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## **Adherence to long-term medical follow-up: a qualitative, experience-focused study of people with spinal cord injury**

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# **Adherence to long-term medical follow-up: a qualitative, experience-focused study of people with spinal cord injury**

## **Abstract**

**Background.** Scientific evidence indicates the presence of secondary conditions (such as pressure ulcers) after spinal cord injury (SCI). Treatment methods focusing on the management of paraplegia and tetraplegia include systematic preventive follow-up. These advances have significantly improved the functional and vital prognosis of people with SCI, but some people may not have access to these specialized organizations or may not adhere closely to this medicalized vision. We used a narrative approach to explore the perceptions of people with SCI to better understand their adherence to follow-up.

**Objectives.** We aimed to determine the “common denominators” that lead to adherence or non-adherence to long-term follow-up after SCI.

**Methods.** People with SCI who had completed their first rehabilitation period for > 1 year were included with regard to 2 variables: 1) an actual medical follow-up or not and 2) a history of pressure ulcer or not. A review of the literature was used as preparation for semi-directive interviews, which were prospectively analysed by using qualitative analysis software. Thematic saturation was reached at 28 interviews, and 32 interviews were ultimately completed.

**Result.** Three main areas concerning participants’ perceptions emerged: people’s readiness, appropriation and modulation of the systematic follow-up. We developed a broad conceptual framework representing follow-up and the promotion of the long-term health of people with SCI from their perspectives.

**Conclusions.** The medical environment should ensure that people with SCI are ready to actively consider the implementation of prevention strategies and should take into account their ability to establish their own truth, to integrate various life stages after SCI and to

negotiate systematic follow-up. The implementation of data about functioning should be conducted using the concept of the Learning Health System.

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**Keywords:** grounded theory, readiness, appropriation, therapeutic education, KABP model

## **Introduction**

Medical systematic and long-term follow-up in a specialist unit for spinal cord injury (SCI) has been recommended “from injury to grave” [1]. It reduces the frequency and severity of complications [2] and improves functioning [3]. Annual follow-up has most often been described in the literature [4]. National regulatory authorities have recommended this long-term follow-up, but compliance with this regimen is low [5].

Researchers have aimed to determine individual profiles that predict long-term adherence to follow-up after SCI [6]. The expected sociodemographic data, such as age, level of education, social and cultural class, professional status and marital status, were not found linked to adherence to follow-up; nor were material factors, such as the cost of consultation, distance to travel, usability of transport, time spent, general discomfort experienced, or the presence of a “good” local physician, linked to adherence[4]. A recent study based on the US National SCI Database showed lost-to-follow-up rates of 23% and 33% for post-injury years 1 and 5, respectively, and >40% between post-injury years 20 and 35. People with more serious SCIs and those with higher levels of education were nevertheless more likely to adhere to follow-up, whereas people potentially at risk of being marginalized in society had the highest odds of lost to follow-up across all post-injury years [7]. Attempts were also made using various “personality” scales, notably based on the health belief model (HBM), according to which a stimulus is required to influence health-promoting behaviors; fear is clearly expressed, and therefore an association is created between danger and behavior [8]. Another concept is the health locus of control (HLC), which compares an individual’s internal level of control (belief in personal control over maintaining health) versus external control related to luck or destiny

[4]. Questionnaires based on HBM and HLC that assessed adherence to follow-up showed no effect of a specific patient profile.

Therefore, we explored the perceptions of people with SCI about long-term follow-up by using a narrative approach. Our primary objective was to determine the common denominators that lead to adherence or non-adherence to follow-up by focusing on the prevention of skin complications given their frequency and their medical and social consequences.

## **Materials and Methods**

The setting of our study was a neurological physical and rehabilitation medicine (PRM) referral department that treats  $\geq 20$  new SCI cases each year according to a ministerial recommendation [9]. The “*systematic preventive medical follow-up of people after SCI in a specialized setting,*” as we defined it, involves the regular control of the site of injury (X-rays of the spine and MRI of the spinal cord), checking the seat by anthropometric and electronic measurements of sitting pressures, and direct assessment of the skin as well as respiratory, orthopaedic, neurological and social status. The number of appointments is 3 to 4 during the first year, then annually and is adapted over time according to the situation of each individual. The official recommendations are under the 2004 French ministerial circular but also the High Authority of Health via the guidelines for Long-Term Illness (ALD 20) “Paraplegia and Spinal Cord Injury” that lead to a complete refunding of healthcare expenses by the social insurance in this context [10]. Referral departments that organize this type of follow-up for individuals with SCI affirm a preventive vision of their health beyond the initial acquired balance. After the first post-SCI rehabilitation, systematic follow-up is organized in the form of external consultations or hospitalization, depending mainly on the individual’s geographical distance.

