“I am just trying to live a life!” – a qualitative study of the lived experience of pressure ulcers in people with spinal cord injuries∗

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A B S T R A C T

Background: Pressure ulcers (PUs) are frequently reported in people with spinal cord injuries (SCI). Wound management in people with SCI involves relieving pressure on the affected area by means of immobilisation and bed rest. The healing time of a PU can vary, but often takes several months or even years, causing people to stay in bed for prolonged periods of time. Objective: This study aims to explore the perspectives and lived experiences of people with SCI who are affected by PUs. Design: and method: This study is a qualitative explorative study that employs individual semi-structured in-depth interviews to obtain the narratives of people with SCI and a pressure ulcer. We used a phenomenological-hermeneutic approach that was inspired by Ricoeur’s theory of interpretation. The analysis was performed in three levels: Naïve reading, structural analysis and critical interpretation and discussion. Participants and setting: Ten people with SCI who were being treated in the Danish healthcare system for their PU participated in this study: six participants had experienced a complete traumatic SCI, three had an incomplete traumatic SCI, and one had a non-traumatic complete SCI. The study included nine men and one woman, aged 49–81 years (mean 64). Nine had a PU in the seating area, while one had the ulcer on the leg.

Results: The analysis revealed three themes: 1. Struggling to balance prevention with an active, meaningful life. 2. Challenges and consequences of pressure relief protocols and bed rest. 3. Experiencing prolonged and incoherent treatment with varying levels of staff engagement and competencies.

Conclusions: People with SCI and a PU have difficulty balancing their active, redefined lives when subjected to a strict pressure relief protocol. The consequences of immobility caused by pressure relief include reduced social and community participation and decreased quality of life. PU treatment is experienced as incoherent and unnecessarily lengthy, leading to a deterioration in the wounds. Improving PU treatment for people with SCI is of utmost importance and has the potential to benefit not only the people with SCI but also the healthcare system and the economy.

1. Introduction

People with spinal cord injuries (SCI) have a lifelong increased risk of developing pressure ulcers (PUs) due to lack of sensibility and mobility and skin changes after an SCI. Treatment of a PU category 4 with exposed bone or tendon (Fig. 1) often extends over many months or even years and includes both wound care and pressure relief recommendations. This often results in prolonged bedrest, which can interfere with daily activities and last for years. This study seeks to investigate the firsthand experiences of people with SCI suffering from PU to gain a better understanding of their perspective.

2. Background

Pressure ulcers or pressure injuries, also known as bedsores or decubitus ulcers, are a common complication in people with SCI [2]. In United States, more than one-third develop a PU during the acute phase and rehabilitation [2]. Additionally, 25% develop a PU the first year after being discharged from rehabilitation, and this risk increase to nearly 40% in the 45th year post injury [3]. Several risk factors for PU
wound care products often needed to provide effective treatment [1, 6, 12]. It is therefore essential that the patient (and relatives) collaborate with the healthcare system for optimal wound treatment [1, 6, 12]. Failing to do so increases the risk of delayed and prolonged treatment, which may be harmful to the individual and have negative economic consequences [1, 19, 21, 22].

The knowledge about prevention and treatment of PUs in people with SCI is comprehensive, but there is very limited information regarding the patient’s perspectives and experiences. There is a lack of understanding of what is essential for people with SCI having a PU and undergoing treatment. The aim of this study is to gain insight into the lived experience of people with SCI of having a PU, and understand their perspectives and experiences.

This qualitative study is part of a broader project with the overall aim improving the prevention and treatment of PUs in people with SCI. First, a scoping review was conducted to shed light on pressure ulcer prevention in transition from hospital to home [23]. The current study will provide evidence on the perspectives and experiences of people with SCI suffering from a PU. Finally, the findings of the review and this qualitative study will inform the development of a management intervention for PUs in people with SCI.

3. Objective

The objective of this study is to explore the perspectives and experiences of people with SCI with an existing PU and undergoing treatment of their PU.

4. Design

A phenomenological hermeneutic approach was used to gain insight into the lived experiences and underlying meaning of people with SCI who have PU. The objective is to get a unique nuanced in-depth knowledge of the perspectives of people with SCI of having a PU and undergoing treatment for a PU. The narratives provide insight in the participants’ lived experiences and being in the world perspective. Data were collected in individual interviews with adults with SCI and PU.

4.1. Ethical approval

This study is conducted in full compliance with relevant data protection and ethical regulations.

