



ARTICLE

# Outpatient and community care for preventing pressure injuries in spinal cord injury. A qualitative study of service users' and providers' experience

Claudia Zanini<sup>1,2</sup> · Nadia Lustenberger<sup>1</sup> · Stefan Essig<sup>2,3</sup> · Armin Gemperli<sup>1,2</sup> · Mirjam Brach<sup>1,2</sup> · Gerold Stucki<sup>1,2</sup> · Sara Rubinelli<sup>1,2</sup> · Anke Scheel-Sailer<sup>2,4</sup>

Received: 26 July 2019 / Revised: 14 February 2020 / Accepted: 14 February 2020 / Published online: 26 February 2020

© The Author(s), under exclusive licence to International Spinal Cord Society 2020

## Abstract

**Study design** Qualitative exploratory study.

**Objectives** Pressure injuries (PIs) are a major secondary condition occurring after spinal cord injuries (SCI). Optimization of outpatient and community care may be a promising approach to better support community-dwelling individuals with SCI in preventing PIs. The aim of this study was to examine the experiences of individuals with SCI, family caregivers and health professionals (HPs) in using or providing outpatient and community services for early treatment and prevention of PIs in SCI.

**Setting** Switzerland.

**Methods** Semi-structured interviews with a sample of Swiss residents community-dwelling individuals with SCI ( $n = 20$ ), family caregivers ( $n = 5$ ) and HPs ( $n = 22$ ) were analysed using thematic analysis.

**Results** General practitioners (GPs), home care providers, SCI-specialized outpatient clinics and an SCI-specialized nursing service are involved in the prevention and early treatment of PIs. Our findings show that the needs of individuals with SCI are not fully met: outpatient and community care is often fragmented, mono-professional and non-specialized, while persons with SCI and HPs prefer coordinated, inter-professional and specialized services for preventing and treating PIs. Our findings also highlight the challenges faced by HPs in providing care to individuals with SCI in the community.

**Conclusions** Although there seems to be a gap in service provision, there is the potential for improvement by better integrating the different providers in a network and structuring their collaborations. Concrete suggestions are: systematizing knowledge transfer to home care providers and GPs; redefining the role of involved HPs and individuals with SCI and reinforcing the role of the SCI-specialized nursing service.

## Introduction

Spinal cord injury (SCI) is a rare and complex health condition including loss or changes of motor and

sensation functions as well as the loss of autonomous regulation of the body [1]. Pressure injuries (PIs) are a major secondary condition occurring after SCI that can be life-threatening [2, 3]. The treatment of severe PIs requires long hospital stays and often surgery [4], leading to high treatment costs [2].

Prevention of PIs remains a challenge due to multiple risk factors, such as age, years since the injury and extent of lesion, as well as lifestyle [5, 6]. According to the Canadian Best Practice Guidelines for the Prevention and Management of Pressure Ulcers in People with SCI and to the National Pressure Ulcer Advisory Panel, many PIs may be preventable [7]. Moreover, evidence shows that early treatment of superficial PIs is effective in avoiding their worsening into severe PIs [8]. Despite existing recommendations and education programs, many persons with SCI will still develop severe PIs during their lifetime

---

These authors contributed equally: Claudia Zanini, Nadia Lustenberger

✉ Claudia Zanini  
claudia.zanini@paraplegie.ch

<sup>1</sup> Swiss Paraplegic Research, Nottwil, Switzerland

<sup>2</sup> Department of Health Sciences and Medicine, University of Lucerne, Lucerne, Switzerland

<sup>3</sup> Institut für Hausarztmedizin und Community Care, Lucerne, Switzerland

<sup>4</sup> Swiss Paraplegic Centre, Nottwil, Switzerland

[9–11]. One of the reasons is that prevention of PIs requires daily commitment, which includes many preventive actions that individuals with SCI must carry out and that need to be incorporated into the person's lifestyle to be sustainable [12, 13].

In this endeavour, the optimization of outpatient and community healthcare services may be a promising approach to better support community-dwelling individuals with SCI. Indeed, a robust system of primary care, characterized by an annual comprehensive health evaluation, multidisciplinary follow-ups and access to disability-specific expertise, is associated with good health outcomes for individuals with SCI [14]. In Switzerland, a variety of outpatient and community healthcare services for persons with SCI are available and frequently used. Research shows that individuals with SCI consult general practitioners (GPs) twice as often and outpatient centres six times more often, than the general population does [15]. One reason may be that individuals with SCI prefer to go to a GP, if the SCI-specialized centre is not offered in their linguistic region [15]. Regionally organized home care services are used by 88% of the population with SCI [16]. Furthermore, a small SCI-specialized nursing service composed of ten nurses offers expert support and education, home visits and phone consultations countrywide. With the exception of the outpatient clinics and one nursing service, these services are not specialized in SCI. Besides, they are not automatically activated after initial rehabilitation, and individuals with SCI play a key role in deciding which services to engage. Only the SCI-specialized outpatient clinics invite individuals with SCI for a yearly check-up.

A better understanding from the perspective of service users and providers of outpatient and community care may provide insights on how the Swiss healthcare system is meeting the needs of community-dwelling individuals with SCI for prevention and treatment of PIs. The aim of this study is to examine the experiences of individuals with SCI, family caregivers and HPs in using or providing outpatient and community services to prevent or treat PIs in SCI.

## Methods

This paper presents a qualitative exploratory study using semi-structured interviews. The design was chosen to examine the experiences of service users and service providers [17].

