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The functioning of social support in long-term prevention after spinal cord injury. A qualitative study

Marc Le Fort, MD, PhD[1,2], Chloé Lefèvre, MD[1]; Pierre Kieny, MD[1]; Brigitte Perrouin-Verbe, MD, PhD[1]; Jean-François Ravaud, MD, PhD[2,3]

1. House of Social Sciences in Disability, School of Advanced Studies in Public Health (EHESP), 15 Avenue du Professeur Léon Bernard, 35043 Rennes, France
2. Neurological PMR department, University Hospital, 85, rue Saint-Jacques, 44093 Nantes cedex, France
3. National Institute for Health and Medical research (INSERM), 101, rue de Tolbiac, 75654 Paris cedex 13, France

Corresponding author

Marc Le Fort

House of Social Sciences in Disability

School of Advanced Studies in Public Health (EHESP)

15 Avenue du Professeur Léon Bernard

35043 Rennes, France

e-mail addresses:

chloe.lefevre@chu-nantes.fr

pierre.kieny@chu-nantes.fr

brigitte.perrouinverbe@chu-nantes.fr

jean-francois.ravaud@inserm.fr

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The functioning of social support in long-term prevention after spinal cord injury.
A qualitative study

Abstract

Background. The impact of social support on the long-term condition after a spinal cord injury (SCI) varies across studies mainly involving self-report questionnaires.

Objective. We aimed to establish the common factors associated with social support leading individuals with an SCI to the effective prevention of secondary complications, including via adherence to medical follow-up.

Methods. Inclusion criteria were a history of acquired SCI of any etiology, wheelchair use, and age ≥ 18 years at the time of the study. Participants should have completed their initial rehabilitation program in France ≥ 1 year earlier and were also enrolled according to 2 related study variables: routine medical follow-up (patients were or were not followed up) and the medically supervised reporting of a pressure ulcer after the initial rehabilitation session (0 or ≥ 1 pressure ulcers). We performed a preparatory quantitative and qualitative literature review to identify factors affecting long-term follow-up after SCI, then adopted a narrative design with 32 semi-structured interviews, transcribed and analyzed progressively by using qualitative analysis software.

Results. We included 42 participants. We categorized our results based on the knowledge, attitudes, beliefs and practices of participants with respect to pressure ulcer prevention and long-term medical follow-up. Our narrative approach allowed us to identify 3 main domains relevant to social support: reciprocity, self-management and timing related to social support.

Conclusions. Our study showed social support as a dynamic process, a reciprocal phenomenon evolving in variations over time. These findings should be central to short- and long-term therapeutic education programs for patients and for people providing social support. Effective changes should also be implemented through the concept of the Learning Health System.

Introduction

Social support is an exchange of resources between individuals to improve the health, functioning and well-being of the recipient [1, 2]. It confers a sense of belonging through the feeling of being loved, supported, esteemed and valued and could promote health

and even reduce the risk of mortality [1-7]. The evaluation of social support is not standardized and is mainly carried out by self-report questionnaires. The concept of social support is multidimensional, instrumental or integrative (physical or technical assistance, etc.), emotional (family, etc.), informative (peers, etc.) or confirmatory (appraisal support of choices and personal actions). It can be described from both quantitative (existence and extent of the network) and qualitative (ensuing satisfaction) perspectives [1, 5].

The impact of social support, from family and friends or from a professional environment, on long-term condition after a spinal cord injury (SCI) varies across studies [8-10]. A review of the role of social support, which is globally salient in individuals presenting SCI [11], did not include qualitative studies but nevertheless noted that the selected studies generally involved a cross-sectional design without clarifying causal links [1]. Prior questionnaire-based studies of SCI patients were nevertheless not selective in predicting adherence to prevention and, notably, follow-up [12].

Therefore, we adopted a narrative approach to investigating the perceptions of individuals with SCI. We aimed to explore the function of social support, among other potentially influencing factors, likely to lead these individuals to adhere or not to the effective prevention of various secondary complications, including via adherence with medical follow-up. We focused on long-term skin prevention given the frequency and medical and social consequences of pressure ulcers (PUs) because 85% of patients with SCI are believed to develop at least one PU during their lifetime, which has major impacts on numerous daily activities and participation [13-15].

