

## Challenges to building and maintaining partnership in the prevention and treatment of pressure injuries in spinal cord injury: a qualitative study of health professionals' views

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### Summary

**AIMS OF THE STUDY:** The effective management of spinal cord injury (SCI) requires partnership between people with SCI and health professionals (HPs). This paper identifies HPs' perceived challenges in building and maintaining this partnership, with a specific focus on how people with SCI and HPs collaborate in the prevention and treatment of pressure injuries in SCI.

**DESIGN:** This study has a qualitative and explorative design. Data were collected through semi-structured interviews and analysed following the principles of thematic analysis.

**POPULATION AND SETTING:** The study population consisted of a purposive sample of HPs (n = 26) working in inpatient and outpatient care in Switzerland with experience in the care of people with SCI.

**RESULTS:** The analysis identified three main challenges: defining responsibilities and expectations, negotiating priorities and establishing and strengthening trust and respect. The HPs argue that the prevention of pressure injuries and self-management are mainly the responsibility of the person with SCI. The HPs have, however, the responsibility to empower, guide, and support persons with SCI in self-management by educating and motivating them.

**CONCLUSION:** Building and maintaining a partnership with individuals with SCI to prevent and treat pressure injuries is crucial, but it is not an easy task for HPs. Specific communication skills can help HPs and patients find personalised solutions that take into account the patients' expertise and preferences. Additionally, the healthcare system must develop solutions that go beyond personal partnership to better integrate the prevention and treatment of pressure injuries into the lifelong self-manage-

ment of SCI. Assistive technologies, such as mobile technology, might help in this endeavour.

**Keywords:** complications, health literacy, prevention, collaboration, negotiation skills, argumentation skills, communication skills, pressure ulcers, paraplegia, tetraplegia

### Introduction

Spinal cord injury (SCI) is a complex, chronic condition resulting from damage to the spinal cord. Individuals with SCI are at risk of a number of complications, such as urinary tract infections, spasticity, respiratory complications, autonomic dysreflexia, pain and pressure injuries [1]. Its lifelong consequences heavily impact many areas of patients' lives, from body functions (e.g., bladder and bowel functions) to participation (e.g., in relationships with family/friends, employment) [1]. For the effective management of a chronic complex condition such as SCI, research has highlighted the importance of establishing a partnership between health professionals (HPs) and patients [2], characterised by the acknowledgement of reciprocal and complementary expertise [3, 4] and oriented toward self-management [5–7]. This orientation is essential, as chronic conditions require monitoring and the adaptation of treatment, and the patients are the most indicated persons to perform these tasks on a daily basis [5, 6]. During inpatient rehabilitation, HPs have a major role in motivating patients and educating them in self-management, alongside providing long-term support and supervision. Patients become the experts on the lived experience of their health condition [8, 9] and act as co-producers of their own health and HPs' partners in disease management [5, 10].

A relationship characterised by a partnership between HPs and patients can provide important self-management support for individuals with chronic conditions [11, 12]. While patients act in self-management on a daily basis, HPs can offer emotional support and contribute to stress reduction

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[13]. Similarly, HPs can offer instrumental support for coping with disability. For instance, HPs can help with the activities of daily living or therapy [2] or provide information [12, 13] or guidance in goal setting and decision-making. This support can enhance the patient's sense of personal control over the health condition [13].

Overall, partnership between HPs and patients form the basis of shared decision-making [14, 15], which is considered a valid way to implement patient-centred care. Furthermore, such a partnership seems to improve patient satisfaction [16, 17] as well as disease management and outcomes [18–20].

Building a partnership between HPs and patients is not, however, an easy task [21]. As Sykes and colleagues [22] have noted, a partnership requires skills on the side of both the HPs and the patients. Some HPs may not be committed to building a partnership because it is demanding, emotional and time-consuming [21, 23]. Similarly, patients may step back from participation because of a perceived lack of knowledge, cultural and demographical factors, the fear of being perceived as a “difficult” patient or a lack of skills (e.g., numeracy, communication skills or advocacy skills) [24–27].

Furthermore, building partnerships to support patients in the self-management of their conditions can raise “tensions between patient autonomy and professional responsibility and the delivery of evidence-based care” [28]. To complicate this goal further, partnership is based on mutual trust and may be put at risk every time HPs offer explanations or treatment recommendations different from those that patients have in mind [29].

By focusing on the HPs' perspective, this study explored the perceived challenges they experience in building and maintaining partnerships with persons with SCI. More specifically, it examined partnership in the context of the prevention and care of pressure injuries. Pressure injuries count among the most frequent [30–32] and severe complications of SCI [33]. They cause severe limitations to the individuals affected [34–36], and their treatment engenders high costs [30, 37, 38]. A functional partnership between HPs and patients in this context can improve the prevention and treatment of pressure injuries, as well as enhance the quality of life of individuals with SCI and reduce the related healthcare costs.

## Materials and methods

This study has a qualitative and explorative design. The results presented in this article are part of a broader project that aims to identify factors that inhibit or promote the prevention and treatment of pressure injuries in individuals with SCI in Switzerland. Overall, we interviewed 26 HPs, 20 persons with SCI and five informal caregivers. In this article, we report the HPs' views on the challenges of building and maintaining partnerships with individuals with SCI while preventing or treating pressure injuries. The perspectives of individuals with SCI on the management of pressure injuries, including their views on collaboration with HPs, are presented elsewhere [39].

## Sampling and recruitment of participants

We recruited a purposive sample of HPs based on a clear set of inclusion and exclusion criteria [40]. Participants were included if they were involved in the care of people with SCI in Switzerland, were >18 years of age and spoke fluent German, French or Italian (Swiss official languages).