### Sampling and recruitment of participants

We recruited a sample of Swiss residents with SCI, family caregivers and HPs. Eligibility criteria for all participants

included: being >18 years of age and speaking one of the official Swiss languages fluently. Specific inclusion criteria for individuals with SCI were that they have lived in the community more than 5 years. In addition, we identified individuals having had none, one or several severe PIs. Considering the major support that many family members offer, we also recruited a convenience sample of family caregivers to complement the perspective of individuals with SCI. The specific inclusion criterion for HPs was being involved in the care of individuals with SCI. We purposively sampled participants working in different settings (inpatient, outpatient and community care) and in different regions of Switzerland (i.e. in different cantons, in urban and rural areas).

Recruitment was conducted with the collaboration of the four Swiss specialized centres for SCI acute care and rehabilitation, and by relying on intermediaries and wheelchair clubs. Potential participants among the HPs were contacted by telephone or email, whereas individuals with SCI and their caregivers were invited to participate by their HPs, and were contacted by the researchers only by agreement. Additional potential participants were identified thanks to a snowballing technique (i.e. individuals with SCI suggesting that their GPs or home care providers be interviewed, or HPs from SCI-specialized clinics suggesting names of other HPs working in the community) [18]. Individuals who expressed an interest in participating were contacted, study information was sent to them and an interview was scheduled.

### Data collection and analysis

One researcher conducted all individual face-to-face semi-structured interviews. The interview topic guide was developed in collaboration with an inter-professional expert group. Interviews with individuals with SCI aimed at exploring their experience with PIs—knowledge and application of preventive measures, as well as the use of healthcare services for the prevention and treatment of PIs. Caregivers were asked similar questions, with a focus on their role in the prevention and treatment of PIs. Interviews with the HPs aimed at capturing the potential benefits and challenges of collaboration with patients and of the coordination of care to improve prevention and (early) treatment of PIs. Sample questions are presented in Table 1. Data were collected until thematic saturation was reached.

All interviews were audio recorded and transcribed verbatim, and analysed using thematic analysis. Thematic analysis was used to identify and interpret patterns, called themes, within the dataset [18]. Themes were developed by reading the interviews and assigning codes to text segments that captured something relevant in relation to the research question. The codes reflecting different aspects of a same

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

Sample questions	
For HPs	<ul style="list-style-type: none"> <li>• According to your experience, what do people with SCI do when they have a PI?</li> <li>- Self-management or with support? Who is the first contact person (family caregivers, home care provider, GP, specialized clinic)? What role plays the GP?</li> <li>- How are you involved in the treatment of PIs? When are you involved? By whom?</li> <li>• What are your tasks/offer for person with SCI with PIs?</li> <li>- Possibilities and limitations?</li> <li>- How do you interpret the personal responsibility of the person with SCI? How do you deal with it?</li> <li>• When do you speak of a successful or unsuccessful collaboration—with the patient, with specialized SCI centres, with home care providers?</li> </ul>
For persons with SCI/family caregivers	<ul style="list-style-type: none"> <li>• How have you learned about the prevention and treatment of PIs? (personal experience, training during rehabilitation, other HPs, Internet, etc.)</li> <li>• Do you think you have enough knowledge? Do you feel confident?</li> <li>• Have you received any support from the health services in the prevention and treatment of PIs?</li> <li>- By whom? (family caregivers, home care provider, GP, specialized clinic)</li> <li>- Is/was this support sufficient for you? What could have helped you more?</li> <li>• In your opinion, what went wrong when you/the person with SCI developed a PI?</li> </ul>

**Table 2** Socio-demographic characteristics of the participants.

Participants	All <i>n</i> (%)	Age (years) median (min/max)	(Working) Experience with SCI (years) median (min/max)
Individuals with SCI	20 (100)	55.5 (26/81)	26 (7/52)
Female	7 (35)		
with paraplegia	9 (45)		
with tetraplegia	11 (55)		
Family caregivers	5 (100)	61 (53/74)	25 (7/38)
Female	5 (100)		
of a person with paraplegia	1 (20)		
of a person with tetraplegia	4 (80)		
Health professionals	22 (100)	50 (31/64)	19 (8/33)
Female	13 (59)		
General practitioners	3 (14)	55 (45/59)	22 (20/24)
Home care providers (nurses)	4 (18)	50.5 (40/58)	21 (13/30)
SCI-specialized HPs working in the centres		47.5 (31/64)	20 (8/31)
physicians	4 (18)		
nurses	5 (23)		
other therapists: occupational therapist, psychologist, social worker	4 (18)		
SCI-specialized nurses working for the nursing service	2 (9)	48 (46/50)	23 (12/33)

phenomenon were collated in a theme. The themes were then reviewed by constantly comparing the excerpts among them and with those of other themes.

We used investigator triangulation to increase the trustworthiness of our findings [19]: NL developed preliminary codes and CZ reviewed the coding of half of the interviews (i.e. accepting the coding as performed by NL, suggesting a new code for the same excerpt or new codes for additional excerpts). This approach was useful to generate and examine multiple interpretations of data and to find convergence [20, 21]. As suggested by Lincoln and Guba [19], to ensure the fit between data and their interpretation, the findings were also discussed with other members of the research team. Furthermore, notes were taken to keep track of the rationale for decisions (i.e. methodological decisions), and a journal was kept by NL and CZ to record impressions and reflections [19]. The interviews were analysed in the original

language and excerpts were translated only for the purpose of scientific publications. The software MAXQDA<sup>®</sup> (version 12.2.0) was used to organize and store data.

## Results

The final sample included 47 participants—20 were persons with SCI, 5 were family caregivers and 22 HPs. Socio-demographic characteristics of the participants are presented in Table 2.

