



## Expectations, Worries and Wishes: The Challenges of Returning to Home after Initial Hospital Rehabilitation for Traumatic Spinal Cord Injury

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### Abstract

Literature highlights the barriers and problems that individuals who sustain traumatic spinal cord injury (TSCI) meet when they attempt to resume everyday life after hospital rehabilitation. However, what do patients think about before returning home, and what should professionals encourage patients to address while the patient is hospitalized in order to balance the patient's expectations and to reveal what is of importance to the patient. This qualitative study explores the expectations, wishes and worries patients have before they return home after hospital rehabilitation due to TSCI. Eight Danish residents aged 25-75 years, admitted for initial rehabilitation at the Spinal Cord Injury Center of Western Denmark, participated in an individual interview before returning home. The transcribed interviews were analyzed according to inductive content analysis. Transversal analyses revealed four categories of barriers and problems: "facing uncertainty when leaving the rehabilitation center and peers", "hoping to get back to work and safe economy", "needing understanding from the community", and "relying on resilience of significant others". These categories were combined into one major theme: "relations". The findings indicate that there is a need for professionals to address patients' close relations and to initiate dialog with patients and their families on how SCI may impact close relations in order to promote a good life on new terms.

**Keywords:** Qualitative study; Traumatic spinal cord injury; Expectations; Return home; Rehabilitation

### Background

Individuals who sustain traumatic spinal cord injury (TSCI) encounter a range of challenges related to their functioning and disability [1-3] as they strive to adjust to their impairments and the consequences of their injury [4]. In the process of getting on with life, vulnerability and strength act together with dependency of others [5], and close relationships are strongly affected [6,7]. In the transition from hospital rehabilitation to home and community, TSCI individuals also meet various barriers [1,8-10].

Rehabilitation goals formulated by Spinal Cord Injury (SCI) individuals returning home reflect these barriers and problems as well as the individuals' hopes [11]. Furthermore, goals might enlighten organizations and processes of importance for the patients, as the most frequently reported goals are related to physical training, equipment services, psychosocial support, accommodation, recreation, and employment [12].

In general, the literature highlights the potential barriers and problems encountered by patients when they attempt to resume everyday life. This knowledge helps professionals to raise these issues when the patient is hospitalized in order to balance the patient's expectations, and to support the patient's positive adjustment to the injury. Lindberg et al. [13] and Van de Veldea et al. [14] both explored SCI patients perspectives on participation in rehabilitation. They stress the importance of recognizing the individual's expectations and perspectives in order to facilitate the patient's recovery. However, little is known about what the patients are concerned about before they

return home after hospital rehabilitation. The overall purpose of this present study is to explore patients' perspectives in order to identify themes to be addressed systematically when preparing the patients for returning to their homes. This present study aims to explore SCI patients' expectations and their wishes and worries before they return home after initial rehabilitation.

### Design

A qualitative study was performed using an inductive content analysis approach in order to obtain knowledge and understanding of the phenomenon under study [15]. Content analysis is a systematic means of describing and explaining a phenomenon, and the outcome of the analysis is condensed themes describing the phenomenon [16].

### Participants

Eight patients who had received initial rehabilitation at the Spinal Cord Injury Centre of Western Denmark due to TSCI were included. In the period from February to October 2013, the patients were contacted by one of the authors (BBN) within the last two weeks before discharge from the rehabilitation center.

The patients were identified via the patient administrative system at the rehabilitation center. Consecutively included were patients who met the inclusion criteria: Danish residents who speak Danish and who were admitted for initial rehabilitation due to traumatic spinal cord injury. The inclusion of participants was confirmed by the clinicians and the clinical director at the center. Exclusion criteria were psychiatric disorders or cognitive impairment that might affect the individual's ability to comprehend the interview, e.g. impairment caused by dementia or different kinds of abuse, which was determined

by the clinicians and confirmed by the clinical director at the center. In all, four patients were excluded. A total of ten patients met the inclusion criteria and were invited to participate; among those, eight patients accepted to participate and were included for an interview. The characteristics of the participants are shown in Table 1.

