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Faculteit Revalidatiewetenschappen

Master in de ergotherapeutische wetenschap

Masterthesis

How do people with a cervical spinal cord injury experience motivation for arm-hand training during subacute rehabilitation? A phenomenological, hermeneutical study

Alexandra Van der Vennet

Scriptie ingediend tot het behalen van de graad van Master in de ergotherapeutische wetenschap

PROMOTOR :

Prof. dr. Annemie SPOOREN

BEGELEIDER :

Mevrouw Nele BERTELS

Mevrouw Eva DELOOZ

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Master of Science in de ergotherapeutische wetenschap

Promotor: prof. dr. Spooren Annemie
Begeleiders: Bertels Nele & Delooz Eva
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UHASSELT KU LEUVEN UNIVERSITEIT GENT

Abstract

Inleiding: Cervicale dwarslaesie zorgt meestal voor een verstoorde arm-handfunctie, wat de activiteiten van het dagelijks leven ernstig kan belemmeren. De motivatie van de personen wordt gezien als een belangrijke factor binnen arm-handvaardigheidstraining om de neuroplasticiteit te vergroten. Tot op heden is dit nog weinig onderzocht bij personen met een dwarslaesie.

Doel: Het doel van deze studie is om na te gaan hoe mensen met een cervicale dwarslaesie motivatie ervaren voor arm-handvaardigheidstraining tijdens de subacute revalidatie.

Methode: Voor deze kwalitatieve studie werden er 10 personen met een cervicale dwarslaesie geïncludeerd uit drie revalidatiecentra in België en Nederland. Er vonden semigestructureerde interviews plaats om de ervaringen van de participanten omtrent motivatie te onderzoeken. De gegevens werden geanalyseerd aan de hand van een hermeneutische fenomenologische analyse.

Resultaten: Motivatie werd ervaren als een proces dat voor het grootste deel wordt beïnvloed door de persoonlijke ervaring van de patiënt en in mindere mate door hun sociale context, namelijk het revalidatieteam, lotgenoten en het eigen netwerk. Daarnaast kunnen ook de inhoud, dosering en intensiteit van de arm- handvaardigheidstraining motivatie modereren.

Conclusie: Motivatie voor revalidatie is belangrijk en omvat een voornamelijk intern proces waarin ook externe factoren een rol kunnen spelen. De bevindingen van dit onderzoek geven een beter inzicht in hoe de persoonlijke ervaringen van patiënten hun motivatie vormgeven en hoe anderen hen kunnen helpen deze positief te beïnvloeden.

Trefwoorden: Motivatie, neurologische revalidatie, bovenste extremiteit, dwarslaesie

Aantal woorden masterproef: 7843 woorden, volgens de richtlijnen van Disability and Rehabilitation

Abstract

Introduction: Cervical spinal cord injury mostly causes impaired arm-hand function, which can severely impair the activities of daily life. The persons' motivation is seen as an important factor in arm-hand training to increase neuroplasticity. To date little research on this has been done in individuals with spinal cord injury.

Aim: This study aims to investigate how people with a cervical spinal cord injury experience motivation for arm-hand training during subacute rehabilitation.

Method: For this qualitative study, 10 people with a cervical spinal cord injury were included from three rehabilitation centers in Belgium and the Netherlands. Semi-structured interviews were used to explore the participants' experiences of motivation. The data were analyzed using a hermeneutic phenomenological analysis.

Results: Motivation was experienced as a process that is mainly influenced by the personal experience of the patient and to a lesser extent by their social context, i.e. the rehabilitation team, fellow patients and their own network. In addition, the content, dosage and intensity of the arm-hand training can also moderate motivation.

Conclusion: Motivation for rehabilitation is important and consists of a primarily internal process in which external factors can also play a role. The findings of this study provide a better understanding of how patients' personal experiences shape their motivation and how others can help them positively influence this.

Keywords: Motivation, neurological rehabilitation, upper extremity, spinal cord injury

Amount of words master's thesis: 7843 words, according to the guidelines of Disability and Rehabilitation

Inhoudstabel

Woord vooraf

Vooraleer mijn masterproef wordt toegelicht, zou ik graag iedereen willen bedanken die dit mee mogelijk heeft gemaakt. Zowel op professioneel als persoonlijk vlak kon ik steeds rekenen op mensen om mij te ondersteunen, mij het nodige vertrouwen in mezelf te geven en een luisterend oor te bieden.

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Het schrijven van mijn masterproef was een proces met ups en downs. Het vereiste een hele weg om tot hier te geraken en op deze weg kon ik steeds rekenen op verschillende steunfiguren in mijn leven. In het bijzonder zou ik graag mijn ouders willen bedanken. Hun steun en hun bereidheid om er altijd voor mij te zijn wanneer ik het nodig heb, gedurende het schrijven van mijn masterproef maar ook doorheen mijn hele leven, waardeer ik meer dan woorden ooit zouden kunnen beschrijven. Daarnaast zou ik ook heel graag mijn tweelingzus willen bedanken. Bedankt dat ik altijd terecht kon bij jou voor jouw opinie en ondersteuning, maar ook om altijd in mij te geloven.