We first conducted preparatory work based on a review of the literature [11], which led to the creation of an item inventory table (T2i) of areas likely to affect prevention and follow-up (Additional material). We then performed a bottom-up approach based on semi-directive face-

to-face interviews, which were analyzed in a gradual inductive process by using a thematic approach based on the key principles of grounded theory modified by the confirmatory process of our T2i. Our complete methods concerning inclusion criteria, interviews and data analysis were described in a previous article focusing on social support [12] and are summarized in Figure 1. All participants had completed their initial rehabilitation period in France at least 1 year earlier and were enrolled according to 2 variables: 1) people were or were not followed up and 2) they reported 0 versus  $\geq 1$  medically supervised pressure injuries (PIs) since discharge from rehabilitation. We screened 42 individuals from our specialized consultations list, and they were contacted by the principal investigator (MLF), who outlined the trial to participants and validated their inclusion eligibility. We aimed to determine common denominators of follow-up adherence after SCI rather than analyse diverging factors according to baseline-related variables.

The principal investigator conducted the one-to-one interviews in a neutral location and noted his own reflections generated during the interviews. The interviews were transcribed verbatim and were progressively analysed by a gradual inductive process with on-going coding. The transcriptions were continuously reviewed when new areas emerged and were analysed by using a thematic approach based on the key principles of grounded theory, modified by the confirmatory process of our T2i. A quality unit was set up to continuously control the thematic analysis. Thematic saturation was reached at 28 interviews, and interviewing continued until 32 interviews were conducted. Two individuals refused to participate because of geographical distance.

### *Ethical considerations*

The local ethics committee approved the protocol of the study (Study 25/15-No. 652/2015). The study design was also approved during 3 independent academic qualitative research seminars.

## **Results: interview content analysis**

The demographic and neurological characteristics of participants are in Table 1.

We classified our interview content analysis according to participants' knowledge, attitudes, beliefs and practices (KABP) regarding PIs, their prevention and long-term medical follow-up [13]. The KABP method contributed to our inductive analysis by facilitating classification. Table 2 reports the terms extracted from the verbatim accounts that were used to provide information on the scope of the data. The participants had secondary access to the results and could critically assess them.

### Multiple sources of shared knowledge

#### *Knowledge of PIs and their prevention*

Participants were given information on skin prevention during the first rehabilitation during daily practice that was generally informal. Sometimes, more formalized learning involved therapeutic education sessions, only within referral centres (RCs). The participants often felt that their personal experiences had helped them to “*know their bodies well enough*” and to “*strike a happy medium*” between professionals' opinions and their own opinions. Similarly, emulation from their peers who were further along in their programs often seemed important.

#### *Knowledge of health care organizations and follow-up for SCI*

The notion of an RC for SCI remained a vague concept for most participants, but occasional experiences with 2 types of departments (i.e., specialized and nonspecialized) led the participants to point out their differences. Concerning systematic follow-up, which was only organized in RCs, the participants sometimes requested it to be modulated (*Participant 12, Verbatim 8*: numbers relate to Table 1 and Table 3).

### Attitudes: the result of multiple forms of support

We defined “attitude” as “the disposition toward someone/something, a set of judgments and tendencies that drive behavior”.

### *Attitudes related to the human environment*

Notwithstanding usual good relationships and trust between patients and healthcare professionals, the participants regularly noted that not all members of the teams expressed things in the same way but rather “*introduced (people) to how their life was going to be, little by little*” without “*belittling*” them by always emphasizing their failures. Nevertheless, readmission for PI treatment sometimes created friction between the individual and carers, with the sentiment of infantilization or even shaming rather than one of self-empowerment (*Participant 3, Verbatim 4*)

### *Attitudes related to the structural environment*

The participants often separated the medical and environmental aspects of a PRM department, describing RCs more favourably (than non-RCs) in terms of their medical aspects and conversely for their environmental aspects, emphasizing “*professional competency*” versus “*well-being*”, “*large factory-like centres*” versus “*small friendly centres*”, and “*effective patient rehabilitation time*” versus “*time taken to talk to the people*”, respectively. The infrastructure of the initial rehabilitation department was often mentioned as a very important aspect of the participants’ experiences. Negative memories usually led to anxiety when they had to contact the department again (*Participant 4, Verbatim 5*).

