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The Beginning of a New Life Following Traumatic Spinal Cord Injury- Patient's Experiences One Month Post-Discharge

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Abstract

Introduction: Studies show that individuals having suffered traumatic spinal cord injury (TSCI) are challenged by barriers and problems in their transition from hospital rehabilitation to home.

This study aims to explore patients' first-hand experiences of returning home and to compare their post-discharge experiences with their pre-discharge expectations.

Method: A qualitative follow-up study using inductive contents analysis. One month post-discharge, we reinterviewed seven Danish TSCI-patients, admitted for initial rehabilitation at the Spinal Cord Injury Centre of Western Denmark.

Findings: We identified two categories from the interviews: "The body as a fatiguing time-consumer causing dependence", "The need for timely cooperation and collaboration". The transversal analyses revealed the overall theme "Timing" highlighting the experiences of returning home.

Conclusion: Patients´ early post-discharge period is complicated by lack of timing in establishing training possibilities and providing equipment needed. This has consequences for the individual in terms of setbacks, and it imposes a burden on the patient, partner and close family. Hope of further progress was dominant, while delays threaten this hope for progress. In order to promote a smooth and safe return to home timing seems of crucial importance.

Keywords Qualitative study; Traumatic spinal cord injury; Experiences; Post-discharge; Return home; Rehabilitation; Transition

Introduction

Traumatic Spinal Cord Injury (TSCI) has a profound effect on various aspects of life due to radical changes in body functions [1]. This is no more clear than in the process of transition from hospital rehabilitation to home where TSCI patients are confronted with their disabilities and meet diverse barriers [2,3]. During the initial rehabilitation process, the individuals strive to adapt to the consequences of TSCI to be able to resume their everyday lives which may include mobility issues, pain [4], problems of dysfunctions of bowl and bladder [5,6], e.g. incontinence, as well as sexual dysfunctions [7]. Apart from the physical issues, psychosocial, personal and emotional issues may impact their quality of life [8-10]. Rehabilitation is of utmost importance to recovery, the overall aim being to support the recovery process and to promote full inclusion and participation of people with TSCI in their physical and psychosocial environment [11]. The in-patient rehabilitation effort is designed to assist the patients in managing their new life situation by addressing many of these issues. Yet, recovery is complex, and rehabilitation outcomes hinge on the individual's particular situation in terms of age, medical status, comorbidities, motivation, personal

preferences, education, financial resources, family and social support, among others [1]. Some do manage after a protracted recovery process to get on with life and to experience that life with TSCI is fulfilling [12,13]. However, the transition process is a critical period [3,14,15], during which well-organised, coordinated rehabilitation service is of utmost importance, wherefore it is given high priority in Danish rehabilitation [16,17].

Knowledge about what matters to persons with TSCI during their transitions is necessary to establish a well-organised, coordinated rehabilitation service that meets the TSCI patient's early post-discharge needs.

We recently explored TSCI patients' pre-discharge expectations, wishes and worries in relation to their return to home [18] and found that relational issues ranked high among their concerns. The patients were worried whether their close relatives would be able to understand how life after TSCI unfolds on new terms. Furthermore, they worried whether their close relatives would be able to cope with the demands of the new situation. Our findings suggest that much may be won from a rehabilitation perspective by systematically addressing issues related to "relations" during the transition period. This present paper is a follow-up study based on one-month post-discharge interviews with TSCI persons. The aims are to explore patients' first-hand experiences of returning home and to compare their post-discharge experiences

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with their pre-discharge expectations. Ultimately, such knowledge may help to provide a smooth and safe return-to-home for this vulnerable group of patients.

Design

A qualitative study was performed using inductive contents analysis to systematically describe and explain the phenomenon studied [19,20].

Patients

Seven patients (one woman and six men) who had received initial rehabilitation at the Centre due to TSCI. They were identified via the patient administrative system at the Centre; all were Danish residents and spoke Danish. The patient characteristics are shown in Table 1.

Gender male/female in number	6/1
Age-group (year at time of injury)/number	(25-35)/2 (36-45)/1 (56-65)/2 (66-75)/2
TSCI Level and completeness /number	Incomplete Tetraplegia/5 Complete Paraplegia/2
Education/number	Skilled Worker/3, Middle Range Trained/3, Academic/1
Employed at discharge Yes /no/ pension in number	3/3/1
Partner Yes/no in number	5/2

Table 1: Characteristics of the participants.