The study was approved and registered by the Danish Data Protection Agency (journal number 20/62146), and follows the General Data Protection Regulation (GDPR). All research material and participant information were secured on a SharePoint site protected against unauthorized access. According to the principles in the Helsinki declaration [24], all participants gave informed consent based on careful and thorough written and oral information. Participants could withdraw from the study until the results were published. All interviews began with a short introduction and information about the purpose of the study and the management of their personal information.

The Scientific Ethics Committee assessed the study and decided that, in accordance with Danish law, the study did not require additional approval or notification to ethics committees in addition to the GDPR and Helsinki declaration.

4.2. Setting and inclusion

This study took place at one of the university hospitals in Denmark. The participants represented three of the five Danish geographical regions and living in 10 different municipalities. Therefore, the participants are treated in 10 different municipalities’ home care and eight different hospitals.

This study included adults with SCI suffering from PU. Inclusion criteria: Age ≥ 18 years, Danish-speaking, and able to carry on a conversation of up to 1.5 h. Participant characteristics are presented in
that it would not be possible to distinguish between multiple healthcare
Page (Facebook). 2. Nurses in the outpatient clinic and on the ward
conducted the interview while lying. Interviews lasted between 40 and
80 min (average 53.5 min). The interviews were semi-structured and
supported by an interview guide with open-ended questions (interview
guide available as Appendix 1). The first author conducted all inter-
views, transcribed them verbatim, and uploaded them to the NVIVO
software programme. We used NVIVO to mark quotes and recognise
patterns and possible themes.

4.5. The research team

The two principal investigators (KS and JRS) are academic nurses. KS
is an experienced nurse with sound theoretical knowledge of PUs and
the treatment of people with SCI, but she is not involved in the treatment in
daily clinical practice. JRS is an experienced wound care nurse who is
involved in daily clinical practice and has a more general knowledge of
people with SCI. KS conducted all interviews and had no clinical or other
relationship with participants. The broad study team are: two re-
searchers with expertise in methodology and in patient perspectives and
experiences (CN and SV). Three are very experienced clinicians and
researchers who possess extensive expertise in people with SCI (FBS),
and PU (DB) and plastic surgery (JAS).

4.6. Data analysis

We used a phenomenological-hermeneutic approach inspired by
Ricoeur’s theory of interpretation in our analysis. This approach in-
volves in-depth, iterative analysis to identify patterns that emerge from
the narratives in order to gain a deeper understanding of the lived ex-
periences of the participants. The quotes and units of meaning in the
transcribed text is describing areas of significance for the participants,
and from these areas, patterns and themes emerged from the narratives
and gave a deeper understanding of the lived experiences and being in
the world perspectives of the participants. The analysis process consisted
of three levels: 1. Naive reading, 2. Structural analysis, and 3. critical
interpretation and discussion [26,27]. The analysis process was an
iterative process between the three levels, as illustrated in Fig. 2,
inspired by Simony et al. [27] and described in the following text.

Short description of the analysis process:

In the naive reading, the two primary researchers listened independ-
ently to the recordings and read the data material as one coherent text.
We attempted to gain an impression and initial immediate under-
standing of the meaning of the text as a whole. The two researchers
worked independently and in mutual discussion, consulting with the
broad research team at this stage.

In the structural analysis, the two researchers independently iden-
tified ‘what is being said’ by marking quotations in the text in NVIVO to
interpret and get a deeper understanding the meaning of the text—
‘what the text is talking about.’ In this process, we identified units of
meaning, patterns and themes that emerged from the material, discussed
and merged them into three overarching themes as presented in the
results section. In this phase, the two researchers also worked alternately