Gender	Age-group	TSCI Level and completeness	Education	Employed at discharge	Partner
Male	25-35	Incomplete Tetraplegia	Skilled Worker	No	No
Male	25-35	Incomplete Tetraplegia	Skilled Worker	No	No
Male	36-45	Complete Paraplegia	Middle Range Trained	No	Yes
Male	56-65	Incomplete Tetraplegia	Skilled Worker	Yes	Yes
Male	56-65	Incomplete Tetraplegia	Academic	Yes	Yes
Male	66-75	Complete Paraplegia	Middle Range Trained	pension	Yes
Female	66-75	Incomplete Tetraplegia	Middle Range Trained	Yes	Yes
Female	25-35	Incomplete Tetraplegia	Middle Range Trained	No	Yes

**Table 1:** Characteristics of the participants.

### Interviews

The interviews were carried out within the last week before the participants' discharge. The interviews were conducted by the primary author (BBN), who was under supervision by the last author (SA). The duration of each interview varied from 30 to 60 min.

The interviews focused on the patients' perspective and allowed the individuals an opportunity to tell their stories in their own words. To ensure that the interviews were in accordance with the research question, the interviews were guided by a semi-structured interview-guide with broad, open-ended questions about expectations, wishes and worries in relation to returning home after hospital rehabilitation (Table 2). The interview started with a few open questions introducing what had happened, the individual's description of his/her condition and thoughts when being admitted to the center, as well as his or her perspectives on the progressions achieved from admission until the time of the interview a few days before discharge. The interviews were audio-recorded, transcribed verbatim, and, finally, the interview text was controlled for consistency with the audio recorded interviews.

Interview guide
What do you feel about returning home?
What do you think about returning home?
What are you looking forward to?
What do you worry about?

**Table 2:** Interview guide.

### Data analysis

The transcribed interviews were analyzed according to inductive content analysis [16-19] in order to describe and explain the spectrum of the individual's expectation, wishes, and worries in relation to returning home.

Firstly, the transcripts were read repeatedly in order to gain an understanding of their contents and to inductively identify the most prevalent topics (codes), which were transformed into categories. This procedure was carried out by BBN who was supervised by SA, and the procedure included initial extraction of sentences with information relevant to the research questions. Secondly, the interviews were sorted into categories reflecting prominent areas. Thirdly (the descriptive level), the categorized data were examined, and meaningful patterns were deduced to describe the main elements of the SCI patients' expectations, wishes, and worries before returning home after initial rehabilitation. Fourthly (interpretative and explanatory level), these elements were interpreted and a comparative analysis was performed to examine how the elements were interconnected, to sort patterns of regularities and variations, and to produce new information in order to explain the participants' expectations, wishes, and worries before returning home after initial rehabilitation [20-22]. To optimize validity of the findings, the third and the fourth parts of the analysis were discussed among all three authors until the final set of categories and the most important theme accurately representing the interviews had been established.

### Ethics

Informed, written consent was obtained. The participants' anonymity was ensured by anonymized transcription and reporting. Only the interviewer, who is not involved in the participants' rehabilitation, and a research assistant doing the transcriptions, had access to the audio-recorded interviews. The project was approved by the Danish Data Protection Agency.

### Findings

Overall, the patients are looking forward to return home, they expect to continue intensive training, and they entertain a wish that practical issues in relation to the community services will be solved and that they can return to work and to their usual everyday lives, at least after a while. However, the patients also had certain worries, and the analysis of the interview identified four prominent areas of worry in relation to returning home after hospital rehabilitation, namely: "facing uncertainty when leaving the rehabilitation center and peers", "hoping to get back to work and a safe economy", "needing understanding from the community", and "relying on resilience of significant others".

#### Facing uncertainty when leaving the rehabilitation center and peers

The participants expressed that they would like to stay longer at the center in order to continue their intensive training. By engaging in training, patients are actively seeking to improve their situation and they felt like actors rather than victims. Physical training is, so to speak, the straw that they may cling to. To the patient, the center represents the vital, intensive training, and they fear setbacks when they get home. They hope that they can continue exercising at home with help from the municipal healthcare services, but worry whether

this training will be just as good and effective as the training they receive at the center. Fear of how everything is going to turn out fills in the patients' minds. Apart from training, their worries concern help at home, help schemes, and permission to resume driving. Finally, they worry about intimate bodily functions, particularly if they will "accidentally" experience urinary or fecal incontinence. Also, it is hard to leave peers and professionals whom they had come to know well, with whom they may discuss the consequences of their illness and who understand their situation. On the other hand, patients are looking forward to returning home, although it is hard to imagine how it will be like. This ambivalence is expressed in the following example.