The findings depict the experiences of individuals with SCI, caregivers and HPs with the outpatient and community care services to prevent and treat PIs. Two core themes were identified: the service users' preference for expertise and the difficulty of providing adequate services in the community. Sample quotes are presented in Table 3.

### Service users' preference for expertise

Individuals with SCI stressed that, when it came to preventing and treating PIs, SCI-specialized knowledge was fundamental. Hence, they tended to seek out the support of and place their trust in HPs who had expertise in the field.

*"I'd rather travel halfway around the world to see an SCI-expert."*

Most participants reported having first contacted an SCI-specialized centre or one of their outpatient clinics in the case of a PI. Some would rather make a long trip to reach the SCI-specialized centre than go to a closer general hospital without SCI expertise (Q1). Despite this preference for experts, all SCI-specialized physicians underscored that patients often made an appointment at the SCI-specialized centre only when the PI was already severe (Q2). One reason may have been that, as mentioned by some participants, distance presented an obstacle to their use of the service (Q3). Calling and digital transmission of photos were mentioned by one family caregiver as a reliable and appreciated alternative for seeking expert advice (Q4). In line with this preference for experts, the SCI-specialized nursing service was highly appreciated by all participants who had experienced its support: they valued its expertise in SCI and connections to the SCI-specialized centres, as well as home visits (Q5).

*"I don't need experiments."*

The limited knowledge of home care providers and GPs appeared to be a reason for their limited involvement in the prevention and care of PIs. While some participants described a well-established cooperation with their home care providers, others reported a feeling of distrust and the need to instruct them (Q6). Likewise, several individuals with SCI perceived themselves as more knowledgeable than GPs with regard to the prevention and treatment of PIs: they reported visiting GPs mostly for general conditions or for refilling prescriptions, and not specifically for PIs (Q7). Only two interviewees valued the advice of their GPs, but it emerged that their GPs had previous working experience in a specialized centre for SCI rehabilitation. It was not only the persons with SCI who considered that GPs generally had insufficient knowledge on the topic of PIs in SCI; the specialized HPs and the GPs themselves acknowledged their limited experience and preferred to leave the task to more experienced HPs (Q8). Indeed, according to the SCI-specialized HPs, the limited knowledge of some home care providers and GPs about SCI complications may have sometimes negatively affected the patient's health (Q9).

### The challenges of providing adequate community services

The analysis showed that HPs faced several challenges in providing care to individuals with SCI in the community.

*"There is always a different nurse."*

More than half of the interviewed individuals with SCI and family caregivers had experiences with home care services. Many reported that their availability and turnover were suboptimal for adequately preventing and treating PIs. They reported that big nursing teams had more difficulties in judging and treating early stage PIs because effective monitoring of the skin over time is better done consistently by one person. Moreover, high staff turnover was also considered problematic by some participants because new staff members would not have the required SCI-specific knowledge (Q10). Other participants complained about the inflexible working hours of home care services, which could accommodate only in a limited way their lifestyle, needs and habits, with appropriate implementation of preventive measures (Q11). Several SCI-specialized HPs also confirmed these limitations of the home care service providers (Q12).

*"We have to work with what we have in peripheral areas."*

Some HPs from the community services pointed out that, due to the limited number of specialized clinics in Switzerland and their concentration (three out of four) in the German-speaking region, in peripheral regions they tended to treat more complex cases and looked for other solutions to cope with the lack of specialized services (Q13).

*"They are few and only work on call."*

The nurses of the SCI nursing service reported working in strict collaboration with the SCI-specialized centres and considered that being the contact person for HPs and patients could improve case management (Q14). This was confirmed by the HPs working in the specialized centres, who reported that the nurses of the counselling service were their eyes in the patients' home (Q15). However, some HPs considered that the small number of nurses working for this service partially limited their potential for coordinating care (Q16). Moreover, the SCI nursing service needed to be activated by the patients, i.e., if they did not contact the nurses, the nurses could not provide their services (Q17).

*"We have to know and respect each other's work."*

Some participants stated that, for inter-professional collaboration to happen there needs to be knowledge of the available services on the part of all HPs. However, from what was reported by other participants, this did not seem to always be the case in our sample. For instance, not all home care providers and GPs knew of the SCI-specialized nursing service (Q18). Among the HPs working in community care, those with extensive experience in rehabilitation valued having a good network (Q19). In addition to the mutual knowledge, acceptance and respect for the expertise of other professionals were essential for inter-professional collaboration. It required tolerance for other ways of working, insofar as they did not harm the patient (Q20).

*“We try to develop a common language and bridge the knowledge gap.”*

The SCI-specialized HPs recognized the efforts exerted in developing a common language and bridging the knowledge gap of the home care providers, by regularly organizing courses for HPs assisting individuals with SCI (Q21). These offers for further SCI-education were well attended and appreciated by home care providers (Q22). In the process, these courses also helped mitigate potential

conflicts between home care providers and individuals with SCI, by explaining that individuals with SCI are trained to self-manage their condition and that it is important to respect their know-how (Q23). Complementary to the training, the HPs pointed out the potential of the SCI-specialized nursing service to act as a key advisor for community services due to their knowledge of SCI-specific environmental and behavioural challenges (Q24).