We opted for a heterogeneous sample (i.e., different professions, years of working experience and working in inpatient or outpatient settings) to gain greater insights into the phenomenon of interest by looking at it from all angles [40]. Moreover, as several authors have stated, the identification of common themes across a heterogeneous sample can further strengthen the significance of study findings [40–42].

We conducted recruitment with the collaboration of the four specialised centres for SCI rehabilitation in Switzerland, utilising a snowballing technique to identify additional participants. Potential participants who agreed to be contacted were called to schedule an interview. The study information and informed consent information were sent to them by post or email.

## Data collection

Individual face-to-face interviews were audio recorded. A topic guide was used to ensure that the topics were covered consistently, while giving the interviewees the opportunity to raise issues of personal relevance. The questions explored how HPs acquired their knowledge in relation to skincare, what worked and what did not work in the prevention and treatment of pressure injuries and who was involved in and carried responsibility for pressure injury treatment. Sample questions are presented in table 1.

The participants chose suitable interview sites, mostly their workplaces. The study obtained ethical approval from the

**Table 1:** Sample questions for the semi-structured interviews.

Topic	Sample questions
Prevention	<ul style="list-style-type: none"> <li>• In your opinion, what works best in the prevention of pressure injuries?</li> <li>• Are there patients who perform better than others? How would you describe them?</li> <li>• Who are the actors involved in the prevention of pressure injuries? How do they coordinate their action?</li> <li>• Where is there potential for improvement? (at which level: the patient, the system, collaboration...)</li> <li>• How do you support your patients in the prevention of pressure injuries? (tasks, challenges)</li> </ul>
Treatment	<ul style="list-style-type: none"> <li>• In your opinion, what are the challenges in the treatment of pressure injuries?</li> <li>• Who is involved?</li> <li>• What is your role in the treatment of pressure injuries?</li> <li>• How would you describe a successful collaboration / a failed collaboration?</li> </ul>
Responsibilities	<ul style="list-style-type: none"> <li>• In your opinion, who generally carries the responsibility for a pressure injury? What are the respective roles of the person and the HP?</li> <li>• A pressure injury may appear during the inpatient stay. Have you already experienced this situation?</li> <li>• If yes, how did you react? What is the procedure in your institution? Who is considered responsible in these situations? How did you feel?</li> </ul>
Knowledge	<ul style="list-style-type: none"> <li>• How have you acquired your knowledge about the prevention and treatment of pressure injuries?</li> <li>• How do you update your knowledge?</li> <li>• Are pressure injuries a recurrent topic at work? With whom are you mostly discussing issues related to skincare?</li> </ul>

regional committee (ref. EKNZ 2015-311). Participation in the study was on a voluntary basis.

### Data analysis

The interview recordings were transcribed verbatim and the original transcripts were analysed using thematic analysis [43]. Thematic analysis is a method used to identify, analyse and report patterns within data. This article presents themes in relation to the collaboration between HPs and persons with SCI for the prevention of pressure injuries.

Two researchers read the transcripts of all interviews and generated preliminary codes that mirrored aspects of this collaboration. The codes were first deductively generated based on the topics of the interview grid and then inductively refined. Subsequently, one researcher optimised the coding scheme by merging the codes that were meaningfully related to each other in a theme. To ensure a clear conceptual differentiation between the themes as well as their internal homogeneity, two researchers consistently compared the statements in support of a theme. Disagreements about the merging and splitting of the codes were discussed until an agreement was reached.

The interviews were coded with the support of the software for qualitative research MAXQDA12<sup>®</sup> (release 12.2.0). The quotes have been translated into English only for the purpose of publication.

### Results

The final sample included 26 HPs, 16 women and 10 men, with a mean age of 49 years and an average of 18 years of working experience in the field of SCI. Different professions are represented, as follows: medical doctors (n = 8), nurses and wound experts (n = 14), occupational therapists (n = 1), social workers (n = 1) and psychologists (n = 2). Thirteen participants worked in clinics specialised in the rehabilitation of SCI, nine worked in outpatient care (e.g. homecare services, family doctors), two worked for an SCI-specialised counselling service and two worked for general hospitals. More detailed information is presented in table 2.

Overall, the analysis of the interviews identified successful prevention measures and the characteristics of persons with SCI who were supportive in the prevention of pressure injuries, which are discussed in detail elsewhere [44,

45]. The present article focuses on themes in relation to the challenges of building and maintaining of a partnership. The analysis revealed that HPs valued a patient-centred approach to the prevention and treatment of pressure injuries. Special emphasis was laid on the value of building partnerships with patients and sharing all important decisions, searching for personalised solutions to treat pressure injuries in the context of patients' lives and not judging patients' preferences and choices. When focusing on the building and maintaining of a partnership, three main challenges were identified. Exemplar quotes are presented separately in tables 3, 4 and 5.

### Challenge 1 – defining responsibilities and expectations

When describing partnerships with patients, one major challenge the HPs mentioned was defining the respective responsibilities and expectations of the HP and the patient. The HPs believed that the prevention of pressure injuries is first of all the responsibility of the person with SCI, who can, if needed, be supported but not replaced in this endeavour by HPs (table 3, quotes 1 and 2). The HPs presented themselves as tutors during rehabilitation, in that they play a key role in educating patients and building health literacy for autonomous decision-making (table 3, quote 3).

The interviewees highlighted that developing a sense of personal responsibility is crucial for self-management in general and for preventing pressure injuries specifically, as homecare providers deliver useful but often insufficient support (table 3, quotes 4 and 5). Likewise, assistive devices facilitate the prevention and treatment of pressure injuries but are not a substitute for personal care and diligence (table 3, quote 6). HPs underlined that individuals with SCI need to take care of themselves, actively and constantly (e.g., by making decisions, such as contacting a specialised clinic for advice, and by performing preventive measures, such as inspecting their skin), to maximise their chances of staying pressure injury-free (table 3, quotes 7 and 8).

