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Research Article

Engaging in the prevention of pressure injuries in spinal cord injury: A qualitative study of community-dwelling individuals' different styles of prevention in Switzerland

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Context: Spinal cord injury (SCI) is a complex chronic condition with multiple self-management requirements and a high prevalence of complications. Pressure injuries (PIs) are among the most common ones and represent a frequent reason for re-hospitalization. This study aimed to identify styles of prevention that individuals with SCI adopt to deal with the risk of developing PIs.

Design: Qualitative explorative interview study. Data was collected through semi-structured interviews, which were transcribed verbatim and analyzed following the principles of thematic analysis.

Setting: Switzerland.

Participants: The participants were a purposive sample of community-dwelling Swiss residents with SCI for at least five years.

Interventions: Not applicable.

Outcome measures: Not applicable.

Results: Although all participants (N = 20) showed at least a basic knowledge of prevention of PIs by describing some preventive measures, they had different prevention styles characterized by different behavioral patterns (i.e. complying with all recommended measures, performing only a selection of them or delegating them to others) and different beliefs and attitudes towards prevention.

Conclusion: By identifying the style of prevention of an individual, it is possible to develop tailored interventions that have an impact on the factors which seem to play a role in determining the adoption of preventive behaviors (i.e. perceived susceptibility to PIs, attitudes towards prevention, and self-efficacy). Such interventions would constitute a concrete effort to support individuals with SCI during their self-management. Besides alleviating a frequent and disabling medical complication and contributing to an enhanced quality of life, these interventions might also help decrease healthcare costs.

Keywords: Self-management, Facilitators, Complications, Bedsores, Semi-structured interviews, Thematic analysis

Introduction

Spinal cord injury (SCI) is a medically complex chronic condition requiring the management of several body functions and adjustments in most life domains,[1,2] characterized by sensory and motor loss and a high prevalence of secondary health conditions.[3–5] Among these, pressure injuries (PIs) are one of the most common serious complications[6–10] and among the most frequent reasons for re-hospitalization in Western countries.[3,11–16]

PIs have a profound impact on individuals' lives on a physical and social level (e.g. reduced participation, loss of autonomy).[17–20] Moreover, treating PIs is very costly for the health system.[15,21–25] Both experts and individuals with SCI agree[26,27] that sometimes PIs in SCI are preventable and that prevention is more cost-effective than treatment.[28] Continuity in the implementation of

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DOI 10.1080/10790268.2018.1543094

preventive measures is crucial considering that the prevalence of PIs significantly increases with time post injury and is influenced by age and health status.[3,29–31] Prevention is more likely to be successful if individuals with SCI take on an active role, comply with recommendations[32] and search for professional help when needed.

However, studies have shown that current recommendations on preventing PIs are not always followed.[33,34] To support individuals in following recommendations, it is important to determine why some do and some do not,[19,35] allowing individuals to learn from each other. This study aims to identify styles of prevention that community-dwelling individuals with SCI adopt to avoid the development of PIs. The results will highlight some of the factors that support individuals with SCI in preventing PIs. These factors could become the target of tailored interventions supporting individuals in their self-management.

Methods

This is a qualitative explorative study in the field of SCI and the prevention of PIs.

Sampling and recruitment of participants

We recruited a stratified purposive sample of Swiss residents with SCI living in the community since at least five years, both with paraplegia and tetraplegia with different experiences of PIs (i.e. none, one or more), of different age groups and times since injuries, as lesion level, ageing and time since injury can influence the development of PIs. Recruitment was conducted with the collaboration of the four specialized centers for SCI rehabilitation in Switzerland and by relying on intermediaries (e.g. wheelchair clubs and health professionals (HPs)). We called the potential participants who agreed to be contacted to schedule an interview and sent them study information and informed consent.

Data collection

Data collection was informed by preliminary data analysis and sampling was interrupted once informational saturation was reached. All individual face-to-face semi-structured interviews were conducted by one researcher and audio-recorded. Participants chose the interview site for their convenience and comfort. The interviews aimed to: examine participants' knowledge and attitudes towards prevention of PIs; explore individuals' strategies for preventing PIs; and describe the role of the different actors involved in the prevention of PIs. Sample questions are presented in Table 1.