### *Attitudes related to systematic follow-up*

Participants had often been “*changed*” when they had to be readmitted for PI treatment. Those who had not experienced a severe ulcer often described the same concern because the “*cutaneous element remains pervasive as it means confinement to bed*”. For both situations, the key word was mostly “*fear*,” and systematic follow-up was often perceived as “*constraining and reassuring all at once*”. The participants generally no longer wished to “*sleep or eat in the centres again*” and wanted “*to know when they were arriving and when they were leaving*”. Although participants understood the need for follow-up involving

“*tangible*” elements such as revision of the sitting position, they less readily accepted going to a centre for a consultation “*only*”. The participants, notably tetraplegic people, often requested that all tests be scheduled at once (*Participant 13, Verbatim 10*).

### Beliefs ranging from ordinariness to fatality

#### *Beliefs about preventive follow-up*

Participants often saw themselves as “*tough*” or “*ordinary after returning home*” because they were independent and stable. When follow-up was not systematically offered, participants often believed that follow-up by their general practitioner could suffice (*Participant 3, Verbatim 11*).

#### *Beliefs about the occurrence of PIs*

Participants who had experienced PIs sometimes attributed the occurrence of a PI “*out of the blue like that, seemingly overnight*” to its almost inevitable nature, for example, relating a PI to “*the buttocks having become more fragile over time*” rather than to direct avoidable causes.

### Routine practices to be individually adapted

#### *Skin prevention practices*

Self-inspection of the buttocks appeared to be practiced universally and was often described as more of a habit than a conscious effort. A severe PI was always considered an event, and the participants said they usually reinforced their prevention practices afterwards. The tiring accumulation of “*everything that has to be done in a day when you have a spinal cord injury*” sometimes led to prioritizing (*Participant 12, Verbatim 12*).

#### *Follow-up practices*

PRM centres were usually perceived as being protective, and early systematic follow-up was seen as reassuring (*Participant 3, Verbatim 13*).

*Participant 4*, who was followed up regularly without complications, described early follow-up as a “*creative base*” that should initially stem from an “*enjoyable objective, whether school-, university- or work-related. A project...*”. However, beyond early follow-up, the participants did not necessarily see the benefit of systematic follow-up. Some participants noted the usefulness of long-term specialist advice (*Participant 15, Verbatim 7*).

## **Discussion**

Questionnaires developed based on the HBM tested specifically in people with SCI were not ultimately discriminant in predicting adherence to follow-up. Canupp et al. showed that people with SCI fully believed in the risk of complications and the importance of regular follow-up but thought it unlikely that they would present severe skin complications within 5 years [4]. We consequently used a narrative approach. Table 3 presents the verbatim responses and observations reported in our results as examples of the transition between the content analysis and our theoretical model. Three common denominators emerged: the appropriation of and readiness for prevention and the modulation of follow-up.

### ***Appropriation: establishing one’s “own” truth regarding risk and prevention***

Even with good knowledge of the risk of complications, participants did not necessarily engage in systematic preventive follow-up. Previous studies have shown that standard practices, such as skin monitoring, do not strictly differentiate people with SCI with or without relapse [14]. Other KABP studies have also shown a gap between knowledge of a risk and preventive practices [13, 15]. People appropriate their own truths that are adapted to their perceptions of their health, functioning and personal experience.

#### *The “formal” truth*

Scientific evidence has defined secondary conditions and advances in treatment and care that have significantly improved prognosis with SCI [16-18]. Medical experts have also recommended systematic preventive follow-up, notably in the field of neurology because of a

permanent risk of secondary imbalance [19, 20]. However, people often do not have access to these specialized organizations for various reasons (lack of information, geographical barriers, etc.) or do not adhere closely to this preventive, medicalized vision [16]. Studies of treatment compliance in people with chronic diseases also suggested an association between lack of early and follow-up information, understanding of the information by the individual and treatment escape [21, 22]. Regarding the differences between what participants were told in specialized and nonspecialized environments, they were not necessarily able to put things in perspective. Indeed, a previously described problem concerning health maintenance was access to competent care [23]. Information on secondary conditions after SCI was provided in our study and in the literature in specialist units via structured therapeutic education sessions [24-26].