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Table 1

<table>
<thead>
<tr>
<th>Participant</th>
<th>Sex</th>
<th>Age</th>
<th>Level, type and severity of the injury</th>
<th>Years since injury</th>
<th>Location of PU</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1</td>
<td>M</td>
<td>56</td>
<td>Paraplegia, Traumatic SCI (complete)</td>
<td>≥30</td>
<td>Sitting area</td>
</tr>
<tr>
<td>P2</td>
<td>M</td>
<td>62</td>
<td>Paraplegia, TSCI (complete)</td>
<td>≥40</td>
<td>Sitting area</td>
</tr>
<tr>
<td>P3</td>
<td>M</td>
<td>59</td>
<td>Paraplegia, Non-traumatic SCI (complete)</td>
<td>≤5</td>
<td>Lower leg</td>
</tr>
<tr>
<td>P4</td>
<td>F</td>
<td>61</td>
<td>Tetraplegia, Traumatic SCI (complete)</td>
<td>≥30</td>
<td>Sitting area</td>
</tr>
<tr>
<td>P5</td>
<td>M</td>
<td>73</td>
<td>Paraplegia, Traumatic SCI (complete)</td>
<td>≥40</td>
<td>Sitting area</td>
</tr>
<tr>
<td>P6</td>
<td>M</td>
<td>75</td>
<td>Tetraplegia, Traumatic SCI (incomplete)</td>
<td>≤5</td>
<td>Sitting area</td>
</tr>
<tr>
<td>P7</td>
<td>M</td>
<td>81</td>
<td>Paraplegia, Traumatic SCI (complete)</td>
<td>≥5</td>
<td>Sitting area</td>
</tr>
<tr>
<td>P8</td>
<td>M</td>
<td>55</td>
<td>Tetraplegia, Traumatic SCI (incomplete)</td>
<td>≥30</td>
<td>Sitting area</td>
</tr>
<tr>
<td>P9</td>
<td>M</td>
<td>69</td>
<td>Paraplegia, Traumatic SCI (complete)</td>
<td>≤5</td>
<td>Sitting area</td>
</tr>
<tr>
<td>P10</td>
<td>M</td>
<td>49</td>
<td>Paraplegia, Traumatic SCI (complete)</td>
<td>≥10</td>
<td>Sitting area</td>
</tr>
</tbody>
</table>

SCI: Spinal cord injury. Complete: complete injury with absence of any sensory
and/or motor function in the lowest sacral segments i.e. no sacral sparing [25].
Incomplete: incomplete injury with preservation of any sensory and/or motor
function below the neurological level that includes the lowest sacral segments i.e.
presence of sacral sparing [24]. Location of pressure ulcers (PUs): Sitting area
covers: ischial tuberosity, sacrum or coccyx.

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Fig. 2. A phenomenological-hermeneutic-inspired iterative analysis process
inspired by Ricoeur’s theory of interpretation [27].
5. Results

We identified three themes in our structural analysis of the material. The three themes and examples of quotes supporting the themes are presented in the following sections.

1. Struggling to balance PU relief with an active, meaningful life
2. Challenges and consequences of pressure relief and bed rest
3. Experiencing incoherent treatment with varying staff commitment and competencies.

5.1. Struggling to balance PU relief with an active, meaningful life

People with SCI value independence and self-reliance. They describe how they have fought hard to regain a fulfilling life rather than succumbing to idleness, self-pity, and a life perceived as a “handicapped life.” They strive to maximise participation in family, work, and social activities. However, following an SCI, PU prevention becomes an essential aspect of daily life—a responsibility and limitation that people with SCI acknowledge:

“… then there are times when you actually feel that, well, doing pressure relief can just wait half an hour to do pressure relief or it can just wait, can’t it? And then sometimes you’re traveling somewhere, well, you know you’re pushing the limits. […] Well then there is always a period afterwards out of the game, where you have spent three weeks or something like that, where you have taken a lot of care and done a lot of pressure relief …” (P2)

“So I play cards, right? And the others can feel that they should move a little, right? But I just feel I should soon play the 8 of clubs, right? So I forget all about moving … I think it might be risky to play cards, but it … if we have to avoid all the fun things, then …” [laughing a bit] (P1)

Balancing activity and pressure relief can be challenging and perceived as barriers to participation for people with SCI. Sometimes people with SCI push it to the edge by prioritizing activities over PU prevention, even though they know that insufficient pressure relief increases the risk of developing PU, leading to an increased need of pressure relief, bed rest and further limitations. However, excessive PU prevention makes participating in an active life impossible.

“I am bombarded with pressure relief, they say you have to get up and lie down I don’t know how many times a day and rest and stuff like that. But then you can’t have a life, right? I also have a job to take care of.” (P9)

Recommendations for pressure relief and bed rest have to become part of everyday life. People with SCI must balance their daily routines between conflicting interests: They have a desire for an active lifestyle and participate in family life and community activities to live a meaningful life. They view work and social activities as “good medicine” that have a positive impact on their overall health and well-being. On the other hand, they express the necessity to alleviate pressure to prevent PUs and to avoid further limitations that may arise as a result of developing a PU. These dilemmas are an integral part of everyday life. When a PU occurs, people with SCI are aware of their responsibilities, but it is evident that they struggle to find a balance:

“Everyone who gets pressure ulcers have themselves to blame. To some extent. I’m just trying to live a life! […] So, yes, to be naive and say it’s not my fault … of course it is. It is me who makes an action. But I really do that for the sake of living. And then you can say, once in a while, the precision in the calculation slips. And sometimes something happens that you might not have anticipated.” (P2)

The PU prevention tasks involve activities such as ensuring pressure relief throughout the day and maintaining physical fitness to facilitate safe transfers in and out of the wheelchair. It is widely accepted that a PU develops due to lack of sufficient caution, even when the efforts were made to prevent it. However, people with SCI may attribute their wounds to factors other than inadequate pressure relief, such as presence of a fistula or abscess. Based on own personal experiences, they do not think that their PU is caused by an imbalance between pressure relief and activities, despite the healthcare professionals opposite opinion.

People with SCI describe that they perceive themselves as responsible for ensuring the quality and effectiveness of their pressure-relieving devices, such as mattresses and cushions. However, they view this responsibility as burdensome, and they often feel unsupported with the task. For example, they may feel insecure about checking the tasks such as monitoring the pressure in an air-filled cushion.

5.2. Challenges and consequences of pressure relief protocols and bed rest

When people with SCI develop a pressure ulcer, they often receive recommendations for extended periods of bedrest and stringent pressure

<table>
<thead>
<tr>
<th>Units of meaning</th>
<th>Units of significance</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>You have to give before you can enjoy and who is really contributing here? It somehow moves one’s male pride, and no matter what, it ruins people’s lives - things like this [the PU]</td>
<td>Bed rest causes compromised fundamental values that affect the role and identity, which is devastating.</td>
<td>Challenges and consequences of pressure relief and bed rest</td>
</tr>
<tr>
<td>I try to do pressure relief, and also try to get up and get some quality time and socializing uh and coffee and clubs…</td>
<td>Difficult to balance between bed rest and participation</td>
<td></td>
</tr>
<tr>
<td>(…) but now I am allowed to attend special events. And then, among other things, I can watch football in a place where they have a big screen indoors. And it’s nearby, so it can be easily done.</td>
<td>Everyday activities become extraordinary, and participation is only allowed when permitted by healthcare professionals.</td>
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</tr>
</tbody>
</table>
People with SCI often experience a lack of coherence among the various healthcare professionals involved in PU treatment and wound assessment, which can result in a failure of staff to monitor and recognise if the wound is deteriorating. This can lead to a failure to respond appropriately to the deterioration of the wound, leaving it at risk of becoming deeper and the patient more susceptible to infection and sepsis. Most of the people in this study experienced acute hospitalisation for sepsis. People with SCI trust healthcare professionals and expect them to respond adequately to deterioration, but the reality is often inconsistent as evidenced by the above quote.

Besides the lack of coherence in treatment, there also appear to be a delay in referral to a higher level of care:

"When a PU occurs, healthcare professionals tend to assume control over wound care and pressure relief protocols, without involving people with SCI. Despite some level of acceptance due to the trust in the healthcare professionals’ expertise, this dynamic creates a power imbalance in which healthcare professionals hold the authority, and people with SCI must comply. By following prescribed protocols, they are rewarded with additional time out of bed. However, if the wound fails to heal, they are not granted more time out of bed, but are instead advised to spend even more time in bed, creating a discouraging and frustrating situation. People with SCI are highly aware of pressure relief protocols and often use powerful language to convey their emotions and the impact of bed rest.

The balance between pressure relief and participation is illustrated in Fig. 3A and B. When people with SCI prioritise highly valued participation, they sometimes find themselves on the edge, with the balance tipping towards an increased risk of PUs, as illustrated in Fig. 3A. The cost of this imbalance can be the development of a PU that results in even more restrictive pressure relief protocols and missed opportunities for participation and an active life. On the other hand, increased pressure relief and bed rest can significantly reduce the risk of PUs. However, it also limits the opportunity to participate in activities that contribute to the quality of life, self-esteem, and self-efficacy, as shown in Fig. 3B.