The study obtained ethical approval from the regional committee (ref. EKNZ 2015-311). Participation in the study was on a voluntary basis.

Data analysis

The recordings of the interviews were transcribed verbatim and analyzed using thematic analysis.[36–38] After the transcripts were read, two researchers – one experienced in qualitative analysis and a trained research assistant – worked on the generation of preliminary codes capturing aspects in relation to prevention of PIs. Codes with consistent patterns were then grouped to form themes, which were revised, merged, or split by comparing all quotes within a theme, until internal homogeneity and mutual exclusivity were achieved. For every theme, the researchers defined the rules for including or excluding a code and met at multiple points throughout the process to discuss and resolve uncertainties. Later on, these themes were used as basis to build a typology of styles of prevention by grouping the cases with similar patterns (e.g. individuals having similar behaviors and attitudes towards prevention). A first tentative grouping identified two styles of prevention. The cases within every style were compared with each other to verify their homogeneity and cases with significant differences

Table 1 Sample questions for the semi-structured interviews.

Topic	Sample questions
Knowledge and attitudes towards prevention of PIs	• How have you acquired your knowledge about the prevention and treatment of PIs? • What have you learnt from the experience of having a PI? • How did you react the last time that you had a redness of the skin? • What kind of feelings does the thought of developing PIs causes you?
Strategies and techniques for preventing PIs	• What are you doing specifically to prevent PIs? • Do you have any successful measure? • What is for you the most difficult thing in preventing PIs? • Have the challenges of prevention of PIs changed over time? How? • How does your behavior differ from the generally taught preventive measures?
Actors involved in the prevention of PIs	• How do you organize the tasks in relation to the prevention of PIs? Is there anyone helping you for some tasks? Who? • How does the collaboration with the homecare services work for the prevention of PIs? • Would you need more support to better prevent PIs (in the future)? Which kind of support?

Table 2 Participants' characteristics by style of prevention.

Prevention style	ID Number	Sex	Age	Years using a wheelchair	SCI Characteristics	Number of PI(s)
Thoughtfuls	T1	w	57	30	Paraplegia, T11, motor complete, sensory complete, flaccid	0
	T2	m	81	52	Paraplegia, T5, motor complete, sensory complete, spastic	0
	T3	m	54	10	Tetraplegia, C2-3, motor complete, sensory complete, spastic	0
	T4	m	54	7	Paraplegia, T11-12, motor complete, sensory complete, flaccid	1
	T5	m	59	35	Paraplegia, L11-12, motor complete, sensory complete, flaccid	> 1
Selectives	S1	m	60	40	Paraplegia, T4, motor complete, sensory incomplete, spastic	0
	S2	w	58	37	Tetraplegia, C6-7 incomplete, T2 complete, motor complete, sensory incomplete, spastic	0
	S3	w	58	9	Tetraplegia, C5, motor complete, sensory incomplete, spastic	0
	S4	w	47	37	Paraplegia, T6, motor complete, sensory complete, spastic	1
	S5	m	26	37	Tetraplegia, C5-6, motor complete, sensory incomplete, spastic	1
	S6	m	57	35	Tetraplegia, T2-3 complete, C5 incomplete, motor complete, sensory incomplete, spastic	1
	S7	w	48	23	Tetraplegia, C6-7 incomplete, T4 complete, motor complete, sensory incomplete, spastic	1
	S8	w	45	41	Paraplegia, L2, motor complete, sensory complete, flaccid	> 1
	S9	m	42	25	Paraplegia, T4-5, motor complete, sensory complete, flaccid	> 1
	S10	m	27	13	Tetraplegia, C6, motor complete, sensory complete, flaccid	> 1
Delegators	D1	m	47	25	Paraplegia, T8-11, motor complete, sensory incomplete, spastic	1
	D2	m	68	47	Paraplegia, T9, motor complete, sensory complete, flaccid	> 1
	D3	m	45	17	Tetraplegia, C3-5, motor complete, sensory complete, spastic	> 1

were flagged. At the end of this process, a third style was identified. The attribution of a case to a style was first performed by one researcher and then discussed and refined with the second researcher. The overall framework of the analysis was refined in collaboration with the project leader.