Methods

The setting of the study was a neurological physical medicine and rehabilitation department with a multidisciplinary spinal unit providing initial rehabilitation, followed by post-SCI preventive follow-up. Official follow-up recommendations are stipulated in the French Ministerial Circular of 2004 and in the long-term illness guidelines (Affection Longue Durée [ALD 20]) for "Paraplegia and Spinal Cord Injuries" issued by the Haute Autorité de Santé (French health authority) [16-18].

We used a qualitative approach with semi-structured interviews for an in-depth investigation of participants' medical and social experiences post-SCI and their opinions regarding long-term secondary prevention [19-21]. A preparatory quantitative and qualitative literature review of adherence to long term follow-up and PU prevention after an SCI led to the creation of a checklist of all factors potentially influencing patients' adherence in the form of an inventory table of items (T2i) to be routinely covered during the interviews (Figure). A multidisciplinary team specializing in disability approved the T2i as the basis for compiling an interview guide. We aimed to determine common denominators of follow-up adherence after an SCI rather than to analyze diverging factors according to baseline-related variables (follow-up and history of PUs).

Patients

The inclusion criteria were a history of acquired SCI of any etiology, wheelchair use, and age ≥ 18 years at the time of the study. Participants should have completed their initial rehabilitation program in France at least 1 year earlier. We enrolled participants according to 2 related study variables: routine medical follow-up (patients were or were not followed up) and the medically supervised reporting of a PU after the initial rehabilitation session (0 or ≥ 1 PUs).

In total, 42 participants were screened and contacted by the principal investigator (PI), who outlined the trial to them and validated their inclusion eligibility. Two patients refused to participate owing to geographical distance.

Interviews

The one-on-one interviews conducted by the PI (MLF) in a neutral location lasted 1 hr, on average, and were recorded digitally. Written informed consent was obtained before each interview. The PI noted the emerging themes and recorded his own reflections generated during the interviews. These interviews were analyzed progressively as they were carried out between March 2016 and May 2018.

The interviews were transcribed verbatim. Each transcription was initially manually coded line by line by using software [22]. We categorized the results from coding based on the knowledge, attitudes, beliefs and practices (KABP) of the participants with respect to PUs, their prevention and long-term medical follow-up. A researcher experienced in qualitative disability research read the first 3 test transcriptions and commented on the quality of the interviews and their coding. A high level of agreement was reached through discussion. Qualitative analysis software (Sphinx iQ2, v.7.0.2.3) was used in a nonautomated manner to assist with the coding and the subsequent organization of the data.

Analysis

The analysis was a gradual inductive process associated with the on-going coding and its tree classification. The PI kept a reflective journal throughout the research process to note any thoughts about emerging codes or ideas resulting from the analysis. The transcriptions were continuously reviewed when new areas emerged and were analyzed by using a thematic approach based on the key principles of grounded theory, modified by the confirmatory

process of our T2i [23, 24]. A quality unit was set up to continuously control the thematic analysis, including a

physical medicine and rehabilitation physician from another SCI specialist center, to ensure that participants had no atypical characteristics.

Thematic saturation was reached at 28 interviews, and interviews continued until 32 were conducted to balance the number of participants with respect to the baseline-related variables. The participants had secondary access to the recorded results and could critically assess them.

Ethical considerations

The local Ethics Committee approved the trial on 4 November 2015 under reference CPP No. 652/2015. The trial protocol was also discussed during 3 academic seminars on qualitative research.

Results: analysis of interview content

The sociodemographic and neurological characteristics of the 42 participants are in Table 1. Participation according to sex was asymmetrical, consistent with SCI epidemiology.

Social support appeared as a main item during our preparatory literature review and remained an important emerging factor during the interviews, independent of the strict confirmation of our T2i. Hence, its frequent occurrence led us to present it apart from other factors, which will be associated within a more global report (QaliPREPS-BM study). We classified our results according to a KABP analysis, usually used for chronic diseases in cross-sectional methods involving questionnaires to investigate social support and to assess changes over time in the perceived health of a target population [25]. This KABP classification facilitated our inductive analysis, leading to the determination of major domains

involving social support influence. Terms relating to the amount of information gleaned from the verbatim statements are in Table 2.

