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ORIGINAL ARTICLE



The ambiguity of goal-setting: a study of patients' perspectives on goal-setting in outpatient multidisciplinary rehabilitation of patients with spinal cord injury

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ABSTRACT

Purpose: Spinal cord injury (SCI) is a complex health condition requiring long-term rehabilitation. Person-centred goal-setting is a central component of rehabilitation. However, knowledge of patients' perspectives on the goal-setting in SCI rehabilitation is scarce. The purpose was therefore to explore patients' perspectives on goal-setting in multidisciplinary SCI rehabilitation.

Materials and methods: An anthropological study combining participant-observation and individual interviews. Data were analysed using reflexive thematic analysis. The COREQ checklist was used to report study quality.

Results: Patients with SCI perceived goal-setting as ambiguous. On the one hand, they considered it insignificant, because it was complicated to transform complex needs of everyday life to recommended criteria of goals being measurable, specific, and realistic. On the other hand, they considered it a potentially useful guiding tool. Patients were uncertain of impact of goals and perceived goal-setting as vague during rehabilitation. Patient involvement was challenged by insufficient integration of patients' experience-based knowledge of everyday life and clinicians' profession-based knowledge.

Conclusions: Goal-setting in rehabilitation is not the patients' need but they accept it as the clinicians' framework for rehabilitation. For goal-setting to become meaningful to patients with SCI, patient involvement should be strengthened by equally integrating the patients' perspectives in the goal-setting process.

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Goal-setting; patients' perspectives; spinal cord injury; multidisciplinary; rehabilitation; qualitative study

► IMPLICATIONS FOR REHABILITATION

- Health-care professionals have to strengthen patient involvement in SCI rehabilitation by to a greater extent integrating the patients' knowledge of their everyday life and preferences rather than primarily focusing on profession-based knowledge.
- Health-care professionals must support patients in setting goals which are practically meaningful and relevant to the patients' everyday life and achievable and if needed go beyond the structured measurement of SMART goals.
- In an acknowledgement of the dynamic nature of goal-setting, clinicians should emphasise formulating goals in a flexible and non-directive manner, thereby providing room for patients' changing needs and challenges over time.
- Goals in SCI rehabilitation cover a wide range from broad, value-based goals to more specific goals, and the health-care professionals must ensure inclusion of such a wide range of goals.

Introduction

Spinal cord injury (SCI) is a complex and life-altering health condition resulting in varying degrees of paralysis. It often affects the quality of life [1], lead to depression [2], influence social life [3], and community participation [4]. Sociodemographic characteristics of people living with SCI have greater impact on their occupation and participation in social activities than the severity of SCI [5]. However, people with SCI experience that community participation is limited by factors as accessibility related to environment and physical impairment [6]. Also inadequate personal care and social support, and lack of appropriate occupational therapy are reported to create barriers to community participation [7].

Patients with SCI need long-term rehabilitation to enhance their quality of life and promote their reintegration into the community [8] but it is important to strengthen attention to factors people living with SCI experience limit their community participation [5,7].

Goal-setting is considered a core principle of rehabilitation as a mean to guide rehabilitation intervention [8]. It is implemented in a collaborative process between the person in need of rehabilitation and the rehabilitation team [9]. Accordingly, goal-setting is linked to a person-centred rehabilitation approach, thus involving a person's needs and values in decision-making [10–12]. Although person-centred goal-setting is considered pivotal for rehabilitation, its implementation in practice is lacking [13]. An important

barrier may be divergent perspectives on goal-setting between health-care professionals (HCPs) and patients. A recent review reported that patients considered it important to relate goal-setting processes to their everyday life while HCPs adopted a professional viewpoint, which meant they sometimes failed to consider the patients' perspectives [14]. Another review also found deficient implementation of setting goals related to the patients' everyday life and moreover scarce knowledge of patients' perspectives on goal-setting in SCI rehabilitation [10]. To improve rehabilitation based on the patients' perspectives, it is therefore important to gain detailed knowledge on how goal-setting in SCI takes place in practice, including how various perspectives, needs, and knowledge appear in co-operation between HCPs and patients when practicing goal-setting. Therefore, the aim of this study was to explore patients' perspectives and experiences of person-centred goal-setting in everyday practice of multidisciplinary rehabilitation following SCI.

Materials and methods

The study design was qualitative, and based on an ethnographic fieldwork conducted between November 2019 and October 2020.

Study setting

The study was conducted at a Danish hospital which provides outpatient multidisciplinary rehabilitation to patients with serious functional disabilities, such as spinal cord injuries. The hospital is operated by a patients' association. Yearly approx. 40 patients with SCI are referred to the hospital. The hospital has an operating agreement with the five regions in Denmark and rehabilitation is free of charge. Patients are referred from general practitioners or other hospitals where acute rehabilitation takes place. Thus, rehabilitation at the hospital concentrate on post-acute rehabilitation, focusing on the patients' return to everyday life, such as continuation of work, best possible self-reliance, and quality of life. The rehabilitation approach which took place at the hospital is described in Table 1.

Participants

The study population was recruited based on purposive sampling. The sampling procedure was chosen to generate data specifically from patients with SCI participating in outpatient multidisciplinary rehabilitation; and from HCPs who possessed experiences and perspectives specifically regarding patient-centred goal-setting. Furthermore, the patients should be able to speak and understand Danish or English and broadness of gender and age were sought. Eligible patients were contacted by mail or phone by the

researcher (LØ) to inform about the study and ask if they were interested in participating. During the recruitment number of participants was guided by information power meaning that the size of the sample depends on an assessment of the quality of information the sample holds in order to elucidate the subject [15]. The sample size was decided based on sample specificity, quality of dialogue, analysis strategy, and study aim. A relatively large sample size was required for this study to reach a high degree of information power because of the study characteristics with a broad aim, a wish to cover a broad range of variations of the study subject and an explorative cross-case analytical strategy. Three of the contacted patients declined to participate due to lack of resources. The included patients formed two groups: 12 patients were initially included to be followed in-depth throughout their courses since a sufficient information power (with reference to the above mentioned variables) at this point was assessed reached. This group of participants constituted the key-informants. To further secure robustness and validate the data additional 10 patients were included to be followed at point of impacts during rehabilitation activities, mainly initial- or evaluation meetings where goal-setting explicitly was discussed. Thus, a total of 22 patients was included since no further important variation in data appeared at this point.