Results

The final sample comprised 20 individuals: seven women and 13 men, with a mean age of 52 years, and on average 29 years of experience using a wheelchair. More detailed self-reported information is presented in Table 2. The interviews lasted on average 55 minutes. Two interviews were excluded from the analysis because the subjects were upset and dissatisfied with the service provision and the interviewer had difficulties in guiding them through the questions.

The analysis of the 18 included interviews identified three main styles of prevention of PIs. The first style is typical of those who tended to comply with all the recommendations and multiplied their efforts to prevent PIs. We will name these people the "Thoughtfuls". The second style is typical of those who tended to only perform a selection of preventive measures (the "Selectives"). The last style of prevention is typical of those who were mostly inactive in prevention and tended to delegate preventive measures to others (the "Delegators"). Most of our participants were Selectives (10), some were Thoughtfuls (5) and a few were Delegators (3). The analysis highlighted that individuals who adopted the same style of prevention shared not only patterns of behavior but also other characteristics, such as knowledge and attitudes regarding prevention, the manner of collaboration with HPs, and an attitude toward life with SCI. The results are extensively presented below and summarized in Table 3.

Patterns of behavior

The Thoughtfuls, the Selectives and the Delegators presented themselves as performing different amounts of prevention measures and as having a higher or lower readiness to give up activities to prioritize prevention. Specifically, the Thoughtfuls reported multiple preventive measures in daily life, including lying down and push-ups to relieve pressure on the skin and always using their own assistive devices. This required not only organizational skills and the ability to anticipate needs and risks in different situations, but also discipline (Appendix A, Q1–Q3). An illustration of discipline is their promptness in canceling a planned activity to prevent the worsening of redness of the skin (Appendix A, Q4).

Compared to the Thoughtfuls, the Selectives seemed to perform fewer preventive measures and to be less likely to give up activities to prioritize prevention. They sometimes trusted their experience and gut

Table 3 Summary table of the characteristics of the three prevention styles.

	Thoughtful	Selective	Delegator
Patterns of behavior	• Adopting all recommended preventive measures • Ability to renounce	• Adopting some of the recommended preventive measures (selection based on experiential knowledge)	• Mostly adopting “passive” prevention measures and delegating prevention activities to caregivers
Knowledge and attitude towards prevention of PIs	• Extensive knowledge • Perceive themselves at risk of PIs • Prevention has high priority • Prevention is a personal responsibility • If PIs develop: co-responsibility or “it can happen” • Between habit and hard work	• Extensive knowledge • Perceive themselves at risk of PIs • Prevention important but does not have to interfere with personal plans • Prevention is a personal responsibility • If PIs develop: co-responsibility or “it can happen” • Between habit and hard work	• Basic knowledge • Do not perceive themselves at risk of PIs • Prevention has no high priority • Prevention is a shared responsibility • If PIs develop: blame others for PIs or “it can happen”
Collaboration with health professionals	• Timely support	• Timely support • Importance of expertise	• Regular supervision (with HPs we are in good hands)
Attitude to life with SCI	• Optimism • Self-efficacy (I can appropriately anticipate problematic situations thanks to my discipline) • Proactivity	• Optimism • Self-efficacy (I can appropriately react to problematic situation thanks to my experiential knowledge and my network)	• Lack of proactivity • Reliance on caregivers

feeling and deliberately made decisions that were not aligned with HPs’ recommendations. In many cases, these choices reflected the tradeoff in a life in which prevention of PIs was in competition with family or work commitments (Appendix A, Q5). Yet, the selecting of measures to carry out is based on careful observation of one’s own body and its characteristics (Appendix A, Q6), its strengths (e.g. good skin) and weaknesses (e.g. delicate feet) (Appendix A, Q7–Q8). Furthermore, some among the Selectives reported living their life and adapting their behavior in case of potentially dangerous situations (Appendix A, Q9).