5.3. Experiencing incoherent treatment and varying staff commitment and competencies

The analysis revealed comprehensive descriptions of their experiences while going through PU treatment:

"Then came a substitute and a substitute. Then one more and another one ... everyday a new one. When I asked them, how does it look? They always answered that they hadn’t seen it before. So, it went from being a pinhead to the bone sticking out. And then all the shit got infected, and I was taken wee woo to the hospital with a massive fever. And I was completely gone." (P5)

People with SCI often experience a lack of coherence among the various healthcare professionals involved in PU treatment and wound assessment, which can result in a failure of staff to monitor and recognise if the wound is deteriorating. This can lead to a failure to respond appropriately to the deterioration of the wound, leaving it at risk of becoming deeper and the patient more susceptible to infection and sepsis. Most of the people in this study experienced acute hospitalisation for sepsis. People with SCI trust healthcare professionals and expect them to respond adequately to deterioration, but the reality is often inconsistent as evidenced by the above quote.

Besides the lack of coherence in treatment, there also appear to be a delay in referral to a higher level of care:
“Well, it has been drawn out far too long. In other words, too much time has passed before people have chosen to say “We can’t do this here. We can’t handle that you have to get on with it” [...] The moment when you can see that now we have started to treat this wound and it has deteriorated during the week. So, then it has to be stopped, then you have to get hold of some others [...] Once these [PUs] occur, yes, that means you have to be able to quickly go to, yes, quickly have some REAL professionals come over.” (P3)

People with SCI describe an experience of unconscious incompetence and a reluctance by health professionals that are hesitant to refer the patient to a more specialised level of care. During rehabilitation, people with SCI learn to respond quickly to a potential PU and seek help from the healthcare system. Unfortunately, they often do not receive an appropriate response - even in a potentially life-threatening situation. It appears that healthcare professionals have limited knowledge and skills and are reluctant to ask for help when needed. When they do, however, there are difficulties in working together, leading to frustration, as illustrated by the following quote about a community nurse:

“She becomes slightly irritable and starts to write some rather blunt messages both to my own doctor and to the hospital.” (P2)

People with SCI observe lack of interdisciplinary collaboration and communication between the primary and secondary health care sector, which leads to frustration of healthcare professionals. They experience unnecessarily prolonged treatment and care, which is frustrating because they anticipate healthcare professionals to take responsibility and manage the situation adequately, but they experience a different level of commitment and accountability:

“And then the home care nurse can continue to change dressings and so on and there are a lot of outpatient visits and where, you could say, it’s new doctors all the time - and maybe that’s what was meant by saying, well come back in three weeks, it probably won’t be me having surgery on my back this time.” (P2)

The experienced lack of skills and commitment from healthcare professionals affects the quality of care and assessment of PU and results in prolonged treatment and non-healing wounds. The result is a misuse of limited healthcare resources, which is difficult for people with SCI to understand and accept.

People with SCI do not always experience an appropriate respond, when they have a health problem, which is described in the following quote:

“But if I myself hadn’t been aware of how dangerous it was, I might not have noticed it in time? I came in with an infection count [CRP] of 237 and felt really bad, and I had said 4 days prior that I felt really bad and was sure I had a pressure ulcer. But they didn’t even bother to check if I had it. And it ended up with me having surgery and I’ve still got it. It is deeply disturbing and it is very dangerous. I’m quite sure that there are people who will get in deep trouble if they don’t have the kind of insight that I have into my own situation. Really deep trouble. Or die from it.” (P8)

Healthcare professionals play a crucial role in responding to and treating the problems of people with SCI. However, the response is not always appropriate, which can cause unnecessary pain, misery and danger for people with SCI and PU.

Despite following the recommendations and seeking help from the health care system, people with SCI are still at risk of further complications. Therefore, people with SCI must be vigilant and take responsibility for their situation. They cannot force themselves into the hospital or demand competent and appropriate treatment and care. People in this study describe that they are trying to collaborate with healthcare professionals, but when they do not succeed, and it leads to feelings of powerlessness and lack of control in potentially life-threatening situations. They also emphasise that not all people with SCI have the ability and knowledge to fight for themselves.

6. Discussion

6.1. Discussion of results

The findings of this study highlight the significant impact that PUs and pressure relief protocols have on the lives of people with SCI, limiting their ability to participate in community, family, and social activities, which affects their role and identity. The skills and commitment among healthcare professionals vary, as well as the level of collaboration between different medical fields, healthcare organisations, and people with SCI. This can potentially extend wound treatments for people with SCI.

In this study, people with SCI describe the struggle to re-create their lives after the SCI in a way that is as close as possible to the life they
prefer with a high degree of independence and autonomy. However, the strict pressure-relief protocols implemented to prevent PU and support wound healing, can impede the realisation of this goal, limiting social and community participation.