**Table 3** Quotes.

Quote number	Quote
Q1	I don't want to go to someone [HP] where I know I don't feel safe. I prefer to go right to the SCI-specialized outpatient clinic, where I know that there are people with experience and expertise. (SCI09, f, 47 y/o) <sup>a</sup> At the beginning of September I went to the SCI-specialized outpatient clinic because I wanted to show it [PI]. I didn't want to go to the [general hospital]. They have no idea. [...] I'd rather travel halfway around the world to go to [SCI-specialized clinic], where I know that they have an expertise and understand my problem. (SCI11, m, 26 y/o)
Q2	Perhaps the GP has already told the person with SCI five thousand times that he should go to X [specialized clinic]. And the patient says that he doesn't want to because the wife can't drive him and the son would need to take a day off. Maybe he just didn't want to. "It'll heal by itself." And then two weeks, three weeks, four weeks, five weeks pass and then it gets inflamed, then they have a fever, become septic, have huge holes, it stinks like God, then they come [to the specialized clinic] of course. (SCI-MED02, m, 49 y/o)
Q3	Of course if we had the SCI-specialized outpatient clinic here in [place of residence], we would go there. But the long trip is a barrier, also because I don't have a driver's license, and with public transportation it's difficult. (CG03, f, 65 y/o)
Q4	I send the picture always through my mobile phone. Last time I sent it on a Friday morning and the nurses [from the SCI-specialized clinic] told me: "You don't have to worry. On Saturday you'll have the material". And indeed it was there. (CG03, f, 65 y/o)
Q5	The SCI-specialized nursing service is my first contact point. If I have a problem, if I need additional care or something, then they support me. They even do home visits. They support you, they instruct you. (SCI10, m, 54 y/o) It's very easy. Thanks to the nurse of the [SCI-specialized nursing service] you have access to the material that it's used at the specialized clinic and you don't have to go there every time. She brings it. That helps, doesn't it? (SCI16, m, 68 y/o)
Q6	By now, they [home care providers] do a good job. But they also had to learn a lot. (HOMECARE01, f, 47 y/o) Of course I can't do that myself. The home care service has to help me. And the nurses have no idea for these kind of problem. [...] And I was afraid every time. I was so afraid when it bleeds. And that happens for two months. (SCI13, f, 48 y/o)
Q7	I'm satisfied [with my GP]. I see him mostly for urological problems, if it is only about antibiotics, the GP can do that. Thank God, my GP has an idea of SCI-issues, more than the average GPs. But still, especially for skin problems, for SCI-specific things, in such cases I always go directly to the SCI-specialized outpatient clinic. Because that's not the daily routine of a GP, I'm his only patient with SCI, and I don't need experiments. (SCI17, m, 42 y/o) Well, I don't go to the GP anymore. [...] If I go to a GP, then I can judge the problem by myself. I might even be able to judge it better than a GP. If I have a health issue that I know is SCI-specific, then I go straight to the SCI-specialized outpatient clinic. (SCI09, f, 47 y/o)
Q8	If I see that other HPs manage the treatment of wounds well, then I don't need to have these specific knowledge and abilities. (GP03, m, 59 y/o) The treatment of PIs in the private practice has decreased, I nearly only treat them in the nursing homes or in the assisted living facilities that I support. This has to do with the fact that there are more and more wound specialists and they keep the patients. (GP03, m, 59 y/o) And that, of course, is the ignorance of the family doctors. The problem is that often professionals feel offended if you want to inform them. That's why the patients themselves should know that they have to check by themselves, especially if their GP doesn't have as much experience in SCI as I do. (GP01, f, 45 y/o) The problem is that very few GPs deal with SCI. [...] I mean, a GP might have 2000 patients. He has two people with SCI and suddenly he should be familiar with SCI specialized knowledge. We cannot expect this. (SCI-MED02, m, 49 y/o) And all the GPs are useless because they have zero experience. (SCI-MED03, m, 61 y/o)
Q9	The home care providers involved their own wound expert and did some kind of a wound management. After four weeks this patient was admitted to the clinic with a hole down to the bone. [...] This should not happen, they should have sent the patient to the doctor much earlier. [...] These people had too little experience. They should have reacted earlier. We see it often, that they wait too long. (SCI-NURSE04, f, 46 y/o)