Despite this strong focus on personal responsibility, HPs acknowledged that their partnership with patients develops day by day and requires regular adjustment. Indeed, depending on specific situations (e.g., with older persons or persons with mental health issues), HPs might take over

**Table 2:** Population characteristics.

Study population			n (%)	Average years of experience (min/max)	
Physicians	Inpatient service	In general hospitals	3	20 (7/24)	
		In SCI-specialised centres	4		
	Outpatient service	In general practice	1		
Total			8 (31%)		
Nurses	Inpatient service	In general hospitals	1		18 (9/33)
		In SCI-specialised centres	5		
		In other inpatient services	2		
	Outpatient service	IN homecare services	4		
		In SCI-specialised counselling service	2		
Total			14 (54%)		
Therapists	Inpatient service	In SCI-specialised centres	4 (15%)	14 (8/26)	
<b>Overall total</b>			<b>26 (100%)</b>		

SCI = spinal cord injury

more responsibility to relieve patients with SCI or their caregivers (table 3, quote 9). It is also important to note that taking over responsibility for pressure injury prevention and treatment does not seem to be linked to the lesion level, as even a person with high tetraplegia can assume this responsibility and then be supported in the practical implementation of the required measures (table 3, quote 10).

According to the interviewees, a minority of patients lacks this sense of personal responsibility (table 3, quotes 11 and 12) and tends to neglect or delegate responsibility for pressure injury prevention and treatment (table 3, quotes 13 and 14). The participants pointed out a few reasons for this lack of personal responsibility. The first is that, during rehabilitation, patients have little time to cope with their trauma and feelings, a prerequisite to taking over responsibility

**Table 3:** Challenge 1 – defining responsibilities and expectations.

1.	'Of course, prevention is still a big topic. [...] in the first place [it] is the responsibility of the patient. But I experience that many, especially those covered by the homecare service, often older people, they think: "They [homecare service] check." They then hand over responsibility. Instead of retaining responsibility for themselves. And then these are the ones who, in the eyes of the homecare service, are frequently the fussy ones. But I think that it's important that the patients show their interest: "What does my skin look like?" And also that they check again if possible and not just rely on the caregivers. To accept the responsibility.' (Nurse N10-SCI counselling service)
2.	'[...] every flyer states: "We decide ourselves, we want to do everything ourselves." Then they should also take care of their buttocks. That's their job.' (Physician P6-SCI clinic)
3.	'You can try by hook or crook. For patients who are really non-compliant, who really do not take it seriously, we've really shown them the worst pictures of how a pressure injury can really turn out to be. There are such great books [laughter]. But [...] that's just ignored. That doesn't help. But the doctor and family doctor, homecare services and healthcare professionals can't do more than talk, show, write and point out, somewhere we have limits. And somehow the patient has to accept responsibility.' (N4-SCI clinic)
4.	'It is not always easy to let them know that we are here and will support them for a while, but also that we are not responsible for their lives. On the contrary, they are responsible for themselves and we are just giving them support for the time being, as well as helping them gain as much knowledge as possible, so that they can deal with their new life situation at home and stay healthy. In fact, we can only support them to build their health literacy, which they require because of their spinal cord injury, since that's a big change in life.' (N5-SCI clinic)
5.	'The [SCI-specialised counselling service] can be sure to provide an overview of the risks and preventive measures, but of course the implementation of these preventive measures must come from the patient and if there is still a need for assistance, they have to say it. The patients, if they are not brain-injured, can always make sure to check first: "Is the pillow in the wheelchair properly placed?" The statement "The health professionals did not put it correctly" does not help. It shows where the problem is. In contrast, if someone were to say "The health professionals did it wrong and I didn't notice, I didn't check", then it's a different situation.' (Therapist T4-SCI clinic)
6.	'[Technical aids can usher in a new era] but certainly not if you think that "It replaces our care." Then it doesn't work. [...] These are all things that you can't rely on too much, you have to always stay active.' (P7-SCI clinic)
7.	'Sometimes they say [to explain why they had PU] "It was just my daily life." Just not keeping up little things like push-ups or, suddenly, it happened. I don't know if we have solutions to all these problems because you have to do things like thinking about what you are doing every day. One day maybe you want to be free of your obligations and it happens. So yes, I think that the high risk of decubitus remains, so we cannot always expect to be lucky.' (N1-SCI clinic)