Interviews

The patients participated in pre-discharge interview from February to October 2013, and were interviewed again one month post-discharge. All interviews were conducted by BBN. The interviews took place in the patient's home. Each interview lasted 30-60 min. A semi-structured interview-guide with broad, open-ended questions about experiences of returning home after hospital rehabilitation guided the interview (Table 2). The interviews started with a few open questions addressing how it was to return home, how the overall situation of the individual was. The interviews were audio-recorded, transcribed verbatim and, finally, BBN checked the consistency of this text against the audio-recorded interviews.

How is it to be at home again

What do you specifically remember in relation to home coming

Is there something that have surprised you

Is there something that you find specifically good/ nice or important

Is there something that you find specifically strange or disappointing

What do you have experienced as specifically positive in your transition from hospital to home

What do you have experienced as the most important

What do you have experienced as the most difficult

Table 2: Interview guide one month post-discharge.

Data Analysis

The transcribed interviews were analysed according to inductive contents analysis in order to describe and explain the spectrum of the individual's experiences. Firstly, the transcripts were read repeatedly to fully understand their contents and to inductively identify the most prevalent topics (codes). Secondly, the interviews were sorted into categories. This procedure was primary performed by BBN in collaboration with SA and discussed with MB in order to rule out misunderstandings and ensure validity. Thirdly (the descriptive level), the categorised data were examined, and meaningful patterns were deduced to describe the main elements of the patients' post-discharge experiences. Fourthly (interpretative and explanatory level), these elements were interpreted, as a comparative analysis was performed to examine how the elements were interconnected and to compare with pre-discharge expectations [21-23]. To ensure the validity of the findings, the third and the and 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

The patients signed informed consent. Anonymized transcription and reporting ensured the patients' anonymity. The audio-recorded interviews were only accessed by the research assistant who did the transcriptions and by the interviewer who was not involved in the patients' rehabilitation.

Findings

Generally the patients were happy to return home and to be together with their partners and families again. However, returning home was more difficult than they expected pre-discharge, specifically because they realised that the changes in body functions were more challenging than they had ever expected. Their experience was further complicated by the fact that the needed equipment was not always available when they returned home. This created frustrating situations and barred them from pursuing social life as they wished.

From the analysis of the one-month post-discharge interviews emerged two prominent experiences of returning home:"The body as a fatiguing time-consumer causing dependence" and "The need for timely cooperation and collaboration".

"The body as a fatiguing time-consumer causing dependence"

Various degrees of paralysis imply learning and implementing new ways of doing daily routines. To adapt to body changes becomes an extremely time-consuming and strength-demanding process. Bathing and procedures for emptying bladder and bowl can take hours. Dressing becomes a demanding process that involves exhausting and demanding transfers from wheelchair to bed and back, e.g. while getting on jeans while lying on the bed. Preparing meals often includes moving around in a kitchen that is not designed for disabled people. The changes in body functions due to the injury meant that basic functions became extensive and took so much time that time ran short. It surprised the patients how complex it was and how much it took to make the body function. A patient explained the strain experienced as follows:

"Well, just getting out of bed in the morning and getting ready; and afterwards going to the toilet and things. Yes, it actually takes up so

much time. It takes several hours, for sure. Getting to the toilet and showering takes so long, and then it is without getting breakfast or anything. It is so because when I am sitting on the toilet, which I do once a day, then I want to be totally sure that I have no mishaps... I would rather avoid that"

Even one-month post-discharge, the changed body functions remain very unfamiliar and they may become a barrier that hampers daily activities and participation in social life. To be able to keep up with the family or one's partner seems to be difficult because things take so much time. This involves the patient constantly trying to be early and to be on the forefront of things, but in practice very often find him- or herself to be lagging behind. To be able to match other persons seems to be important in order to interact and participate. Troubles in this regard imply that difficult situations arise that give way to sorrow, disappointment and misunderstanding. This experience is illustrated in the following example.

Well, my partner don't really understand it either... there was one morning when I was running a little late, my partner had actually almost finished eating breakfast and I had even skipped showers that morning because I thought that today I would have my morning coffee together with my partner and then I couldn't do both, well... But then my partner hinted that things really took long ... I feel that I am always lacking behind... and I don't like that; I never used to be like

Asking for help influences self-confidence and when the patient has to do so he or she is confronted with the post-injury struggle and with the discrepancy between the current situation and the pre-injury selfimage of a person able to solve things.