Most participants were aged 20–45 years. Half of them had short-term SCI, approx. one third medium-term SCI and the rest long-term SCI. Half of the participants had a cervical injury. Five of the participants had non-traumatic causes of SCI. Table 2 provides an overview of the participants' characteristics.

Methods

Data were generated through participant-observation and individual interviews [16,17]. Triangulation was ensured, using different methods to allow various aspects of the study area. An experienced qualitative researcher, trained in anthropological fieldwork (LØ), conducted the participant-observation and the interviews.

Participant-observation formed the foundation of the study. To gain detailed insight into all possible rehabilitation aspects the 12 participants were followed throughout their rehabilitation courses in all their rehabilitation activities (examinations, treatments, training and meetings), and 10 participants were followed at rehabilitation activities to further secure information power and data validity. Participation involved being present and observing what happened at the rehabilitation activities, so the researcher was not involved in the treatments. Approximately 130 activities were observed, covering all phases of rehabilitation from preadmission assessment over initial and evaluation meetings to rehabilitation activities involving medical doctors, physiotherapists, occupational therapists, psychologists, social workers and dietician. The various

Table 1. Rehabilitation approach at the hospital.

The rehabilitation approach at the hospital follow the international standards and recommendation. Thus, a systematic goal-setting approach, including decisions on goals that are person-centred and specific, measurable, realistic and time-based, is used at the hospital. The requirements and procedures following these principles are described in the hospital's guidelines. The time frame for a rehabilitation courses is three months, eventually allowing prolongation. The rehabilitation courses are individually organised and cover the following stages:	
1.	It is initiated by the doctor's medical examination to determine the patients' eligibility for the rehabilitation course. The doctor also introduces goal-setting by asking the patient to consider his/her expected benefits and wishes for the rehabilitation as preparation for meeting other HCPs.
2.	Initial meeting between the patient, relatives and multidisciplinary team responsible for the course. One hour is allocated and usually it takes place a few weeks after the medical examination. The purpose of the initial meeting is to introduce the involved persons and clarify treatment possibilities at the hospital. At the meeting goals are set by inviting the patients to talk about their everyday life, based on a questionnaire about their everyday life, values and challenges, which they are asked to complete beforehand. A plan for the rehabilitation activities is decided upon.
3.	Shortly after the initial meeting therapy sessions are initiated. These are conducted by a team of physiotherapists, occupational therapists, psychologists, social workers and dieticians. The patients participate in activities two to three times a week.
4.	Evaluation of the rehabilitation course: the patient, possible relatives and the team of HCPs participate. The purpose of the evaluation meeting is to assess the achievement of planned goals and discuss plans for the future.

Table 2. Characteristics of participants.

	Categories	N (%) (total 22)
Sex	M	9 (41%)
	F	13 (59%)
Age ^a	20–45 years	14 (64%)
	46–70 years	8 (36%)
Marital status	Married/cohabitant	13 (59%)
	Single	9 (41%)
Educational level	Primary/high school	5 (23%)
	Vocational	5 (23%)
	Bachelor	7 (31%)
	Graduate level	5 (23%)
Job status	Unemployed	6 (28%)
	Employed	9 (41%)
	Retired	7 (31%)
SCI due to:	Trauma	13 (58%)
	Non-trauma (various forms of neural tube defects)	5 (23%)
	Congenital Disease	4 (19%)
SCI injury level	Cervical	11 (50%)
	Thorax	7 (31%)
	Lumbar	4 (19%)
Years since trauma/disease leading to SCI ^b	<3	11 (50%)
	4–10	6 (28%)
	>10	5 (22%)

^aThe age-categories represent respectively young and middle-aged/elderly groups.

^bThe categories represent respectively short-, medium-, and long-term since injury; duration of time since injury influence the difficulties patients with SCI meet in their everyday life.

activities lasted approximately 1–1.5 h. Before and after observing each activity, the researcher met with the participants for informal talks regarding their expectations, opinions, motives, and reflections on the specific activities as well as their general concerns and condition. Observation guides were used to provide a focus to the participant-observation, and guides were adjusted to the specific activities. The following different types of field notes were written: notes regarding events and concrete actions and activities, descriptive notes regarding the essence of empirical data and analytical and reflexive annotations [18].

Individual interviews were conducted with the key-informants. The interviews were held to allow the participants to reflect and elaborate on their experiences [17]. Each participant was interviewed twice, at the beginning and at end of their rehabilitation course. Thus, a total of 24 interviews were conducted. The first interview allowed the participants to elaborate on their expectations and experiences of goal-setting and the second interview to reflect on the overall course and the importance and meaning of goal-setting. The first interview was conducted at the participant's home, and the final interview at the hospital, apart from two interviews that also took place at home. Home-based interviews enabled to build confidence between the researcher and the participants and created familiarity with their everyday life. To direct the interviews two semi-structured interview guides were developed, based on the intentions with the interviews and the relevance for the aim of the study. The following subjects were discussed: (1) everyday life before and after the accident; (2) expectations regarding the rehabilitation course; (3) reflections on approach to goal-setting in SCI rehabilitation, activities and co-operation with the HCPs (4); experiences and perceptions of goal-setting during various phases of the SCI rehabilitation; and (5) importance of the SCI rehabilitation with regard to their everyday life (see Table 3 for generic interview guide). Each interview lasted 1–2 h and was audiotaped as well as transcribed verbatim.

To strengthen the study quality and relevance, patients were involved in the initial phase of the fieldwork (other patients than study participants). They contributed with feedback regarding study focus, important themes to focus on and study feasibility.