**Table 3** (continued)

Quote number	Quote
Q10	<p>There are HPs in nursing homes or assisted living facilities, and everyone tries something and the PI is treated for half a year like this and then when they've tried all sorts of things, then they send the patients to us [SCI-specialized clinic]. (SCI-MED02, m, 49 y/o)</p> <p>If someone else comes every day, the person who saw the red spot will come again in four weeks, then you can't really monitor. (SCI11, m, 26 y/o)</p> <p>It changes constantly by them [home care service has high staff turnover]. [...] but if there is always a different person coming and it is not always the same person who checks the skin, well this is how it happened. (SCI07, m, 47 y/o)</p> <p>This afternoon I'm going to visit a patient. We've trained the nurses of the home care service three times, the team has already changed three times, I think it's terrible. (SCI-COUNS02, f, 50 y/o)</p>
Q11	<p>I chose a private home care service [because] they were available 24/7. So you don't have to go to bed at nine or half past nine. And you could call them anytime if there was any problem. This was very reassuring for me. (SCI09, f, 47 y/o)</p>
Q12	<p>[...] the public home care providers usually work from 8 until 12 or I don't know, but no service at night and so on and we also have patients who work, and they have to be ready at 8 o'clock, which means that the service should start at 6 o'clock. [...] That's why we have many persons with SCI who have private home care providers. But that's not enough either. (SCI-COUNS02, f, 50 y/o)</p> <p>People with tetraplegia can't check their skin by themselves. They are dependent on other people. And there it is again the problem of continuity. If a different nurse from the home care service comes every day to check his ischium, then there is no monitoring of the process at all. (SCI-MED03, m, 61 y/o)</p>
Q13	<p>When the home care provider has a team of 20, 30 or 40 people which change every week, you cannot expect a high quality unfortunately. And the patients sometimes are tired to repeat and repeat the instructions. [...] That is why we involve the SCI-specialized nursing service or ask patients to call us or come here. But I cannot reorganize the home care providers. (SCI-NURSE01, m, 42 y/o)</p> <p>Since we don't have a specialized clinic close by, we treat more complex situations or complex wounds at home than perhaps in German-speaking Switzerland, where patients are more easily referred to a specialized clinic. (SCI-COUNS02, f, 50 y/o)</p> <p>[Going to the specialized clinic] means to drive there and have the visit and all in all it takes the whole day. Many patients tell me: "Ah, no, it's annoying. Couldn't you do that here?" [...] Then you often try something else until the patient agrees to travel to the specialized clinic. I see this as a problem. If in these situations the SCI-specialized nursing service could come here with the necessary instrument to measure the pressure, [...] I think that would be brilliant. (GP01, f, 45 y/o)</p> <p>We have medical supply shops in the region. But this is not the same as when you have a trained occupational therapist, like the ones in the specialized clinics, who works with every patient to have the best adapted wheelchair. But they don't come to the rural areas. Of course that would be great (GP01, f, 45 y/o)</p>
Q14	<p>Well, I recently had two patients who had to be admitted for inpatient treatment and that worked out well, it was helpful that I was the contact person for everyone. (SCI-COUNS01, f, 46 y/o)</p> <p>And then we found a way to work together with the GP, that really was a good cooperation with him, and he was happy that I was the contact person for the specialized clinic. (Laughter) Simply because of the language. I think that the language is a big obstacle for some HPs [from other linguistic regions] to get in contact with the specialized clinic [mostly German-speaking]. (SCI-COUNS01, f, 46 y/o)</p> <p>The SCI-specialized clinics opened temporary outpatient clinics in different regions, they are there once per month. [...] We work in close collaboration with this outpatient clinics, we are in contact per email, per phone, we send pictures with the protocol. (SCI-COUNS02, f, 50 y/o)</p>
Q15	<p>You don't necessarily need a GP. Nurses have got eyes too, and a mouth and hands. They can measure and take photos. That's the best. Then the patient doesn't have to come here [SCI-specialized clinic]. The nurses of the SCI-specialized nursing service are almost like GPs to me. They are my eyes. (SCI-MED04, m, 64 y/o)</p> <p>We have the nurses of the SCI-specialized nursing service, they do home visits, they check the patients, they do an excellent job on site, we work really well together. With their information we stay up to date. (SCI-MED02, m, 49 y/o)</p> <p>Sometimes I really have complex cases, where I'm glad that real experts look at it, that home care providers have appropriate support. I'm very happy that there is the SCI-specialized nursing service. [...] It's really great. And in some cases I'm glad if they do some home visits, they check, see if there are any mistakes. Sometimes the situation is completely different than I imagine. (SCI-MED04, m, 64 y/o)</p> <p>The SCI-specialized nursing service does home visits, they also do assessments, for instance they check if a new mattress is needed. They see who else could be involved because they know the people. So the SCI-specialized nursing service plays a central role, so to say. (SCI-NURSE02, f, 49 y/o)</p>
Q16	<p>The SCI-specialized nursing service alone can't do it alone either. They are limited in their capacity. They do home visits, they organize assistive devices and other material for the wound treatment, they have contact to the GPs and the home care services. They know the situation at home, they can involve the occupational therapists if needed. They are really the pivotal point, so to say. But when I hear how far they travel and they are only few people. (SCI-NURSE02, f, 49 y/o)</p>