"The need for timely cooperation and collaboration"

Several time dimensions are involved in the rehabilitation process. It takes time for the body to recover and for the individual to accept and learn how to manage changed body functions. Also, it takes time to find viable solutions to the challenges encountered and to meet the needs that arise in everyday life. It takes time and patience to find ways to unfold life on new terms after TSCI. Apart from demanding patience, the process of awaiting progress invites feelings of hope and uncertainty patience is demanded. Feelings of hope prevail as long as the ultimate level of functioning has not been determined. Feelings of hope were prevalent among the interviewed persons, even if they were occasionally overshadowed by uncertainty and frustration over inability to perform everyday activities which made it difficult to keep up spirits.

"I think that I am making progress, and every day when I see progress ... then I think that I will recover a lot... Also it has helped to keep up my spirits... when I am tired, it is as if I am in low spirits.. You want to do so many things, but you can't.. This is bloody difficult.... Anyway, I have the guts to fight on ... I am cheerful; we are going to France next summer with our mobile home... and we are going to make it, aren't we?"

The hope to make progress so at so be able to reach personal goals and to improve physical functioning kept the patients doing whatever it took to be better. Thus, in the immediate post-discharge period, delays were felt to threaten progress. Common features in this period were experiences of delayed physical training and unintended events, e.g. that relevant information about needs and training plans did not reach the right municipal healthcare professional. This is illustrated by this example;

"It took time before it (i.e. training) got started; i.e. it was as if they (the local training centre) didn't really know; so I had to call them ... and then holidays came and ehh, then we got past the holidays before I really got going on the training ...apparently they had not received the papers; I don't know what happened"

Delays have a serious negative effect on the patients, i.e. their faith in their ability to recover and their faith in the system, notably delays in the first period post-discharge. This experience is illustrated like

"I had hoped that I could start before... because I felt that going from training a whole lot to being responsible for my own training ... that was really difficult... and I very quickly tightened up. And I had so hoped that I could start training, but... that was not possible... and then it took ... three weeks; I felt as if everything was coming to a

Patients leave the centre optimistic that if they make an effort, show responsibility and are hard-working, there is hope for progress. They feel that the responsibility to achieve progress lies with themselves, which a patient express as follows:

"I wish to say that you cannot say on beforehand that this will not be possible... that I will become 100% like I was before... you are your own master when it comes to the progress you will achieve from training...if I don't bother do anything, then I won't get anywhere ... then I won't make any progress"

The patients shared this attitude and they therefore felt devastated if delays meant that they missed the opportunity to do training and they therefore felt that they were taking a step backwards.

Discussion

The patients interviewed in this study find the early post-discharge period more difficult than expected. In their experience, their changed body functions make even the simplest tasks time-consuming and strength-demanding. Delays in rehabilitation service delivery challenge their patience and lead to setbacks. Still, their hope for further progression prevailed although delays threatened their hope of progress. The previous pre-discharge study [18] showed that the patients were facing uncertainty when they left the rehabilitation centre and their peers, and that they were hoping that the community would understand their situation and meet their needs. Pre-discharge, the patients feared demanding too much of their close relatives. The present comparative analysis revealed that post-discharge, the patients' concern had a dual focus, viz. a concern about their collaboration with the community healthcare services and a concern about their close relations.

