Facilitators and barriers in the rehabilitation process described by persons with spinal cord injury: a deductive-inductive analysis from Finnish Spinal Cord Injury Study

Susanna Tallqvist (✉ susannatallqvist@gmail.com)
University of Helsinki

Kaarina Eskola
University of Helsinki

Anni Täckman
Finnish Association of Spinal Cord Injured Akson

Anna-Maija Kauppila
Oulu University Hospital

Eerika Koskinen
Tampere University Hospital

Heidi Anttila
Finnish Institute for Health and Welfare

Marketta Rajavaara
University of Helsinki

Jari Arokoski
Helsinki University Hospital

Sinikka Hiekkala
Finnish Association of People with Physical Disabilities

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Abstract

Background

A spinal cord injury (SCI) has multiple effects on the persons' life, and can lead to impairments in activities, social participation, and environmental factors. Rehabilitation is important for regaining functioning and new skills. The aim of the study was to determine the factors that people with SCI perceived as promoting and facilitating their rehabilitation, and what they found to be challenges and possible barriers.

Methods

This study was part of a larger, mixed method Finnish Spinal Cord Injury study (FinSCI). The current study had a qualitative approach and used a deductive-inductive content analysis. The deductive approach was guided by a theory of six phases of a rehabilitation process by Autti-Rämö, followed by an inductive analysis to describe in-depth the perceptions of persons with SCI in each phase of the rehabilitation process. We collected the data by interviews from 45 persons representing participants from FinSCI study and used a structured interview guide.

Results

We found 28 facilitators and 19 barriers in the rehabilitation process. The majority of the facilitators and barriers were related to the phase of rehabilitation planning. There were more barriers than facilitators at the beginning of the rehabilitation process in applying for and accessing treatment or rehabilitation, and during the implementation of rehabilitation. As for the facilitators that progressed the rehabilitation process, some of them included: successful or realized, planned treatments, rehabilitation events, clear goals, multidisciplinary teamwork, support, and monitoring various changing situations, and rehabilitating one's own capability and activity. The barriers were: delays, challenges and deficiencies in the planning and implementation of their treatment or rehabilitation, the lack of different rehabilitation professionals’ skills and resources, and different patients’ personal factors, which made the progress of the rehabilitation process cumbersome.

Conclusions

We identified that communication and interaction were common denominators for the facilitators and barriers. Good communication and interaction among rehabilitation professionals and rehabilitees promoted the occurrence and repetition of facilitating factors during different phases of the rehabilitation process. Good care and good rehabilitation practice for people with SCI were the result of multidisciplinary teamwork, in which a person with SCI was an active member.
Introduction

A spinal cord injury (SCI) can be traumatic (TSCI), resulting from an accident or an injury, or non-traumatic (NTSCI), resulting from a congenital disorder, a disease, or a degenerative condition (1). The care and rehabilitation of a person with a SCI starts with rescue or a diagnosis of a disease, followed by an acute treatment, rehabilitation, and continuing life-long care with monitoring visits and independent exercise. In-patient rehabilitation periods have an important role in improving their functional status and optimizing independence, as well as helping persons with SCI to return to their communities (2). SCI has an effect on a person's body structure and functioning, and can further influence the person's performance and capacity for activity and participation negatively. Environmental factors might influence each component of functioning (3). The use of outpatient rehabilitation services, like physical or occupational therapy, is higher among persons with SCI in comparison to other chronic neurological conditions (4).

There has been a great interest among researchers in recent years to study the barriers and facilitators in the lives of persons with SCI. Scientific publications with a qualitative research sample have been published, e.g. related to bladder (5) and bowel (6) functions, pain (7), work and employment (8)(9)(10)(11), education (12), and social participation (8)(13)(14). However, there are very few publications concerning facilitators and barriers in rehabilitation; Mlenzena et al. (15) published in 2013 a systematic review about barriers and facilitators of rehabilitation services, and found two studies (16)(17) where people with SCI, among other persons with some neurological conditions, were involved. A quantitative study by Zongjie et al. (16) identified facilitators, such as the provision of information, doctors with good skills, easy access to doctors, good understanding, and confidence in the value of rehabilitation services, and easily accessible rehabilitation services. Respectively in a qualitative study, Kroll et al. (17) identified structural-environmental barriers like facilities, equipment, procedural accessibility issues, and transportation; and process barriers, which prevented the use of healthcare services, such as problems with scheduling an appointment, patient-provider communication, professional manner, disability-specific knowledge, personal motivation, cognitive issues, information and self-education, and lack of a personal doctor or their usual source of care.