Community and social participation are key rehabilitation goals after an SCI [9] and related to the individuals’ perception of their social functioning [28]. Community participation is defined as: “Being part of the mainstream of family and community life; living independently; discharging the roles and responsibilities that are considered normal for someone of a specific age, gender, and culture; or being an active and contributing member of one’s social groups and society as a whole” [29]. This study reveals that engaging in activities and participating in society are experienced as “medicine” and contribute to maintaining a healthy life. PU prevention requires constant effort and is ongoing responsibility, which is challenging and stressful for the individual, who strive to participate in community.

Studies showed a strong association between social and community participation and quality of life in people with SCI [30,31]. A study by Halvorsen et al. [30] showed that having a job or studying is associated with a higher quality of life, better social relationships, self-efficacy, and self-esteem in people with SCI [30]. It has been described in both the literature and guidelines that PUs and the need for strict pressure relief protocols can limit participation and thereby affect mental health negatively and decrease quality of life [1,6,12,16,19,20,32,33].

An SCI is a life-changing event; nevertheless, many people manage to regain a valuable, independent life with a high quality of life [34] and achieve post-injury growth and high life satisfaction [35]. However, compared with the general population, people with SCI have, on average, a lower quality of life [31,36].

The findings of this study are consistent with previous studies and guidelines, emphasizing the significance of engaging in social and community activities as part of the rehabilitation process to establish a new life, ultimately leading to a healthy and satisfactory lifestyle. Bedrest is a significant threat to a healthy life, and its impact is often perceived as worse than the PU itself. Due to impaired or lost sensory perception, many people with SCI do not feel pain from the PU. The wound is typically located in the sitting area (on the buttocks), and therefore, often not visible to the individual. The pressure relief protocols and bed rest restrictions are very visible and present problems and, therefore, are of greater concern than the wound. Implementing a more individualised approach to pressure relief for people with SCI could increase participation and thus increase the QOL for the individual.

People with SCI are primarily responsible for PU prevention following their injury, but in the event of a PU healthcare professionals take charge by determining pressure relief protocols as well as the duration of bedrest and the amount of time spent sitting during the day. A majority of people with SCI feel responsible for PU prevention as noted in a cross-sectional study [37] where the majority (94 %) of 162 included participants with SCI considered themselves responsible for PU prevention. The guidelines suggest that PU prevention entails monitoring the quality and functionality of support surfaces, performing skin inspections, avoiding shear forces, and executing transfers [1,12].

The clinical practice guidelines for preventing and treating PUs recommend that people with existing PUs should have an individualised schedule and spent limited time in a seated position, while also taking into account their emotional wellbeing [1,6,12]. However, the pressure-relief protocols are based primarily on expert opinion due to the lack of evidence regarding the optimal duration of pressure relief and time spent in a sitting position.

People with SCI experience that healthcare professionals focus primarily on wound healing and strictly adhere to rigid pressure relief protocols without considering person-specific knowledge or engaging in collaboration with them. Healthcare professionals are sometimes reluctant to discuss the pressure relief protocols with the individual - even when people with SCI are trying to influence the decisions of pressure relief.

It appears paradoxical that healthcare professionals prescribe strict pressure-relief protocols without involving the individual. People with SCI are typically experienced and responsible for pressure relief and PU prevention, and possesses knowledge of their own priorities, core values and life circumstances. Furthermore, the lack of evidence-based support for these protocols underscores the importance of an individualised approach and careful monitoring of wound healing to find the optimal balance between pressure relief and activity. In clinical practice, a more differentiated and individualised approach to pressure relief is needed for people with SCI and PU so that – under careful observation and close follow-up – they can sit upright and be active as much as possible without compromising wound healing. Following rigid pressure relief protocols is potentially more restrictive than necessary, resulting in physiological and psychological consequences that harms the individual. There is a gap in knowledge and a need for further research to establish optimal pressure relief protocols for individuals with SCI recovering from a PUs.

This study reveals an incoherent and unnecessarily lengthy treatment process for PUs that involves multiple staff members with varying levels of skills and commitment. Additionally, there is a lack of interdisciplinary collaboration between health sectors, which leads to worsening despite early involvement with the healthcare system potentially resulting in life-threatening infections. These findings are consistent with other studies [38-40] that have addressed the needs of people with SCI who require home care and have limited access to healthcare professionals with specialised knowledge. Managing PUs in this population is complicated due to loss or reduced sensation and mobility, but also due to the skin changes after an SCI and the reduced oxygen tension and small vessel blood flow [2]. Therefore, it requires a cross-sector involvement of various health professionals with the appropriate skills and knowledge. Optimal PU treatment and care depend on systematic observation, documentation, and skilled assessment and evaluation to avoid unnecessarily prolonged treatment [41,42].

