

# Towards personalized care for persons with spinal cord injury: a study on patients' perceptions

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**Objective/background:** A newly designed Spinal Cord Unit (SCU) was set up at the Orthopedic Traumatology Center (OTC), Turin, Italy, in July 2007. With the relocation of the SCU came the need to reorganize and improve the delivery of its services. The study reported here is a preliminary part of a project entitled 'Experimentation and evaluation of personalized healthcare for patients with spinal cord injury', which is a component of an overarching program of targeted research into healthcare funded by the Piedmont Region in 2006. The aim of this study was to assess the perception of care by patients with spinal cord injury (SCI) by collecting important data in order to determine whether an integrated and personalized care pathway could be effective both in hospital and in a rehabilitation setting.

**Design:** Qualitative research study. The interview format was based on a narrative approach.

**Methods:** Qualitative in-depth semi-structured interviews were conducted with 21 patients with SCI. Qualitative content analysis was used to identify categories and themes arising from the data.

**Results:** Six main categories emerged from the perspectives of patients: expectations of rehabilitation care, impact and welcome, relationship with nurses and their involvement in treatment, relationship with physical therapists and participation in rehabilitation programs, relationship with physicians and their availability and attendance, and imparting of information on injury and rehabilitation outcomes. Care was the aspect new patients admitted to the SCU found most important. When closer relationships with staff formed, the healthcare professionals became an essential support. Patients with SCI commonly stated that receiving explicit information was necessary for accepting their condition.

**Conclusions:** Analysis of the patients' perceptions revealed a wealth of details on their experience in the SCU and the need for flexible planning of care time in particular. Incorporating the patients' perceptions into a new care model could increase professionals' awareness of patients' needs and provide a useful basis for constructing a personalized care plan.

**Keywords:** Spinal cord injuries, Disability, Physical therapy, Advocacy, Patient satisfaction, Rehabilitation, Spinal cord injury nursing care models, Qualitative research, Healthcare system

## Introduction

Since 1988, the Functional Rehabilitation Center (FRC) of the Orthopedic Traumatology Center (OTC), Turin, has been caring for people with spinal cord injury (SCI) in the sub-acute or chronic clinical stage. In July 2007, the Spinal Cord Unit (SCU) operating within the FRC was transferred to a new facility. With this move, the total bed capacity was expanded from 25 to 46 beds in two wards where patients with SCI received

care from the acute stage to discharge home after having completed a rehabilitation program.

The relocation of the SCU brought about the need for reorganization and improvement of services for persons with SCI. Subsequently, a study was carried out to evaluate the criticalities of the care model and to find ways to revise it within a broader perspective of health management. To do this, the project entitled 'Experimentation and evaluation of personalized care for patients with spinal cord injury' was launched. The project was part of targeted healthcare research funded by the Piedmont Region in 2006. The current

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study was core component of the initial phase of this action-research project, which used context analysis to identify strengths and weaknesses, to propose solutions, and to implement changes by assessing processes and outcomes. The aim of the project was to identify the strengths of the previous model from which new organizational methods and tools could be developed and presented in a 3-day training course for the healthcare professionals (physicians, nurses, rehabilitation, and support staff) working at the SCU.

A personalized rehabilitation care model reflects the needs and expectations of people with SCI, set in the context of their family and life and within a prospective of return to the community. Care also reflects the real potential of patients, their unique strengths, problems, and coping abilities, as well as the progressive changes in goals they aim for.

The aim of this study was to assess SCI patients' perception of care by collecting important data to improve the current hospital and rehabilitative model of care. It is believed that an approach which draws on patients' viewpoints of how they experience the care they receive will enable us to further improve services and to overcome difficulties in delivering them.

### Review of the literature

Assessment of patients' perception of care is difficult to analyze owing to many different services provided and the complex interaction with many providers delivering them. Patient satisfaction can be measured according to a service-centered model, wherein the degree of satisfaction is rated in terms of care as an end product. The research following this model measures patient satisfaction against a yardstick of user criteria for services rendered and possible discrepancies. In brief, satisfaction lies at the point where patients' expectations of ideal care match their perception of the care they actually receive.