8.	'He must learn to live with the fact that he has to lie down once or twice per day and change the time when he goes to bed in the evening.' (N14-Assisted living facility)
9.	'They just have to know the risks and opportunities. [...] I would say, I guess, that about 10% of the patients do not want that. They say, "[name of the nurse] just do it, you know what's best." That's really a generation issue sometimes, they think that the doctor or the expert would do it well and they don't want to accept responsibility. We have to respect this. We try to get them involved anyway, showing them the procedure, what we do, why we are / but not too much. They are often elderly people. And for people who have mental health issues, we, of course, try to make it easy and instruct the relatives and the homecare provider. Because the mentally impaired are no longer capable. It wouldn't be fair to impose on them something they can't bear.' (N8-Homecare service)
10.	'I have to say that this client [with tetraplegia, high lesion level], it's already great that he takes a lot of self-responsibility. [...] Sometimes, not always, but often he pays attention and also to the caregivers and is able to instruct the caregivers very well.' (N6-Homecare service)
11.	'I mean, we have a negative selection here, one should not forget. Because in the consultation for wound treatment we don't see the 80% of people who do not have a pressure injury. You have to keep that in mind.' (P6-SCI clinic)
12.	'So it's not that everyone who comes here with a pressure injury is a "neglector", these are the extreme cases.' (T2-SCI clinic)
13.	'[Patients] who once again have a pressure injury do so because they check themselves too little. In these cases, it's a problem of self-responsibility.' (N14-Assisted living facility)
14.	'The [homecare provider] reported: "We feel exploited." And just now we have reached a similar point. She lets herself be served but the [homecare provider] noticed that she could actually do it herself. [...] Then we had the meeting and I told the patient: "This and this movement she can actually do herself and I expect her to do them".' (P2-GP private practice)
15.	'[...] I have the impression that the stays at the specialty clinics are always shorter. There is the shock of the trauma to process, there are a lot of things to process, there are a lot of things to learn. And sometimes I have the impression that patients can't learn everything.' (N11-SCI counselling service)
16.	'[In the past, patients would lie for 10 weeks before being mobilised]. In this phase, they had time to ponder. They had the time to say goodbye to their old life, to suffer, to be sad. And then finally to go forward again. Finally. Patients would hit rock bottom and they could only get better. And they would do all that was possible to not to lie again. [...] Today surgery techniques, early mobilisation. [...] Then within a short time they are discharged and you are lucky if the crisis takes place before. Often it will take place once they are at home.' (P5-SCI clinic)
17.	'I think that sometimes there are people with SCI who do this to have people at home. And sometimes, probably, very very unconsciously, but sometimes, too, because they can't accept their bodies, they injure themselves. [...] And the more I'm in this field, the more I see the impact of the mental situation on everyday life.' (N11-SCI counselling service)
18.	'Good rehabilitation. It completely depends on it. So, in principle, accepting the lesion. When you accept it, then you can also accept the prevention measures.' (P2-GP private practice)
19.	'I sometimes have the impression that the rehabilitation philosophy got a bit lost [...] The patient pays and you just have to be nice to him [...] The patients have to learn to do things for themselves. And that means that you have to provide a structure [...] And sometimes I have the impression that the learning is pushed to the background and that the focus is on the freedom.' (N11-SCI counselling service)
20.	'Maybe during first rehabilitation the focus has shifted away from self-responsibility. [...] Now you [patient] look after yourself, now you inspect the skin. Maybe the healthcare professionals didn't do it quite right, but when we started working here [specialty clinic], we were stricter [...] But not in a negative sense, but really fostering, this is what is needed. Otherwise the patient always delegates. So I think self-responsibility is certainly a big topic.' (N10-SCI counselling service)
21.	'We now have one [patient] here [specialty clinic]. I have to say that it can't be solved. I don't treat the pressure injury now. What should I do? You have to first solve the essential, otherwise there is no point in treating the pressure injury. [...] Care, support, this of course we do. Showing. If you were to do that [the surgery] now, it wouldn't work. In a year or two you can ask the patient, "Do you still have your wound?" and he'll tell you "yes, I still have my wound". And he knows why. [...] How can you convince a person who doesn't see the problem, how can you convince him that he should do something? You can forget about it. You may do the surgery, wonderful, but then the surgery is done and you know it's going to happen again, then you do a second surgery, or even a third, then you've got no tissue left.' (P5-SCI clinic)