Analysis

The analysis was conducted by two of the authors (LØ and CH) supplemented by a third author (TM); all of them experienced researcher within rehabilitation research, two of the (LØ, CH) trained and highly experienced in qualitative research methods, LØ as an anthropologist and MPH and CH as nurse, MPH and PhD. The data were analysed using reflexive thematic analysis, which is characterised by developing themes as patterns of meaning from the researcher's interpretation of the data material [19] and can thereby provide insights into the patients' perspectives on goal-setting. Analysis of data deriving from the various methods were combined to strengthen the analysis. Interview transcripts and field notes from participant-observation were coded using an inductive and iterative process, going back and forth to the data material to accommodate the researcher's conceptualisation of data. This was followed by the development of themes identifying a coherent meaning grounded in the data and organised around the central concepts. The process included the following analytical levels: (1) familiarisation with data by repeated and open-minded reading of interview transcripts and field notes to gain an overall understanding of the data and a sense of "what's brought into play"; (2) generation of initial codes from the data, followed by discussion and their adjustment by two of the authors (LØ and CH) and recoding of the dataset accordingly. Five overall codes were used: Patients' everyday life, patients' experiences of rehabilitation meetings: initial, evaluating meeting; final meeting, patients' experiences of goal-setting in rehabilitation activities, co-operation between patients and health-care professionals regarding goal-setting, patient involvement; (3) condensation of the data by investigating connections between codes and identification of patterns across the codes; and (4) identification of themes by compiling codes into coherent clusters of meaning.

Quotations and excerpts from the field notes were used throughout to illustrate the findings of the study [20]. The selection of these quotations and excerpts was performed to ensure that a broad variation in perspectives found in the data material was presented [21]. The qualitative data analysis software NVivo¹²

Table 3. Generic interview guide.

Themes	Subjects/questions
First interview	
Introduction	Presentation; frame, content and purpose of the interview etc.
Opening questions	Why do you wish to start rehabilitation at the Specialised Hospital for Accident Victims? What do you know about the hospital? Who referred you?
Everyday life	Have you previously participated in rehabilitation courses? Are you working, enrolled in education or anything else? Can you tell me about your everyday life before your situation changed? (work, leisure, family etc.) Is there something you were particularly interested in or liked to do before your situation changed? How is it different now? Can you describe situations or examples where your changed situation affects the things you did or liked before? Are you able to do some of the things you like and are interested in? If so, can you give an example? How can you best be supported to be able to do activities which are important to you? Do you receive any get help in your daily life to be able to take part in the activities you want? If so, by whom? How does it work?
Perspectives of the rehabilitation course	Do you have some needs or issues that are more difficult to talk about and receive help to than others? Can you please tell me about your ideas and incentives to start the rehabilitation course at the hospital? What do you like to achieve by the course? What do you expect will happen during your rehabilitation course?
Everyday life after the rehabilitation	Can you please tell me about your impression and experience of the initial meeting you attended at the hospital (e.g., what was it like to set goals; does it make sense to set goals; to divide them into short and long-term; could the staff have done anything differently to help/make it easier/more meaningful) How do you expect or imagine your everyday life after finishing the rehabilitation? (e.g., worries, concerns family, education, job, housing, interests?)
Closing	Do you dream about anything particular? Do you expect your rehabilitation course will help you to achieve this? If it is not clear from the above interview: type of dwelling, civil status, children etc. Do you want to add anything to our conversation—anything important we haven't talked about?
Second interview	
The evaluation meeting	Now you have joined the evaluation meeting; can you please tell me about how you experienced that? (did it proceed as expected; anything surprising; was it meaningful, difficult, easy—why was it so)
Experiences of the overall rehabilitation course	Can you please tell me about your opinion of the rehabilitation course as you have experienced it? What do you think you have achieved during the rehabilitation course? What is your opinion of the collaboration with the staff, how do you experience that? Do you experience differences between the staff and/or the various professions?
Working with goals	Do you feel that your wishes and needs have been taken into account during the rehabilitation? How/in what ways? How has it been to work with goals? What significance do you think it has had? Which goals for your rehabilitation did you initially agree upon? Have the goals been changed along the way? How?
Rehabilitation course and everyday life	What are your experienced of working with the goals during the rehabilitation activities and sessions? Has anything changed in your everyday life during the rehabilitation course; in what ways? Have you achieved what you expected, what you wished for when you started the rehabilitation course? Does it correspond to the goals you agreed upon or have worked with?
Closing	Has your rehabilitation course in any way influenced your everyday life? Do you want to add anything to our conversation—anything important we haven't talked about?

(QSR International) was used to manage data. The COREQ checklist was used to report the study [22].

Ethics

This study was approved by the Danish Data Protection Agency (J.nr. 2017-41-5202). Permission to contact patients for study information and eventual participation was obtained via the HCPs. The patients were contacted by phone or mail to introduce the study. All participants provided written informed consent. The participants were promised confidentiality and their data were anonymised.

Results

Three themes were identified to describe the patients' perspectives on goal-setting in SCI rehabilitation: (1) *Goal-setting is experienced as ambiguous*, which concerns the patients' understanding of goal-setting as an equivocal notion; this theme was divided into sub-themes—namely “goal-setting perceived as insignificant” and “goal-setting perceived as sometimes useful”—to emphasise its two very different yet coexisting attitudes to goal-setting which bring about the ambiguous perspective of goal-setting (2);

Different forms of knowledge challenge patient involvement, which concerns how various perspectives of goal-setting appear, resulting in both consistent and conflict-filled rehabilitation courses; and (3) *Goal performance is experienced as vague*, which concerns the patients' experiences of goal-setting practice as vague and tacitly performed (Figure 1). The themes are presented below.

Goal-setting is experienced as ambiguous

Patients with SCI mainly experienced that goal-setting was challenging. Although some patients, especially those who had experiences with goal-setting from work or attending courses in the health-care system, considered goal-setting as relatively unproblematic. However, even these experienced patients reported that it was difficult to transfer knowledge from workplaces to health care. The analysis focussed on the dominant narrative of goal-setting as challenging and ambiguous, as highlighted by a quote from one of the patients during the informal talks linked to the participant-observation activity:

Well, I'm not that concerned with goals. It might be important for the staff here, it appears so, but for me, it doesn't matter that much.