1) Knowledge: comprehensive sharing with social support

The vast amount of knowledge to be absorbed post-SCI concerned not only the patients per se but also their social support, starting from the first rehabilitation session for spouses/partners or parents, depending on the patient's age at the time of SCI onset, and was generally based on information provided by the individual patient. *Treatment weekends* in the patients' own homes enabled patients and their families to assimilate this information, to make future plans and to be trained. For tetraplegics in particular, the spouse/partner often played a crucial role in skin preventive strategies:

"*My wife visited me regularly and gradually knew the different points to check, as soon as I was able to go out on weekends in particular. The team showed her (…) and she soon picked it up. (…) We had a nurse initially (…), but that didn't work out (…), particularly since she was not able to come very early in the morning, which made it difficult for me to get to work. As time went on, we managed to do it ourselves, because it was easier (…), it was a mutual choice…*" *(Patient #32)*

Social support outside the family circle (especially parents and spouses/partners) was generally only marginally affected by the follow-up to be carried out within the scope of SCI. The person with SCI sometimes had to explain his/her situation (e.g., the need to pay attention to the sitting position) to be better understood, thus facilitating the pursuit of joint activities with friends or professional activities.

2) Attitudes: maintaining a balance with social support

Here, we define the term "attitude" as "the disposition toward someone/something, a set of judgments and tendencies that drive behavior".

The presence of family social support was frequently a factor in secondary prevention according to participants. Typically, toward the end of the first rehabilitation session, family

members could remember preventive measures, such as the relief of an injured skin area, and could also influence follow-up according to life events:

"*I was more careful thanks to my skin breakdown and to my wife! (…) In the end, it was my wife who told me to pay more attention. We hadn't talked about it (follow-up) for a while, but my wife said, 'It would be good if you could keep an eye on things more often'. If it had been left to me, I wouldn't have done that. It's true I had been in and out of hospitals for a while (…). There was the birth of my son, and four months later, the death of my mother…*" *(Patient #3)*

Meeting one's spouse/partner or thinking about starting a family sometimes made our participants "more aware" of the importance of prevention. The loss of the main social support (by separation or death) sometimes contributed directly to the formation of a serious PU. Similarly, as in the case of a single parent, the relationship with a child could sometimes be a cause for concern as well as a motivation:

"*During my longest hospital stay, my son was with my sister for almost five months. (…) I eventually realized that I have a son and had to look after my health. He told me that he was fed up with me being in the hospital, that we didn't see each other and that I wasn't taking care of him.*" *(Patient #16)*

However, occasionally, the routine involvement of the spouse/partner could be, or could be perceived as, too prescriptive by the individual with SCI. It could also "wear down" the spouse/partner in cases where the latter had too much to do when the return home was poorly organized due to the accumulation of family and administrative obligations as well as potential complications, or in the case of confusion between the roles of spouse/partner and caregiver. Occasionally, an overprotective attitude by the family hampered the participants' efforts and progress:

"*And my mother, very protective, (…) that worried me a bit during my rehabilitation. We've always been close, but that didn't go well. (…) She stopped me. She used to say to me - (you are) my daughter, what are you going to do? I didn't want to hear that - I had already moved on…*" *(Patient #11)*

3) Beliefs: specialist social support for everyday life

Participants sometimes felt that things were returning to normal after the initial rehabilitation period. The beliefs expressed by the participants notably concerned the impact of social support. Some participants believed that the situation was managed more efficiently when the spouse/partner was a health professional (i.e., a nurse or caregiver). This was the case for a participant who had been paraplegic for 23 years and had spent more than 7 years in the hospital at the study referral center because of recurrent pelvic PUs:

"*We are cocooned when we stay here (and) I fell in love with a caregiver. (…) I have been living for a few months with the person who sometimes looked after me in the department (…). As I've been advised to inspect my buttocks with a mirror every morning - I don't do it, she does, not every day, obviously, but from time to time, enough to make sure that (a pressure ulcer) doesn't get too big. (…) I'm lucky because someone is monitoring me rather than me monitoring myself. If I were on my own, I don't know if I would monitor myself so much.*" *(Patient #27)*