for themselves (table 3, quotes 15 and 16). Another possible reason is psychosocial barriers, linked, for instance, to a lack of acceptance of the SCI (table 3, quotes 17 and 18).

Last but not least, the participants stated that rehabilitation focuses more on the right to self-determination than on the responsibility that a life with SCI entails (table 3, quotes

**Table 4:** Challenge 2 – negotiating priorities and setting common goals.

1.	'Prone position, for example. The elderly knew to lie prone, they stay on their stomachs for 4-6 weeks. It's just like that and you do it for yourself. And there are others who say today: "Impossible, I can't sleep in this position." And? Do you have to sleep? [...] These are changes in the values of the population that we perceive.' (P5-SCI clinic)
2.	'I have already experienced many patients who are annoyed because their freedom is partially reduced. Because people just say, "No, we won't do this".'
3.	'You always have to explain why you want them to achieve something and so on. [...] You can be demanding, but I think you have to always explain why you do it.' (N11-SCI counselling service)
4.	'The most difficult is when the goals are not the same. And that's why in our rehabilitation meetings, the patient formulates his goals and we also explain our goals to him. Because sometimes they are the same, but sometimes they are completely different. And it costs a lot of work and a lot of time to reach a common denominator. For instance, to tell someone "your wife is not always there, try it yourself" and then maybe he sees that it's not that bad. It works. But it requires a lot of work to convince people.' (N3-SCI clinic)
5.	'She will always get up and I understand that. She's just better when she's sitting. She can drink better, you don't have to give her the drink in the lateral position. It's no life for her when she's always in bed.' (N9-Homecare service)
6.	'Ideally, I'll send them [patients] to [the specialty clinic] but nobody wants it [because it's a long way away]. So I'm taking a look at the wound, I'll do my best for the diagnosis, I'll try to do what needs to be done. And then, as a rule, after a week or so, if it does not heal with my treatments, then they agree to go to [the specialty clinic]. That's actually my way. It works for everyone. [...] I think you have to respond to the patients' needs. If they don't want to go, then you try first, you regularly check the wound, you just talk. And I see again and again that in the end everyone goes [to the specialty clinic]. But not at the beginning. That never.' (P1-GP private practice)
7.	'It's just a tightrope walk because you have to work together. [...] but the question is always, to what extent do the healthcare professionals have to concede to the patients' will? [...] And that is always a clinch of personal freedom and nursing responsibility – or "where can you set limits?" [...] You have to compromise.'
8.	'I think that at the beginning [of my career] I probably wanted to change a lot more things and over time, you say, "Okay, no. Not too fast. You have to, but not now." I've learned a lot more to work with the patient, where he is and what he wants, and I think that's the goal of [SCI-specialised counselling service].'
9.	'When I wondered about how good the situation at home really was, what I did is that I negotiated that I would call home from time to time, or I organised a meeting with the life coach, who has the opportunity to visit people at home or with the counselling service.' (T2-SCI clinic).
10.	'You just have to take the patient perspective and show some empathy: "It's certainly annoying to lie an hour at noon, then the day is gone, and it interrupts your routine. But you said that you are planning a long trip next year. We would like to support you, so that you can achieve this objective, so that you'll be able to make the journey." Have a goal and promote autonomy. Because they are already sufficiently dependent in their life. And in situations in which you can offer autonomy or support, that brings quality of life.' (N8-Homecare service)
11.	'What is difficult for us is the tension between specialist knowledge, which we also try to share with the patient and their family, and the patient's will. Here there is often a tension.' (N8-Homecare service)
12.	'Yes, that has changed. What one can demand from the patients [e.g. lying time, dealing with pain and medication]. It also makes us even more hesitant to ask about what is really necessary. That's why we need to know exactly what the concepts are and that these are right.' (P5-SCI clinic)
13.	'[...] they have almost half a year of bed rest when they are surgically treated. They are trained intensively, this is almost one-to-one training with the occupational therapist, the nurses, so that the patients really learn how to change position, how to inspect the skin with the mirror, what to do when they have redness on the skin. [...] and two weeks later they come back [to the specialty clinic] again. [laughter] A bit depressing. It is very difficult for the patients. In some cases we really don't know what else to do with these patients.' (N4-SCI clinic)
14.	'She wanted us to do the bowel management every morning, every morning. Otherwise she didn't feel clean. That's not what they did in [the specialty clinic] and since then the wound has also got better. [...] They probably just said, they don't do that, bowel management every day. They don't do it in the hospital. But we couldn't say this.' (N9-Homecare service)
15.	'I may try to influence [the patient] eventually. But [...] this is his decision. And I support him the way he is. I don't want to change him because otherwise I'll also run out of energy [laughter].' (N11-SCI counselling service)
16.	'For example, there is a patient who likes to be in a very warm environment and the caregivers don't force him to lower the heating if he doesn't want to. Even if everyone thinks it's harmful. [...] So then you make a deal. Let's say that for a while you try to influence the decisions and if this doesn't work, then it just stays like it is. And he keeps having skin problems. [...] The caregivers may have much more work because they have to treat these wounds. But it was a patient's decision and it was respected. Well, it can be difficult to respect a patient's decision.' (P3-GP private practice)
17.	'I always say that every patient is an adult. [...] We recently had a patient who came with a pressure injury, with multiple recurrences and we didn't want to discharge him [...] He didn't want any homecare provider. But he needed it. And we convinced him by making an arrangement with the surgeon, saying that he needed a follow-up. And now I've heard that he rejected the homecare provider. [...] He can make his own decisions and therefore our hands are bound, of course. Our hands are bound by medical confidentiality. [...] One thinks to have done the best and discharges a patient knowing already that in the home setting it'll go wrong. But one's hands are tied. Because you can't change it. You can organise the homecare provider and everything. But if the patient does not accept it, that's his responsibility, even if it is sometimes not so good. And with no good outcome. That is a difficult situation.' (N3-SCI clinic)
18.	'There are also patients [...] who say, "Okay, I want to do this and this. I know that I can develop a pressure injury, but for me now it is more important to do this. And then I might need to be hospitalised." But they decide it. There are some patients who think like this. [...] They know, that if they would stay in bed right now, it might be healed in two weeks but they prefer to go on working and so on and accept that it might take three or four months. They understand what this is about. And they take the responsibility. For me, I prefer to have someone like that, who makes it deliberately, than someone who does the same but without understanding the consequences. And I think that's okay. That may not be what I would do, but there are many ways of dealing with a situation [laughter].'
19.	'Yes, you try to show him [the patient] the risks and to talk to him and finally, when he understands, he has to decide for himself. But you have to explain the risks well. There are those [patients] who have bed rest and still go around and go out to smoke anyway. [...] So you can talk to them but you can't force anyone. After all, everyone can leave the hospital if they want. The [doctor] talks to him [the patient], but ultimately that is the patient's own responsibility. We just have to document that well. That we talked, that we explained everything, that he really understands the risk that he is taking on. And finally, yes, it his responsibility.'
20.	'There are many pressure injuries that are not acutely problematic. They just don't heal. But then you have to clearly agree on a treatment plan with the patient. For the pressure injury to heal, it needs this and this. Then, to last, it needs that and that. And I sell only the whole package or nothing at all to my patients. Take it or leave it. If you want it to heal, you can take my package. You'll find other solutions if you do an internet search. But that's my package. And if you don't want it, go ahead. I'm not judging, it's their life, but then we have a different goal. Then we have to help them live their lives and just make sure that the pressure injury don't get worse. And then they live with a pressure injury. And if one day they come and ask me to do something, then they know that they have to take the whole package. This situation isn't rare.' (P5-SCI clinic)
21.	'We [homecare service] are not authoritarian, we don't endorse this style. We do a deal for a week, or we say, "We do it this way and if it doesn't work, please call. Or you stop it if it doesn't work". We hand over responsibility to the patient, but you also clearly guide him.' (N8-Homecare service)

19 and 20). When patients lack this sense of responsibility, they are likely to develop a pressure injury and even have recurrences. In these situations, some HPs will limit the treatment to conservative options, as the postoperative rehabilitation is very strict and the surgery can only be performed a limited number of times (table 3, quote 21).

