CASE REPORT

The influence of clarification and threats on life situation: patients' experiences 1 year after TSCI

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INTRODUCTION: The study was conducted at the Spinal Cord Injury Centre of Western Denmark (VCR). The aim of the study was to explore patients' experiences following traumatic spinal cord injury and to identify characteristics of positive versus negative life situation 1 year post discharge from hospital rehabilitation. This was a qualitative study conducted using inductive content analysis.

CASE PRESENTATION: In this qualitative study seven patients were interviewed one year after discharge from initial rehabilitation at the VCR. The interviews were analysed using inductive content analysis.

DISCUSSION: We found that two categories condensed the patients' experiences of their life situation 1 year post discharge: 'clarification in relation to overall life situation' and 'threat to core competences'. The transversal analysis across the derived categories identified different combinations of clarification and threats to core competences explaining the patients' experiences: high degree of clarification combined with low degree of threat to core competences was indicative of positive life situation. Also, positive life situation was seen when a high degree of clarification compensated for high degree of threats on core competencies. In contrast, an overall stressful and negative life situation was influenced by poor clarification combined with a high degree of threat to core competences. However, when core competences can be transformed into new skills, threats were manageable. This study revealed that clarification related to overall life situation in combination with threat to core competences may explain traumatic spinal cord injury patients' overall life situation 1 year post discharge. An appropriate balance characterises a positive life situation. There might be a need to pay attention to patients who are challenged by low degree of clarification and high degree of threats on core competencies 1 year post discharge as this may influence the life situation negatively.

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INTRODUCTION

During the first year following spinal cord injury (SCI), several factors potentially impact on patients' life situation. Previous studies have explored patients' life situation understood as aspects of functioning, participation and involvement in family and network, accommodation, employment, leisure time, accessibility and compensation.^{1,2} Individuals' problems and barriers in the transition from hospital rehabilitation to home are detailed in many studies, stressing that the rehabilitation after SCI is a complex process.^{3–10} The return to home and community living is complicated by psychosocial and environmental issues^{4–6} besides issues in relation to body functions, daily activities, home modifications, equipment and employment.^{7,8} In addition, patients report that lack of support in the process of, for example, return to work, and solving insurance issues are particularly problematic in the first year post discharge.¹⁰ On the basis of these findings, we planned a longitudinal study on patients' experiences of returning home after hospital rehabilitation to traumatic SCI (TSCI). First, we explored patients' expectations before discharge from the Spinal Cord Injury Centre of Western Denmark. The findings indicate that patients feel uncertainty by leaving the rehabilitation centre, and their peers and their worries concern whether the community authorities have the knowledge needed to understand how their life situation has changed following TSCI.¹¹ Second, we explored patients' early post-discharge experiences and found that returning home is harder than expected and that delays in establishing training possibilities and providing equipment threatened hope for progress, imposed setbacks and burden on the patient and close relations.¹²

These findings support that there is a need of increased concerns regarding discharge into the community in order to facilitate the transition and the early post-discharge period. Despite worries, problems and barriers, some patients do succeed in achieving an overall positive life situation.^{13–15} Some patients have explained this by their ability to find ways to do things differently, to use available resources and to have social support.¹⁶ Therefore, balancing the knowledge about problems and barriers with knowledge about positive experiences post injury is important.^{4,17}

The aim of this present qualitative study, which is the third part of our study, is to explore the patients' experiences 1 year post discharge in order to identify characteristics of the patients' positive and negative life situation. Knowledge about what contributes to either positive or negative life situation is important in order to inform health-care professionals in hospital and in the primary health care on how to promote long-term well-being.

DESIGN

This qualitative study uses inductive content analysis of interview scripts to identify the characteristics of positive and negative life situations.^{18,19}

Participants and procedure

Seven patients (one woman and six men) diagnosed with TSCI, who had received initial rehabilitation at the Spinal Cord Injury Centre of Western Denmark participated in this present study.

Table 1. Characteristics of patients

Gender (number of patients) male/female	6/1
Age group at the time of injury (number of patients)	25–35 years (2) 36–45 years (1) 56–65 years (2) 66–75 years (2)
TSCI level and completeness (number of patients)	Incomplete tetraplegia (5)
Education (number of patients)	Complete paraplegia (2) Skilled worker (3) Middle range trained (3) Academic (1)
Employed at discharge (number of patients)	Yes (3) No (3) Pension (1)
Married (number of patients)	Yes (5) No (2)

Abbreviation: TSCI, traumatic spinal cord injury.