4) Practices: an adjusted intervention with social support

Most participants seemed to have acquired the basic procedures to prevent skin complications, including routine follow-up that could involve their social support, whose roles varied after the return home. If patients relapsed on a regular basis, social support figures reminded them individually of prevention practices, especially the relief of PUs. Sometimes, the spouse/partners' schedules coincided, such as when one got up early to go to work and the other had to catheterize or change the weight-bearing area at the same time. Generally, skin management by a third person was a one-off event that occurred when there was a concern or difficulty with checking a risk area or more regularly, for instance in the case of tetraplegia. Obviously, the tetraplegic participants sometimes had to impose decisions to his/her team of caregivers. When both partners were paraplegic, each one "managed his/her own problems" but without hesitating to ask the other partner for assistance, if necessary.

Assistance was particularly useful in the case of a PU requiring relief at home, even for an ordinarily independent SCI patient because without assistance, the situation could deteriorate:

"*(For) a small pressure ulcer, they told me (at the hospital), 'You stay here', I said, 'No, I don't want to stay here, I can go home. I have a nurse who can come to my house, and my mother isn't far away. She can look after me - no problem.' (…) And I have a lot of friends who drop in regularly. So I had two months at home, going back every fortnight to check on changes in the pressure ulcer.*" *(Patient #12)*

Table 3 gives the verbatim responses and observations reported in these results as examples of the transition between the interviews' content analysis and our theoretical model. Our narrative approach allowed us to identify 3 main domains relevant to social support related to the issue of skin long-term prevention and follow-up: reciprocity, self-management and timing.

Discussion

Two essential principles: reciprocity and self-management

As in the literature, the family (parents and partners) was the main source of social support in our study [1, 26]. Marital status was not unequivocally beneficial, and there were variations in the quantitative and qualitative aspects of marital social support in that being married appears to be helpful only in healthy marriages [1, 10, 27]. The social support figures of our interviewees generally played a substantial role in skin prevention, either directly in terms of position changing or skin monitoring notably in case of tetraplegia or in a more or less directive advisory capacity.

Although social support is considered a positive concept, social relationships can also be a source of stress. A constant reminder of the impact of the disability reflects a relative imbalance in communication between the provider and the recipient. In the case of an SCI, a negative support experience could lead to dysfunctional coping mechanisms and numerous

health-related problems [1]. Conversely, our participants recounted desirable situations toward prevention, in which social support was reciprocal: even though they needed assistance, notably for skin checks, participants extended social support by offering aid in other activities (working etc.), as described previously by Anson et al. and Amsters et al., who linked this mutual approach to improved health and quality of life [28, 29]. *Reciprocity* was described in various ways in our study, such as within couples (mutual choices made by couples who were together before the SCI; defined roles in a post-SCI couple; a paraplegic couple in which each partner managed himself/herself but could also help the other partner, etc.). *One-sided contributions* appeared less protective (management of both partners' activities by one partner, delegated skin control or repeated reminders by a third party, etc.), even involving a risk of exhaustion for the third party. In the case of typical conjugal assistance post-SCI, including skin prevention and long-term follow-up, changing roles have frequently been reported in the literature with the partner appearing less satisfied with his/her life depending on the amount of assistance required by the person with SCI [30]. King et al. also reported conversations with people committed to post-SCI skin prevention to curb anxiety among relatives or the inability to adapt individual practices when skin problems were monitored by third parties [31].

The impact of social support is indeed linked to the internal resources of those affected, especially since physical assistance for SCI patients is often paid for [9]. This s*elf-management* was found a preventive factor in the onset or recurrence of PUs in several studies [31-35]. One of our paraplegic participants who experienced recurrent PUs on several occasions described delegating skin monitoring to his partner, whereas self-management involves taking control of decisions, regardless of the level of physical assistance required in theory (e.g., a tetraplegic individual could need help to check the skin state but will decide him/herself what should consequently be done).