**Table 3** (continued)

Quote number	Quote
	Our problem is that we are a small team. Our service is free too. That's why we can't be everywhere. (SCI-COUNS02, f, 50 y/o)
Q17	When there is a problem, the SCI-specialized nursing service is a great support. I think it's great if you can call someone who understands something about PI and about SCI. [...] I work a lot with the specialized nursing service, but I don't think that it can solve the problem of a patient who misses the moment. (SCI-MED03, m, 61 y/o)
Q18	No, I've never heard of it. I don't know it [SCI-specialized nursing service], what is it? (HOMECARE04, f, 40 y/o)
Q19	I work together with other HPs as I used to do when I worked in the rehabilitation clinic. We are simply not in the same building anymore. But the important thing is to know each other. I have a huge network. That's really important. (GP01, f, 45 y/o) If a GP at least knows that the SCI-specialized nursing service exists, then we can work together (SCI-COUNS01, f, 46 y/o)
Q20	And we work with the GPs. We can't prescribe, I don't have the right to do so. We only give advice and afterwards we always contact either the GP or a doctor in the SCI-specialized clinic. (SCI-COUNS02, f, 50 y/o) I can only write them [community care HPs] what they should do, and I am always ready to discuss it by phone. [...] As I said, I also don't freak out if something is done differently than I said. But it shall not be changed fundamentally. (SCI-MED04, m, 64 y/o)
Q21	It's often like this that every HP has his own "garden" and that you don't dare go in. [...] So it seems to me that you always have to be very diplomatic [...] to be accepted. But I think that this might change with time, depending on how good the experience [of collaboration] is. (SCI-COUNS01, f, 46 y/o) With the nurses of the home care services, it's about learning a common language. That is the goal. (SCI-MED01, m, 44 y/o) What the nurses of the home care services know concerning the assistive devices, pressure reliefs, transfers and mobilization. With people with SCI we just do it differently from what they've learned. This is why we show them and we teach them. (SCI-COUNS02, f, 50 y/o) I think that a major problem is the inappropriate early treatment [of PIs], when they underestimate and say, "it's not so bad, it'll heal". It's important to teach the nurses of the home care services because they are often involved in the care of people with tetraplegia. (SCI-COUNS01, f, 46 y/o) We regularly offer two-day training, mostly for home care providers or physiotherapists. The demand is high, and the courses are well attended. [...] We usually also have telephone contact [...] And of course it is important to have an open door. That is also very important. We need to be accountable when we say that we are there when there is a problem. (SCI-MED01, m, 44 y/o) We have already taken some patients who were discharged from the specialized clinic. [...] I know that my colleagues went to the clinic for one or two-day training, the whole team, then they also get instructions here and finally the patient is moved. (RESHOME-NURSE01, f, 32 y/o)
Q22	We invite them [home care providers] to come here [SCI-specialized clinic], to get to know the patient and his needs. So we usually call them before discharge and even after, if they like. And then once per year we have a two-day training course. [...] So they can get some new knowledge and also talk to us, ask questions. The Q&A sessions are long, they have lots of questions. (SCI-NURSE01, m, 42 y/o) We collaborate from the beginning with the SCI-specialized clinic and their nursing service. Everything has been discussed, all our questions and fears, and now we are following their guidelines. (HOMECARE01, f, 47 y/o)
Q23	They [nurses of the home care service] call us and they say: "This patient is very unpleasant, he tells us what to do, to check the skin of the bottom and of the heel. But I have a diploma, I am a temp, but I have learned that, and he wants to be the leader". And we explain them that the patient during first rehabilitation was taught to become autonomous and that he might not move his hand and feet anymore but he has his brain. He was taught to take over responsibility for himself. When we explain this to the home care service, then the problem becomes much smaller. (SCI-COUNS02, f, 50 y/o) It's a big challenge to tell the home care service that the patient is knowledgeable. (SCI-COUNS01, f, 46 y/o)
Q24	Well, actually for me the SCI-specialized nursing service is always present. [...] At first we probably had two hours of training and instructions. And later they came for another hour or so. We then had telephone contact because our patient had a PI on the elbow. I think we even sent them a photo. They then advised us to refer the patient to the specialized clinic for an inpatient stay. The specialized nursing service are a contact point for me, if we have an issue, then I would contact them gain. (HOMECARE01, f, 47 y/o) For the home care providers it is often something completely new to support a person with SCI at home. They have all the same questions and the SCI-specialized nursing service is the contact organization. (SCI-NURSE05, f) The SCI-specialized nursing service is great. Because when we have doubts, we can simply call and send photos. Most of the time they can tell us by phone or email what we should do, or they pass by. They also bring the first material to treat the wound and that is very helpful for us. We are very grateful that we have this opportunity. (RESHOME-NURSE02, f, 46 y/o)

<sup>3</sup>SCI person with SCI, CG caregiver, SCI-MED SCI-specialized doctor, SCI-NURSE SCI-specialized nurse working in the clinics, HOMECARE home care provider, GP general practitioner, SCI-COUNS SCI-specialized nurses working for the nursing service.

## Discussion

Outpatient and community healthcare services are central players in supporting people with SCI and their caregivers in the daily management of SCI and in the prevention of secondary conditions. In spite of this, some services seem to be more valued than others are when it comes to the prevention and treatment of PIs, a very common and severe complication. Thanks to its SCI-specialized knowledge and good connections with the specialized clinics, the SCI-specialized nursing service was considered a popular contact point by people with SCI and their caregivers, and a valid partner by other HPs. In contrast, GPs and home care providers were often criticized for their lack of expertise, and the latter also for the structural limitations of their service. SCI-specialized HPs reported that individuals with SCI often contacted the specialized services only when the PIs were already severe.

To sum up, a handful of services are involved in the prevention and early treatment of PIs in community-dwelling individuals with SCI in Switzerland. Our findings show that they do not always respond adequately to the needs of individuals with SCI: the various providers are not integrated into a network and often their collaborations are unstructured. Further, patients with SCI and HPs express a preference for coordinated, inter-professional and specialized services for preventing and treating PIs. In the reality, outpatient and community care are frequently fragmented, mono-professional and non-specialized. In the following, we discuss the extent of this gap in service provision, relate it to previous studies and reflect on the practical implications for the development of services that better meet the needs of individuals with SCI. By focusing on how to improve the services, our findings complement the existing literature, which emphasizes the role of self-management and personal responsibility of individuals with SCI in preventing complications [8, 22, 23].

Our study illustrates the problem of the lack of integration of care, which is already well-known in the fragmented Swiss health care system. Different from many other health conditions [24], in SCI the GPs do not seem to represent the first contact and are not in charge of the coordination of care, when it comes to the prevention and treatment of PIs. The connection between specialized and non-specialized services is established on a service-to-service level at discharge from rehabilitation (e.g. through the training of home care providers by specialized HPs), but a structured long-term collaboration is not formally established. In addition, the team of home care providers is often unstable, making an efficient exchange of information challenging in a system without integrated, shared e-health information. Consequently, SCI-specific expertise seems to be missing in the community. Indeed, GPs often have limited experience with

PIs and specifically PIs in individuals with SCI, or they are unfamiliar with the complex interventions to reduce the incidence of PIs [4, 8]. The reason may be that SCI requires highly specialized knowledge and experience, which are difficult to build outside a specialized clinic and in the absence of recurrent contact with persons with SCI. Likewise, the competence of home care providers for preventing and treating PIs in SCI is limited. This is evidenced in studies in other specialized fields, such as heart failure or pain management, highlighting certain deficits in the knowledge of the nurses [25, 26].

GPs and home care providers have a general knowledge and expertise base to support individuals with all kinds of conditions. Therefore, expecting them to also provide specialized expertise in treating patients with SCI may not be realistic. However, it is essential to offer training and support to non-specialized HPs in order to improve the continuity of care and case management for individuals with SCI. This is even more important considering that individuals with SCI in Switzerland would rather go to GPs if the SCI-specialized service is not offered in their linguistic region, and that the treatment of PIs is currently one of the main reasons for being treated outside the residential canton [27].