*"How will it be to return home, when I've got used to the safety at the center, it (the center) is kind of a "school", everything is organized and scheduled ...returning home it not the same, there is nobody to take you by the hand ... I haven't finished the physical training; although I have been offered training, now it must be fair that I return home when others need training more than I do".*

In general, many things are easier at the center than in the home environment. To be injured involves radical change, and it is with sorrow that patients leave the rehabilitation center where they do well and feel safe. Returning home means facing being alone and having to continue recovery on one's own.

### **Hoping to get back to work and safe economy**

The participants' concerns and aspirations in relation to return to work are dominant; their concerns are very much related to having a job, but also their financial situation comes into play.

Some of the participants have to change their social roles from having a job and being independent to a new situation of being unemployed and dependent on other and their resilience. The younger, skilled workers with heavy physical work pre-injury have serious worries about their future work and economy. They fear that their possibilities of having gainful employment, even in a physically less demanding job, are poor. In contrast, the elderly participants above the age of 60 are guaranteed a work they are capable of doing despite their impairments.

It seemed that some of the patients tried to convince themselves that a return to work was realistic even if the underlying "tone" suggested that they had their doubt; maybe due to lack of prospect if this did not work out.

*"I have a hope, a dream of coming back to work and regain full-time employment, but I know it's not for sure, - it's not for sure".*

### **Needing understanding from the community**

The patients speak about the "municipality" as a generic term designating the professionals employed in the local healthcare services and the assessments of the need for rehabilitation services these professionals arrive at on the basis of current laws and regulations. The patients express their aspirations and skepticism regarding how they might be met and understood. The patients have both hopes and doubts as to whether the training proposed by the center will be established, how long it will take, and what consequences the wait will have for their physical function. The patients are also concerned about the municipal funding of the adaptation of their home setting proposed by the center. Overall, concerning the practical things, the patients express great hopes that the municipality will understand their difficult situation that may seem hopeless and include sensitive

issues. Specifically, they hope that the person who will assess their case will be open and willing to try to understand the physical, psychological, and social consequences that spinal cord injury has for the individual and his or her family.

*"I really need that there is a safety net, when I return home, that I have a trusting relationship with the municipal system, and that I can reach out if I need it... So it must just be in place before I come home... I really need them to understand what is going on... I have much space and love in our home and for my children; this is not the problem; the problem is just that I need time for myself, too...; time to become better, and they must help me with that".*

### **Relying on resilience of significant others**

How the injury will effect close relations is of great concern. The concern varies much depending on whether it is in relation to partners or parents, sisters, brothers, or children. The patients are worried whether their partner or close family can cope and are able to mobilize the strength needed. Importantly, patients tend not to doubt their own capability to cope with the demands of their injury and the new situation as long as the partner or close family is able to stand it.

*"Strange, but I accepted it immediately... as a new situation; of course, it is shit, but now one must get on from here... I hope she (wife) will stand it...It is a very big change for my wife ...It will be a hard time for my wife, it will".*

*"It bothers me... yes, she (wife) is about to jump off the side... I wonder what the hell I should do".*

The participants expect neither to be the same nor to get back to the same situation as before their accident. For some, this is in contrast to what they feel their partner, family, friends, or professionals in the community expect; and they therefore feel a pressure. They know that the injury has changed them and their situation, although not all of them look ill. They express this mismatch between "looking good, but feeling bad". Looking good means that others might expect too much of them when they return home. They worry about what they are expected to be able to handle and to take part in when home again.

*"I would also like to go home, but at the same time I know that as soon as I'm home, then there are some expectations; so, people will say: hey, you are looking good; it's great that you are completely well again... , and I have some hassles too... something with the intestines; I had to sit on the toilet for 20 minutes; it almost takes longer than to shower...".*

Participants felt nervous of being honest about what they could manage, and sometimes they did not know that themselves. It was important to them that their new situation was being understood by close relatives and family.

### **Discussion**

This present study focuses on what patients are concerned about just before returning home after initial rehabilitation. The eight interviews with patients with traumatic spinal cord injury reflect various expectations, wishes, and worries in relation to returning home after hospital rehabilitation. Each interview reflected an individual's unique perspectives. There was some variation between the interviews which may be related to differences in the patients' age at time of injury, educational level and social circumstances, as well as

differences in the patients' psycho-social challenges, financial status, and economic possibilities.