Timing related to social support

Social support relationships are believed to affect health in the early stages, with challenges being perceived by couples after the first rehabilitation session [36]. The roles of social support in long-term skin prevention varied in our study, with one-off assistance being the norm except in the case of tetraplegic individuals, who required regular assistance. Although the literature has reported the major impact of SCI on spouses/partners [32], partners have also reported some positive changes within the couple, such as more open communication [1]. Our study showed that the influence of social support on long-term prevention affected various features within personal organization. According to our interviews, a couple who were together before the SCI could choose an *ad hoc* organization at home, and a romantic relationship post-SCI could also be seen as beneficial, with independent daily management carried out by the couple. Events with an equally positive weight, such as the birth of a child, could paradoxically lead to a lapse in skin prevention and follow-up, probably because of an increase in other activities. Finally, negative “real-life” events such as a break-up or the death of a loved one were also deemed risk periods for prevention.

Our study highlighted the equivocal benefit of social care variables (positive and negative aspects with variable effects, the courting period, the duration of a couple's relationship, partners’ respective roles and the general organization of daily life, etc.), which could explain the difficulties associated with questionnaire-based studies in precisely determining the ambiguous impact of social support on long-term complication prevention and systematic follow-up. The impact of social support could vary over time and gradually merge into a more global “social network” concept [37]. In our study, social support could occasionally take on a professional guise, as with the participant who considered himself “cocooned” when he was rehospitalized for skin complications. Jones et al. also described patients who considered hospital stays to treat PUs as “vacations” from their routine home lives [38].

Study limitations

The fact that the interviews were conducted by a doctor possibly already treating the interviewees could be a limitation. On the one hand, this PI had appropriate theoretical and practical experience with interview research, but on the other, the framework of the long-term follow-up of SCI could forge a privileged bond of trust, facilitating the expression of individual perceptions. Our analysis showed that the participants obviously provided sincere, informative and adversarial data. Furthermore, a holistic vision of the multi-systemic disruptions caused by SCI could enable a global approach to the problem during the interviews. Finally, our study was a single-center study with a risk of selection and declaration bias, but it was approved externally as a quality exercise involving experts in social sciences and SCI specialists.

Conclusions and perspectives

Our study showed that social support was a dynamic process in the sense of being a reciprocal phenomenon, evolving in variations over time, which should be central to short- and long-term therapeutic education programs for patients and for those providing social support. Indeed, our results are integrated in a research program aiming to establish practical applications. At a national level, our data reinforce the national recommendations of the French Ministerial Circular of 2004 for long-term management after an SCI, reaffirming the implications and need for accompanying social support. Similarly, further effective changes should be implemented by the development of police briefs and stakeholder dialogues within the pragmatic concept of the Learning Health System, emerging at an international level, with a notable perspective of long-term health promotion after an SCI [39, 40].

Conflict of interest. None declared

Legend

Figure. Inventory of potential factors of patient compliance with follow-up: domains, subdomains and components raised by the medical literature.