The discussion is structured by the two categories concerning body changes and need for timely cooperation and collaboration additionally the findings are compared to our pre-discharge findings [18]. Finally, an overall theme revealed from the comparative transversal analyses highlighting the post-discharge experiences will be discussed. That body-changes means extremely time-consuming and strength-demanding daily routines particularly in the early postdischarge period is important information to the health care system. Our findings suggest that in order for the patients to be able to learn and to cope with the body changes and diverse adjustments needed, they may need support and guiding in at home coming. In the early post-discharge period so many questions arise with nobody to ask how to manage this and that and how to solve emotions and difficult interpersonal situations, which may occur. Peer mentoring has been suggested as a mean [24,25] to support newly injured in this critical home coming period. Although high priority is given to wellorganised, coordinated rehabilitation services in Denmark, a critical interface seems to exist between hospital rehabilitation and community-based rehabilitation. The patients appear to be particularly vulnerable during the early post-discharge period; and it is concerting that delays and errors arise at this interface between inhospital and home-based rehabilitation. It may appear as if the municipal healthcare service adopts an expectant attitude in anticipation of an improvement as time passes; yet, this is not necessarily so. Indeed, our findings suggest the opposite. This situation harbours an inherent conflict because the municipal healthcare service seems to prefer to adapt its service provision to a needs level where progress has already taken place; yet, progress may hinge on the availability of training facilities, housing modifications and aids provision to support such progress. The present study strongly suggests that careful timing is necessary in the transition process. This is partly acknowledged and transitions programs have been suggested in order to facilitate the delivery of rehabilitations services [26]. Similarly, community rehabilitation support for patients and families has also been suggested [27]. Furthermore, the creation of cross-sector partnerships has been suggested as a model that may ensure healthcare continuity across sectors, help formulate transition goals, inform interventions to remedy current gaps in rehabilitation service provision, and evaluate service delivery [27]. Such a process should be informed by patients' preferences, not least in light of the complex nature of TSCI patients' needs [28]. The present post-discharge findings underscore the patients' pre-discharge worries concerning cooperation with the community and delays seem to assume particular importance, which is also found in studies from other countries [2,3,14,15,26,19,30]. The patients are concerned about their physical training in order to progress and cope with body-changes. The institution of physical training immediately after discharge is suggested to be the ideal for promoting exercise and good health among disabled persons, for reducing the risk of setbacks [31]. It has been suggested [29] that the substantial adjustments required after TSCI may be aided by participation in social and leisure activities and support provider involvement. This study stresses that timely coordination and collaboration between the patient and his/her family, the rehabilitation center the community seems of great importance to the patients.

The experience of uncertainty and hope expressed by the interviewees is in line with Lohne et al. [32,33], who expound that if the outcome of TSCI is certain, hope is impossible as hope is related to expectation and involves a plan for achieving goals as a response to the threat of injury. The patients hope for progress and demonstrate willpower in an effort to manage practical issues themselves as they do not want to place a strain on their close relationships. Delays in the delivery of rehabilitation services that should help the patients become independent are therefore experienced as extremely destructive. Patients seem to mobilize personal resources in the form of patience to accept whatever time is needed to ensure progress, but they find it difficult to accept delay in the provision of the services that are required to support the personal effort to make progress. Waiting time also offers respite and gives the TSCI patient time to reconsider and cope with the fact that what the persons deeply wishes will happen might, unfortunately, not happen. In that way waiting time may be merciful because it gives the patient a period to balance pleasant dreams to the hard realities. Getting on with life after TSCI,

vulnerability is inevitable [34]. However, strength may be gained despite the challenges imposed by impairments, for instance by providing adequate, relevant and timely resources to help and support the TSCI patient. Timing seems crucial in order to meet the patients and to ensure a smooth and safe return to home. Of particular importance in this situation is to recognise the critical importance of the bodily functions to the ability to uphold social relations and for family to cope with the demands of living with a person who has suffered TSCI. In this situation, any delays may impose severe strain because so much is at stake for the patient. Social life may become so severely strained that irreversible damage, like divorce [35], may occur. This worry goes to the very heart of the patients' pre-discharge concerns and their post-discharge fears. "Timing" spans the described categories and is a recurrent theme emerging from the comparative transversal analysis [20,36,37]. The present study findings offer information on what matters to persons with TSCI one month postdischarge. It worries the patients how to be able to keep up with demands of everyday life and minimize the burden on partner and close family. Timing of the training possibilities and the equipment delivery together with support from persons with insight into consequences of the injury may aid the patients in the early postdischarge period.

Limitations and strengths

Previous findings concerning pre-discharge worries and wishes and these present one month-post-discharge findings call for further follow-up in order to find out how patients experiences their situation in the long-term. We consider, it important specifically to report patients need for timing during the first period at home. The participants reflect a variation in terms of age at time of injury, level and completeness, educational level, employment and partnerships corresponding the diversity in the TSCI population. In our predischarge interview study eight patients participated and in this postdischarge interview only one of those did not want to continue participation.

Conclusion

The analyses of the one month post-discharge interviews with TSCI-patients revealed two categories "the body as a fatiguing timeconsumer causing dependence", "the need for timely cooperation and collaboration". The transversal analyses revealed the overall theme "timing" highlighting the experiences of returning home. Patients' early post-discharge period is complicated by lack of timing in establishing training possibilities and providing equipment needed. This has consequences for the individual in terms of setbacks, and it imposes a burden on the patient, partner and close family. Hope of further progress was dominant, while delays threaten this hope for progress. In order to promote a smooth and safe return to home timing seems of crucial importance.

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