What distinguished the Delegators from the Thoughtfuls and the Selectives was their preference for passive (e.g. air-flow bed) versus active preventive measures (e.g. skin inspection), their tendency to act under the guidance of caregivers and not on personal initiative, and their preference for handing over responsibility prevention to others (e.g. homecare service) (Appendix A, Q10). Additionally, the Delegators had high expectations from the performance of assistive devices (e.g. no need to change position in bed) (Appendix A, Q11) and could consequently be annoyed if a PI developed despite their use (Appendix A, Q12).

Knowledge and attitude regarding prevention of PIs

Individuals adopting different styles of prevention also differed in their knowledge and attitude regarding prevention of PIs.

An extensive or a basic knowledge

During the interviews, the Thoughtfuls and the Selectives described in detail many actions that revealed an extensive knowledge of PIs and preventive measures. For them, this knowledge was useful, for instance, for recognizing and dealing with situations that might foster the development of PIs (e.g. long trip, new wheelchair) or to adequately interpret and react to body signs (e.g. spasm, headache) (Appendix B, Q1–Q3). The Delegators did not engage in a real discussion about prevention, described only a few basic measures (e.g. lying down) and revealed knowledge gaps (Appendix B, Q4–Q5).

Prevention: A personal or a delegated responsibility

For some participants, preventing PIs was considered a personal responsibility, whereas others tended to delegate it. The Thoughtfuls and the Selectives thought that preventing PIs, and in general staying healthy, was their responsibility (Appendix B, Q6–Q7). They usually did not blame others for the development of PIs and depicted themselves as co-responsible (Appendix B, Q9). Conversely, the Delegators tended to consider the development of a PU as a failure attributable to others (e.g. homecare service) (Appendix B, Q9).

Prevention: A priority for some but not for all

The analysis showed that people adopting different styles of prevention attached more or less importance to prevention: the Thoughtfuls reported considering prevention as central in their daily life, followed by the Selectives and finally by the Delegators. The discourse of the Thoughtfuls was anchored in the belief that PIs are a serious health condition and in the awareness that the risk of developing a PU is always present. Prevention thus becomes a priority (Appendix B, Q10). Likewise, the Selectives believed that prevention is better than cure and some expressed their fear of lying for weeks or months. However, they also stressed that to maintain a good quality of life, preventive measures should be compatible with life commitments and preferences (Appendix B, Q11).

The Delegators did not express much fear of developing PIs and seemed not to consider PIs to be a serious health condition (Appendix B, Q12). Consequently, they appeared to relegate the role of prevention of PIs to the background, to the point that one participant stated that he does not do anything (Appendix B, Q13).

Prevention: between habit and hard work

The analysis of the interviews also highlighted that the perception of prevention can differ among the participants. However, in this case, there is no clear-cut difference among the participants adopting different styles of prevention. Despite the gestures of prevention becoming a habit or an automatism for many participants, some emphasized that prevention required commitment, time, and effort (Appendix B, Q14–Q17).

Collaboration with HPs

The analysis indicated that individuals adopting different styles of prevention tended to collaborate differently with HPs in skincare-related issues. In accordance with their perception of prevention as a personal responsibility, the Thoughtfuls and the Selectives reported contacting experts for timely support and had a network of HPs that they could turn to for advice or care if they believed it necessary (Appendix C, Q1–Q2). Expertise in SCI seemed to be crucial especially for the Selectives, as some participants stated that they preferred to find solutions on their own rather than turning to HPs who had no expertise (e.g. general practitioners) (Appendix C, Q3).

In line with their preference for delegating the responsibility of prevention, the Delegators seemed to prefer more supervision (e.g. regular checkups in the outpatient clinic, home visits from the specialized counseling service) (Appendix C, Q4–Q5).

Attitudes toward life with SCI

By looking at similarities and differences among the three prevention styles, we identified attitudes toward life with SCI that appeared to be related to a higher commitment to prevention activities, and others that appeared to be linked to a lower commitment.

Optimism

The Thoughtfuls and the Selectives tended to focus on their abilities and on their future perspectives. Comparison with people with a higher lesion level, for instance, helped with seeing the glass as half full (Appendix D, Q1–Q2). This was also useful in the context of prevention of PIs because optimistic people were more likely to have an interest in taking care of themselves to pursue their life goals (Appendix D, Q3).