In analyses of patient satisfaction with delivery of care, patients were asked to describe health priorities and give detailed descriptions of their experiences. Concato and Feinstein<sup>1</sup> used patients' responses to develop a taxonomy for classifying patient satisfaction. The taxonomy was divided into five main areas: medical staff, non-medical staff, clinical staff, related services, and the setting. However, additional elements need to be taken as quality indicators when evaluating the perceptions of people with SCI as regards mobility limitation and quality of life, for example.<sup>2-4</sup>

Various studies have analyzed patients' needs, focusing on those considered most relevant to SCI patients and the importance placed on patient participation for

the design of rehabilitation programs.<sup>5,6</sup> These studies heralded the rights stated in the United Nations Convention on the Rights of Persons with Disabilities.<sup>7</sup> Working in this direction, Sand *et al.*<sup>8</sup> reported on how patients with SCI experienced rehabilitation and the three priority areas they felt were most important for them: participation, informativeness, and relationship.

As regards participation, Tooth *et al.*<sup>9</sup> observed that patient satisfaction with rehabilitation and quality of life after rehabilitation was more closely linked to greater patient involvement in care processes and rehabilitation than to the severity of the injury. Analyzing patient interviews, Pellat<sup>10</sup> found that patient involvement was key to the rehabilitation process. Dixon *et al.*<sup>11</sup> exploring various constructs of self-efficacy in neurological rehabilitation, discovered several recurrent themes: self-reliance and independence. Furthermore, patients recognized the magnitude of willpower, making time to take an active role and working in partnership with the multidisciplinary team; being able to recognize for themselves that they were making progress and that they valued external reassurance on this from other patients, staff, and visitors. One of the difficulties that interfered with developing self-efficacy in rehabilitation was structuring their time.

In a study on a goal-planning project in an SCU, MacLeod and Macleod<sup>12</sup> found a significant correlation between perceived information and successful outcome of rehabilitation. Within a broader scope, informativeness comprises the development of skills enabling patients to become experts of their own abilities,<sup>13</sup> adopt coping strategies,<sup>2</sup> and educate others as regards themselves.<sup>14</sup>

When defining their satisfaction with care, patients give high priority to forming relationships with others by building partnerships through communication, setting balances of power, and sensing staff attitude towards disability.<sup>15</sup>

This paper addresses the question: to what extent can analysis of patients' perception of their experience of care and rehabilitation contribute to the development of a personalized care plan?

### Methods

Patients' perception of care was assessed by means of qualitative in-depth semi-structured interviews,<sup>16</sup> taking a narrative approach.<sup>17</sup> The topics were decided beforehand. From a literature search, keywords were selected according to word frequency and/or relevance, and then grouped by conceptual areas: participation, informativeness, and relationship. Topics specific to

the care and rehabilitation of people with SCI were identified, the idea being that during long hospital stays patients gained deeper insights into and more complex opinions about the care they had received. The aim here was to collect data on the patients' point of view, from which their lives could be described and understood.<sup>17</sup>

Subjects for the study were initially contacted by telephone. They were informed about the purpose of the study, that the content of the interviews would remain anonymous, and that their written informed consent was required. The interview items investigated patients' expectations about the SCU, focusing on the three areas described above. All interviews were conducted by the second author, tape recorded (mean duration 45 minutes) at the patient's home, transcribed, and filed as hard copies. The study protocol was approved by the hospital ethics committee before the beginning of the study.

### Sample

Interviewees were selected from patients admitted to the SCU between 2005 and 2006, who had recovered from the post-traumatic acute phase, were clinically stable, had started therapy and rehabilitation programs, and had been discharged more than 3 months before the time of the interview (February 2007). Of the 24 patients selected, 21 (5 women and 16 men; age range, 34–63 years for women and 19–70 for men; length of stay, 3–20 months; mean length of stay, 8.7 months) accepted to be interviewed (Table 1).