### Challenge 2 – negotiating priorities and setting common goals

The prevention and treatment of pressure injuries frequently imply limitations on patients' freedom (e.g., the necessity of lying in bed during the day or renouncing long travel for holidays). In the past, patients accepted this, whereas they now sometimes contest it (table 4, quotes 1 and 2). Hence, HPs feel that they must convince patients that these

limitations are needed, that going to the specialised clinic is necessary or that their desired goals are unattainable (table 4, quotes 3 and 4). If, despite explanations and discussions, patients do not change their opinions and behaviour, a viable solution must be negotiated. For instance, in the case of a person with a wound, this means finding a compromise between the best medical treatment and its requirements and the person's priorities and quality of life (table 4, quotes 5 and 6). This solution allows the collaboration with the HP to continue and is medically valid (table 4, quotes 7 and 8).

When negotiating a viable solution, the priority is sometimes to guarantee continuity of care, whereas in other cases, the priority is specifically the treatment of the wound (table 4, quote 9). One way of finding common ground for

**Table 5:** Challenge 3 – building a basis of mutual trust and respect.

1.	'We aren't moral judges. [...] And you don't have to drive anyone crazy. But the trust has to be there. And also the knowledge that there are no reproaches. [...] A very authoritarian style is also an option, maybe there are some patients who need it.' (N8-Homecare service)
2.	'First of all, we establish a contact, a collaboration, what we call a therapeutic alliance, to try to work together. And sometimes it takes time [...]. Then it's actually the time to introduce a change, and that's obviously always at the patient's pace. [...] to impose a change, it never works.' (T1-SCI clinic)
3.	'My first task is to build trust and create a feeling of safety: "You are taken seriously. It's nice that you are here. It's about you now." This takes a few minutes. It's also good, the first meeting with the patient always lasts one hour. This creates a good basis.' (N8-Homecare service)
4.	'It doesn't help to have medically perfect concepts when you have a patient who doesn't believe in them. Then they won't work. Maybe in the short term. But not really.' (P5-SCI clinic)
5.	'[...] you [homecare service] can tell the patient: "You have to lie four hours and only sit for one hour." But when we're gone and they're home alone, they can just do the opposite, I have no idea, they can lie to me. We just have to work based on trust, and believe them, and just say, "Okay, at home we can't do the same thing like in the hospital, we have to make a compromise".' (N11-SCI counselling service)
6.	'Yesterday we had a patient who needed special shoes and special insoles. And now he came back after a few months and it's not so good. [...] My colleague during the anamnesis tried to find out what happened, why it's not so good. And then he said: "Listen, Mrs. [homecare service], I once wore the special shoes, and they I don't like them and I don't find them so comfortable, they are at home in the closet." Everything was clear. And we are not there to judge. [...] Putting pressure on him by saying "as long as you don't wear the shoes, we won't help you", in my opinion it's pointless.' (N8-Homecare service)
7.	'I think that the most important thing is to try to build a support network, something that the people will perceive as support and not as control. Especially in situations in which people hardly accept help, they tend to see it as control and not as support. But sometimes it can work well, if people have a good contact to the service, for instance to ProInfirmis, if there is a relationship of trust.' (T2-SCI clinic)
8.	'It's a matter of relationship, that patients see that you don't want to control them, but you want to see how it goes at home and what might be needed. You never know how the situation is if you don't go home, you can only estimate it. And I think that this is the most valuable thing to do when there are difficult situations. For instance, a life coach [could do home visits].' (T2-SCI clinic)
9.	'I think anyone who was in contact with me for the wound care, the next time they have a problem will call me sooner. This is the experience I have made. Even only to have a look, this is already important for early detection.' (N10-SCI counselling service)
10.	'Sometimes it takes so long for people to call, and if you already have had the chance of getting to know each other, then they know you and say, 'Ah, they're nice, they want to support me.' And then people will contact you sooner inquiring about the services.' (T2-SCI clinic)
11.	'And, of course, after 15 years we have a lot of experience. We have over 6000 treatments per year. In other words, there are many people in the area of north-western Switzerland who have noticed that we work well and for this reason there is also trust.' (N8-Homecare service)
12.	'Search together for it [cause of pressure injury], and show the patients that we have the knowledge. It's important. It's fundamental. It's showing the confidence, but for them it's also about feeling listened to and feeling understood and this is very important to develop resilience.' (T1-SCI clinic)
13.	'We take everyone very seriously. It is not about us, [...] it's about Meier, Müller, about every person. That's it. I think patients valued that too.' (N8-Homecare service)
14.	'And the quality of care in the other hospitals, again the infrastructure is the minor problem for me, what matters is seeing to the needs of patients with SCI. The nursing staff might not know anything about SCI, but they are smart enough to listen to the patients. If a patient says, 'Listen, I've got a SCI for 20 years, I know that there is something wrong with my stomach, I need to take that juice [...]. Then it's a matter of human and medical understanding to say: "I trust this patient".' (P5-SCI clinic)
15.	'Yes, it's really about trust, ensuring safety, making clear that you don't want to restrict their autonomy. On the contrary, you want to help them preserve their autonomy. That's the goal, right? [...] I think the relationship, or when they realise that you don't want to force them, but that this is an offer, suggestions and they can decide for themselves what they want to take.' (T2-SCI clinic)
16.	'Yes, first [I communicate with the patients]. And I also ask them, "Is it okay if I tell the doctor?" because there are critical situations legally, data protection and privacy issues. And just to avoid problems, I ask the patients if it's okay for them that I discuss this and that with the doctor. I often discuss with the doctor when the patients are also there.' (N8-Homecare service)
17.	'Of course one always first seeks a dialogue [...] and in many cases, we've experienced that it works.' (N7-Homecare service)
18.	'Well, it can go so far that you really try to 'pick up the patient where he is'. [...] [It] also depends a lot on the relationship, on the trust, that's always an important topic in social work. And then when there is trust, you sometimes have the chance they can accept some help or you can also organise a meeting with the homecare providers, who could provide some additional support. And then there are very extreme cases, in which you have to say – but that's always in agreement with the doctor – the person is putting himself in danger, so you have to inform the authorities. Although this isn't always effective.' (T2-SCI clinic)
19.	'I'm the principal caregiver, and I've been there most often. She [patient] also liked that she always has the same person for the care.' (N9-Homecare service)
20.	'We have people, many people we know from the beginning. They come again and again. They are also happy when they see familiar faces. And they know how it works. I have the feeling that they can ask open questions because they know the people. I think the relationship plays a very important role. The therapeutic relationship and the closeness. The closeness that one already had during the rehabilitation. This is part of the fact that people, in my opinion, are more open. The trust is already there. That's part of the therapeutic relationship. And I think people enjoy it too.' (T3-SCI clinic)
21.	'We once had a resident who came from another ward. [...] she had a lot of skin problems, as she often refused the care. In the first week, it was also often like this: "no, I don't want it now" and then we simply said: "Listen, you smell very strongly of urine. We'll just do it, we'll try it and if it doesn't work, you'll tell us." She went through it like a process. Today that's no longer an issue. It's wonderful. She always says "thank you very much" and [...]. I think over time she realised that she used to smell, that she had redness of the skin. That her bottom hurts when she is red. [...] It's very nice when the residents become so cooperative.' (N13-Nursing home)