Based on a previous publication of the Finnish spinal cord injury study (FinSCI), it is known that persons with SCI have more comorbidities compared to the rest of the Finnish population (18). Considering the need for treatment caused by SCI, and potential additional comorbidities, people with SCI need a lot of healthcare and rehabilitation services. The earlier research from Finland (19), and internationally (20), has shown that persons who need a lot of health care services suffer from the fragmented system and the resulting lack of continuity in care and service. To our knowledge, there is no research that has been published about facilitating and hindering factors of rehabilitation as described by persons with SCI. Thus, more research about rehabilitation as a part of the health care services would be necessary. This study is a part of the FinSCI study, and the aim of this paper is to describe the factors that people with SCI perceive as promoting and facilitating their rehabilitation, and what they find to be challenges and possible barriers.
Materials And Methods

FinSCI is a mixed-method collaborative study among The Finnish Association of People with Physical Disabilities, The Finnish Association of Spinal Cord Injured Akson, The Finnish Institute for Health and Welfare (THL), and the SCI outpatient clinics at three university hospitals (Oulu, Tampere, and Helsinki), which are responsible for immediate rehabilitation after the acute phase of treatment and life-time care of persons with SCI in Finland (21). The purpose of the FinSCI is to identify the factors that are related to the health and functioning of persons with SCI, their challenges with environmental factors regarding accessibility, and how these factors are interconnected. The detailed protocol, the precise patient selection process, the ethical considerations, and the other parts of the mixed-method study have been presented in a separate publication (21).

Theoretical Framework For The Analysis

This study had a qualitative design. The data collected from thematic interviews were analyzed by using a qualitative content analysis with a deductive-inductive approach as described by Elo and Kyngäs (22). The rehabilitation process described by Autti-Rämö (23) (Fig. 1) was utilized to organize the results into six different phases. This process has a lot of similarities with the well-known model of Wade (24), which is added as a last part of the process the independent exercise in order to maintain their functioning.

In this study, rehabilitation is understood as a process that progresses with a purpose. The process starts with the need for rehabilitation identified by a professional, and a part of the process includes setting a goal and rehabilitative measures to achieve it. The rehabilitee and the experts plan the rehabilitation process together, and the rehabilitee's own active role is in a key position. Unforeseen factors and motivation related to the rehabilitee's life situation, as well as an interactive co-operation between the rehabilitation professionals and responsible administrative sectors, play an important role in a process. The aforementioned factors must be considered in order for the process to be timely and smoothly implemented (Fig. 1) (23). The process can proceed to its destination, which is independent exercise that maintains person's functioning, or it can start from the beginning if, as a result of monitoring the goal achievements, it is found that the need for rehabilitation should be reassessed, like the arrow pointing right the Fig. 1 describes (Fig. 1).

Participants

The participants (45 persons) were chosen among the respondents from the FinSCI Study. The eligible population for the FinSCI study was 1,772 and the final number of participants was 884 (18). Fifteen participants from each of the three university hospitals (Helsinki, Tampere, and Oulu) (18) Supplementary Figure A), were selected for the interviews.

The inclusion criteria for participants were to find 5 participants for each time period since their injury (1–5 years since SCI, 6–10 years since SCI, < 11 years since SCI). We also took their age into account, which
was divided into five different age groups (20–30 years, 31–45 years, 46–60 years, 61–75 years, and < 75 years of age). Additionally, we considered gender, etiology (trauma or no trauma), and the severity of SCI, which was classified by recommendations of The International Standards for Neurological Classification of SCI (ISNCSCI) (25), as in other publications in the FinSCI. ISNCSCI is recommended to be used to determine the level and the completeness of the SCI by The American Spinal Injury Association Impairment Scale (AIS) (25), which grades the degree of impairment into five categories from A to E, where E means normal sensation and muscle function (26). The severity of SCI is recommended to be reported in categories, where all patients with AIS D form one category. The patients with AIS A, B and C are recommended to be categorized by the level of injury into three groups: C1-C4, C5-C8 (cervical spine), and T1-S5 (thoracic and lumbar spine) (25). The higher the lesion is in the spinal cord, the less functioning remain (27). Persons with SCI and multiple injuries, or a high level of lesion and AIS A, B, or C, have an increased length of stay in rehabilitation compared to persons with lower SCI (28)(29). These characteristics were analyzed separately from the eligible population in each of the three above-mentioned hospital areas in Finland, and the incidence of these characteristics was sought to be considered as well as possible. The selection of participants was systematic, and at first, every 10th person was searched from the suitable group to meet the predetermined criteria. If the criteria were not met, the next most suitable person was selected. At the end of the selection process, the most suitable person was searched based on the predetermined criteria so that the ensemble would correspond as best as possible to the goal for the selection. Additionally, the research group decided that every geographical area had to have at least one participant from each severity of the SCI group (although the incidence of the severity of SCI groups was very low).

ST or KE contacted the suitable participants by phone. The characteristics of participants are presented in Table 1. Table 1 shows that we were not able to implement the selection process totally as planned. The main reason for this was that younger persons with SCI neither participated actively in the FinSCI study (18), nor were they willing to take part in the interviews; There were 10 persons who declined from interviews, and 5 of them were under the age of 30. For this reason, more persons were selected for the next age group (31–45 years of age). Additionally, one person did not answer the phone shortly prior to the interview, and it was very hard to fulfill all the criteria for all general and personal characteristics.