### Data analysis

Conventional content analysis was used to identify and code categories arising from the interviews.<sup>18</sup> The data were analyzed by two researchers (NC and LG). The interviews were read through several times to gain a sense of the whole. The participants' comments about their experience at the SCU, which constituted the unit of analysis, were extracted and grouped together into one text. Each author read the transcripts separately and used open coding to break down the data into units of information and to code them. The categories were compared and discussed among the authors. The results of the data analysis were summarized and set up for the selected interview of the participants. This process resulted in minor revision and modification of the definitions of the categories and themes.

### Results

A total of 21 patients were interviewed. Six main categories and two themes emerged from the perspectives of patients (Table 2). Each category illustrates a relevant topic on the patients' perception that could contribute to the successful implementation of a personalized care model. The six categories were: expectations of rehabilitation care, impact and welcome, relationship with nurses and involvement in treatment, relationship with physical therapists and patients' participation in the rehabilitation program, relationship with physicians and their attendance, and delivery of information as regards injury and rehabilitation outcomes. In addition, two key themes emerged from the

**Table 1 Participant characteristics**

Age	Gender	Level of injury	Education	Employment pre-injury	Marital status
35	M	T8 complete	Senior high school diploma	Full time	Single
64	F	T10 incomplete	Junior high school diploma	Unemployed	Married
63	M	T12 complete	Senior high school diploma	Full time	Single
55	M	T12 complete	Junior high school diploma	Full time	Married
20	M	T12 complete	Junior high school diploma	Full time	Single
45	M	T12 complete	Junior high school diploma	Full time	Married
44	M	T12 complete	University degree	Full time	Single
50	F	D4 complete	Junior high school diploma	Unemployed	Married
35	M	T3 complete	Senior high school diploma	Full time	Single
52	M	C4 incomplete	University degree	Full time	Married
27	M	T6 complete	Junior high school diploma	Full time	Single
33	F	T1 complete	Junior high school diploma	Full time	Single
45	M	T4 complete	Junior high school diploma	Full time	Married
53	F	T5 complete	Senior high school diploma	Unemployed	Married
25	M	C6 complete	Senior high school diploma	Full time	Single
56	M	C5 incomplete	Junior high school diploma	Full time	Married
60	F	C5 incomplete	Junior high school diploma	Pensioner	Separated
61	M	L1 incomplete	Junior high school diploma	Full time	Married
45	M	T2 complete	Senior high school diploma	Full time	Married
30	M	C6 complete	Junior high school diploma	Full time	Single
45	M	D4 complete	Senior high school diploma	Full time	Married

**Table 2 Categories and themes identified the perspectives of the participants**

<i>Categories</i>	<i>Excerpt from interviews</i>
1 Expectations of rehabilitation care	You expect quite a bit of efficiency; I'm on my way there, I will wake up at 8 a.m., I'll work out in the gym for three hours, then two more hours gym in the afternoon, and after that there will be a series of other activities I'll have to do. (patient 1)
2 Impact and welcome	Everybody was looking at us. As soon as I arrived, I had 6 or 7 people around me. I was carefully washed, medicated and dressed when necessary. (patient 11)
3 Relationship with nurses and involvement in treatment	Actually, I was getting on very well with two or three nurses. In fact, when they were on duty I would go into their room and talk with them. If there was something I needed, I felt more at ease if I could ask them. (patient 13)
4 Relationship with physical therapists and patients' participation in the rehabilitation program	They never forced me to do anything I didn't want to; they always tried to adapt the program to my needs. (patient 17)
5 Relationship with physicians and their availability and attendance	When you say, "Doctor, I wanted to ask you something." again and again, and they really are available and don't just say, "Come back later for an appointment" (patient 12)
6 Delivery of information about injury and outcomes	I wanted a final confirmation in order to cope with what would come. (patient 1)
 <i>Themes</i>	
1 Concept of holistic care	
2 Availability of information	

data: the concept of holistic care and the availability of information.

*Expectations of rehabilitation care*

Patients' expectations were strongly influenced by how they perceived the rehabilitation facility and the modality of rehabilitation care. During their initial hospitalization, the patients developed expectations of the environment where they would go for follow-up therapy and rehabilitation.