In light of the above, we therefore suggest to, first, clarify the capacity of each involved partner—patient, family caregiver, GP, home care provider, specialized nurse and doctor. Being aware of the advantages and disadvantages of the different services could allow a clearer allocation of tasks and responsibilities. Second, in line with Cox et al. [28], we suggest an expanded inter-professional collaboration between SCI-specialized services and non-specialized services to improve the long-term care of individuals with SCI. This could start with a systematization of knowledge transfer to home care providers and GPs who are involved in the care of individuals with SCI. On the one hand, home care providers could take full advantage of the training offered by the SCI-specialized clinics. This also implies that each team caring for a person with SCI has enough trained personnel and that this specialized knowledge is taken into consideration when organizing shifts, to ensure that a trained person is available for serving the person with SCI. On the other hand, the SCI-specialized nursing service could ensure further education and support in the long-term and in situ for the home care providers. The experience of the inter-professional primary care-based Mobility Clinic in Canada is an encouraging example of how to improve primary care beyond just better physical accessibility for persons with SCI [29]. Last, we favour a reinforcement of the role of the SCI-specialized nursing services. As Williams highlighted, nurses can be change agents to promote more patient-centred care [30].



Nevertheless, the nurses of the SCI-specialized service currently suffer from limitations that hinder their role as case manager and coordinator of the outpatient care for people with SCI. The service is not automatically involved in community care—it only becomes involved on the initiative of the SCI-specialized HPs or of the patients themselves. Besides, its mandate is limited due to lack of financing. In order to help close the above-mentioned gap, the scope and support of the SCI-specialized service should be expanded. Concretely, this could enhance the timely referral to the centres and help overcome the current problem of delayed consultations.

Our study has certain limitations. The qualitative design generated rich and multi-perspective data, achieving thematic saturation, though limitations to the generalizability of our findings need to be acknowledged. To increase our chances of reaching a diversified population, we recruited our participants through different channels (SCI rehabilitation centres, wheelchair clubs and HPs). In spite of this, a self-selection bias cannot be excluded. Moreover, the final sample included many more specialized than non-specialized HPs, as it was difficult to identify non-specialized HPs who had experience with individuals with SCI. Further, although two researchers worked on the interview transcripts and regularly met to discuss alternative interpretations and refine the codes, no systematic independent coding was performed.

The current study provides an in-depth view of the potential weaknesses in the way the Swiss healthcare system responds to the needs of community-dwelling individuals with SCI for the prevention and early treatment of PIs. We suggest that outpatient and community healthcare services could be improved by three means to better support individuals with SCI in prevention and early treatment of PIs. First, the capacity of each involved partner should be clarified; second, inter-professional collaboration between SCI-specialized services and non-specialized services should be expanded; and third, the role of the SCI-specialized nursing services should be reinforced. Overall, in Switzerland there seems to be a service provision gap, but also the potential to improve the involvement of HPs in the prevention and early treatment of PIs in community-dwelling individuals with SCI.

### Data availability

The transcripts of the interviews analysed in the current study are available from the corresponding author on request. Transcripts will be provided in the original language (mostly German).

**Acknowledgements** The authors would like to express their gratitude to the participants for their time and engagement. We also thank Nadja Münzel for her comments on an earlier version of the paper, and Hans

Georg Koch for his assistance in the recruitment of study participants. Thank you also to Lisa Adey, who carefully checked the translation of all quotes from the interviews.

**Funding** This project was supported by the Suva, the Swiss National Accident Insurance Fund.

**Author contributions** NL contributed to the preparation of the protocol for the Ethics Committee, recruited the participants, conducted and transcribed the interviews. She also contributed to data analysis and publication drafting. CZ was involved in the design of the study, supervised data collection, mainly contributed to data analysis and interpretation of the findings, as well as to drafting, revising and finalizing the manuscript for submission. SE was involved in interpreting the findings, drawing implications for practice as well as in drafting, revising and finalizing the paper for submission. ASS was involved in developing the study protocol, interpreting the findings, drawing implications for practice as well as drafting the paper. GS, SR and MB developed the study protocol, provided feedback and approved the manuscript draft. AG provided feedback on the manuscript draft. GS, MB, AG, ASS and SE were also part of the Expert Advisory Group for this project.

### Compliance with ethical standards

**Conflict of interest** The authors declare that they have no conflict of interest.

**Ethics** We certify that all applicable institutional and governmental regulations concerning the ethical treatment of human volunteers were followed throughout the study. The study obtained ethical approval from the regional committee of north-western and central Switzerland (Ethikkommission Nordwest- und Zentralschweiz, reference number EKNZ 2015-311).

**Publisher's note** Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

### References

1. Bickenbach J, Biering-Sørensen F, Knott J, Shakespeare T, Stucki G, Tharion G, et al. Chapter 1: understanding spinal cord injury. In: Bickenbach J, et al. editors. *International perspectives on spinal cord injury*. Geneva: World Health Organization; 2013.
2. DeVivo M, Farris V. Causes and costs of unplanned hospitalizations among persons with spinal cord injury. *Top Spinal Cord Inj Rehabil*. 2011;16:53–61.
3. Brinkhof MWG, Al-Khodairy A, Eriks-Hoogland I, Fekete C, Hinrichs T, Hund-Georgiadis M, et al. Health conditions in people with spinal cord injury: contemporary evidence from a population-based community survey in Switzerland. *J Rehabil Med*. 2016;48:197–209.
4. Regan MA, Teasell RW, Wolfe DL, Keast D, Mortenson WB, Aubut JA. A systematic review of therapeutic interventions for pressure ulcers after spinal cord injury. *Arch Phys Med Rehabil*. 2009;90:213–31.
5. Marin J, Nixon J, Gorecki C. A systematic review of risk factors for the development and recurrence of pressure ulcers in people with spinal cord injuries. *Spinal Cord*. 2013;51:522–7.
6. Gelis A, Dupeyron A, Legros P, Benaim C, Pelissier J, Fattal C. Pressure ulcer risk factors in persons with spinal cord injury part 2: the chronic stage. *Spinal Cord*. 2009;47:651–61.