Data Collection And Analysis

Data were collected by thematic interviews between September and December 2019 primarily in participants' homes. Four participants were interviewed in a quiet workspace organized by the interviewers at the request of the participant. Participants joined the interviews mainly by themselves, but for some, their partner or adult children also took part. KE interviewed 22 and ST 23 participants. Both interviewers were warmly welcomed, and the atmosphere during the interviews was open and natural. An average duration of interviews was 1 hour and 10 minutes (Range: 45 minutes to 2 hours and 54 minutes). We used a structured interview guide (see Additional file A), which consisted of open questions addressing six themes: Rehabilitation and its different phases (acute, sub-acute, and current
rehabilitation), settling down after SCI, functioning and its importance in daily living, employment situation and paths to employment, accessibility and related factors, and the quality of life and well-being. The themes were agreed upon in the research group, and KE, ST, and SH prepared the auxiliary questions supporting the themes. The interview guide was used to support the flow in an interview, and as a reminder that all themes had been discussed. Interviews were audio-taped, recorded, and transcribed verbatim by professional typists. In total, almost 53 hours of interviews were accumulated, and interviews generated 1500 pages of text. Before the actual analysis, ST and KE read and listened to their interview data, and corrected words that had remained unclear to the typists. After that, ST, KE, and SH made rules for the anonymization of the participants. ST or KE anonymized their interviewers. SH read and accepted all the anonymized text data.

For the first step (deductive content analysis), ST used the Atlas.Ti version 9 program. As a theoretical framework for coding, ST used the rehabilitation process and its six phases described in Fig. 1. KE checked 5 of the interviews that ST had coded, and no further citations to be coded were found. After finalizing the coding with the Atlas.Ti program, ST exported the coded text data to Excel. ST created a matrix for each of the six rehabilitation phases, including the initial coding and the original citations from the text data. To enhance the credibility of this first step of the analysis, the primary researchers (ST and KE) discussed the analytical results until a consensus was reached and step 1 was finished. After the deductive part, ST started the inductive part of the analysis. ST read original citations and initial coding again, moving back and forth to form subcategories for each citation (Step 2). These six matrixes with original citations, initial coding, and subcategories served as a basis for workshops, where the analysis was checked by the research group (Step 3). The members of the research group received the matrixes 2 weeks prior to a workshop in order to familiarize themselves with the coded text data. In the workshop, the research group went through each citation and its analysis, discussed, and accepted or edited the subcategories suggested by ST. If there were differences in the interpretation of citations between the research group members, the interviewer's (ST or KE) interpretation was chosen to be the name for the subcategory. Altogether, 6 workshops were held and each lasted 1 1/2 hours. At the fourth step of the analysis, ST combined subcategories with similar meanings into categories, and as a final step (Step 5), marked them either as a facilitator or a barrier; The facilitators promoted the progress in the rehabilitation process when barriers slowed it down, making it difficult or even prevented it. The final two steps were approved by the research group. The study was carried out and reported according to the Consolidated Criteria for Reporting Qualitative Research (30). An example of the analysis regarding participants’ citations from phase 2 is provided in Table 2 (Table 2).

Results

Altogether, 887 citations were analyzed, categorized, and marked either as a facilitator or a barrier. The condition for categorization was that each category had to contain citations from at least two participants. As a result of the analysis, 289 subcategories were conceptualized, which formed 47 categories. The majority of the citations were related to the rehabilitation planning (368), and the implementation of the rehabilitation (275), whereas monitoring the achievement of goals had the least
number of citations (35). The sub-categories, categories, and number of citations divided into six phases in the rehabilitation process are presented in the Additional file B. Figure 2 summarizes all categories divided by phases in the rehabilitation process.

**Phase 1: Applying and access to treatment or rehabilitation, and approval of the need for rehabilitation**

The analysis of the first phase of the rehabilitation process revealed two categories, which promoted the rehabilitation: ‘Successful treatment, successful rehabilitation, or both, after the spinal cord injury’, and ‘The treatment of a secondary health condition followed by a spinal cord injury was clear’. A successful start to the rehabilitation process took place in acute and subacute care, and rehabilitation in hospitals or rehabilitation centers, as well as in public health care. For example, one of the participants described where the care and rehabilitation started and progressed after the accident:

*Well, it stated right away that I am tetraplegic; nothing worked from the neck downwards. They took me with an ambulance to the University Hospital, and I was in the intensive unit [for] about 1 1/2 weeks, and then about two weeks in a ward before I got transferred to the rehabilitation center where I was for three months. P7:1*

The majority of participants, who had had comorbidities (pain, spasticity, pressure ulcer, bladder problem, misalignment) due to their SCI, told in interviews about good access and good results concerning the treatment of these comorbidities. One participant described the treatments that was received in the following example:

*Baclofen pumps have been put in and taken out when they become inflamed. And then put in again. And then, I got a pressure ulcer in 2015, and it was operated a dozen times, before it was finally grown together.... Well, it has been... I don't remember what surgery I went to, but in the university hospital, I went to the operating room and the staff hardly saw me when they already said, "are you here again?" I was like that, yeah. P2:19*

A delayed assessment for the need of rehabilitation caused distrust in the rehabilitees. Also, the experience of diagnosing or treating a SCI was partly challenging. Challenges included inappropriate treatment, paying treatments by their own cost, uncertainty about the rehabilitation place, additional injuries caused by the treatment after SCI, and difficulty in accessing special care due to the SCI caused by a disease. This was exemplified by one participant, who experienced delays several times, saying:

*I had a job as a nurse at the health center, and then my legs started to be numb, so of course, I went to the company doctor. And the company doctor then immediately said he will send me for a magnetic resonance imaging (MRI), and I was really worried because I had never had anything like this before. And then I was there for a MRI, and then there was spinal stenosis in my lower back. ... Then I could not walk anymore, I had to use the sticks. ... Our community is involved in this private occupational health care thing, so I did visit an orthopedic doctor at the private occupational health care. But then, when it seemed that it was always getting worse and worse, he (orthopedic doctor) then promised that it would probably*
have to be operated on. I called them twice in August. Well, it was summertime and the doctors [were] on a vacation in the private sector, and maybe he was working somewhere else, but then he came from his vacation to operate on me when I called and I said that I really need this...(After operation and being home for a few weeks, the functioning got worse and a friend who had worked with persons with SCI insisted P33 to call the orthopedic doctor again). So, I told him that I’ve gotten worse, I need some rehabilitation, I have nothing, that I need to get somewhere where I can rehabilitate myself. Then my friend shouted behind me that “she has paraparesis”. The doctor asked that who is shouting there, and I thought that now he will be angry, but then he said that I understand that you are getting worse, and he fixed me a new MRI for the next day... and then they took the MRI from the whole back. In the first MRI, they took just the 1/3 ... and he told me that they had found a tumor in the upper part of my back, which filled almost my whole spinal cord. The tumor had grown very fast, which is why the symptoms also became so quickly. And then he said that he was so relieved because he thought that he had made a mistake in the operation. And then he said that he will send me right away to be operated on in the University Hospital. P33:3–4

Distrust and difficulties in gaining access to treatments were described by one participant in the following way:

Our health center is not working at all now, so you can never get an appointment there, when all the doctors have left because of social and health care messes. And the fact that if something would happen to me, I will call the health center, but I must first know exactly what’s bothering me, and then I can call... P43:18

As a third barrier, participants reported inadequate and challenging treatments for comorbidities. The very same problems (pain, bladder function) that some participants had perceived as well-treated, were perceived as challenges for other participants, and all of them had a TSCI. Treating autonomic dysreflexia and bowel problems were described as deficient, which formed a big barrier for participants.

This autonomic dysreflexia is a horrible thing...it is a horrible, horrible thing, and in the beginning, there was not very much information about it. Nobody had heard about it and my situation was so acute. And there was not at all any kind of patience or understanding, and it was like they had never heard about it. And then you try to explain to doctors and nurses, and then you can't help yourself anyhow. P10:10

**Phase 2: Recognition Of Self-relevant Goals And Their Concretization With Professionals**

As a self-relevant goal of promoting rehabilitation, the participants reported maintaining or developing their body functions (joint mobility, muscle strength, balance, walking, weight management, fitness), pain relief, increasing their self-sufficiency, and maintaining their functioning.
The goal is that I can stay at home as long as possible. But for the time being, that means I can be at home by myself, no-one has to take care of me or look after me. In other words, my condition remains good; I can go from place A to place B by myself. P32:15

Achieving the self-relevant goals was a facilitator as well, and this had happened during rehabilitation, and with the help of a peer or a family member. In one example, one of the participants talks about setting and achieving his goals during the sub-acute rehabilitation period:

Well, to put it briefly and succinctly, I became independent. Like doing transfers, dressing, showering, all these daily things. I thought about it afterwards, so in a way when I got out of there (sub-acute rehabilitation), I was able to do everything the way I wanted. And it was my goal there. That I said that I can't be let out of here until things are in such a way that I can completely take care of everything myself. P13:10

The professional's actions were partly seen as a barrier in the realization of their self-relevant goals: participants said that their goals were not taken into account, recognized or not achieved in their cooperation with professionals. Also, conflict among professionals in setting goals was reported as a hindrance for achieving the self-relevant goals. Conflict between the high goals set by professionals and the rehabilitee's own experience about her capability to walk and return home is described in the following citation:

There were four or five male doctors, who had the opinion that my walking with an aid went well, you can move quite well, just go home [with a tearful voice]. And I'm such a gutsy person that if they say that to me once, and I have asked for help and I don't get it, I won't ask a second time. So, I came home, and when I was being brought by ambulance-taxi in a laying position, the taxi chauffeur was about to drop me [laughs]. It was something horrible, I texted my husband from there, lying in the taxi, to come and help me when the taxi comes to the yard, I don't want to fall. P16:1

Phase 3: Rehabilitation Planning

The planning phase in the rehabilitation processes brought up 12 categories that facilitated rehabilitation, and 9 categories that functioned as a barrier in rehabilitation. A part of the participants no longer had rehabilitation plans, so their rehabilitative activities related to the SCI were finished. Several participants talked about a successful plan, which had taken place either in health centers, university hospitals, occupational health care, or in SCI outpatient clinics. Assistive devices and home remodifications were perceived as facilitators for rehabilitation planning. Collaboration and multidisciplinary teamwork were often mentioned as a part of a successful plan.