### *The “informal” truth*

In our study, peers acted as a source of emulation from the time of the initial rehabilitation or when people were hospitalized for skin complications. Garrino et al. described “living by proxy” based on the pathways of other people with SCI, which enabled individuals to plan the stages of their own progression. Participants claimed to receive information from their peers that was not always reassuring and to hear about difficult situations and how the people involved faced them [24]. A high proportion of “first” episodes among people with SCI receiving treatment for a PI suggested that this event was a sufficiently important “lesson” [8, 27]. The fear described by our participants could be related to their perceived vulnerability — a notion of the HBM — to PIs. King et al. also reported that people with SCI described that something “terrible” was likely to occur in the event of a PI, associated with isolation and depression [8]. Informed awareness of the consequences of a PI could be a trigger for systematic follow-up, as our participants described it. Over time, our participants called for their personal experiences to be accounted for, which reflects the relation of “self-expertise” to “responsibility” in the literature [8]. The time-consuming nature of skin prevention described in our study was also previously reported [8]. Our participants factored the aspect

of “comfort” into daily management, which was likely to compete with the “safety” aspects upheld by healthcare professionals.

### ***Readiness: integrating various life stages after SCI***

#### *Early follow-up*

The apparent paradox between the *discharge* of a person who is able to manage independently and their early return for follow-up is linked to the long-term unstable balance caused by SCI [28]. The time after initial rehabilitation seems to not cause much anxiety in medical terms [4]. Our participants discussed discharge from initial rehabilitation in relation to social reinsertion issues. Follow-up in the “protective” environment of the PRM centre enabled them to feel reassured, on the condition that follow-up was offered. Indeed, one of the main causes of non-adherence to treatment is believed to be the absence of the identification of people who require it [29]. Early follow-up was even said to be a “creative base” in our study if it was associated with a tangible personal “project”, like a “launching pad”. A similar notion was described by other authors in the time between preparing to return home during the rehabilitation period and the effective return to real life [30]. Additionally, the participants in our study mentioned different phases during their lives after SCI and different behaviors with respect to prevention.

#### *Long-term follow-up*

According to the literature, the usefulness of follow-up specifically related to skin prevention is to remind people of certain information, to maintain equipment and to adapt relevant information to the current life phase. King et al. justified long-term follow-up based on the difficulty of absorbing all the necessary information during the initial rehabilitation phase after SCI, as our participants also explained. After returning to real life, follow-up visits were an opportunity to periodically evaluate, at any stage of the person’s life, their beliefs and daily routines and to address any obstacles and skepticism in relation to care [8]. Drop-out from follow-up is believed to increase over time [4, 7], but in our study, the occurrence of a severe

PI often led to more systematic follow-up re-established at the waning of a rehospitalization for treatment. As described by Anselm Strauss in relation to the “negotiated” order of the hospital, a specific period or expiration date is often included in an agreement [31]. However, the contract for follow-up for SCI is a tacit agreement. Manns and May related various “life moments” to the notion of readiness to optimize long-term health. People with SCI were believed to be “ready” to absorb information about prevention at a given time according to their medical and social situations [23].

### ***Modulation: negotiating systematic follow-up after SCI***

In the literature, simply telling paraplegic or tetraplegic people that they are “in good health” after a year has not been clearly found sufficient to promote adherence to follow-up. Some authors have described the need for a “return on investment” for individuals [4]. The theories of interactionism describe the “mutually beneficial” relationship and suggest that people “bargain” with a number of healthcare professionals to influence their treatment type and method [31 (e.g., tetraplegic participants in our study notably for geographical distance), which could support previous results [7]. During readmission to RCs for complications, our participants had to yield to the doctrine of care in a “military” manner without ever being in a position of power to negotiate adjustments.

Participants expressed a strong desire for negotiation to make the organization of follow-up acceptable in light of their daily obligations. Consequently, another area for negotiation was the “modulation” of follow-up, such as by activating it only in the event of a complication. Jones et al. also reported the opinions of individuals who wanted appointments close together in the event of complications but removed follow-up from the main aim of prevention [32]. According to our participants, the ability to modulate follow-up depended on the competency of the physician with whom negotiation had to occur. Interactionist theories suggest that doctors use a general model to specify what they will do, how it will be effective and the resources available to individuals. A “trajectory scheme” is “thought up” by the doctor that is based on official recommendations when applicable but is not planned in detail; therefore, it

leaves room for negotiation [33]. According to Strauss et al., the term “trajectory” refers to any “work organization” established to follow the course of the disease and the repercussions on those involved [31]. Thus, the trajectories could be modulated according to life cycles and lifestyles, and their participation is necessary for their formatting.