Collaboration between the patient (and family members) and the health care system is essential [1,6,12,32]. The challenges of delayed and prolonged treatment are well described in the literature [1,19]. It is essential to optimise treatment and secondary prevention are crucial for both the individual and the health economy [13,14,16,21,22]. It is widely acknowledged that PUs pose a significant risk of fatality for people with SCI [6]. Infections are the second most common cause of death in people with SCI, and 90 % of the infections are septicemias, typically caused by PUs, urinary tract infections, or respiratory infections [3].

The present study found that people with SCI feel unsafe and lose confidence in the health care system, due to inconsistent and prolonged treatment. This motivates them to take greater responsibility for their condition, and participate actively in their treatment and care to enhance wound healing. The negative impact of such treatment on PUs is significant, leading to unnecessary deterioration of PUs and extended time of strict pressure relief protocols. This approach represent a wasteful use of the limited resources available within the health care system, which is also of great concern for people with SCI in this study. They express a desire for a clear responsibility for their care and improved interdisciplinary and inter-sectoral collaboration, with easier access to specialised healthcare professionals with knowledge of people with SCI and PUs. The description of a more optimal organisation of PU treatment to people with SCI with multidisciplinary cooperation between the different health care sectors and patient involvement would be beneficial. Furthermore, a more systematic evaluation of wound healing, and a pathway describing further diagnostics would be beneficial for non-healing wounds.

The present study provides a comprehensive description of how individuals cope with an SCI and PUs, as well as the significant changes that occur in their life situation following an SCI.
Coping is defined as the “constantly changing cognitive and behavioural efforts to manage specific external and internal demands that are appraised as taxing or exceeding the resources of the person” [43]. Coping is a well-described concept in rehabilitation literature and research on coping and adjustment after an SCI [44]. Literature shows that an active coping strategy and a positive attitude are essential for the outcome of people with SCI [45], and the coping strategy is relatively consistent over time [35].

An active coping strategy is conducive to a positive outcome after an SCI according to the literature mentioned above appears to be preferred by individuals with SCI in this study. Having a PU is another external demand that the individual must cope with that strains and may exceed their resources. The individual’s personal values and desire to contribute and participate are internal demands that the individual must also cope with. The active coping strategy is a strength in coping with an SCI, but coping with a PU requires bed rest and immobility and may require a completely different coping strategy.

People with SCI experience a lack of dialogue and collaboration with healthcare professionals that are not listening to their inputs. They want to be involved in treatment and pressure relief, and they feel left alone in PU prevention. ‘Guided self-determination’ [46] is a method to secure the systematic involvement of patients and service users. It builds on the principle that the individual (and relatives) and the healthcare professionals are working together in treatment and care decisions: the healthcare professionals impart evidence-based knowledge, and patients share their values, beliefs and preferences. Through mutual information and discussions they decide the best treatment and care for the individual [46]. Self-determination can increase staff engagement and satisfaction, increase service user satisfaction, decrease disease-related loneliness, improve treatment outcomes, and increase the feeling of being seen and believed in a trusted patient-caregiver relationship [46].

When a PU fails to heal, the healthcare professionals tend to prescribe more pressure relief without exploring person-specific knowledge about the individual. Based on their personal experiences, people with SCI ask for re-assessment and adjustment to optimise treatment in non-healing wounds. Implementing guided self-determination in prevention and treatment of PUs in people with SCI could support the dialogue and mutual exchange of information and secure a more individualised approach.

6.2. Methodological discussion

The participants in this study consists primarily of men (nine out ten) and the mean age is 64 years. To some extent, this would be expected, given the population and PU risk factors: 1. More men than women have SCI [3,47], 2. The average age at injury is increasing [3–5,47], as is life expectancy for people with SCI in developed countries [3,47], 3. Age and time since injury are risk factors for PU [1,3], and 4. More men than women with SCI have PUs [48].

After conducting the first four interviews, we observed that there were repetitions and surprisingly similar narratives, despite the fact that the participants live in different communities, are treated in different hospitals, came from different backgrounds and life situations, with different types of injuries and PU histories. However, we wanted to collect comprehensive narratives and conduct all planned interviews.