There was good service there (sub-acute rehabilitation period in a university hospital). I have nothing to say about it. [Interviewer ST: You said that there was always a big crowd of people sitting in the
In many interviews, a successful plan was followed by the success in implementing rehabilitation as well. This was recounted by one participant:

Two years ago, I was there, there, hmmm, in (name of a city), at the SCI outpatient clinic, yeah. And then luckily, they gave me that three years like this (three-year rehabilitation plan). Yes, and it's been like two years now. So that it was still like this one year (left). So I got this 40 times physiotherapy and then 30 times occupational therapy, and she comes home to me. P44:8

The educational changes and changes in the workplace related to work accommodations promoted rehabilitation, as well as the fact that their return to work was planned. Successful accommodations in the workplace were a facilitator. The person's active role and good cooperation among professionals also promoted the planning of their rehabilitation. Facilitators like working as an entrepreneur, having a part-time job, furthering their studies, and cooperation with an employee promoted the work accommodations, as explained in the following two examples:

I believe that it is possible to get a job, and an organization for disabled persons is one where I would like to do all the practical periods and possibly work... Or get a job there. There's a lot that interests me and I would like to have an impact on. Especially those young people's things, which I am now involved with. Because I feel that my strength is not to work in the field of youth work, but maybe in the administrative side, that's why I'm at an university of applied sciences (now), so I can do those jobs someday. P1:27

Well, it progressed quickly. I went to our own doctor and said that the employer is agreeing to this (part-time work), and I got the paper from there already. He (doctor) doubted that I wouldn't get it, but it came from Social Insurance Institute, or where it came from, I don't remember, so I immediately got a positive decision. There must have been a smart doctor there as well reading the papers. [Interviewer KE: So you applied for a partial disability pension?] Yeah, yeah. That's the 50%. And it came true. I work two days at one week, and three days at the second week. P34:7

The barriers in the planning phase of the rehabilitation process consisted of challenges and deficiencies. The reasons for these obstacles were, among other things: ambiguities in planning and the organization of their treatment, rehabilitation or both, the small amount of rehabilitation and guidance, conflicts among the rehabilitee and professionals or among professionals, environmental barriers and attitudes, and unfulfilled goals. An example of an ambiguity in planning was exemplified by one participant saying:

I think a lot of things were overlooked in this accident. First, that person fell on my head, and I fell from my straight legs to the back of my head on the ground. And yes, I got a small scratch or wound on my head. I had a beanie on. I wasn't (wearing a helmet) because we weren't at that kind of job at that moment. And then I lost consciousness for a moment. My assessment is that I had got a concussion because I got dizzy and vomited for a long time, but my condition was so serious that this has been
completely missed by everyone...And this thing with my memory, I've lost a bit of it, I don't know what's going on in my head if they don't scan it. P28:4

Additionally, finding the right medication for pain and mental problems was perceived as challenging and time-consuming, thus hindering the rehabilitation. Opportunities to influence the rehabilitation planning were partly felt as inadequate. Some of the participants talked about challenges in the realization of home remodeling and the acquisition of aids, which were felt to hinder the process. Deficiencies in the professionals' working (insufficient language skills or knowledge about SCI) was experienced as a barrier, as such in the following example from one participant who gave up the monitoring visits related to his perceived lack of professionalism:

I went there once (SCI outpatient clinic). Twice actually. The first and the last. The idea is probably very nice and good, but that... If you don't get competence, permanent competence there. If a person comes into it, whose purpose is only to pursue their own interests, i.e. to seek effort from it in order to move forward, to get profit from it, or in the best in the case just to auscultate, or to get some final work for themselves done, or something else, then how on earth does it serve my cause, if it's there on their own? P19:4

Challenges in returning to work were perceived as a hindrance, and reasons for these barriers included: pain, depression, sleep problems, lack of motivation, insufficient support, and environmental barriers. A few participants stated that it was not possible to return to work, and that work was not adjusted because they had already been on sick leave before the SCI occurred. Sometimes barriers gathered, like the lack of motivation, pain, and depression, as exemplified by one participant saying:

At the moment, at least, I don't have the ability to work, and I don't know if there ever will be. Of course, that's not up to me. But what I'm experiencing is that depression makes it sometimes so lacking in initiative that it feels like I can do that tomorrow, or not. I have noticed that it is no longer there, I don't start doing things that I used to. When the pain is at its worst, nothing really interests me at that moment. P12:14

Phase 4: Implementation Of The Rehabilitation

In the fourth phase of the rehabilitation process, more categories were discovered, which prevented the process (5) instead of facilitating (4) the process. The facilitator, that was often described by participants, was a category: 'Successful planning and implementation were based on the support of professionals, multi-professionalism, good pain management, adequate targeted training and progress, and a successful return to home'. The successful implementation of rehabilitation took place in outpatient therapy sessions, health centers, in-patient rehabilitation, outpatient clinics and hospitals. This was exemplified by one participant saying:
And then there were all these therapists of all kinds and so... It's the best hospital I've ever been to. It was so incredible. [Interviewer ST: Okay. What kind of professionals did you meet? Like physiotherapists, sports instructors, or occupational therapists?] It was. Isn't he the one who makes such block tests? Yes, it was. Then a social worker. I think at some point, I had a speech therapist. There were these sports instructors. There were nurses who helped with everything at the ward. And then there were those doctors. They visited me two or three times a day at best. P23:6,8