### ***Synthesis: a conceptual framework***

We recommend applying our results in a pragmatic manner by a final conceptual preventive follow-up framework (Figure 2), which is based on the perspective of people with SCI. We referred to a conceptual framework developed by Manns and May based on the transtheoretical model of health behavior change from the HBM modified with aspects related to individual behaviours such as general health, social and demographic history and the effect of triggering factors. The Manns and May conceptual framework has a pyramidal form, the summit of which is the “long-term maintenance and improvement of health in people with SCI” [23].

Our conceptual framework was based on a number of initial education sessions grounded in evidence-based management within referral centres. The infrastructure of the initial rehabilitation department was an important part of participants’ experiences and was related to the risk of an individual rejecting the offer for preventive follow-up. The specialized PRM centre environment must always ensure that access to health care is available and that the individual is ready to actively consider the implementation of prevention strategies. Thus, people with SCI can comply with follow-up when they understand the preventive aspect and when the follow-up is organized and modulated according to explicit medical criteria over the years post-SCI. The referral should remain available at any time and should be easy to access; the individual should be clearly informed of the availability of the referral, especially for preventive care, as well as for curative treatments within situations with the least complications possible. Staff in specialist units must participate in specialist continuing training for personnel to acquire and refresh their knowledge of SCI and communication. Similarly, continuing therapeutic education must involve peers with SCI and must be offered

again throughout the life to update their knowledge, functioning and practices. We kept the “long-term health promotion” item from the Manns and May conceptual framework as the ultimate objective.

After initial management in RCs, appropriation and modulation interfering with these pathways also depend on a combination of major context-related factors (i.e., environmental and personal factors such as those described in the International Classification of Functioning, Disability and Health that interact with and influence long-term follow-up) [34]. Appropriation is directly related to the individual and especially focuses on functioning, readiness and the various routes of permanent access to RCs. Modulation is related to the medical sphere linked to the individual and is situated between follow-up and long-term improvement of health.

### ***Study limitations***

We did not specifically study the interference of likely significant psychological factors in adherence to follow-up. Studies that have used personality tests have not been able to determine specific profiles [4]. Our study was monocentric with a risk of selection bias, but the bias was controlled by the incorporation of the outside perspectives of SCI specialists. The participants we included were all in contact with a study RC at some point, so we did not assess the perceptions of those who never had access to RCs. Having a principal investigator who was a physician and who could both care for patients and conduct interviews with them was one of the main topics of discussion. It was concluded that the principal investigator had completed sufficient theoretical and hands-on training and that the long-term SCI follow-up could allow the creation of trusting relationships with the patients, which would likely facilitate participants’ expression of their individual perceptions. A multidisciplinary unit for quality control of the analysis was established and validated the analysis.

### **Conclusions**

Our study showed that the readiness of people with SCI was a central notion in long-term follow-up. Therefore, people with SCI can comply with follow-up when they understand the preventive aspect and when this follow-up may be modulated. This readiness was also affected by context-related appropriation, which was directly related to the individual and their functioning, and modulation, which is related to the individual's specialized medical sphere. Finally, further effective changes should be implemented by the development of police briefs and stakeholder dialogues within the concept of the Learning Health System at an international level with a notable perspective on long-term health promotion after SCI [35, 36].

## FIGURES

**Figure 1.** Study design. T2i, inventory table of items; SCI, spinal cord injury; PRM, physical and rehabilitation medicine; PI, pressure injury; KABP, knowledge, attitudes, beliefs, practices.