Self-efficacy

Both the Thoughtfuls and the Selectives presented themselves as confident in their ability to recognize body signals and apply their knowledge. However, the former thought that through their behavior and proactivity, they could forestall risky situations, and did their best to implement a range of preventive measures (Appendix D, Q4). The latter believed that – thanks to their knowledge, skills, and networks – they could react appropriately to problematic situations and sometimes act contrary to HPs' recommendations (Appendix D, Q5).

Proactivity

The Thoughtfuls reported asking peers how they dealt with their problems or looking for therapies other than the ones prescribed by their HPs (Appendix D, Q6). Their proactivity was often expressed through solution-oriented behavior to optimize preventive measures based on their individual needs (Appendix D, Q7–Q8). In contrast, a lack of proactivity and a tendency to rely on caregivers for structuring daily life was observed by the Delegators). This passive attitude in life translated in a passive style of prevention, in which prevention measures are applied not on personal initiative but on the initiative of caregivers (Appendix D, Q9).

Discussion

The analysis of the interviews highlighted that, although every participant could describe some preventive measures for PIs and show at least a basic knowledge in this context, they had different prevention styles, characterized by different behavioral patterns and attitudes towards prevention. Individuals with a "thoughtful" or a "selective" style of prevention considered PIs to be a severe secondary condition and felt at risk, but they also believed that PIs could be prevented and that the implementation of preventive measures was a personal responsibility. However, if the Thoughtfuls reported always giving prevention priority in daily life, the Selectives occasionally chose to relegate prevention to the background, for instance, to respect family or work commitments. A minority of participants adopted a "delegating" style of prevention and seemed not to consider PIs to be a serious condition. They stated that they actively engaged only in a few preventive measures and relied on technical devices or on caregivers to prevent PIs.

In addition to the attitudes toward life with SCI identified by the analysis, other factors, such as professional background, could play a role in explaining behavioral patterns and attitudes towards prevention. For instance, among the Selectives, four are HPs, one is a peer counselor and one is a life coach for people with SCI. People with these professional backgrounds are likely to believe that prevention is an important part of self-management and to be associated with personal and environmental factors promoting prevention.

A core finding of our study is the presence of beliefs and of attitudes that, as the Health Belief Model (HBM)[39] explains, can contribute to a lack of engagement in preventive behaviors. The HBM postulates that individuals tend to engage in preventive behaviors if they believe that they are at risk for a health condition and that this condition is severe (perceived susceptibility, perceived severity), if they perceive that by acting they can avoid it (perceived benefits), and if they think that they can successfully take this action (self-efficacy). Personal factors (e.g. education, motivation, past experiences) and cues to action (e.g. the advice of a friend) can also influence preventive behaviors.

In our study, individuals adopting a selective or a delegating style of prevention reported performing fewer measures than individuals adopting a thoughtful style. The Selectives, who perceived the risk of developing PIs and were afraid of their consequences, tended to restrict their prevention activities to a few areas because they saw benefits as well as costs in terms of quality of life in adhering to all recommendations. This is in line with a study by Jackson *et al.*[40] showing that the need to apply preventive measures is sometimes overruled by the desire to live a full and meaningful life, and the fear of a decreased quality of life. A selective application of the recommendations to avoid restrictions in daily life and the adaptation of the treatment depending on the symptoms were observed in other chronic conditions.[41] Such a strategic non-compliance can lead to risky behaviors, as is sometimes the case with the Selectives in our sample. To limit risk-taking behaviors, Jackson *et al.*[40] suggested that HPs acknowledge experiential knowledge, discuss life priorities, and support the personalization of preventive measures to fit the lifestyle of every individual. This personalization can help in finding a tradeoff between the need to self-manage and prevent secondary conditions, and the desire to have a "normal" life.[40] The search for such a tradeoff is a phenomenon common to many chronic conditions.[41]

In the case of the Delegators, the limited engagement in preventive behaviors might be partially explained by their low perceived susceptibility to PIs. Conversely, the high engagement of the Thoughtfuls could be explained in part by their high perceived susceptibility. This supports findings from previous research stating that awareness and motivational commitment are key drivers of successful prevention of PIs in SCI[40] and that personal responsibility triggers the adoption of preventive behaviors.[42,43]