Overall, the study findings stress what is known about community needs, various barriers, and problems [1,2,9,10]. The comparative analysis of the deduced categories revealed that TSCI patients want the best and have positive expectations; however, a degree of uncertainty is apparent and with good reason. In line with the literature, the present study shows that the patients expect some barriers and problems in relation to practical issues like training and accommodation, besides maintenance work and economy [1,3,8]. Beyond these practical issues, the interviews uncover that the patients are concerned about a number of more basic issues such as their new identity, social relationships, and being understood.

The patients worry and feel uncertain by leaving the center, which is in conformity with previous findings [23] that show that the rehabilitation center is ideally designed for SCI individuals, among others because it offers continual presence of professionals to support and guide the patients. Patients worry about how it will be when they return to "the real world" environment at home without the presence of professionals. Our finding that peer support is of high value is also in line with previous studies that find that peers exchange experience of living with SCI, both in terms of practical and personal issues [24]. Leaving peers means leaving some who know what it implies to be injured.

Return to work is a major challenge in rehabilitation after SCI, [25-27], and unemployed SCI persons deem themselves capable of working [28]. In line with that, we found that the patients are confident that they can manage a job and that they hope to return to work. For patients, work involves identity, colleagues, earnings, and independence. There is much at stake, and they therefore cling to the hope of getting back to work.

In relation to the municipality, the patients hope that their real needs are met and that their situation is understood. They hope that they can safely reach out when they really need it, and that decisions will be based on confidence in the person who seeks help and on insight into the TSCI patient's situation.

The relation to the partner is also changed, and several of the patients worry about the relation and their marriage. This is with good reason because it has a tremendous impact on a person when the partner sustains TSCI [6]. In this vulnerable situation, communication is difficult [29], and fear of being left or being lonesome was expressed by the majority of the patients.

Relations, a recurrent theme spanning all four identified categories, encompass relations to partner, children, parents, family in general, friends, acquaintances, colleagues and health professionals, as well as the health and social staff in the municipality. The TSCI patient understands that because of the injury, he or she has a new life situation that unfolds on new terms. The staff at the center have insight into this situation and understand the patient, and this provides reassurance. At home, the same deep insight into what SCI involves cannot be anticipated, and this may be frightening. The SCI individual is "not the same" and "will not return to the same"; so in this sense life as such, living with a partner, or the premises for dealing with others will never be the same again. Therefore, the TSCI patient must get on with life under new conditions. Their worries, hopes, and wishes therefore concern whether those with whom they have relations will be able to achieve the necessary insight to understand their new situation. It concerns the TSCI patients whether the partner

will be able to cope physically and mentally and will be able to live with the demands that arise following the injury.

Addressing relations seems to be of crucial importance to the individual. Meeting with patients' network, defined as individuals who have an important relation to the injured individual, has been suggested as a means to promote openness in communication during the transitions process [30]. At such, network meetings discussing the impact of SCI on relationships could be arranged; situations that might cause misunderstandings could be discussed; and values, norms, and traditions could be debated. Network involvement might solve the patients' dilemma of needing to be understood by significant others while being nervous of being honest about their worries and concerns. In such an approach, it could also be possible to address the partners' need for support.

The present study findings enhance our understanding of issues related to returning home perceived at first hand by the affected individuals. The interviews provided a broad description of expectations, wishes, and worries in relation to returning home after hospital rehabilitation. Because life never will be the same again, there are good reasons for open communication about what TSCI means to the individual and his/her relations.

The findings offer information important to the rehabilitation team. The interviews suggest that addressing patients' relations in their returning home process is important to the patients.

## Limitations and Strengths

The findings of this study underscore the need for further insight into the time after discharge. This issue will be explored in a follow-up with the eight participants one and twelve months after discharge to see how they are doing compared to their expectations and worries. We consider it very important specifically to report patients' expectations and worries before discharge as this may provide clinicians with valuable information. Although our inclusion procedure implied that we did not select participants, we succeeded in obtaining a variation across participants according to age at injury, level and completeness of injury, educational level employment, and partnership that reflects the heterogeneity in the population of TSCI patients.

## Conclusion

The eight interviews of patients with traumatic spinal cord injury unveiled a broad range of expectations, wishes, and worries in relation to returning home after hospital rehabilitation.

The transversal analyses revealed four categories from the interviews: "facing uncertainty when leaving the rehabilitation center and peers", "hoping to get back to work and safe economy", "needing understanding from the community", and "relying on resilience of significant others". These categories were combined into a major theme: relations. The findings indicate that there is a need for professionals to address patients' close relations and to initiate dialog with patients and their families on how SCI may effect close relations in order to promote a good life on new terms.

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## Conflict of interest

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