Progress in functioning, pain relief, achieving goals, receiving support and guidance, multidisciplinary teamwork and sufficient resources, among other things, were facilitating factors for rehabilitation. Also, one's own activity and social relationships supported the implementation of rehabilitation, as described by the following two participants:

You can say that it was such a communal place (a rehabilitation center during subacute rehabilitation); that is to say, everyone was connected with everyone there, so it wasn't so isolated...nobody was isolated, and no one became isolated. But all the time, there was someone in the group who was rehabilitating, so there became such terribly good friendships because of that. P26:5

But I had that kind of a little special situation the whole time since the surgery and rehabilitation, my wife and I were together all the time. My wife was there with me, ever since the hospital...My rehabilitation was also quite active, like independent rehabilitation with my wife. P4:4

As a main barrier in implementing the rehabilitating measures during the process, the participants reported deficiencies in the work of professionals. The reasons were similar like in the planning phase of rehabilitation: the lack of knowledge, lack of guidance, lack of language skills, lack of time, lack of multidisciplinary teamwork, lack of suitable equipment or place, and the inadequate amount of given therapy were seen as barriers. Professionals' pejorative attitude towards disability, and their distrust towards professionals were also mentioned, preventing rehabilitation. Also, personal factors (young age, previous experiences about rehabilitation, anxiety about family members at home) and problems with co-rehabilitees, were experienced as barriers for the process. Some participants had experienced several barriers simultaneously, as described in the following example:

...it was quite a disaster. It was called a rehabilitation hospital. There were old people, and there were people who had a brain injury or circulatory disorder in their head or something else, who were really, really messed up... I made a patient injury report. Because, practically speaking, I rehabilitated myself there, because there were so many people in bad shape. And people died there during the time I was there and... [Interviewer KE: For example, did a physiotherapist visit you?] I had a name, but there was the fact that they were moving to a new place, they were being trained. [speaks in a tearful voice] There really wasn't anyone in sight for long periods of the day. Not even weekly. P36:2

The rehabilitee's own possibilities for influencing the implementation of rehabilitation were partly seen as inadequate. The fact that their functioning deteriorates, and self-sufficiency decreases despite rehabilitation as time passes, can hinder the implementation of rehabilitation.
That's why I stopped farming, because I don't know if rehabilitation could do anything to it anymore, because I've been walking so persistently for twenty years. Walking like that, I have such bad detritions. The ligaments in the ankle are stretched so that it is in terrible pain, and then the knee is worn, and I can't really walk much anymore... P27:8

Phase 5: Monitoring The Achievement Of Goals And Redesigning Actions

Monitoring the achievement of goals and redesigning actions disclosed four categories that promoted the rehabilitation process. Monitoring and changes in functioning, led to creating new goals for rehabilitation. This was exemplified by one participant saying:

We do it in the way that she (physiotherapist) gives me (home exercise program), we have agreed so, and I go there every month and a half. It won't help you at all if you don't do them. We do this in cooperation. I have asked this, and she is satisfied; we will make a program for me, which I will carry out very obediently, because these are very important things to me. P35:9

There were also participants whose monitoring and rehabilitation planning were finished, and participants who were still monitored, but had no new rehabilitation plan. Both categories were interpreted as facilitators since the rehabilitation process had progressed as planned, like in the following citation from a participant:

[Interviewer ST: And now every three years, you have those visits to the spinal cord injury clinic?] Yes, now is the first time that it is every three years. Earlier, it was every year... but now this situation hasn't changed anymore...P42:5

There was one category, which functioned as a barrier in monitoring and redesigning the rehabilitation process. Professionals’ lack of language skills and lack of monitoring, as well as uncertainty, and insufficient possibilities for exerting one's influence, made it difficult to redesign the rehabilitation.

You can't expect much from there. It just depends on who is there as a doctor. The last time was when I went to the MRI in September, and then I went there to the neurologist to listen to the results, so I was there just under five minutes; it didn't even take that long. He said that he brings these MRI results to a meeting, and they will decide. He will call. He called the next day when the meeting had been held, then the medical case summary came home, and it said that the patient was satisfied with the decision and period, and nothing else. [Interviewer KE: Well, were you asked about the decision, how to proceed?] No. I don't know. It wasn't even a Finnish doctor; he didn't speak Finnish. I feel like it's stinking shit to go there because of this. First, wait for an appointment with the neurologist in October and then it will be like this. They could treat me better. P29:15

Phase 6: Independent Exercise In Order To Maintain The Functioning
The last phase of the rehabilitation process had only facilitative categories (3). Few participants did goal-directed independent training and aimed for competitions or had other measured goals. Several participants talked about how the regular independent training, and everyday activities (doing handwork, outdoor activities, relaxing etc.) supported their functioning, as it was recounted by one participant:

[Interviewer KE: You seem to have a standing stand (at home), how often do you use it?] Well, every day, every day. I also have an aid and a hand bike, so I do handcycling with it. I use it in the summer, now the season is over a bit. Then I have one, it’s called a trainer, I bought it now you can get it upstairs and I can pull it inside, it’s a bit more boring but...P5:11

Discussion

In the current study, we identified more facilitators than barriers in the rehabilitation process described by persons with SCI. However, in two out of six phases in the rehabilitation process, there were more categories that hindered more than facilitated the process. These phases were the first and fourth in the process, which are the phases of ‘Applying and access to treatment or rehabilitation and approval of the need for rehabilitation’ and ‘Implementation of the rehabilitation’.