*They were talking about a nice place. They said there will be other people like myself; I will make friends; it won't be like a hospital but more like being at home with my family. (patient 5)*

In this context, 'environment' comprises a setting, an atmosphere, activities, and communication models. Patients with an SCI expected to spend treatment and rehabilitation time in a more familiar and less clinical medicalized environment as compared to the hospital ward. Expectations also centered on what the activities were going to be like.

*I knew I wasn't going to do much during my first week of hospitalization as a patient with a SCI whether in a place like the OTC or any other hospital. Even with the use of a wheelchair, very little rehabilitation is done. (patient 1)*

Patients expected a big change, mainly as regards their active involvement in the rehabilitation program at the FRC where they could engage in care and not just be cured.

*It's a place where you work; you need to be autonomous and learn many things. (patient 14)*

In some cases, patients' expectations of the FRC went beyond the actual possibility of improving their condition. In others, their wish for immediate and successful recovery was precisely what they expected of a very efficient place (Table 2, quote 1).

*Impact and welcome*

Coherent with their expectations, the first thing patients noticed when arriving at FRC was how much it differed from the hospital environment. In comparison, the physical appearance of the ward was seen as being neither very welcoming nor entirely accessible. However, differences went beyond these aspects. At the FRC, patients felt a noticeable change in what they were asked to do and a shift in emphasis on rehabilitation.

*In 24 hours they taught me things I had never learned before in the 45 days on the ward; very simple things, such as how to move from my bed to a wheelchair and the other way around. They taught me that in 24 hours, so I said, 'Whoa! Amazing, it can really take your breath away!' (patient 3)*

Right from the start, the patients were asked to do all they could on their own; they were constantly encouraged to put into practice the abilities and skills they had acquired during rehabilitation.

*They were a bit strict with us because they wanted us to learn how to do things on our own and they*

*weren't very happy if we said we couldn't do something.* (patient 2)

The first days at the SCU were both emotionally intense and tiring as the patients had to learn new skills. Moreover, the impact with the center was dramatic for many patients, since it was the first time they had encountered other people with disabilities. Furthermore, most were not yet autonomous in their activities of daily living.

*During the first days, I had problems with moving around autonomously. I was in bed and had to call for everything.* (patient 19)

One of the most frequent feelings was that of 'being worn out'.

*Because one thing is meeting one person alone: you can learn immediately. Another is when you meet 10 or more people altogether; that makes you feel a bit weary.* (patient 14)

The perspective of a long hospital stay, together with the new environment, made the first days particularly critical.

*The first days were quite hard, partly because I didn't know anyone there. Besides that, I was in a different physical condition, not very autonomous. I could barely feed myself; I could push my wheelchair only with great effort. The first days were a bit tough.* (patient 15)

During the early period of adaptation, the patients started to approach SCU staff who practiced a series of welcome procedures.

*Upon entering the room, staff normally introduced themselves and said that we could call each other by our first names.* (patient 14)

The patients were informed as to what their life at the SCU was going to be like. Most remembered being welcomed upon their arrival (Table 2, quote 2).

Through the primary care procedures they received, the patients could indirectly familiarize themselves with the new environment.

*One thing that impressed me was that as soon as I was settled in, they bathed me. That was something I wasn't expecting, it was a real surprise.* (patient 13)

Sometimes, however, the patients did not comment on the explanations they had received on admission.

### *Relationship with nurses and involvement in treatment*

Nursing care is fundamental at the FRC. Nurses are the first persons patients meet on arrival at the center and on whom they rely during their stay.

*Nurses look after us and very often establish a very close relationship with us.* (patient 1)

The type of activities nurses perform also make them a reference point.

Patients' comments on nursing care reflected their total dependence on the nurses for their everyday needs, both in the initial stage and over the entire course of hospitalization.

*Starting with the morning shower, I was washed every day because I couldn't do it myself [...]. I had to be dressed. I remember them feeding me yogurt and coffee with a teaspoon.* (patient 10)

Dependence on the nurses generated feelings of both gratitude and frustration. A source of frustration was nurses' behavior that was considered inadequate and felt to increase the already heavy burden, causing misunderstandings and non-acceptance. Frustration was mainly referred by quadriplegic patients who required special assistance and care during their initial hospitalization period.

