained or followed up. Ultimately, healing leads to emptiness when ulcer management is suddenly terminated.

7.1 | Implications

Including patients in ulcer management means seeing them as an active partner. Patients' experiences are an important part of ulcer management and therefore need to be included. A patient who is cared for is one who is noticed. A straighter transit through ulcer management could result in increased ability to self-care and fewer ulcer recurrences. Good experiences of ulcer management influence whether a patient revisits health care if needed, which in turn affects the management of possible ulcer recurrences.

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CONFLICT OF INTEREST


The authors declare no conflicts of interest regarding the present study.

DATA AVAILABILITY STATEMENT


Research data are not shared.

ORCID

Marcus Rosenberg  <https://orcid.org/0000-0001-7875-0985>

Gunilla Lindqvist  <https://orcid.org/0000-0003-4630-7385>

Hanna Tuvevsson  <https://orcid.org/0000-0003-1020-5141>

Cecilia Fagerström  <https://orcid.org/0000-0002-4257-282X>

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