There were 28 facilitative categories that described what factors were helpful in the rehabilitation process. Characteristic for the facilitators was that they were either successful or they realized planned treatments or rehabilitation events: clear goals or achieved goals, and support and monitoring in various changing situations (need for aids, home remodeling work, rehabilitation planning, etc.) In addition, the view of oneself as an active actor - one who has social relationships and one who independently exercises or is able to work - promoted the rehabilitation process. The 19 barriers were the opposite of the facilitators since the things that promoted the progress of the rehabilitation process acted as an obstacle if they were not successful: delayed or incomplete planning, and the delayed or incomplete implementation of their treatment or rehabilitation, professionals’ lack of knowledge or language skills; as well as the challenges, conflicts or deficiencies in responding to the changes (such as obtaining aids, home remodeling, desired treatment, or rehabilitation, etc.) made the progress of the process difficult. Not being able to return to work or challenges at work were barriers as well. Some personal factors and the fact that functioning deteriorates with age did hinder the rehabilitation process.

These opposites, which do not include personal factors, language skills, or professional ability, seem to have a clear common denominator, which is communication and interaction. There were many types of communication, and it took place especially among a rehabilitee and professionals, in addition to their peers, family, and friends. In a successful rehabilitation process, the facilitators followed each other and there were several events that promoted rehabilitation. Correspondingly, the barriers also followed each other and caused a vicious circle, where the exact causes for challenges were difficult to pinpoint.

It has been known from previous research that communication and interaction have a central role for the successful education, health care, and rehabilitation since the patient-provider communication (17), communication gaps (5) and professionals’ lack of communication (12) were reported as barriers for
persons with SCI. In the studies where health care professionals were interviewed, these problems have been noticed; in a study by Röthlisberger et al., the communication among various medical disciplines was found to be a challenge, and delays in the communication of a prescription between doctors and nurses created inefficiencies (31). And in contrast, a study by Johnston et al. has shown that good communication between the whole staff is a critical element in their work (32). Additionally, in some studies where persons with SCI were interviewed, an effective patient–provider communication (7) and enhancing communication between the patient and the care team (33) have functioned as a facilitator in their lives. These results support our study, which showed that good communication and interaction were crucial for the progress of the rehabilitation process.

Another interesting result was that even though the rehabilitation process contained much more facilitating factors than barriers, there were two phases in the process where barriers were in the majority. Difficulties during the first phase, applying and access to treatment or rehabilitation and approval of the need for rehabilitation, consisted of delays in making a diagnosis, treatment or rehabilitation, and challenges in finding suitable treatments for comorbidities caused by SCI. There can be several reasons for delays and challenges in treating comorbidities; Finland is undergoing a reform where so-called wellbeing services counties will be responsible for health, social, and rescue services instead of municipalities and hospital districts. The reform has not been easy, as it received criticism regarding the many challenges in implementing the reform (34). Secondly, the number of persons diagnosed with SCI has increased in recent years, which has to do with the aging of the population, as well as increased awareness of symptoms and findings suitable for SCI; even mildly injured patients are referred to treatment, rehabilitation and monitoring (35). This fact has increased the need to care for persons with SCI. Thirdly, based on our results, it can be stated that the diagnosis and treatment of SCI and its comorbidities can be demanding. Professionals working with persons with SCI should have adequate education and know-how, which can be difficult to achieve due to the recent labor shortage in healthcare in Finland (36).

Diverse deficiencies in the work of professionals were the largest barriers in implementation of the rehabilitation, which is the fourth phase in the rehabilitation process, and also had more barriers than facilitators. The professionals did not have enough know-how, time, or they did not guide or work in a multi-professional manner to promote the implementation of the rehabilitation. Additionally, the rehabilitee had inadequate opportunities to influence the implementation of their rehabilitation, which was named as a barrier as it relates to the cooperation with professionals. We interpret our results so that one of the root causes behind these challenging barriers is also the lack of better communication and interaction among professionals and the rehabilitee.

The question is: how can we promote good communication and interaction in the rehabilitation process? The rehabilitation process itself is not enough to achieve effectiveness, i.e. rehabilitation. It is important to understand that rehabilitation also includes a learning phase for professionals and depends on a professional’s ability to create a good relationship with a rehabilitee. Such a relationship is confidential, committed, goal-oriented, and identifies the factors that have an effect on the rehabilitee’s situation and
the achievement of their goals (23). In order to improve communication and interaction among a rehabilitee and professionals, they all need time and understanding to learn from each other. It is very important that all those involved in the planning, implementation, and monitoring of the rehabilitation have a positive, appreciative attitude towards one another, and that they are motivated to work towards common goals, which are meaningful for the rehabilitee (37).