Our findings emphasized that the perceived burden of prevention does not seem to be related to the number of prevention measures performed: both among the Thoughtfuls and the Selectives there are people who reported that prevention has become an undemanding routine activity and people who stressed that prevention is hard work. This is in line with Weijman *et al.*,[44] who established that people with diabetes performing self-management activities more frequently did not perceive self-management as a burden. In our sample, this might be explained by high self-efficacy and optimism, two factors that facilitate self-management in SCI.[45,46] The central role of self-efficacy for self-management and in supporting the adoption of prevention behaviors (according to the HBM) suggests that the Delegators could benefit from interventions aimed at increasing their confidence in performing preventive measures.

Our study has some limitations. Considering the qualitative nature of the study, the findings cannot be generalized to the entire SCI population and the styles of prevention identified here should be validated in a larger study. Moreover, it is important to highlight that this study does not allow to draw conclusions on which style is more effective. Furthermore, although two researchers worked on the corpus of data and regularly met to discuss doubts and alternative interpretations, and refine coding, no systematic independent coding was performed. Finally, despite our recruiting strategy based on SCI rehabilitation centers, wheelchair clubs and HPs increased our chances of reaching a diversified population, a self-selection bias could be present.

In conclusion, prevention of PIs is an endurance performance over a lifetime that requires knowledge of preventive measures and of how to apply them, a sense of responsibility for one's own health, and self-efficacy. Not all individuals possess all these characteristics. However, by identifying individuals' style of prevention, it is possible to develop targeted interventions to support them in self-management. These interventions are supposed to impact the factors which seem to play a role in determining the adoption of preventive behaviors, namely perceived susceptibility to PIs, attitudes towards prevention, and self-efficacy. Moreover, to facilitate the adoption of a behavior and the transfer of knowledge within life situations, interventions should incorporate strategies based on behavior change[35] and adult learning models.[47,48] Besides alleviating a frequent and disabling medical complication and contributing to an enhanced quality of life, these interventions might also help decrease health costs. For these interventions to be put into place, HPs should be trained to recognize the styles of prevention and screening tools should be developed.

Acknowledgements

The authors would like to thank the Suva, the Swiss Accident Insurance Fund, for the funding of the project at the basis of this paper. The authors would also like to thank all the participants for their precious insight and collaboration.

Disclosure statements

Conflicts of interest The authors report no conflicts of interest.

Funding This project was funded by the Suva, the Swiss Accident Insurance.

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Appendices

Appendix A: quotes about patterns of behavior

1. "So that's how it is, um, in my situation, that's clear, I have to be very careful. That's actually how it is, I just have to plan. I have to make sure that I can rest every 4–5 h. This means laying down." (T5)
2. "When I go on vacation, I bring all the assistive devices with me. From the special toilet seat to the sheep skin for the bed. And whether I go on vacation for a week or if I'm only away for a night, I always take the devices with me." (T1)
3. "And it was important to me from the beginning that I did not get any ulcers and I was also very disciplined right from the start. […] So the fear of getting a pressure injury is so great that I really try to be disciplined and behave accordingly." (T1)
4. "Next week I planned to go to the jazz festival in Zurich. I also listen to jazz. That fell through now. [note of translator: He is hospitalized due to a PU] In the summer I'd like to go to Wilisau, Jazzfestival. Well, this is my life, I cannot make concrete plans. Based on the experience, I've learned to adapt." (T5)
5. "Because if she [the daughter] is there, then you have to be fully present. And I cannot lie in bed. I always think that she is rarely at home. So I can't expect from her that, during the time she's at home, she must handle everything by herself. And with the son, you cannot leave him alone. You have to keep an eye on him nearly 24 h a day. And discussing and doing and ranting and putting pressure and playing the policeman. Otherwise, he doesn't go in the direction we imagine. And that's it. Thus resting is illusory at the moment." (S7)
6. "But of course there are places I haven't looked at for a long time, places in which I've never, never had anything. So huh. Yes, because I sat on one side, the load was all on one side and on the other side I've never had a redness of the skin in my entire life. And there you have to look less. You look every now and then, but not so regularly." (S4)
7. "What I personally find extremely important is a gift that I have, a genetic gift, I have good skin. So I don't burn myself fast in the sun. I don't have any kind of skin allergies. I have a good skin quality even though I smoke (laugh)." (S2)
8. "I have to pay attention to my foot, it should always be well protected. I do a foot massage, apply body lotion. I mean, from the shoe. There, where other people have a bunion, it's where the shoe presses. Then I really have to, there I have to pay attention." (S3)
9. "When I'm staying at a hotel and I have the feeling that the mattress is harder than the one I have at home, then maybe I'll turn once more consciously during the night. But not that I take sheepskin and things with me. I don't have to." (S2)
10. "I had a Jay pillow and then there was a redness of the skin there. And then they [homecare service] saw something while showering. Then they said: "Yes you have a red bottom, you have to lie down." And then I lied down, of course on the other side. And then they looked at it every time. And said: "That's still red. That's still red." Yeah, what's red? I don't see exactly how it is with the mirror. […] And then all of a sudden other places were red. Then they said that I have to turn." (D1)
11. "And I think, now with the air-flow bed / sure, a big danger is already gone. You notice that, right? Well, you have to get used to it - sure - to the bed. But once you get used to it, that's actually nice, isn't it? Then you can lie on your back." (D2)
12. "Yes, I had an electric bed with a special mattress. And still got the two pressure injuries and this annoys me." (D1)