7. Limitations and methodological considerations

The study exhibits an uneven distribution of age and gender, although it does partially mirror the actual population. It remains uncertain whether a different gender composition or mean age could provide additional insights into our findings. While acknowledging the potential limitations in generalizability, we regard our results as a valuable contribution to enhancing our understanding of the lived experiences of individuals with spinal cord injuries who develop PUs.

It takes a certain amount of energy to enrol in a research study and there is a risk that the included participants with many resources and strong attitudes. People with fewer resources might be less willing to participate in such a study. Therefore, our results may represent a resource-strong group of people with SCI that is not representative of all people with SCI.

This study was conducted in a developed country with a publicly funded health care system, and the results are probably not directly applicable to other types of societies or health care systems.

8. Conclusion

We aimed to explore the perspectives and experiences of people with SCI with a PU and treatment for PU in this study. Participation in social life and the community is critical for people with SCI and is related to quality of life and increased self-esteem and confidence. After a SCI, PU prevention is a daily task, and people with SCI struggle to balance pressure relief and activities. They have to cope with SCI and PU, and the strict pressure relief protocols after a PU have a significant impact on people with SCI. They are just trying to live their lives, but their role and identity, as well as their opportunities for social and community participation, are impacted, severely threatening their quality of life and mental health.

People with SCI experience incoherent and unnecessarily prolonged treatment leading to unnecessary worsening of PUs, resulting in hospitalisations and potentially life-threatening situations due to the risk of sepsis. They experience variable engagement and knowledge among health professionals, high staff turnover, and suboptimal inter-sectoral collaboration leading to delayed access to specialised professionals. These factors lead to suboptimal assessment and wound management, resulting in unnecessary wound deterioration and months or even years of treatment without wound healing. In addition, suboptimal treatment of PU leads to misuse of healthcare resources. Prolonged wound treatment leads to more time spent on rigorous pressure relief protocols, putting the re-created high-value active life on hold for months or even years. The more individual approach to pressure relief recommended in international guidelines does not seem to be implemented in the Danish healthcare system.

According to this study, people with SCI do not experience to be sufficient involved in collaboration with the healthcare professionals which leads to a feeling of not being seen and heard. People with SCI does not experience that the healthcare professionals explore and include person-specific knowledge in treatment and pressure relief protocols. Furthermore, they do not experience that healthcare professionals listen to symptoms and experiences of the person with SCI. Thus, important knowledge and symptoms are not managed sufficiently.

This study points out the need for improvement of the PU treatment in people with SCI in the Danish healthcare system. There is also need for improvement of the organisation of healthcare services, and a need to increase the knowledge and skills of the healthcare professionals. Implementation of a more individualised approach and a systematic evaluation of wound healing, and a clinical pathway for non-healing wounds could improve PU treatment in people with SCI, and decrease pressure relief for the individual. In addition, implementation of a method such as guided self-determination could possibly improve systematic dialogue and collaboration and improve management of PUs in people with SCI.

9. Perspectives

This study highlights several areas of improvement for people with SCI and PU. Systematic observation and documentation, skilled assessment, and treatment evaluation have yet to be implemented in clinical practice. Early detection of PUs is a prerequisite for early intervention, and there is a need for knowledge and skills among people with SCI and healthcare professionals. The organisation of PU treatment for people
with SCI must ensure inter-sectoral collaboration, easy access to expertise in PUs for people with SCI, and clear treatment responsibilities. Specialised units with an outreach function combined with telemedicine solutions and a responsibility to ensure close cross-sector collaboration could be a solution and should be explored.

The development of effective individualised secondary prevention strategies and initiatives could mitigate the consequences of pressure relief protocols and improve the quality of life of individuals. More research in this area could pave the way for a more individualised approach to primary and secondary prevention of PUs that focuses on the individual’s knowledge, habits, and lifestyle; individual risk factors and motivation; and home care environment, including habits and pressure relief aids. Improving PU treatment for this group of individuals is essential and would benefit people with SCI as well as the health care system and the economy. The recommendations of the available international guidelines on PUs in people with SCI need to be implemented in clinical practice to ensure the best possible evidence-based practise. However, the evidence underlying these guidelines is variable, and further research on the organisation of health care and clinical practice, including health technology, is warranted.

Conflict of interest
None.

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Declaration of competing interest
The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. Supplementary data
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