Later, the same patient remarked:

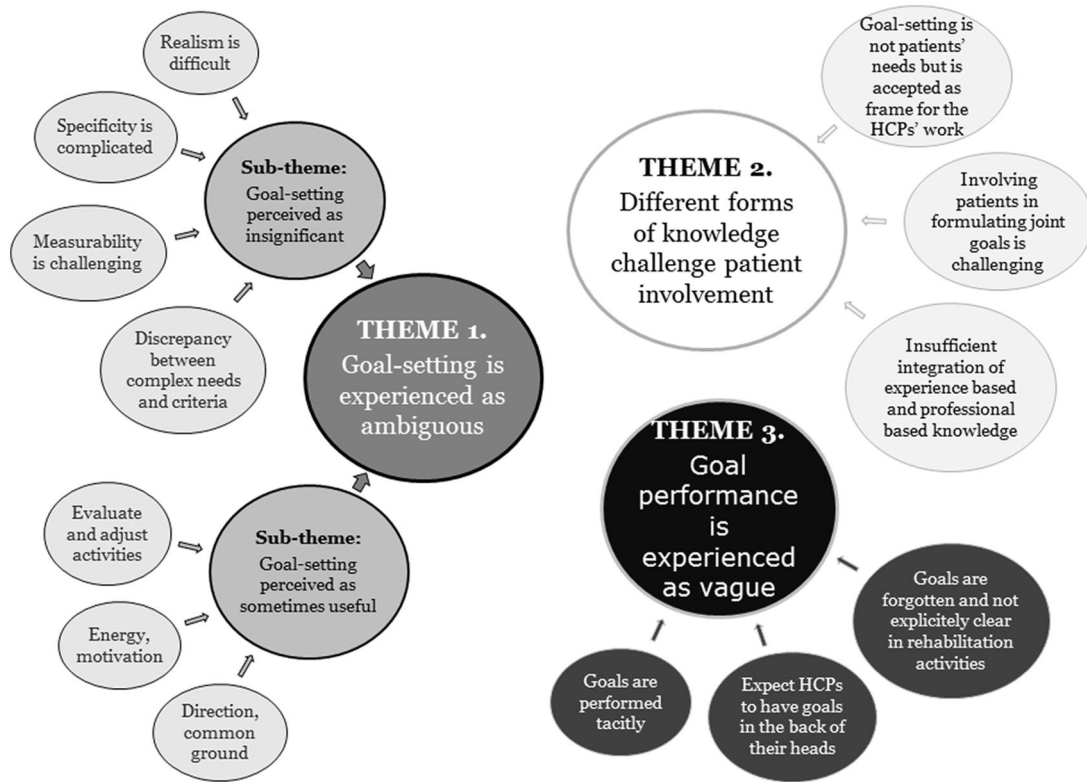


Figure 1. Definitions and delimitations of the themes.

... it is not unimportant to have goals, it is good to have something to stick to, something which shows the way, so it doesn't come to nothing. (ID16, Isabelle, 46–70 years, <3 after injury)

Goal-setting perceived as insignificant

When discussing goal-setting with patients with SCI and observing how they together with the HCPs participated in decisions on goals for their rehabilitation course, the patients did not appear active. They generally expressed that goal-setting was not really important to them and overall they found it challenging. Most patients considered it abstract to talk about their values, which the HCPs commonly asked about as a way to identify goals that were essential to the patient's rehabilitation. Several patients found it awkward to set goals because they were uncertain of what to expect from multidisciplinary rehabilitation and what they could achieve with the support of the HCPs. Some patients said:

Somehow, I'm not crazy about setting goals. I don't know what they can offer here. It's like having to accomplish something, and I don't necessarily know what I can achieve. They are the experts, and they know much more about what's possible. (ID16, Isabelle, 46–70 years, <3 after injury)

Goals are something you must be able to achieve, something that's realistic. You may set goals that you will never achieve. That's depressing! (ID7, Rebecca, 20–45 years, <3 after injury)

These quotes illustrate how the patients recognised that the goals were expected to be realistic and concurrently were unsure about what to expect from multidisciplinary rehabilitation. Therefore, they did not set too high or low goals, because of the fear that they would be disappointed if they did not achieve what they expected or would limit themselves and not reach their potential. Thus, being in unfamiliar territory, they requested the HCPs' expertise and mostly accepted what the HCPs suggested.

Furthermore, patients with SCI found goal-setting inappropriate because the requirement of measurable and specific goals contrasted the complexity of their everyday life and as such, challenged the relevance of the goals. Some patients explained:

I was totally blank (when they discussed goals). Well, I do hope my everyday life becomes better and that I will be able to handle my life and my pain. But it's really difficult, because I certainly can hear it has to be something specific, and something they (HCPs) can evaluate. And then it becomes something like learning things about my body, what I can manage—and is that exactly what I want, what improves my quality of life? (ID2, Alexandra, 20–45 years, 4–10 after injury).

Well, I have 50 things that could be important to touch on, lots of things that have a strong presence in my everyday life. So, to balance that it should be meaningful to me and specific, so it is workable for them (HCPs), that's difficult. (ID1, Madeleine, 46–70 years, >10 after injury/congenital)

It's far too detailed if we have to investigate how I can work with an onion chopper. Because, basically, it concerns how do I myself manage to provide food for my son in a kitchen? But if you have to measure, well ... It becomes, like a small pawn of something, but it doesn't change anything about the overall picture, really. (ID18, Emily, 20–45 years, >10 after injury/disease)

The quotes show a common issue among the patients that they often found goal-setting insignificant because it was complicated to transform their complex and varied needs into measurable, specific, and realistic goals. One of the patients reflected on why goal-setting within the framework of health care sometimes appeared meaningless:

Usually, I like to set goals and have a focus. But here (at the hospital) it is difficult to dare to set goals, because what are we aiming for? It is probably easier to set goals in a production, at a sausage factory, where you can talk about quantity, size and quality. It's harder with people. (ID8, Leah, 46–70 years, <3 after injury)

Several patients further pointed to their dynamic situations because their problems and needs changed with time, and

therefore, it could be difficult to hold on to the relevance of the appointed goals. Time was also an important factor for attitudes towards goal-setting with regard to the duration of time elapsed since the accident. Some patients had been exposed to the accident leading to their SCI several years ago, and they expressed difficulty in attaching importance to goal-setting. For example:

I've tried everything, and I've been very optimistic. But nothing is happening, I'm not improving anymore. I feel like, I cannot stand it anymore, I think it's hopeless. That's why I think of early disability pension—but I guess, that cannot be a goal, or what do you think? (ID2, Alexandra, 20–45 years, 4–10 after injury).