*They couldn't understand that we sometimes needed to have a shower a bit more often and that we couldn't be washed only when they wanted to.* (patient 15)

On the topic of relationships, most patients recalled a good atmosphere overall. The extremely informal atmosphere, together with the long hospital stay, helped to foster personal relationships which in most cases were described as friendships.

*We're still on good terms and hug each other when we meet...* (patient 6)

*They were very caring to the point that even when I was deep in thought they would come to have a chat with me...* (patient 9)

It was often underlined how this type of relationship appeared atypical for a hospital ward.

The relationships appeared to work on two different levels. On one level, the extremely informal and cheerful atmosphere at the center was conducive for engaging in friendly conversations between patients and staff during coffee breaks, for instance.

*It was a rather cheerful place, as I was saying. Ok, I'm in a hospital but at least it's not like being in a morgue!... (patient 18)*

On another level, the situation of working together over an extended period of time invariably led to building a network of stronger relationships where the nurses played a supportive role or became a reference point for patients who sought help or were just looking for someone to speak to (Table 2, quote 3).

Two critical points were nurses' attitudes and work organization. Criticalities in nursing care were related to an intricate knot of episodes, explanations, and complaints. Many patients underlined how even minor episodes of inadequate care could arouse frustration if they persisted during a long hospital stay in an already complex situation. The criticalities were related to the organization of care and not keeping to set time schedules.

*In the morning, the nurse would wake me. Especially at the beginning, I needed help with my daily activities. The nurse had maybe started from the last room, and by 10 a.m. I still had to go to the gym, and I had wasted my time doing nothing. (patient 19)*

Although dependent on the nurses, the patients were the ones who ultimately judged and controlled; and while they were a target of care, at the same time they had to compensate for organizational shortcomings.

#### *Relationship with physical therapists and patients' participation in the rehabilitation program*

Physical therapy was mainly linked to patient participation. Patients' involvement in the gym during their rehabilitation program was an issue that constantly emerged. Right from the beginning, patients perceived their rehabilitation program as an ongoing process, an interweaving of care, shared knowledge between patient and therapist, an exchange of information and explanation, assessment of improvement, and redefinition of the program.

*Physical therapists had to organize their work on my rehabilitation program, but they waited for me to arrive because they wanted to see my condition first. (patient 13)*

Rehabilitation was not limited to a single session of therapy, but rather involved patients in making decisions that oriented their recovery process (Table 2, quote 4).

A dysfunctional patient–therapist relationship was sometimes an obstacle to progress on the rehabilitation program.

*Every physical therapist has his/her own method and theory, it's all very subjective. (patient 10)*

The opportunity to negotiate goals was sometimes conceded but only after having been won by the patients. The patient–therapist relationship was based on reciprocal trust. On the one hand, the patients realized that only by placing complete trust in their therapists would lead to successful rehabilitation. Sometimes indifference or indolence was interpreted by patients as a lack of interest in their rehabilitation, leaving them with the impression that they had to manage their rehabilitation process on their own, at least emotionally.

*So I started doing things on my own. I realized what really cheered me up [...] and at the same time I was doing the therapist a favor if I didn't go. (patient 10)*

On the other hand, the trust the physical therapists showed in the patients' potential fueled their motivation to recover and become autonomous. Interaction with therapists had to be judiciously managed, trying to balance contending demands for self-management and the need for a supporting and motivating presence.

#### *Relationship with physicians and their availability and attendance*

In the SCU, if the physicians were willing to step out of their formal central role and cooperate with the rehabilitation project and the relational atmosphere, they would paradoxically reacquire a fundamental function. Patients' perceptions improved when the physicians' work was globally integrated with the rehabilitation project. The patients appreciated the physicians' availability and attendance in an informal climate. They did not care very much about formal contacts with physicians, because they could be available in other instances.