Appendix B: quotes about knowledge and attitudes towards prevention of PIs

1. "Spasms are signs that you have to take seriously. That's what they taught us. That comes from pain, right? And if I cannot figure out the cause, or if that's inexplicable, then I'll go to the doctor. Then I go to the family doctor. Or I come here to the outpatient clinic, huh. But it's important to do it timely, huh. One shouldn't risk anything, huh … You shouldn't risk anything, huh. This is tremendously important for the overall impact on pressure ulcer prevention." (T2)
2. "I learned to listen to the signals from my body. I do not feel the pain in my left or right toe, but I can, if I have pain in one foot, I notice that. It gives me prickling, it may give me some spasticity, then I know that there is something wrong and I change my position." (S1)
3. "If I have to drive to Genoa for six hours or so, then I notice that it's redder than usual. Then I'll arrive at the camping place or at the hotel and then I'll lie down three, four hours, right?" (T4)
4. "If you have a pressure ulcer, if the wound is one cm or a half cm, then you for sure have to lie down for a week to ten days." (D3)
5. "And not simply saying that the skin is red. They [homecare services] did not do anything. And I didn't know that you treat the red skin with [skin ointment]." (D1)
6. "I think, as a person with paraplegia, you have to look after yourself a lot. And even if I go to a general hospital, I'll bring my assistive devices with me because I know best what I need, and then if I cannot do the care by myself, I instruct the staff on how to care for me." (T1)
7. "We used to have the full responsibility for our own lives. For all things in life. Not just for preventing pressure injuries, but for eating properly, for making all the decisions that you need to make in life, about work or about quality of life, about the adaptation of the house and, and, and." (S6)
8. "But I did not notice that I had a pressure ulcer over that long time. That was, actually, from above the skin was not open, it developed from the inside." (S9)
9. "I have to say it very clearly. They [homecare service] wanted to blame me for that. But hold on, who repositioned me? They did it. They should have known how to do the wound treatment and everything. Well, they are not that innocent. That annoys me quite a lot." (D1)
10. "[…] because there are many with paraplegia who say: "Yes, when I go on vacation, I would like to take a vacation from my SCI." And that doesn't work. So there are some people who leave the mirror at home, because they say: "Now I would like to have holidays from my everyday life." And that won't work. The SCI comes on holiday with you." (T1)
11. "But I kept doing sport. I've never been consistently lying down on my stomach and I went to high school. Then I did an internship. Otherwise I could not have done all this. And in this way I preserved a lot of my quality of life." (S10)
12. "I haven't had big problems with my skin so far. Not yet. So I hope that stays this way." (D2, several PIs with hospitalizations and surgeries)