Thus, feeling more or less stagnant and losing hope of further progress may result in goal-setting becoming meaningless, implicitly indicating that goal-setting targets change of a future situation rather than acceptance of the status quo. In contrast, some patients for whom rehabilitation was initiated a short time from being exposed to the accident leading to the SCI, in some ways were more specific regarding their goals. For example, one of these patients said:

Well, I was prepared (for goal-setting), and for me, it is important to return to work as soon as possible, so I have to be able to use my left hand better to use the keypad properly and in general to be physically stronger and also better to keep balance. (ID17, Jack, 46–70 years, <3 after injury)

Accordingly, attitudes towards and experiences with goal-setting in SCI rehabilitation were related to the rehabilitation stage. Time was also an essential component in relation to the organisational framework of goal-setting. Most patients found the time allocated to set goals at the initial meeting of the rehabilitation course to be too short and scheduled at a too early stage of their rehabilitation course because it was reserved at a time when the patients and HCPs did not know each other well. The patients indicated that at that time of the goal-setting process, it could be difficult to discuss rather delicate and personal issues meaningful to the patients.

Goal-setting perceived as sometimes useful

Although the patients with SCI voiced that goal-setting at times appeared to be meaningless, it did not mean that the patients were indifferent to goals or that goal-setting was perceived as being insignificant. The patients commonly acknowledged that goal-setting could provide a point of orientation and focus as well as a possibility to evaluate the courses. Some patients said:

It (goal-setting) helps to provide a direction for what we are heading at. After all, some point of orientation is necessary. They (HCPs) should also know what I am interested in for the treatments to make sense. (ID5, Sharon, 46–70 years, 4–10 after injury)

If you want to make a comparison, then you need to have a point of departure and a goal, because most likely, you won't remember how it used to be after a while. After all, I'm happy when I can see I have achieved something or at least have become better. I probably wouldn't have had this realization if no goals were set. (ID7, Rebecca, 20–45 years, <3 after injury)

Goal-setting may function as a motivating factor to support what the patients wished to achieve, or, as some patients also suggested, as reflections of what was possible to achieve, thus supporting the acceptance of the patient's actual capacities and competencies. Moreover, goal-setting may provide a framework for common ground and form the basis for co-operation between the patient and HCPs, as illustrated by the following quote:

It might be okay to set goals because it provides a united approach—where we are heading. If only the HCPs are not that strict. Goals don't have to be formulated sharp on three lines. I think they (HCPs) have a

holistic perspective, so goals are something we test together so I might move on. (ID3, Karl, 46–70 years, 4–10 after injury)

Nevertheless, as the quote also indicates, the patient emphasised certain conditions that could benefit goal-setting, such as working with goals in a flexible manner based on consideration for the patients' wishes.

Different forms of knowledge challenge patient involvement

Involving persons with SCI in goal-setting is considered essential for implementing meaningful rehabilitation and is also expected to improve treatment adherence and promote autonomy. Still, the practice of goal-setting in SCI rehabilitation showed that it was challenging to involve patients in formulating joint goals. Some patients stated:

The HCPs are very professional and loyal to their assessment and evaluation systems. It is probably helpful to their work, but it doesn't help the individual patient if it's a kind of package solution you receive. In my case, it didn't end like that, I did participate in influencing what it should revolve around. Then, you are also more concerned about how it works. (ID6, Neil, 46–70 years, >10 after injury)

The HCPs are the ones who decide what to do and I adapt to that. But it also has to provide meaning to the patient. I'm the one who knows what's important in my life. I'm not questioning their competencies and professionalism at all, I certainly need that, but it's my body that is broken after all. (ID4, Patricia, 20–45 years, <3 after injury)

The most difficult thing about goal-setting is that to me, the predominant factor concerns the quality of my life, which their professionalism cannot really cover. How to translate my subjective assessment of what provides meaning to me in my life into something specific, so it makes sense to the HCPs? (ID2, Alexandra, 20–45 years, 4–10 after injury).

The quotes illustrate how patients with SCI emphasised the importance of being involved in the goal-setting for their rehabilitation, stressing their specific knowledge about their bodies and the problems that affected their lives. However, they concurrently requested profession-based knowledge to achieve the everyday lives that they desired or could live. Thus, different types of knowledge were brought into play in the goal-setting process: profession-based knowledge and experience-based knowledge represented mainly by the HCPs and patients, respectively. The quotes indicate that although the patients experienced their involvement in joint goal-setting differently, patient involvement was complicated to implement and took diverse directions, resulting sometimes in conflict-filled rehabilitation courses and at other times, in consistent courses, as illustrated by the following field note excerpts:

During Emily's rehabilitation course, the physiotherapist and occupational therapist continuously suggest clarifying compensatory strategies. They are worried that she uses her body inappropriately by straining herself and thereby further harms her functioning. Emily expresses that she doesn't experience the comprehensive help that she thus far received to reduce her pain or provide her with more energy. Now, she—despite her disease—wants to prioritize things that strengthen her quality of life. The HCPs tell me that their impression is that Emily objects to receiving help and has inadequate disease recognition and that she needs comprehensive care and assistive technologies to not “wear out”. At a treatment session, Emily indicates that she is not observing any progress and after the session, she explains to me that she wishes to be supported in how to make decisions about doing things that are meaningful to her despite the reactions of her body. She said: “... there are some conflicting expectations in this. It's not because the HCPs should be indifferent to what I do with my body. I do understand they uphold their professionalism. But some middle ground, I think, is what I am looking for—how can I on a qualified basis make decisions about what I want to use myself for?” Gradually, she scales down her expectations

regarding the course and limits her activities to the training programme that she is offered. (Field note excerpts from treatment sessions; ID18, Emily, 20–45 years, >10 after injury/disease)

In this case, goal-setting was initially formulated as resource management. Based on her experiences with what had helped/not helped her thus far and what improved the quality of her everyday life, Emily was concerned regarding how to make competent choices to improve the quality of her life. Grounded in their specialised knowledge, the HCPs were concerned about how Emily should spare her body using compensatory strategies to reduce the risk of further harming her functioning. Thus, the field notes present a situation where profession- and experience-based knowledge were conflicting, demonstrating the challenging task of reaching a common ground based on the HCPs' and patients' respective agendas and forms of knowledge. In this case, the result was an unsolved conflict, where Emily decided to scale down her expectations regarding the course because she did not receive the help she needed.