Strengths and limitations

As a strength for the study, we had the large size of the data, which was collected by interviews from 45 persons with SCI. The interviews and analysis were carefully planned and implemented, and all authors participated in the inductive steps, from which the categories presented as results were formed. We found the research method suitable for this study; The theoretical reference framework we used helped to structure the analysis of the interviews, and the phenomena relevant to the rehabilitation process was found in the data. The majority of the authors had worked with persons with SCI for several years, and they were familiar with the issues they were analyzing. One of the authors has a SCI, thereby bringing the stakeholders’ viewpoint to the analysis as well. We think that these facts have increased the reliability of the research results. However, due to the qualitative design of this study, any generalization of the results should be carefully considered. As a limitation to the study, it can be mentioned that it was difficult to encourage younger participants to join the study, and mainly for this reason, the selection process was not realized exactly as planned. Nevertheless, we appreciate all participants and their experiences, and every interview deserves to be heard and analyzed. Due to the factors mentioned above, we were able to reach the goal of saturation and redundancy across citations and categories, and we found the most central categories to describe barriers and facilitators in the rehabilitation process.

Conclusions

We identified more facilitators than barriers in the rehabilitation process of persons with SCI. Facilitative factors, like the successful planning and implementation of treatment or rehabilitation, self-relevant goals and achieving the goals, support, and monitoring in changing situations in life, as well as good interaction and multi-professionalism, promoted their rehabilitation. Barriers were, on many occasions, the opposite of facilitators. Difficulties in the planning and implementation of treatment or rehabilitation, lack of different professionals’ skills and resources, and different personal factors made the progress of the process difficult.

We found out that communication and interaction were common denominators for both the facilitating and hindering factors in the rehabilitation process. The facilitative rehabilitation process included several good communication and interaction situations among the rehabilitee and professionals. Since rehabilitation is a process, whose different phases are closely connected, even one barrier can significantly complicate the progress of the entire rehabilitation process and prevent rehabilitation from taking place. Solutions for the experienced barriers should be searched by an interprofessional manner where a rehabilitee has an active and equal role among professionals.
**Abbreviations**


**Declarations**

**Ethics approval and consent to participate**

All participants received information about the study. The written informed consent was obtained from all participants for the study. The study was approved by the HUS Coordinating Ethics Committee (HUS/1776/2017). The study complies with the Declaration of Helsinki.

**Consent for publication**

Not applicable.

**Availability of data and materials**

An anonymized version of the data can be made available from the research leader SH on a reasonable request.

**Competing interests**

The authors declare that they have no competing interests.

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**Authors’ contributions**

The study was conceived by ST, KE and SH. ST planned the study and participants were recruited by ST and KE, who also interviewed the participants. ST analyzed and coded the data. KE checked and edited the deductive part of the analysis. All authors joined the workshops, and made significant contributions to the inductive part of the analysis. ST wrote the manuscript. KE and SH made significant contributions, interpretations, along with subsequent revisions of the manuscript for intellectual content. All authors read and approved the final manuscript.
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Author details

1 Doctoral programme in Population Health, University of Helsinki, Helsinki, Finland.

2 Doctoral programme in Social Sciences, University of Helsinki, Helsinki.

3 Tampere University Hospital, Department of Rehabilitation and Psychosocial Support.

4 The Finnish Association of Spinal Cord Injured Akson, Helsinki, Finland.

5 Oulu University Hospital, Department of Medical Rehabilitation/Spinal Cord Injury Outpatient Clinic, Oulu, Finland.

6 Tampere University Hospital, Department of Neurosciences, Tampere, Finland.

7 Finnish Institute for Health and Welfare (THL), Public Health and Welfare Department, Knowledge Management and Co-creation Unit, Helsinki, Finland.

8 Faculty of Social Sciences, University of Helsinki, Helsinki, Finland.

9 Helsinki University Hospital, Department of Internal Medicine and Rehabilitation/Spinal Cord Injury Outpatient Clinic, Helsinki, Finland, and University of Helsinki, Helsinki, Finland.

10 The Finnish Association of People with Physical Disabilities, Helsinki, Finland.

11 Validia Rehabilitation, Helsinki, Finland.

References


Tables

Tables 1-2 are available in the supplementary files section.

Figures
Figure 1

Rehabilitation process. The process is modified from the original figure from Autti-Rämö, 2021 (23).

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Figure 2

Summary of categories divided by six phases in the rehabilitation process. The phases of the rehabilitation process (Figure 1) are the following: Phase 1: Applying and access to treatment or rehabilitation, and approval of the need for rehabilitation; Phase 2: Recognition of self-relevant goals and their concretization with professionals; Phase 3: Rehabilitation planning; Phase 4: Implementation of the rehabilitation; Phase 5: Monitoring the achievement of goals and redesigning actions, and Phase 6: Independent exercise in order to maintain the functioning.

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- AdditionalfileA.pdf
• AdditionalfileB.pdf
• Tables.docx