13. "I don't do anything, absolutely nothing. As little as possible. (Laughter) Body lotion, no. Nothing at all." (D2)
14. "I try to do everything so that I do not get a pressure ulcer. (laughs) But it is a hard job." (T4)
15. "And just, to put it in pretentious words, solution-oriented. Just do not stop, but search. Move on. But that's not always easy (laugh)." (S3)
16. "At the beginning it was a bit difficult. But meanwhile it has become normal. You have to decide, if you want to do something, you have to structure it. […] Certainly this limits my freedom, that I have to structure everything. But I don't notice that anymore […]." (T5)
17. "So after 36 years, it's so integrated that somehow, that's just normal. […] [In those years it has changed] I don't feel that taking care of myself is a burden, or something." (S2)

Appendix C: quotes about collaboration with health professionals

1. "And otherwise I would see a doctor right away instead of doing it by myself for long, especially if I'm sitting on the pressure ulcer. Now, when I burnt my leg, I knew that I was not sitting on the wound and I can treat it by myself." (S2)
2. "What I first do, is that I check if it's swollen or not. Is there anything under the skin? And does it react to pressing or something. Then I put on some body lotion, I treat it in this sense, and then I monitor, huh. And if it stays as it is, then I leave it like this. Otherwise, I contact my family doctor, ask. That's the first thing I do. Then he tells me to monitor it or to go and show him. Yes. Well, when I call, it's usually something serious. And then it usually means that I have to go and show him." (T2)
3. "I also stopped going to the Polyclinic because there is a new resident physician every six months. And they actually have / I know a thousand times more than these residents." (S7)
4. "I go once a month to [specialized clinic] so that they know if it improved or not" (D3)
5. "Yes, I've been supported by the counselling service since a while. […] you can just call them and they'll come immediately. That's absolutely awesome. […] Yes, that's really good. And Ms. X [the counselor] is as fast as a lightning when I call her. […] She knows of course what is being used in the specialized clinic. And I don't have to go there every time. That helps a lot, doesn't it? […] she usually brings things. She brings packages with plasters, everything is ready. Or you give her the prescription and she goes and get it for you, if there is too little again. […] and what is also very good is that she is connected with the specialized clinic. So if I have someone from the counselling service, then I know that they can organize a consultation for me." (D2)

Appendix D: quotes about attitude toward life with SCI

1. "Well, you see brutal fates in [specialized clinic]. I saw them myself when I was there. These young with tetraplegia. You know, that's a terrible thing. For this reason I always say, I'm one of the lucky ones. Of course, it is also terrible what I have. But in comparison to those I belong to the lucky disabled." (T4)
2. "I'll just read more. I like to read and then I can devour books again and see the positive out of it. It's not just negative, lying down (laugh)." (S4)
3. "Or the motivation. What kind of attitude a person has towards his own body, how can I accept the paralysis, how do I handle the disability […] that certainly has a great influence, the love for your body and how carefully you treat your body." (T1)
4. "So I think you can influence a lot with your behavior, whether you get a pressure ulcer or not." (T1)
5. "And every time I went to [specialized clinic] I took the Roho [a type of cushion] because I knew that if they saw me sitting on the Jay [another type of cushion], they would say, "Yeah, why don't you use the Roho?" But for me the Roho is not ok. So I have it and sometimes I use it too. I use it for a change. And then a little to train. But it did not get any better at all." (S7)
6. "I knew that he [a colleague] was in hospital for a pressure ulcer and I saw that he was using electrical stimulation, huh. And then I thought, let's take a closer look at it. When I went to my physiotherapist, I told her that I wanted to do electrostimulation. She checked this option, organized the prescription and then I bought the machine. Since then, I've been doing electrostimulation too." (T2)
7. "Even with the sheep skins and stuff. For example, I don't know anybody else who has sheep skins like that. These are all things that I found out and organized by myself." (T3)
8. "[…] with the clothes you can do a lot against pressure injuries. But I admit, it took me years to find out the right thing." (T1)
9. "Actually, if I would live alone, I'd make different decisions. I think if I'd decide myself, I would not lie. But here [assisted living facility] I have to be more careful." (D3)