The inclusion process involved the chief physician and the charge nurse at the centre, who evaluated the hospitals list of patients admitted. Together with interviewer (BBN) relevant patients were identified. Three patients were excluded due to dementia, abuse and imprisonment, which were deemed to hinder participation in interview. The interviewer informed nine potential participants and invited each to participate in a three-phased longitudinal study implying three individual interviews at three different time points. One patient did not want to participate, therefore eight patients, two women and six men aged between 27 and 73 years participated in the first interview before discharge. One patient was withdrawn before the second interview due to depression and social circumstances leaving seven patients who participated in the second interview 1 month post discharge, and again in this third part of the study 1 year after discharge. Findings from the first and second part of the study are published.^{11,12} The patients' characteristics are shown in Table 1.

Interviews

The first author, who was not involved in rehabilitation at the centre, carried out all the interviews. The insight into the patients' life situations was gained by an open approach to facilitate the patients' perspective on positive as well as negative aspects of returning home. 'The interviews were carried out in the patients' own homes from February to October 2014. The interviews lasted 1 h and were guided by a semi-structured interview guide (Table 2). The interviews were audio-recorded and transcribed verbatim.

Data analysis

In an inductive content analysis process the interviews were analysed.^{18,19} First, the interviews were read repeatedly to understand the content and to identify on an inductive basis the most prominent topics of the patients' experiences generating

Table 2. Interview guide 1 year post discharge

How are you by now
How do you think things have worked out until now
Is there anything which has surprised you
What makes you feel glad/happy
What makes you feel unhappy/sad or angry
How do you see yourself by now
How do you see your overall situation to day
Which hope do you have

a list of meaning units. Second, the identified meaning units were analysed and organised into categories describing the main elements of the patients' experiences of their life situation 1 year post discharge. Third, a transversal analysis across the derived categories was performed to identify how these categories were interconnected and thereby explain how patients' experiences their life situation 1 year post discharge.^{20,21} All three authors participated in the described analytical process. In order to strengthen the validity the findings were discussed with the health-care professionals at the centre.^{20,21}

ETHICS

The project was approved by the Spinal Cord Injury Centre of Western Denmark, and the Danish Data Protection Agency. The patients signed an informed consent form.

FINDINGS

Six categories were inductively derived from the transcribed interviews describing that experiences of life situation 1 year post discharge were markedly divergent. Obvious, some of the patients had mainly a positive view on their life situation and expressed optimism and joy, whereas others had mainly negative experiences and expressed uncertainty, sadness and hopelessness. The six categories that represent the prominent topics related to patients' life situation were: 'Life on new terms is one's own responsibility', 'The changed body', 'There is much more to be done', 'Ability to articulate one's case to the authorities', 'Compensation and work', 'Finding new ways'. These subcategories were classified as belonging to two main categories; 'Clarification in relation to overall life situation' and 'Threats to core competences'.

'CLARIFICATION IN RELATION TO OVERALL LIFE SITUATION'

In this study, clarification refers to the individuals' experiences of how problems and barriers related to issues important to them are solved or managed. The extent to which clarification was achieved seemed to determine whether the individuals had a mainly positive or negative view of their situation. For example, positive overall life situation was influenced by the degree of clarification regarding work situation, finances, insurance and compensation, as resolution of these issues brings relief, hope and gives perspective in life. Knowing how matters would resolve led to a sense of calmness. In addition, positive experiences were related to whether the municipality authorities, who assess individuals' cases, understood the difficulty of their situation and were able to take appropriate action to resolve things. Clarification supported the strength to move on and focus on positive aspects of life, as expressed by one patient:

'I am happy as I have now resolved things that had troubled me-how would it go, could I get incapacity benefit or would I be sent out to do supported income work. ... I have got incapacity benefit... so things have settled down now and I have received a substantial compensation... I can do a lot myself, I can drive a car again... It's going forward... just onwards with life. I never thought I could get this far... so there is also a life for us'. (male in the fifties)

Thus, the ability to find new ways of performing daily activities and finding comfort in new roles influenced the overall life situation positively.

By contrast, sadness and anxiety characterised those who experienced a low degree of clarification. Problems concerning body functioning, for example, bladder, bowel and pain made

Figure 1. Four scenarios of the interconnection between clarification and threats.

patients' daily living and participation in social life difficult. These problems influenced their ability to achieve clarification in terms of work, which again related to financial problems. On-going uncertainty about how the consequences of the injury affect patients' overall life situation led to severe stress:

'I can, of course, have a normal job... because it's not sitting in a chair that's the problem. It is my bladder, bowel and pain that preoccupy me. It can mean that I can't undertake full-time work. I am now in a programme to get a supported income job at some point... I first need to get a traineeship, have a coach and see how much I can manage. I am really depressed... everything look bleak... family... economy. I have no energy at all... no wish to get out of bed, but want to dream myself away'. (male in the forties)

Uncertainty caused by low degree of clarification was indicative of a negative overall life situation with stress and hopelessness, while a high degree of clarification brought peace, hope and perspective.