negotiation is to identify an objective that is personally relevant to the patient and set a plan for achieving it. Such an objective can motivate the patient to stick to the agreed-upon care plan (table 4, quote 10).

These negotiations, however, can create tensions for the HPs (table 4, quote 11), and in some cases, the interviewees reported a sense of frustration, helplessness or uncertainty (table 4, quotes 12 and 13). To overcome these difficulties, some HPs adopted a 'live and let live' strategy, which not only helped guarantee the continuity of care, but also facilitated their daily work by reducing disputes (table 4, quotes 14 and 15). In addition, this strategy showed respect for the patients' right to self-determination, through acceptance that, at times, patients make decisions and take actions that do not first prioritise pressure injury prevention or treatment. Occasionally, the predominance of patient self-determination over medical advice seemed to be strictly followed. In the case of a patient whose choice to live in a very warm room was fostering the development of pressure injuries, the caregivers did not force him to change this unhealthy habit (table 4, quote 16). The HPs sometimes had difficulties accepting their patients' habits, as they felt that their hands were tied when patients refused the recommended support (e.g., in the form of homecare services) (table 4, quote 17). For the interviewees, what mattered was that patients were aware of the possible consequences of their actions (table 4, quotes 18 and 19).

If they negotiate priorities for pressure injury treatment with patients, HPs sometimes set conditions. For instance, HPs may offer patients a 'contract' for the surgical treatment of a pressure injury, which requires commitment to a number of conditions. If the patient does not accept these conditions, the HP will suggest a plan to treat the pressure injury conservatively (table 4, quote 20). Similarly, an HP will sometimes suggest an action plan and negotiate with the patient to apply it for a limited time (e.g., a week) and will then hand over responsibility for the plan to the patient while offering guidance (table 4, quote 21).

### Challenge 3 – building a basis of mutual trust and respect

Some HPs underlined the importance of a relationship based on trust and free from judgment (table 5, quotes 1 and 2). One explained, for instance, that building trust and security is the main objective of the first meeting with a patient because this constitutes the basis of the relationship (table 5, quote 3). Similarly, another explained that, without trust in the HP, there is no point in developing procedures and concepts because the patient will not follow them (table 5, quote 4).

Trust was also considered essential because it is impossible to check if patients follow recommendations in their daily lives, and HPs must rely on patients' reports (table 5, quote 5). In addition, when patients trust their HPs and do not feel judged by them, they are more open to discussing delicate issues in relation to their prevention strategies or treatment adherence (table 5, quote 6). Trust also plays a crucial role when HPs estimate whether the situation at home poses risks for the development of pressure injuries and suggest homecare services. The HPs reported that some persons with SCI tend to perceive this kind of support as a form of control and that it is better accepted when suggest-

ed by a person with whom the patients have a good personal relationship (table 5, quotes 7 and 8). Finally, the interviewees observed that if patients with SCI establish a relationship based on trust and respect with their HPs, they will be more likely to contact their HPs promptly to ask for future advice (table 5, quotes 9 and 10).

The interviewees mentioned several factors as essential to building a basis of mutual trust and respect. The first of these is a good reputation based on demonstrated and recognised expertise (table 5, quote 11). Second, it is important to listen to patients, take them seriously and recognise that they have expertise resulting from the daily management of their health condition (table 5, quotes 12–14). Overall, the interviewees emphasised the value of clarifying that their roles as HPs are to offer counselling and guidance for strengthening self-determination (table 5, quote 15). Trust is further fostered by clear and transparent communication and respecting confidentiality (table 5, quote 16). Some participants mentioned that, even with patients who collaborate little, seeking a dialogue is often successful, whereas sending an endangerment notice does not often contribute to resolving difficult situations (table 5, quotes 17 and 18). Another way to promote a trustful partnership is continuity of care, such as when the same HPs take care of the same patients or, more generally, when the care team remains stable over years (table 5, quotes 19 and 20). One participant also recognised balancing patience and strictness as a strategy to gain a patient's trust while respecting his or her timing (table 4, quote 21).