*When you say, 'Doctor, I wanted to ask you something.' again and again, and they really are available and don't just say, 'Come back later for an appointment'.... At lunch time we could see them everywhere, all of them; they would join us for coffee in the coffee room.... They were never strangers with us. (patient 12) (Table 2, quote 5)*

#### *Delivery of information about injury and outcomes*

The outcomes after SCI differ enormously, but severe disability is frequent. Because the type of lesion does not allow for early prognosis, no definitive prognosis is

given in the first months after the injury. However, even when the clinical and rehabilitative picture becomes clearer, the tendency is not to communicate information directly.

*They tended not to commit themselves, so they never told me openly that I would never walk again.*  
(patient 6)

Patient judgment was shaded in various nuances of context. All believed that by not communicating the diagnosis was negative in terms of both acceptance and reaction. But while they criticized certain negative elements at the FRC in other situations, in this case they were tolerant.

*Doctors never committed themselves by saying you will never walk again. However, the poor things really didn't know what to say.* (patient 18)

The patients understood the difficulty with making such a decision; they realized that it could be a challenge, and so they tolerated awkward or confused behavior.

*I never asked, because it was useless to ask if you already knew; it was useless to go there, I think. You'd just make a nuisance of yourself to go and ask again.* (patient 9)

Patients were unanimous in the belief that receiving clear-cut information was a necessary condition to start the acceptance process (Table 2, quote 6).

*I wanted a final confirmation in order to cope with what would come.* (patient 1)

They understood that the healthcare professionals faced a particularly delicate task having to give clear information as well as provide adequate emotional support. Important consequences emerged from patients' stories as a result of inaccurate information management.

Unsurprisingly, patients may also build their own view of the outcomes.

*Nobody has ever told me, not even now, but I understood it by myself. Because they never say whether you are going to walk or not [...]. Then when I arrived at the FRC, everyone said that with a complete injury you have no chance of standing up, while if it is incomplete there could be some chance. Then, when I went to the OTC for a follow-up examination I heard them say it was a complete injury. So I said, 'Ok, fair enough'.*  
(patient 5)

In some cases, patients created false expectations, in others they dwelt on pessimistic scenarios. All,

however, had strong perceptions about the outcome, especially those who were wheelchair bound.

*Yes, I knew I was going to be wheelchair bound, and anyway it is evident unless you are stupid [...] It's not as if you can just stand up and say, 'Let's try and see if I can walk.' It's impossible.* (patient 12)

A paradoxical situation was created where everybody knew, but everyone pretended not to know.

*My parents knew, they wanted to tell me in due time. I kept saying, 'Look, this is the way things are.' Even the head nurse was trying to understand from my words whether I knew or not.* (patient 11)

## Discussion

The findings described patients' expectations about their experience in a more familiar and less medicalized environment at the FRC as a valuable way to introduce patients to their life environment during rehabilitation. Compared with their first hospital stay, the main difference was their active involvement in the rehabilitation program, where they could engage in care and not just be cured. Patients were constantly encouraged to apply the abilities and skills they had acquired during rehabilitation. Active patient participation in rehabilitation was key to a good outcome of the program.<sup>9,10,19-21</sup> Patients in therapy who had been given the opportunity to express their opinion about their rehabilitation program considered certain aspects important, but sometimes just took them for granted. Pellat<sup>10</sup> identified five detectable levels of participation: open paternalism; they tell me what they are doing; I can either agree or disagree; they are making the right choice; and active participation. Since most patients held a positive opinion about their active participation, this was chosen as the target therapeutic model.

The patients in our study considered nurses as their primary reference points. The role nurses play in rehabilitating people with SCI was confirmed in many studies. Nordby<sup>22</sup> reported that nurses were close to patients and Pellat<sup>10,15</sup> described how nurses play a major role in patient empowerment. Our interviews also indicate that nurses hold a central role in taking care of patients and accompanying them through their rehabilitation process, both physically and emotionally. In agreement with Pellat,<sup>15</sup> our results highlight the need for nurses to be given adequate tools to promote patient empowerment.