Bringing the different types of knowledge into play impacts co-operation involved in goal-setting in various ways, as observed in the following field note excerpts:

The physiotherapist suggests exploring compensatory strategies, which she—and the occupational therapist—have recommended several times. Jack says he is not interested and that he wants to return to his usual self. Right from the beginning, he wished to undergo strength and endurance training to improve balance and walking speed, and to improve the functioning of his hands to be able to use a computer at work. After the treatment session, the physiotherapist explains to me that they consider it unrealistic that Jack would achieve the same functioning as before the accident and that they are worried that he will do more harm to himself by not paying regard to his changed functioning. At the following treatment sessions, they continue to discuss the issue of assistive technologies, mentioning eating utensils, special chairs and a walker for decompression to spare Jack's body. He says that he has several devices at home but does not use them because he perceives their use as giving up. After a while, they agree on just training in ways that the physiotherapist considers appropriate, e.g., quality of movements rather than pace, if that is what Jack wishes. At the evaluation meeting, they decide to continue the rehabilitation course by individual training. Jack says he has already achieved a lot and that it has been important that they have listened to him although they have not always agreed with him. (Field note excerpts from treatment sessions; ID17, Jack, 46–70 years, <3 after injury)

These field notes exemplify how various types of knowledge manifested in different agendas were integrated, resulting in well-functioning co-operation between the patient and HCPs. It is an example of how professional assessment based on specialised knowledge without being neglected was adapted to the patient's wishes, resulting in different forms of knowledge being put into play even though at first they were not consistent.

Thus, the process of joint goal-setting to guide SCI rehabilitation evolved around different types of knowledge. In this process, patient involvement may be challenged by potentially divergent forms of knowledge, representing respectively the patients' and HCPs' agendas.

Goal performance is experienced as vague

During SCI rehabilitation activities, the established goals that were agreed upon did not play a noticeable role. Goals were seldom mentioned or discussed between the individual patients and HCPs, and most patients did not pay any attention to their goals throughout the rehabilitation course. Goals mainly played an explicitly active role at the two ends of the rehabilitation course: at the initial meeting where goals were decided upon and at the evaluation meeting where goal achievement was evaluated.

Discussing goals at these events was always the HCPs' initiative. Moreover, most patients were often not aware of the goals that they had set when they were asked to assess their goal achievement at the evaluation meeting. This scenario is illustrated by the following field note excerpts from an evaluation meeting:

Physiotherapist: "Now, we have to talk about evaluating the goal-setting. Which goals are achieved, which are not attained? How do you think things have worked out?"

The patient (smiling): "Well, do you really expect me to remember that? I do remember we talked about goals, but I've completely forgotten what we decided upon".

Physiotherapist (reads aloud): "Yes, we set some long-term goals: you wished to have a more active social life and be in control of the functioning of your intestines. And short-term goals, you wished a better balance and ..."

The patient (interrupting the physiotherapist): "Well, that might be. You see, I think I've benefitted a lot from being here, it's been really good. I've become stronger and now I work out in the mornings when I have energy and I've become better at resting during the day. I don't know if I have achieved a goal, or achieved the goals, but I have become more aware of taking care of myself and what's tending me well". (Field note excerpts; ID1, Madeleine, 46–70 years, >10 after injury/congenital).

In general, the patients expressed that they benefitted from the SCI rehabilitation. However, they seldom related the activities to the goals agreed upon, which appeared to be rather vague. They indicated they were uncertain if or how goals influenced their rehabilitation activities although the individual HCPs always explained to the patients at the rehabilitation sessions what they were doing and why.

However, goal-setting was not perceived as being solely vague during rehabilitation activities by the patients. They also understood goals performed tacitly, as indicated by the following quotes:

Goals don't have a strong presence in my everyday life. When I am at the hospital, we talk about the present situation. But I guess the goals are implicitly behind. And the treatments they are performing, most likely they have something to do with what I have said more or less directly. (ID3, Karl, 46–70 years, 4–10 after injury)

... there is no point in these meetings (introduction and evaluation meetings) if we didn't have the goals to talk about. I'm sure that they (HCPs) have a plan to make me stronger and take charge of all that mess in my life. Like that, the goals are probably present. (ID6, Neil, 46–70 years, >10 after injury)

Thus, although the patients did not experience goals to be explicitly manifested during rehabilitation activities, they did not perceive the goals to be absent or dismiss a potential significance of goal-setting. One of the patients expressed:

It's not really important to me to achieve the goals. It's more a matter of having a common orientation, I hope for. I do hope that I will be in a better position to fend for myself when I finish out here (at the hospital), that's what I hope the HCPs can help along. In that way, I think of being here as the meeting of hope. (ID8, Leah, 46–70 years, <3 after injury)

Therefore, patients with SCI experienced goals agreed upon as vague during the rehabilitation activities while concurrently recognising them to be the basis for the HCPs' decisions regarding the performed rehabilitation activities. The vague expression of goals during rehabilitation activities may relate to the patients' complex needs. The criteria of goals being specific, realistic, measurable and time-based were challenging to apply to the comprehensive and complex issues of the patients. Thus, a tacit framework developed; on the one hand, holding on to the goals

agreed upon and on the other hand, modifying goals to a practice relevant to the specific situation of the individual patient.

Discussion

Person-centred care is considered fundamental in health care, stressing the importance of addressing a person's individual needs and resources. Accordingly, rehabilitation at the hospital where the study took place was organised within frames of a person-centred approach and hereby aiming at involving patients with SCI in the goal-setting process. However, as the findings overall demonstrate, this ideal was often challenged in practice. In the literature there is an ongoing discussion of how to apply person-centred care and terminologies as person-centred, client-centred or patient-centred are used randomly [13]. Despite the lack of agreement about implementation as well as terminology, there seems to be nuances between patient- and person-centred expressions, the latter involving a broader context of human beings compared to a more disease-specific approach [10]. The focus of the present study was goal-setting performance in everyday rehabilitation practice which provides new insight into why a patient-centred approach may be difficult to practice. The findings of the study showed that patients with SCI perceived goal-setting in rehabilitation as ambiguous. On the one hand, they considered goal-setting as insignificant and more essential to the HCPs' work rather than to meet their needs. On the other hand, they regarded goal-setting as potentially motivating and useful to guide joint rehabilitation. The main reason for perceiving goal-setting as ambiguous was that the patients found it difficult to comply the needs of their complex everyday life to the recommended criteria of goals being measurable, specific, realistic and time-based which also constituted the rehabilitation approach at the hospital. Some of the participants had non-traumatic causes of SCI but this did not seem to give rise to different perspectives of goal-setting. All of them were in the post-acute phase of rehabilitation which may influence their perception and experiences of goal-setting. At these stage rehabilitation activities go beyond possibilities for physical training and focusing on return to everyday life emphasise the multi-faceted character of their challenges. Return to everyday life implies more complex issues and aspiration than e.g., being able or not to walk a certain distance, and this goal-setting context is therefore not an either-or issue, and therefore challenging criteria of formulating goals in a directive manner. Thus, although patient-centred goal-setting is a recognised cornerstone in rehabilitation as a mean to guide rehabilitation interventions [8], the present study revealed that patients with SCI did not necessarily experience goal-setting as meaningful or relevant to their rehabilitation. Other studies also pointed to a discrepancy between intentions of goal-setting in rehabilitation and patients' experiences and perspectives. A recent review reported that patients with SCI considered relating goals to their everyday life more important than measurable goal attainment or physical functioning, which were the HCPs' main concerns [14], and a study found that the HCPs employed a mainly prescriptive approach to goal-setting while patients expressing a need to outline goals in a flexible manner [23].