## Discussion

This article presents the three main challenges that HPs experience in building and maintaining partnerships with individuals with SCI to prevent and treat pressure injuries. The identified challenges are as follows: defining responsibilities and expectations, negotiating priorities and setting common goals and building a basis of trust and respect. According to the HPs, the prevention of pressure injuries and self-management are mainly the responsibility of the person with SCI. The HPs have, however, the responsibility to empower their patients and guide them in taking over this role (e.g., patient education, involvement in decisional processes, motivation) and to support them in maintaining it. These findings are in line with previous research [46] and add to the literature that supports the value of patients as partners in the management of chronic conditions [5, 6] by complementing studies that acknowledge the value of HP-patient relationships in rehabilitation [47–50] and those that specifically focus on the patients' perspective [44, 49–53].

The HPs participating in our study saw the value of and need for partnership in the management of a complex chronic condition such as SCI, but they also highlighted the additional effort that such a relationship imposes on HPs and patients. Partnership requires the acknowledgment of mutual expertise (professional expertise and lived experience), mutual trust and understanding, and the setting of common goals [54]. Conflicts between HPs' and patients' beliefs can compromise trust and put partnership at risk [55, 56]. Moreover, the absence of mutual understanding or of common goals can engender frustration or a feeling of powerlessness for HPs [56].

Hence, these study findings point to the need for HPs to develop specific skills that go beyond medical knowledge. Competence with pressure injuries as a health condition [23, 57, 58] and experience [59] are not enough to build and maintain partnerships. Indeed, this requires from the HPs specific communication and relational skills [60] that cannot depend on their personal characteristics. To meet this challenge, HPs need training, for instance in argumentation and negotiation skills [61, 62]. On the one hand, argumentation skills are important to facilitate the exchange of views between doctors and patients. By providing information that is not only understandable but also relevant to patients, HPs can better support their medical advice and contribute to patients' understanding of it [61, 63, 64]. On the other hand, negotiation skills are important to ensure that agreements are reached with patients on courses of action, preferably ones that align with patients' priorities and maximise their health and quality of life [65]. These skills are especially decisive when the patient's priorities and preferences are not in accordance with medical recommendations and the patient may make different choices from the ones suggested by the HPs [56, 62].

Yet, as shown in other empirical studies [66], agreeing on a viable solution with a patient raises ethical dilemmas. To what extent can HPs make compromises? Is there a 'minimal responsibility' that a person with SCI must carry when it comes to the prevention and treatment of pressure injuries? As the results of this study show, this 'minimal responsibility' can change depending on the patient's condition (e.g., age, mental health). In the field of SCI, being newly injured or feeling unwell have been mentioned as reasons for diminished participation [48, 50]. Similarly, it has been established that the ability to self-manage can be hindered by co-morbidities and competing demands on time [67, 68] but can be enhanced by the stability of the symptoms, easy access to HPs and a relationship based on mutual trust [69]. It is therefore not possible to impose the same level of responsibility on everyone. HPs must respect the fact that some people cannot or prefer not to assume complete responsibility for making decisions [68, 70] and that patients may be ready to take over responsibility at different points in time [71, 72]. As Rogers and colleagues have mentioned [73], healthcare services must take into account that people have unequal resources for responding to their illnesses.

This study also shows how difficult it can be for HPs to balance the protective aspects of care (e.g., avoiding the development of a pressure injury) with elements of patient self-determination and personal responsibility [71, 74, 75]. The findings point to the need for health services providers to reflect on the meaning of self-management and on the expectations for a 'good self-manager'. As Lawn and colleagues have highlighted [76], providers otherwise risk imposing responsibilities and engagement and stigmatising those patients who do not fulfil them. These are often patients with complex needs who would mostly benefit from a self-management support that takes into account their lifestyle and personal contexts, including their health literacy level and socio-economic status [77–79].

The starting point for a good partnership could be to 'find a way of adapting to [a patient's] existing strategies' [80], hence recognising patients' knowledge of their own bod-

ies. When a pressure injury develops, the responsibility should not be simply attributed to a lack of patient engagement [74]. It is important to acknowledge that not all pressure injuries can be prevented by behavioural measures [79, 81, 82], that the evidence in support of behavioural and educational interventions to prevent pressure injuries is mixed [83–85] and that the prevention of pressure injuries should be personalised and integrated into the complex self-management of the SCI [78, 79, 86, 87]. This means, for instance, that HPs and health institutions must develop solutions that go beyond the personal partnership to better support patients who have different resources and attitudes toward self-management. Among the potential solutions, telehealth solutions have shown potential [79]. In particular, in their scoping review, Tung and colleagues recommend a multifactorial approach, integrating monitoring, support and feedback technologies to sustain long-term adherence to prevention measures, promote situational awareness and access to professional resources [79].

## Conclusion

Building and maintaining partnerships with individuals with SCI is necessary for preventing and treating pressure injuries, but it is not an easy task for HPs. Specific communication skills (such as active listening and the ability to elicit preferences and beliefs, as well as more advanced skills, such as argumentation and negotiation) can help HPs and patients reach agreement on pressure injury prevention and treatment. According to HPs, the building of a partnership is also not an easy task for patients, who, despite desiring it, may not be ready to take over the responsibilities that it implies. Appropriate self-management is rooted in a functional partnership between HPs and individuals with chronic health conditions and, as this study shows, this partnership is to be achieved with competence and skills that go beyond medical knowledge and the clinical management of health conditions. Here, healthcare systems are called upon to develop solutions to support persons with SCI in the lifelong self-management of their complex chronic condition. Assistive technologies, such as mobile technology, might help in this endeavour.

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## Potential competing interests

The authors report no conflicts of interest.

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