In relating their experience with rehabilitation programs, patients frequently underlined two main aspects: self-determination and context. Self-determination is included in the Convention for the Rights of Persons

with Disability,<sup>7</sup> which addresses the subject from a legal point of view. In this connection, Lucke<sup>19,23</sup> highlighted the correlation between knowledge acquisition and decision making and rehabilitation outcomes. Similarly, our data indicate that patients who had been given enough opportunity for acquiring knowledge and exercising, decision making became critically aware of their potential and the ability to make good use of the services provided. Our patients also pointed to the importance of early rehabilitation as part of their program. At the FRC this approach was applied throughout: from gym activities to leisure outings, from weekends at home to the choice of adapted cars. Nelson<sup>24</sup> described in detail the final period of rehabilitation as the ‘launching’ phase and divided it into four sub-phases: presenting patients to the real world; exploring possibilities for a community life; promoting autonomy and decision making; and helping them out of the rehabilitation program.

Patients appreciated the physicians’ availability and the informal climate. Patients admitted to an SCI unit enter a small closely-knit community and as they require a lengthy period of rehabilitation, the relationship that they will have with a professional will be close. Pellat<sup>5</sup> reports considerable agreement between professionals’ and patients’ perceptions on the role the professionals play in rehabilitation, and underlines their role as coordinating and supervising the work of other team members.

Information management, transparency, and coherence were fundamental aspects. Our data suggest that acceptance and reaction were challenging issues that needed to be judiciously addressed when beginning patient care. Dewar<sup>25</sup> stressed that imparting information on the diagnosis and prognosis of an SCI requires communication and relational abilities that need to be part of a staff’s professional skills and must therefore be implemented through specific training courses.

Dixon *et al.*<sup>11</sup> argued that many patients recognize the importance of self-determination. Patients had complex information needs but were able to use goal setting and the vicarious experiences of other inpatients to map out the stages of their own recovery. Several patients agreed that seeing fewer doctors meant they were improving.<sup>5</sup>

This study has some limitations. The findings are related to the specific geographical, regional, and national context of the Italian healthcare system. As a purposeful and small sample size was used, this may have introduced bias. The authors acknowledge that one could never be able to fully describe an individual’s experience, but data saturation may have been reached at the end of the interviews.

## Conclusions

The present study develops reflections on the rehabilitation process within the SCU based on patients’ perceptions. Our research enabled us to explore the data on two different levels. First, we identified specificities and criticalities in the current FRC rehabilitation model. Second, patients’ views strongly underlined the importance of a holistic approach to care, together with the need to overcome barriers between professional areas in order to create a therapeutic environment. Patients demand complete care and assistance, consistent with their final objective of returning to a life worth living. In a study on patient perception at the SCU, Sand *et al.*<sup>8</sup> identified the final aim of rehabilitation as coming back to ‘a life worth living’.

In the care process, information cannot be delivered ‘piecemeal’. Furthermore, patients’ time on a rehabilitation program needs to be adequately planned to accommodate a range of rehabilitation activities (hydrotherapy, sports therapy, bladder and bowel elimination, and self-care). Moreover, the organization should be flexible and account for physical problems that can modify activity plans, which would otherwise lead to conflicts between the professionals involved in patient care.

Mismatched role expectations between patients and professionals raise the risk that patients may adopt a passive rather than an active role in their rehabilitation. Nonetheless, the fact that all the professionals have contact with the patients at a very early stage may help to build a good relationship and therefore a better understanding of that professional’s role.<sup>5</sup>

It would be counterproductive to view the various different components of rehabilitation and the different healthcare professionals involved in delivering care separately, for they furnish key elements in a continuous dynamic exchange and definition.

Experimentation with a personalized approach to care will contribute to develop reflection and professional growth. Training thus becomes an opportunity for professionals to improve their skills and competences and, above all, give meaning to their own work. At the end of the research phase, the results will be evaluated accordingly. Further research could imply monitoring changes in patient perception according to treatment received. A better evidence base may be necessary to persuade healthcare providers to place greater emphasis on patients’ views when making decisions about services.<sup>21,26</sup>

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