Ten slotte zou ik ook graag even stilstaan bij mijn klasgenoten. Voor een masterproef omtrent motivatie is het niet meer dan gepast om hen te bedanken voor alle motiverende woorden. Het was fantastisch om hen deze laatste twee jaar beter te leren kennen en samen de weg tot master in de ergotherapeutische wetenschappen af te leggen. De steun- en gunfactor van deze klasgroep is immens groot en zal ik niet snel vergeten.

Background

This study falls under neurological rehabilitation, more specifically under upper extremity training in people with a spinal cord injury (SCI). It is situated within the doctoral study of Nele Bertels with the title 'Training components crucial to optimize the training of arm/hand skill performance in subacute cervical spinal cord injury', funded internally by Bijzonder Onderzoeksfonds (BOF) 21OWB23.

This doctoral study aims to gain insight into the crucial training variables to optimize arm-hand training in people with a cervical spinal cord injury (C-SCI). To do this both quantitative and qualitative studies are conducted in three different rehabilitation centers, two of which are in Belgium and one in the Netherlands.

Preliminary research from the doctoral study shows that motor training strategies, therapy dosage and the person's motivation for arm-hand training are three important training variables of motor training programs within the subacute rehabilitation of people with a C-SCI (Bertels et al., 2023). This master's thesis will therefore attempt to further investigate one piece of this larger puzzle in order to gain insights that can complement the whole.

To do this, this study will investigate the person's motivation for rehabilitation, more specifically arm-hand training, in people with a C-SCI. There is currently very little literature available on this, especially in people with a SCI. This study can hence also provide an impetus to close the gap in the literature concerning motivation for rehabilitation.

This master's thesis is a qualitative study that is carried out in the same three rehabilitation centers as the doctoral study. The two rehabilitation centers in Belgium are UZ Leuven campus Pellenberg and UZ Gent. The rehabilitation center in the Netherlands is Adelante. All three of these have a specialized department for the rehabilitation of people with SCI.

This master's thesis has been developed individually. Its topic was determined by the thesis advisor and the research question was formulated by the master's student under the guidance of her thesis advisor and co-advisors. Finally, the master's student participates in this study from data collection to analysis and reporting.

Corpus

1 Introduction

Each year between 250.000 and 500.000 people worldwide suffer a spinal cord injury (SCI) (World Health Organization, 2013). Cervical spinal cord injuries (C-SCI) account for approximately 50% of the total SCI (Wirz & Dietz, 2015). A C-SCI can severely impair self-care and activities of daily living of patients, as their hand function is mostly affected (Wirz & Dietz, 2015). Regaining arm and hand function is consequently found to be one of the most important factors to improve the quality of life as indicated by patients (Anderson, 2004; Snoek et al., 2004). Studies suggest that the rehabilitation should be performed by an interdisciplinary team using a client-centered approach to facilitate better decision-making and therapy planning (Nas et al., 2015; Ozelie et al., 2012; Spooren et al., 2009). Occupational therapists are an important part of this team, as they strive to maximize the level of independence of their patients (Arsh et al., 2020; Foy et al., 2011).

According to Dunlop (2008), neuroplasticity contributes majorly to the functional recovery of people with a SCI. Activity shapes neuroplasticity by promoting the survival, differentiation and growth of neurons (Dunlop, 2008). Research suggests that rehabilitation can harness the power of neuroplasticity that occurs in the brain and spinal cord after a SCI (Walker & Detloff, 2021). The growing knowledge on activity-dependent plasticity has led to a shift in the rehabilitation of people with a SCI from a more compensation-focused to an activity-focused approach (Dunlop, 2008).

It has been shown that motor training drives neuroplasticity in studies involving people with neurological conditions (Bowden et al., 2013; Dunlop, 2008; Spooren et al., 2009; Spooren et al., 2012). Three training factors are shared between the training principles for functional recovery of motor learning and neurological rehabilitation according to both Kleim and Jones (2008) and Dunlop (2008). These three factors, i.e. motor training strategies, therapy dosage and the motivation of the person, seem to be key factors for the functional recovery of people with a SCI (Bertels et al., 2023; Dunlop, 2008; Kleim & Jones, 2008). Regarding motor training strategies, evidence suggests that task-specific motor training programs, focusing on those tasks that are important for the patient, lead to an improvement in arm-hand functioning of people with a C-SCI (Chompoonimit & Nualnetr, 2016; Spooren et al., 2011). The second factor, training dosage, involves both training repetition, which is important to induce lasting

neural changes, as well as intensity, which can affect the induction of neural plasticity (Kleim & Jones, 2008). Lastly, the motivation of the person is essential to promote task engagement (Kleim & Jones, 2008). Different motivational elements, such as positive reinforcement, role models, goal-oriented training as well as cognitive and behavioral strategies, can increase cortical representation by improving the involvement of people with a SCI in physical activity (Dunlop, 2008). To date, little research has been conducted on motivation for rehabilitation in people with a SCI.