- medical follow-up (current systematic medical follow-up ongoing for the participant at the time of the study) = yes / no

- previous PI ( $\geq 1$  medically supervised pressure injury since discharge from rehabilitation) = yes / no



= chronological sequence

= control by the quality unit

**Figure 2.** Conceptual framework for promoting preventive follow-up from the viewpoint of people with SCI. EBMgt, evidence-based management; SCTP, specialist continuing training for personnel; PCTE, patient continuing therapeutic education

**Additional material.** Item inventory table.

**Conflict of interest.** None declared.

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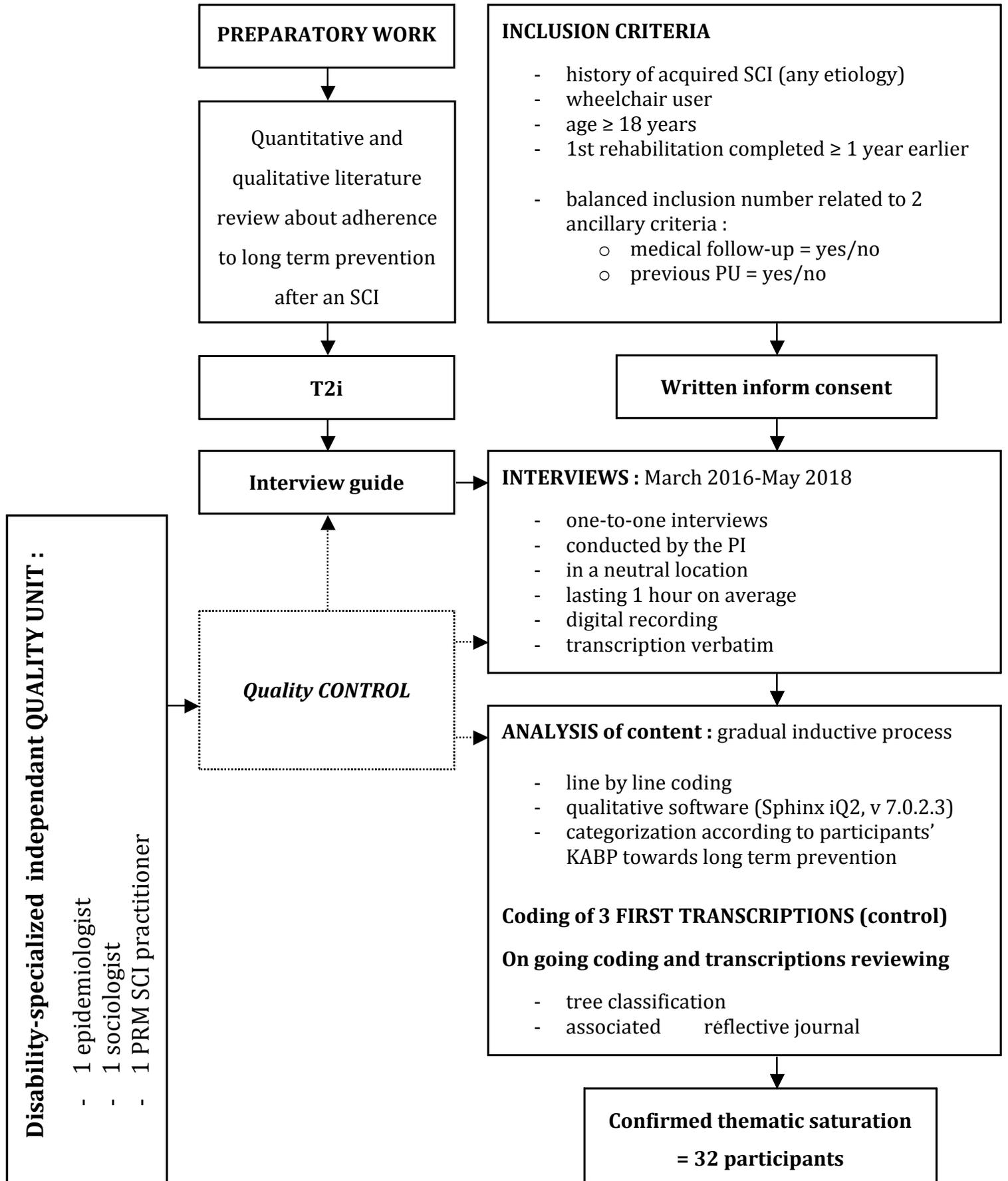
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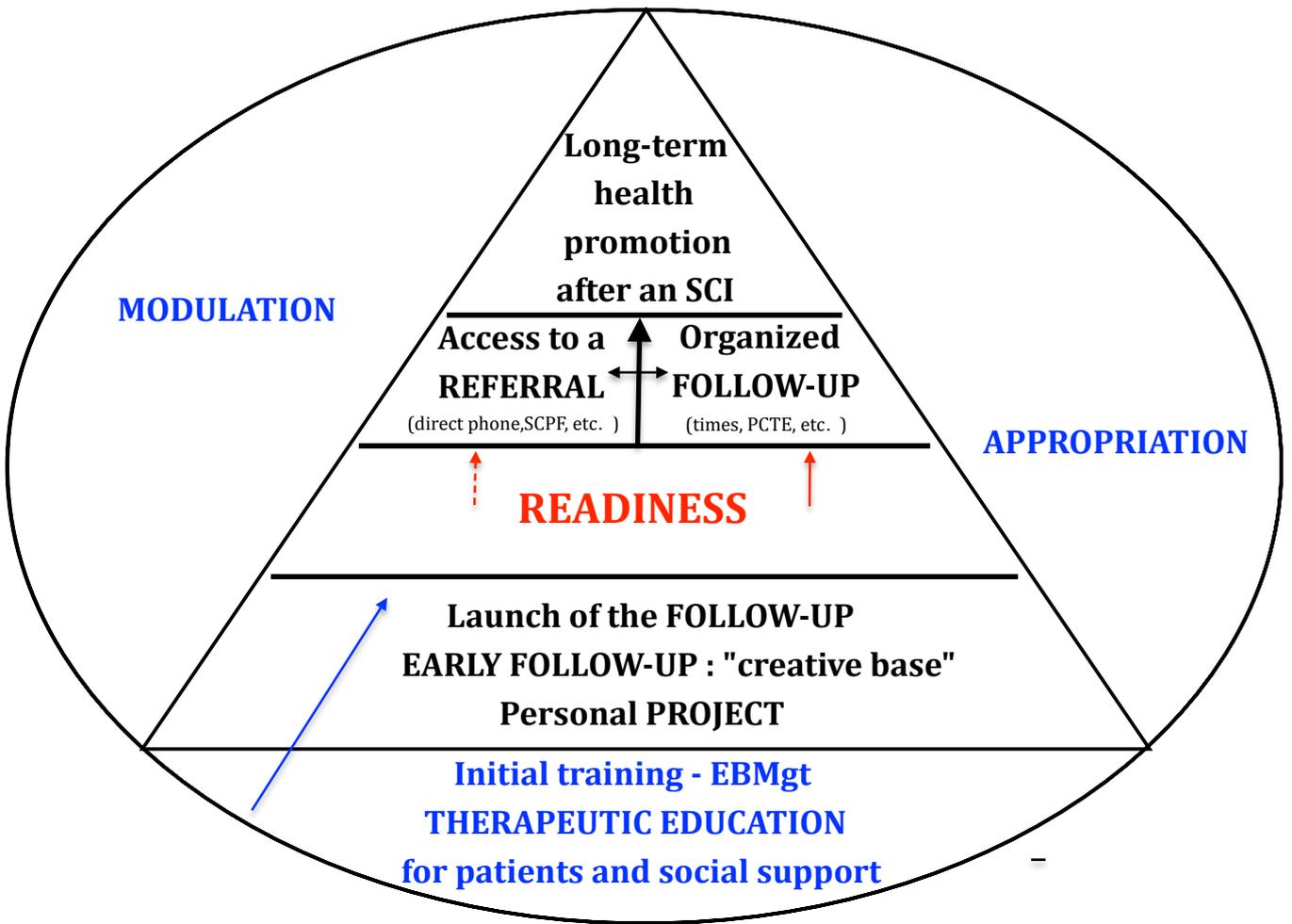
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**Table 1.** Study participants.