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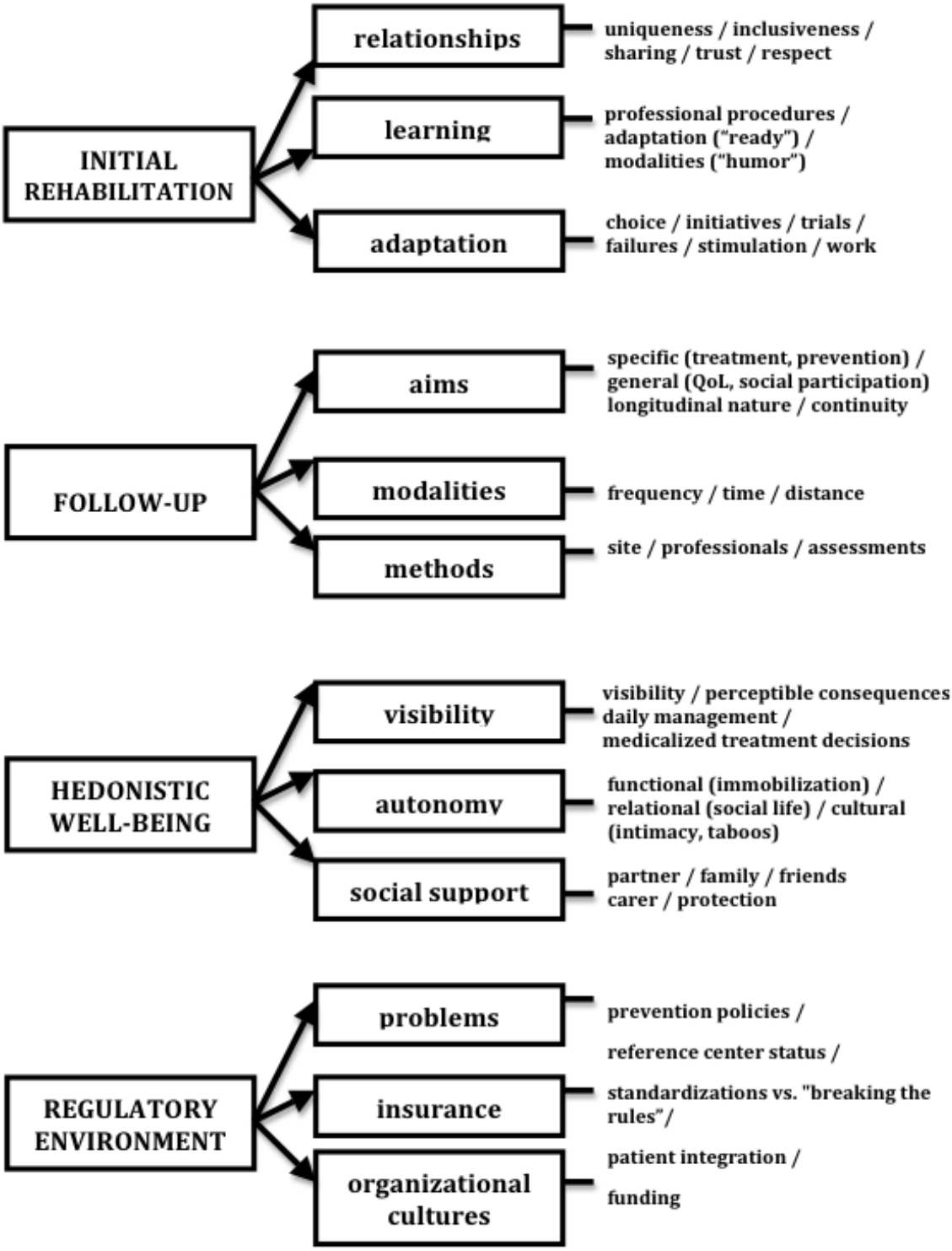
INITIAL REHABILITATION
relationships
uniqueness / inclusiveness / sharing / trust / respect
learning
professional procedures / adaptation ("ready") / modalities ("humor")
adaptation
choice / initiatives / trials / failures / stimulation / work
FOLLOW-UP
aims
specific (treatment, prevention) / general (QoL, social participation) longitudinal nature / continuity
modalities
frequency / time / distance
methods
site / professionals / assessments
HEDONISTIC WELL-BEING
visibility
visibility / perceptible consequences daily management / medicalized treatment decisions
autonomy
functional (immobilization) / relational (social life) / cultural (intimacy, taboos)
social support
partner / family / friends carer / protection
REGULATORY ENVIRONMENT
problems
prevention policies /
reference center status /
insurance
standardizations vs. "breaking the rules"/
organizational cultures
patient integration /
funding