7. Black JM, Edsberg LE, Baharestani MM, Langemo D, Goldberg M, McNichol L, et al. Pressure ulcers: avoidable or unavoidable? Results of the National Pressure Ulcer Advisory Panel Consensus Conference. *Ostomy Wound Manag.* 2011;57:24–37.
8. Jackson J, Carlson M, Rubayi S, Scott MD, Atkins MS, Blanche EI, et al. Qualitative study of principles pertaining to lifestyle and pressure ulcer risk in adults with spinal cord injury. *Disabil Rehabil.* 2010;32:567–78.
9. Garber SL, Rintala DH, Hart KA, Fuhrer MJ. Pressure ulcer risk in spinal cord injury: predictors of ulcer status over 3 years. *Arch Phys Med Rehabil.* 2000;81:465–71.
10. Fuhrer MJ, Garber SL, Rintala DH, Clearman R, Hart KA. Pressure ulcers in community-resident persons with spinal cord injury: prevalence and risk factors. *Arch Phys Med Rehabil.* 1993;74:1172–7.
11. Chen Y, Devivo MJ, Jackson AB. Pressure ulcer prevalence in people with spinal cord injury: age-period-duration effects. *Arch Phys Med Rehabil.* 2005;86:1208–13.
12. Munce SE, Webster F, Fehlings MG, Straus SE, Jang E, Jaglal SB. Perceived facilitators and barriers to self-management in individuals with traumatic spinal cord injury: a qualitative descriptive study. *BMC Neurol.* 2014;14:48.
13. Fogelberg D, Atkins M, Blanche EI, Carlson M, Clark F. Decisions and dilemmas in everyday life: daily use of wheelchairs by individuals with spinal cord injury and the impact on pressure ulcer risk. *Top Spinal Cord Inj Rehabil.* 2009;15:16–32.
14. McColl MA, Aiken A, McColl A, Sakakibara B, Smith K. Primary care of people with spinal cord injury: scoping review. *Can Fam Physician.* 2012;58:1207–e635.
15. Ronca E, Scheel-Sailer A, Koch HG, Gemperli A. for the SwiSCI Study Group. Health care utilization in persons with spinal cord injury. Part 2: determinants, geographic variation and comparison with the general population. *Spinal Cord.* 2017;55:828–33.
16. Gemperli A, Ronca E, Scheel-Sailer A, Koch HG, Brach M, Trezzini B, et al. Health care utilization in persons with spinal cord injury. Part 1: outpatient services. *Spinal Cord.* 2017;55:823–7.
17. Rubin HJ, Rubin IS. *Qualitative interviewing: the art of hearing data.* Thousand Oaks, CA: Sage; 2011.
18. Clarke V, Braun V. Teaching thematic analysis: overcoming challenges and developing strategies for effective learning. *Psychologist.* 2013;26:120–3.
19. Lincoln YS, Guba EG. *Naturalistic inquiry.* Newbury Park, CA: Sage; 1985.
20. Creswell JW. *Qualitative, quantitative, and mixed methods approaches.* Thousand Oaks, CA: Sage; 2014.
21. Johnson RB. Examining the validity structure of qualitative research. *Education.* 1997;118:282–92.
22. Kruger EA, Pires M, Ngann Y, Sterling M, Rubayi S. Comprehensive management of pressure ulcers in spinal cord injury: current concepts and future trends. *J Spinal Cord Med.* 2013;36:572–85.
23. Clark FA, Jackson JM, Scott MD, Carlson ME, Atkins MS, Uhles-Tanaka D, et al. Data-based models of how pressure ulcers develop in daily-living contexts of adults with spinal cord injury. *Arch Phys Med Rehabil.* 2006;87:1516–25.
24. Peytremann-Bridevaux I, Burnand B, Cassis I, Nolte E. Assessing chronic disease management in European health systems: country reports. In: Nolte EKC, editor. Copenhagen, Denmark: European Observatory on Health Systems and Policies; 2015.
25. Delaney C, Apostolidis B, Lachapelle L, Fortinsky R. Home care nurses' knowledge of evidence-based education topics for management of heart failure. *Heart & Lung.* 2011;40:285–92.
26. Glajchen M, Bookbinder M. Knowledge and perceived competence of home care nurses in pain management: a national survey. *J Pain Symptom Manag.* 2001;21:307–16.
27. Ronca E, Scheel-Sailer A, Koch HG, Metzger S, Gemperli A. Inpatient migration patterns in persons with spinal cord injury: a registry study with hospital discharge data. *SSM Popul Health.* 2016;2:259–68.
28. Cox RJ, Amsters DI, Pershouse KJ. The need for a multi-disciplinary outreach service for people with spinal cord injury living in the community. *Clin Rehabil.* 2001;15:600–6.
29. Milligan J, Lee J. Enhancing primary care for persons with spinal cord injury: more than improving physical accessibility. *J Spinal Cord Med.* 2016;39:496–9.
30. Williams S. Improving the continuing care for individuals with spinal cord injuries. *Brit J Nurs.* 2005;14:161–5.