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

31	M	58	1993	T	Th10	A	NFU	PU	RC
32	M	34	2005	T	C5	A	NFU	NPU	RC

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M, male; F, female; NLI, neurological level of injury; AIS, American Spinal Injury Association Impairment Scale; FU, follow-up; NFU, no follow-up; PU, pressure ulcer; NPU, no pressure ulcer; RC, referral centre; NRC, no referral centre

**Table 2.** Frequency of the data from the verbatim accounts.

<b>Terms indicating frequency</b>	<b>Occurrence in the verbatim accounts (%)</b>
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.

No.	Verbatim Quotation/Observation	Comments	Domain
1	Emulation of their peers who were further along in their programs often appeared to be important	Hospitalized peers <i>at any moment</i> in their own SCI histories acted <i>as a source of informal exchange</i> from the time of the initial rehabilitation or when <b>participants</b> were hospitalized for skin complications	Appropriation
2	Occasional successive experience of two types of departments (i.e., specialized and nonspecialized departments) led the participants to point out their differences more	Subsequent individual experiences within specialized or nonspecialized centers led participants <i>to better distinguish the two types of centers</i> , notably in terms of training and follow-up	Appropriation
3	The participants regularly noted that not all the members of the teams expressed things in the same way	Various health professionals <i>may not use the same words</i> (e.g., formal or informal discourse) and may even use more or less positive words, but not definitively cleaving talk	Appropriation
4	“When you know what it’s like to live outside, when you have your routine, etc., returning to a rehabilitation center is a little like returning to military service, like you have to do this like that. (...) It’s not like in real life. (...) I used to say, ‘Hang on, I know that you know what you’re doing, but I do too’. It’s like going back to the very first days after becoming disabled...”	Disputes between <b>the person</b> and professional in case of a rehospitalization - notably for the treatment of a complication -, illustrate the <i>importance to strike a right balance</i> between orthodox training and adaptation to real life after discharge from the first rehabilitation	Appropriation
5	“It’s not always easy to come here (for follow-up) because I have really, really bad memories of it. But it is close by, and they are competent, it has to be said...”	The participants often <i>separated the various aspects</i> of a PMR department, but the <i>overall experience within the one providing a medical follow-up</i> often stood out as being very important to make choices	Appropriation
6	“The cutaneous element remains a pervasive concern, as it means confinement to bed”	<i>Bad experiences or the perceived risk</i> of their occurrence may enhance <i>fear of complications</i>	Appropriation
7	“It’s very reassuring. (...) It’s a little like an occupational health check-up. We get a “passed” stamp, and we’re off again. On the day of the consultation, I can talk about all my little problems and questions, even if they are unfounded. But at least I have someone who’s there to reassure me in person. As I know there’s a center, may as well use it!”	Follow-up may be part of a <i>give-and-take relationship</i>	Appropriation
8	“It’s a good thing to keep an eye on things and to have follow-up (...), even if it bothers me at times. (...) and yes, I’d like it to be a little less often than every year”.	Even when <i>acknowledging the benefit</i> of a systematic follow-up, people may <i>negotiate organizational adjustments</i>	Appropriation Modulation
9	The need for follow-up involved “ <i>tangible</i> ” elements	Follow-up not only can serve to check that people are in good health for a preventive approach but also should provide <i>concrete benefits</i>	Modulation

No.	Verbatim Quotation/Observation	Comments	Domain
10	<p>“What annoyed me was to have to travel. (...) Also, everything was separate. I had to go there on one day, then come back two or three days later for another appointment. (...) Then we have to go back a week later; it takes me an hour to get there (...). It’s also sometimes very early in the morning. It’s not easy organization-wise”.</p>	<p>People may <i>ask for organizational adjustments</i> based on the perceived benefit compared to the induced constraints</p>	Modulation
11	<p>“I was followed up by a (general) practitioner who was very good. I didn’t see the need for follow-up for my disability. I think the more time that goes by, the more we are living a ‘normal life’, and if everything’s fine, everything’s fine!”</p>	<p>Within everyday life, people may have difficulties <i>making sense of things</i> between general healthcare access and specific follow-up for an SCI</p>	Modulation Readiness
12	<p>“I took a building designer training course. There was one week’s training left, and I had a week to submit our paper. I got (...) a small pressure ulcer. I said to myself, either I get through the two weeks, or I stop, and I don’t know how long I’ll have to stop for, and I wondered, ‘When will I be able to finish the training?’ I neglected my health a little. I preferred to get through the two weeks’ training, and I spent two months in bed at home afterwards. And I passed my exam, great!”</p>	<p>The accumulation of everything that people with an SCI have to do may lead to <i>prioritizing</i></p>	Readiness
13	<p>“When we discussed my case with the physical medicine specialist, (...) we talked about a lot of things. (...) When you are in a rehabilitation center, you (the <b>person</b>) are all the same in a very shielded environment. When you go back out into real life, from one day to the next, and you have to do your shopping, to begin with, I had a lot of difficulties being on my own in a shop. It’s true that these connections enable us to get our bearings, to know where the paraplegia is, how we feel and also how daily life is”.</p>	<p>The context of follow-up in the “protective” environment of a PMR center enabled people to feel reassured after discharge from initial rehabilitation</p>	Readiness
14	<p>‘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. . .’ (in ref.11)</p>	<p><b>People</b> may be <i>ready</i> to accept third-party help and actively consider the implementation of prevention strategies according to various events in their lives</p>	Readiness