Table 1. Study participants

Patient number	*Sex*	*Age at interview (years)*	*Year of accident*	*Etiology*	*NLI*	*AIS grade*	*Follow-up*	*Previous pressure ulcer*	*Initial referral*
1	M	23	2007	T	Th6	A	N	Y	RC
2	M	43	2004	T	Th2	A	N	Y	NRC
3	M	38	1997	T	Th2	A	N	Y	RC
4	M	37	1994	T	Th3	A	Y	N	RC
5	M	33	1997	T	Th10	A	Y	Y	RC
6	M	51	2007	T	Th10	A	Y	N	RC
7	M	68	1988	I	Th7	A	N	Y	NRC
8	M	51	1997	T	Th4	B	N	Y	NRC
9	M	62	1978	T	Th3	A	N	Y	RC
10	M	43	1989	T	C8	B	N	Y	NRC
11	F	39	1998	T	Th3	A	N	Y	RC
12	M	32	2010	T	Th3	A	Y	N	RC
13	M	41	1994	T	C5	A	N	Y	RC
14	M	63	1972	T	Th3	A	N	Y	NRC
15	M	56	1976	T	Th3	A	Y	N	RC
16	F	35	1984	T	Th1	A	N	Y	NRC
17	M	38	2001	I	Th12	A	N	Y	RC
18	M	34	2002	T	Th10	A	Y	Y	RC
19	M	78	2003	SCC	Th8	A	Y	Y	RC
20	M	31	2012	T	C4	B	Y	N	RC
21	F	56	2002	T	Th5	A	N	Y	NRC
22	M	56	1980	T	Th4	A	N	N	RC
23	M	63	1981	T	Th3	A	N	N	RC
24	F	91	1976	T	Th12	A	Y	Y	RC
25	M	66	1993	T	C3	A	N	Y	RC
26	F	53	1990	T	C4	A	Y	N	RC
27	M	64	1994	T	Th3	A	Y	Y	RC
28	M	79	2012	SCC	Th8	C	Y	N	RC
29	M	46	1992	T	L4	A	N	N	RC
30	M	39	1997	T	Th4	A	Y	N	RC
31	M	58	1993	T	Th10	A	N	Y	RC

32	M	34	2005	T	C5	A	N	N	RC

M, male; F, female; Y, yes; N, no; AIS, American Spinal Injury Association Impairment Scale; T, traumatic; I, ischemia; NLI, neurological level of injury (C=cervical, Th=thoracic, L=lumbar); NRC, nonreferral center (number of new SCI cases treated each year < 20); RC, referral center (number of new SCI cases treated each year ≥ 20); SCC, spinal cord compression from hematoma; SCI, spinal cord injury

Table 2. Frequency of data from the verbatim accounts.

Terms indicating frequency	***Occurrence in the verbatim accounts (%)***
all, always, universal, exclusively	100
often, usual(ly), general(ly), in general, typical(ly) regular(ly), essential(ly), frequent(ly), most(ly)	>50
at times, sometimes, more so	25-50
occasional(ly), rare(ly), some	<25

Table 3. Thematic identification of the 3 main domains

Verbatim / Observation	Comments	Domain
Treatment weekends enabled patients and families to assimilate the information	Patients and their families underwent *parallel learning and training about prevention* during the rehabilitation period.	**Reciprocity**
"It was a mutual choice"	*Decisions about everyday life were made within couples*, including healthcare and social participation (family, work…).	**Reciprocity**
Facilitating the pursuit of joint activities	Explanations by the SCI patient to friends and colleagues could lead to a better *integration of secondary condition prevention in social participation* (leisure, work etc.)	**Reciprocity**
The spouse/partners' schedule may coincide	The *phasing of participants and partners' personal obligations* may facilitate usual organization and improve the experience of prevention for both.	**Reciprocity**
Managing one's own problems and asking the other partner for assistance if necessary	Functional independence in everyday activities *does not exclude reciprocal help* by partners.	**Reciprocity** **Self-management**
Skin management by a third person was a one-off event	Social support may *only occasionally intervene* in a way to limit complications worsening.	**Self-management**
The routine involvement of the spouse/partner could be too prescriptive	*Constant call to order* by social support in terms of prevention could make patients upset**.**	**Self-management**
Confusion between the roles of spouse/partner and caregiver	Complications and prevention *management combined with everyday duties* could lead to *partners' exhaustion.*	**Self-management**
"I don't inspect my skin, my partner does"	The *inadequate whole delegation* in prevention management to a third party may lead to a risky collaboration.	**Self-management**
"We hadn't talked about follow-up for a while"	The issue of follow-up could be a *discussion launched by partners at any time*.	**Self-management** **timing**
"There was the birth of my son and the death of my mother"	*Positive and negative lifelong events* could have *various influences* at any time on the prevention attitudes of participants.	**Timing**
Meeting one's spouse/partner; loss of the main social support	*Changes in lifelong private life* could have *various influences* on the prevention attitudes of participants.	**Timing**
"He was fed up with me being in the hospital"	*Social support's more or less progressive reaction* could lead to changes in participants' prevention management.	**Timing**
Feeling of a return to normal after the initial rehabilitation	The *time after initial rehabilitation* does not appear to cause much anxiety in medical terms.	**Timing**