'THREATS TO CORE COMPETENCES'

Maintaining and using pre-injury core competences, that is, skills and qualifications closely related to identity and personality, seemed closely related to positive experiences. Those who could maintain their life goals had a positive view of their life situation as they found joy in finding alternatives and imagining new possibilities and they did not feel that their core competences were threatened. For these patients, the new situation seemed straightforward; they did not spend much time mourning their losses, although they occasionally felt really sad. The ability to use pre-injury working skills and regain previous employment, which was adjusted meaningfully in relation to their new situation contributed to an overall positive view:

'I am still at work and work 4 days a week and could for that matter also work 5 days, but think it is nicer to reduce it to 4 days a week... Work-wise, I participate in the events I want to. Socially, there are, of course, some situations where I am not as much involved... Previously, we cycled and went to gymnastics. But there are other things one can do and can be glad about.... One has to work out for oneself how to move on'. (male in the sixties)

Being manual worker, core competences seemed threatened to a greater extent than the competences of those who were more academic and undertook sedentary work. Stress and frustration followed when pre-injury core competences seemed useless and previous life goals appeared unrealistic. This challenged especially manual workers in relation to both livelihood and identity.

'I used to do loads of things, but I can't any more, I can't participate in anything. So, I just talk [instead of just doing the things needed], I can't do anything else... but what is mainly needed... is manual work... It is a colossal frustration... it affects me terribly... Before, I used to be the hard-working type... and now I can't be that any more'. (male in the seventies)

Threats to core competences and lack of work alternatives led to negative experiences. These were intensified when municipality authorities and employers lacked insight into the consequences of SCI. Limited insight into consequences following less severe lesions was expressed by the majority of the patients, who might not look that sick and as such they were deemed to have generally minor problems. Although, they suffered from various body changes that made it impossible to have a normal work. These patients experienced difficulties in articulating their case and finding new roles and alternative work, as practical skills had defined their identity pre-injury:

'I get tired so quickly... Many employers won't put up with that... I'm not bookish at all, so I can't work in an office or... But they think I should just get started... And that's right-I have to - but I can't manage all I did before'. (male in the thirties)

Threats to patients' core competences and difficulties transforming previous skills into alternative skills led to an overall negative life situation, whereas the ability to use previous core competences was associated with overall positive experiences.

DISCUSSION

The comparative transversal analysis^{20,21} of the two above described main categories suggests that an appropriate balance between clarification and threats to core competences seems to influence on patients' life situation in a positive way, whereas an inappropriate balance might influence patients' life situation negatively. The interconnection between 'clarification' and 'threats' can be illustrated in four different scenarios (Figure 1). These scenarios show the balance between clarification and threats, which can influence on patients' life situation.

The first scenario, characterised by a high degree of clarification combined with a low degree of threat, indicated overall positive experiences. Hence, those who felt that they received the needed support and encouragement from partner, family, employers and municipality staff had positive experiences 1 year post discharge. These findings correspond with findings, that social support buffers against distress, and that fighting spirit is related to adjustment.²² Furthermore, the findings of what characterises a positive life situation are in line with previous findings that individuals with SCI who realise their potential and whose life goals are unchanged have positive psychological outcomes.^{15,16} Our findings support the idea that the process of getting on with life moves faster if persons are able to imagine elements from their previous life in their thoughts, about their future life and are able to find new identity and new values of life.³ The characteristics of a positive life situation explored here, therefore, can be explained by the individuals' ability to maintain their previous values, clarify important issues and maintain work with simple adjustment of competencies.

The second scenario, characterised by a high degree of both clarification and threat, indicated an overall positive life situation. A positive view can be gained, despite the fact that patients' previous manual work had become impossible. When patients articulate the difficulties and these, in turn, are understood by the municipality authorities, clarification seems to compensate for threat to core competences. This is an important finding adding to existing knowledge, as not only do personal coping styles and psychological factors play a significant role in recovery after SCI,^{16,22} but so too do factors in the individuals' environment.^{7,8,23} In line with findings of Angel *et al.*³ these two scenarios suggest that patients' ability to image a future, which seems worthwhile is important in order to get on with life.