Other studies exploring perceptions of goal-setting in patients with SCI have emphasised the patients' expression of goals in terms of hopes and visions rather than in terms of measurability [24]. Studies of people with other diagnosis found similar results, for example people with disabilities perceived hope as pivotal to their recovery process [25], or patients receiving physiotherapy found it meaningful to talk about goals as aspirations and dreams rather than dichotomised into realistic and unrealistic goals [26].

The present study did not explicitly demonstrate a perception of goals as hopes or aspirations, although a few patients talked about SCI rehabilitation as "the meeting of hope". Rather, the patients made goal-setting meaningful by advocating for goals to be defined in a flexible and broad manner to better accommodate their complex life situations, thus more explicitly challenging a SMART approach to goal-setting.

The study contributes to the field by providing a more nuanced understanding of the patients' perception of goal-setting in identifying patients' perception of goal-setting as not solely insignificant. It was found that the patients did not dismiss the idea of goal-setting since it also was perceived as a potentially relevant tool to support motivation and guide towards a common ground between them and the HCPs. However, the potential usefulness of goal-setting was seen to be closely related to a well-functioning integration of the patients' needs and wishes in decision-making about goal-setting and they sometimes found it challenging to fully involve their perspectives in goal-setting. The study provides new knowledge by showing how this evolves in the daily practice of goal-setting, emphasising that potentially conflicting agendas based on different forms of knowledge—profession-based and experience-based knowledge—appeared to difficult to integrate. The study revealed how the patients occasionally strived to position their needs in the goal-setting process by explaining how they used certain strategies to make things work according to their wishes. Other studies also pointed to difficulties in involving persons in their rehabilitation. For example, a study found that involving persons with disabilities is impeded by inadequate recognition of the disabled person as an expert, and unequal relationships with specialists created barriers to the disabled person taking control over their own life [25]. Another study focusing on acute inpatients SCI rehabilitation also found to barriers to patient involvement [27]. Despite the different target groups, with the present study concentrating on outpatient post-acute SCI rehabilitation, the findings are similar, indicating how unequal positions between HCPs and patients may challenge patient participation in rehabilitation across target groups and diagnoses.

Acknowledging individual needs and equal partnership as important components of goal-setting in rehabilitation seems to impact the effects of rehabilitation. A review about person-centred rehabilitation found positive effects on users' satisfaction with rehabilitation as well as functional performance and quality of life [13]. However, several reviews also emphasised that although patient involvement is commonly acknowledged as a central rehabilitation approach and goal-setting as an important tool to secure rehabilitation according to the patients' interests, it is still not fully reflected in practice [10,13]. Reflecting upon the historical background of goal-setting in rehabilitation, a study reported that the concept thus far has had multiple meanings and has been used widely outside the context of rehabilitation and disability and therefore still raises both practical and theoretical challenges [11]. Some of these challenges have been highlighted in the present study, overall indicating a need to strengthen patient involvement in rehabilitation. Despite the growing knowledge of patients' perspectives on goal-setting in rehabilitation, there is still a need for further investigation on how to improve the implementation of person-centred rehabilitation in an acknowledgement of patients' preferences and perspectives.

Methodological considerations

The present study adhered to the COREQ checklist [22]. A further strength of this study was the use of triangulation in data

generation: participant-observation, which provided in-depth insights into patients' perception of goal-setting practice, combined with several individual interviews with each participant. Triangulation allowed for checking interferences drawn from different data sources and added depth to the description of the data, which strengthened the study validity [28]. Performing interviews in the participants' homes created familiarity with the participants and confidence between the researcher and participants. In addition, the numerous informal conversations during participant-observation activities provided both confidence and valuable opportunities to reflect on specific situations and general experiences among the participants. Thus, this study provides solid and comprehensive data material contributing to descriptions of patients' perceptions of goal-setting practice. Finally, thorough and systematic descriptions of the data-gathering process, coding and analytical approach provide transparency to how the study was accomplished.

Previous studies called for expanding knowledge across health-care professions, settings and diagnoses [29,30], and the present study with its qualitative approach to multidisciplinary SCI rehabilitation contributes to this. However, the specific patient group studied (patients receiving post-acute SCI rehabilitation) may limit the transferability of the study findings because the patients' needs, preferences and possibilities for involvement in goal-setting may differ from patients in the initial stage of their rehabilitation, with other diagnoses or physical impairments. The gender distribution of the study sample with a slight overrepresentation of women does not match real life SCI population (a preponderance of men despite geographic variations, e.g., in Denmark approximately twice as many men as women [31]). Since we did not adequately comply with this variable in our sample procedure this gender distortion may also impact transferability of the study findings. Nevertheless, the possibility of generalising our study findings is supported by the identification of similar findings across diagnoses and rehabilitation stages, e.g., the findings of patients' wish for a flexible and non-directive goal-setting approach and challenges in integrating the patients' agendas in a shared goal-setting process.

Conclusions

The present study presented three main findings. First, patients with SCI experienced goal-setting as ambiguous: on the one hand, they expressed goal-setting as insignificant, which was related to a perceived discrepancy between the requirements of goal-setting being specific, measurable, realistic and the complex needs of their everyday life; on the other hand, the patients found goal-setting a potentially useful tool to guide rehabilitation. Second, goal-setting evolved around different forms of knowledge: profession- and experience-based knowledge, represented respectively by the HCPs and patients with SCI. The integration of these kinds of knowledge could pose challenges, resulting in difficulties to fully implement person involvement. Third, patients with SCI experienced goal-setting as vague during rehabilitation activities, and they were doubtful if or how goals may impact their rehabilitation. Overall, the study contributes to the discussion of the challenging issue of person involvement in SCI rehabilitation by demonstrating how difficulties in integrating the perspectives of patients with SCI and HCPs evolve in rehabilitation practice.

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References

- [1] Nas K, Yazmalar L, Şah V, et al. Rehabilitation of spinal cord injuries. *World J Orthop.* 2015;6(1):8–16.
- [2] Hartoonian N, Hoffman JM, Kalpakjian CZ, et al. Evaluating a spinal cord injury-specific model of depression and quality of life. *Arch Phys Med Rehabil.* 2014;95(3):455–465.
- [3] World Health Organization. World report on disability. Geneva (Switzerland): World Health Organization; 2011.
- [4] Adriaansen JJ, Ruijs LE, van Koppenhagen CF, et al. Secondary health conditions and quality of life in persons living with spinal cord injury for at least ten years. *J Rehabil Med.* 2016;48(10):853–860.
- [5] Halvorsen A, Pape K, Post MWM, et al. Participation and quality of life in persons living with spinal cord injury in Norway. *J Rehabil Med.* 2021;53(7):jrm00217.
- [6] Cobb JE, Leblond J, Dumont FS, et al. Perceived influence of intrinsic/extrinsic factors on participation in life activities after spinal cord injury. *Disabil Health J.* 2018;11(4):583–590.
- [7] Barclay L, McDonald R, Lentin P. Social and community participation following spinal cord injury: a critical review. *Int J Rehabil Res.* 2015;38(1):1–19.
- [8] Levack WM, Weatherall M, Hay-Smith JC, et al. Goal setting and strategies to enhance goal pursuit in adult rehabilitation: summary of a cochrane systematic review and meta-analysis. *Eur J Phys Rehabil Med.* 2016;52(3):400–416.
- [9] Wade DT. Goal setting in rehabilitation: an overview of what, why and how. *Clin Rehabil.* 2009;23(4):291–295.
- [10] Jesus TS, Bright FA, Pinho CS, et al. Scoping review of the person-centered literature in adult physical rehabilitation. *Disabil Rehabil.* 2021;43(11):1626–1636.
- [11] Leplege A, Gzil F, Cammelli M, et al. Person-centredness: Conceptual and historical perspectives. *Disabil Rehabil.* 2007;29(20-21):1555–1565.
- [12] Levack W, Dean SG. Processes in rehabilitation. In Dean SG, Siegert RJ, Taylor WJ, editors. *Interprofessional rehabilitation: a person-centred approach.* Hoboken (NJ): Wiley; 2012. p. 79–107.

- [13] Yun D, Choi J. Person-centered rehabilitation care and outcomes: a systematic literature review. *Int J Nurs Stud*. 2019; 93:74–83.
- [14] Maribo T, Jensen CM, Madsen LS, et al. Experiences with and perspectives on goal setting in spinal cord injury rehabilitation: a systematic review of qualitative studies. *Spinal Cord*. 2020;58(9):949–958.
- [15] Malterud K, Siersma VD, Guassora AD. Sample size in qualitative interview studies: Guided by information power. *Qual Health Res*. 2016;26(13):1753–1760.
- [16] DeWalt KM, DeWalt BR. Participant observation: a guide for fieldworkers. 2nd ed. Lanham (MD): Rowman & Littlefield; 2011.
- [17] O'Reilly K. Ethnographic methods. 2nd ed. London (UK): Routledge; 2012.
- [18] Spradley JP. Participant observation. USA: Wadsworth; 1980.
- [19] Braun VC, Hayfield V, Nikki Terry G. Thematic analysis. In Liamputtong P, editor. *Handbook of research methods in health social science*. 1st ed. Singapore: Springer Singapore; 2019. p. 843–860.
- [20] Thorne S. On the use and abuse of verbatim quotations in qualitative research reports. *Nurse Author Editor*. 2020; 30(3):4–6.
- [21] Ramian K. Casestudiet i praksis. 2. udgave ed. Kbh.: Hans Reitzel; 2012.
- [22] Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007;19(6):349–357.
- [23] Dekker J, de Groot V, Ter Steeg AM, et al. Setting meaningful goals in rehabilitation: rationale and practical tool. *Clin Rehabil*. 2020;34(1):3–12.
- [24] Draaistra H, Singh MD, Ireland S, et al. Patients' perceptions of their roles in goal setting in a spinal cord injury regional rehabilitation program. *Can J Neurosci Nurs*. 2012;34(3): 22–30.
- [25] Hanga K, DiNitto DM, Wilken JP, et al. A person-centered approach in initial rehabilitation needs assessment: experiences of persons with disabilities. *Alter*. 2017;11(4): 251–266.
- [26] Melin J, Nordin Å, Feldthusen C, et al. Goal-setting in physiotherapy: exploring a person-centered perspective. *Physiother Theory Pract*. 2021;37(8):863–880.
- [27] Scheel-Sailer A, Post MW, Michel F, et al. Patients' views on their decision making during inpatient rehabilitation after newly acquired spinal cord injury - a qualitative interview-based study. *Health Expect*. 2017;20(5):1133–1142.
- [28] Hammersley MA. Ethnography. Principles in practice. New York (NY): Routledge; 2007.
- [29] Knutti K, Bjorklund Carlstedt A, Clasen R, et al. Impacts of goal setting on engagement and rehabilitation outcomes following acquired brain injury: a systematic review of reviews. *Disabil Rehabil*. 2022;44(12):2581–2590.
- [30] Smit EB, Bouwstra H, Hertogh CM, et al. Goal-setting in geriatric rehabilitation: a systematic review and Meta-analysis. *Clin Rehabil*. 2019;33(3):395–407.
- [31] Hagen EM. Traumatic spinal cord injuries – incidence, mechanism and courses. *Tidsskr Nor Lægeforen*. 2012; vol.132(7):831–837.