The third scenario relates to the combination of a low degree of both threats and clarification. The scenario was characterised by severe threats on core competencies, which seemed to be manageable if the patients were able to transform previous core competencies into new ones and imagine themselves in new roles and jobs. These findings support findings that employment is more than a mean of financial support. Employment promotes relationship, social network and provides a sense of purpose, which supports psychological and emotional well-being.^{24,25}

Unfortunately, some patients were kept in a state of poor clarification, specifically, when problems were strongly interconnected. The overall life situation was stressful, for example, when bladder and bowel issues were severe and not straightforward to manage. Such on-going severe body function issues influenced

the ability to achieve clarification in relation to return to work, which again influenced the family economy. This is in line with findings from a review on life priorities²⁶ among individuals with SCI, which found that body problems, for example, bladder and bowel issues are particularly important. Also, a meta-synthesis²⁷ found that quality of life is influenced by, for example, body problems. What seems to matter is to achieve optimal clarification in relation to issues important to the individual as this helps to move forward. This is crucial knowledge for rehabilitation teams across health-care systems. Clarification as a vital mean to improve patients' life situation has, to our knowledge, not been explored previously. Although, there are several studies that describe and count barriers^{4,6,7,10} or explore psychological aspects with impact on long-term well-being.^{5,13,28}

The fourth scenario relates to the combination of poor clarification and a high degree of threat to core competences. This boosts negative experiences and indicates the worst case scenario. Although, a lesion may be categorised as less severe, threats on core competencies can be severe in terms of loss of jobs. When such a situation is combined with limited possibilities to obtain new and alternative competences problems seemed to accumulate. It seemed that a less severe injury is indicative of poor understanding by decision makers. Particularly, vulnerable were those younger ones, who had held positions as manual labourers and who found it difficult to articulate their case to the municipality authorities. Patients with less severe injuries were deemed suitable for normal work and forced to apply for jobs they knew they could not manage.

These findings add to existing knowledge on psychological aspects,⁵ as the patients in this study who have difficulties fighting their case seemed to use disengagement as a way of coping. It has been suggested that patients' long-term well-being is influenced negatively by too little focus on developing problem-solving skills and emotional recovery when patients are hospitalised.⁹ The present findings actualise this. Similar, Silver *et al.*¹⁰ found that patients might be discharged from hospital rehabilitation without skills necessary for successful transition to life at home.

Our findings indicate that there may be a need to pay more attention to the balance between clarification and threats as this appear to influence patients' recovery and reintegration processes. Specifically, those who are forced to develop new competencies in order to get a job and furthermore are forced to redefine their life goals and values seem to need attention. The findings also stresses that those younger people with SCI who are in their prime working years may be particularly challenged as employment contributes to the creation of personal identity.²⁵ The findings underline that problems regarding psychosocial issues, community services, employment and social interaction should be acknowledged in order to improve well-being after discharge as suggested by Kennedy *et al.*^{4,5}

The present analyses of an interconnection between clarification and threats as an indicator for the life situation following TSCI expand upon previous studies. The present findings are like the findings from a meta-synthesis of qualitative studies.²⁷ Those findings suggest that the quality of life is influenced by losses, relationships, control of one's life, occupation, environmental context and new values. Previous, 'life satisfaction' has been investigated in a multicentre cohort study indicating that high functional status, low pain, good social skills and high self-efficacy were related to high life satisfaction.²⁹ Quality of life and life satisfaction are different concepts and they differ from the term life situation used here and in previous studies,^{1,2} although there are several similarities. Those with poor clarification related to issues like work, work capacity and economy seemed to have negative experiences compared with those with a high degree of clarification, despite threat to core competences. Adjustment to SCI requires time and psychological resources, it is therefore important to consider processes that influence it.²² Our study has

identified important characteristics of patients' life situation that may assist professionals in supporting patients' rehabilitation processes.

In this third part of our longitudinal study seven patients were interviewed. The patients' experiences are considered to form an appropriate data source in ensuring sufficient richness for the present analysis.³⁰ In terms of age, gender, level and completeness of injury the participants reflect the epidemiological data on TSCI in Denmark,³¹ further they had different background and education. We used a semi-structured interview guide with open questions, which invited the patients to address positive as well negative aspect of returning home. Such an approach challenges the 'taken for granted' assumptions that returning home is difficult and that patients meet barriers and problems. We have taken steps to increase validity through engaging a group of health professionals at the centre, who discussed the findings, which they found identifiable. The figure presented in this study may serve as an inspiration for patients, health-care professionals and social workers to initiate a dialogue on how to promote a helpful balance between clarification and threats.

CONCLUSION

This study revealed that clarification in combination with threats to core competences may explain TSCI patients' life situation 1 year post discharge.

An appropriate balance characterises a positive life situation. There might be a need to pay attention to patients who are challenged by low degree of clarification and high degree of threats on core competencies 1 year post discharge as this seem to influence the life situation negatively.

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COMPETING INTERESTS

The authors declare no conflict of interest.

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