Research concerning motivation for neurological rehabilitation has gained attention specifically in the field of stroke rehabilitation (Solbakken et al., 2023; Tan et al., 2023; Yoshida et al., 2021). The study of Yoshida et al. (2021) identified seven factors, divided in personal and social relationship factors, that influence motivation for rehabilitation in subacute stroke patients. The four personal factors include the goals of the patient, experiences of success and failure, physical conditions and resilience. The three social relationship factors include the influence of rehabilitation, the relationships between patients and the patients' supporters (Yoshida et al., 2021). The importance of social relationships to enhance motivation is highlighted in multiple studies (Solbakken et al., 2023; Tan et al., 2023; Yoshida et al., 2021). In addition to these seven factors, other studies identified factors such as the coping strategy of the patient and the transfer of knowledge from the professional to the patient to be key factors influencing the motivation for rehabilitation in subacute stroke patients (Maclean et al., 2000; Solbakken et al., 2023; Tan et al., 2023). While the study of Yoshida et al. (2021) found that motivation is mainly based on extrinsic factors, other studies found that internal factors such as self-esteem, self-determination, volition, disability acceptance, empowerment and uncertainty were more significant than the external factors such as physical functioning, social support and rehabilitation environment (Cheong et al., 2021; Signal et al., 2016).

Besides motivation in people with a stroke, few studies were found on motivation for rehabilitation in other neurological conditions. Ghaidar et al. (2022) reported that personally meaningful and specific goal setting prior to rehabilitation may help to increase the motivation of people with multiple sclerosis for rehabilitation (Ghaidar et al., 2022). In patients with Parkinson's disease, being surrounded by people with the same disease, support from health professionals, the patients' perceived success and exercises related to the individual challenges in the everyday life of the patients, were found to be motivating for the rehabilitation (O'Brien et al., 2008; Vistven & Groven, 2023). Specifically in people with a

chronic SCI, the study of Littooij et al. (2016) found that the fundamental beliefs and life goals guiding people in their lives, affect motivation. In addition, support from family, friends and professionals as well as peer mentoring can enhance motivation (Littooij et al., 2016). Another study adds that peer mentoring only increases motivation in people with SCI if they perceive their mentors as using transformational leadership behaviors (Beauchamp et al., 2016).

Even though motivation is suggested to be an important part of functional rehabilitation (Dunlop, 2008; Kleim & Jones, 2008), no study to date has investigated how it is experienced by people with a C-SCI during subacute rehabilitation. Thus, this specific study aims to investigate this in relation to arm-hand training, which leads to the following research question: "How do people with a cervical spinal cord injury experience motivation for arm-hand training during subacute rehabilitation?".

2 Materials and methods

2.1 Study design

This study aimed at gaining a better understanding of the phenomenon, i.e. motivation for rehabilitation, more specifically for arm-hand training, as it is experienced by people with a C-SCI. A qualitative research design was used with a phenomenological-hermeneutical philosophy (Lindseth & Norberg, 2004). This interpretative design allows for the investigation of the meaning of experiences of people with a C-SCI with the phenomenon as well as the interpretation of the transcripts describing the phenomenon (Guerrero-Castañeda et al., 2019; Horrigan-Kelly et al., 2016).

2.2 Research team

This study is conducted by the primary researcher as part of her master's thesis and is supported by her thesis advisor and two co-advisors. The primary researcher is a female master's student in occupational science who has little experience in working with people with a SCI. She received training in qualitative research, but has no practical experience. Her thesis advisor is a professor in the domain of neurological rehabilitation with research expertise in goal- and task-oriented training of the upper extremities, who also has a special interest in SCI. She has experience in qualitative research and will help supervise this study. Lastly, there are two female thesis co-advisors, one of whom is doing a PhD in the domain of SCI and rehabilitation. Both thesis co-advisors are masters in occupational science who have some

experience in qualitative research. They will also be responsible for the supervision of this study. The researchers had no prior relationships with any of the participants.

2.3 Setting, participants and sampling method

Participants were recruited between November 2023 and March 2024 from two rehabilitation centers in Belgium, i.e. UZ Leuven campus Pellenberg and UZ Gent, and one rehabilitation center in the Netherlands, i.e. Adelante. A criterion sampling strategy was used to purposively select participants who met predefined criteria (Moser & Korstjens, 2018). The inclusion criteria were as follows: (1) age > 16 years old; (2) a traumatic or non-traumatic SCI between C1 and T1; (3) AIS A, B, C or D according to the American Spinal Injury Association Impairment Scale; (4) subacute phase (4-30 weeks post-injury); (5) ability to follow standard arm/hand skill training; (6) receiving usual care; (7) ability to understand and speak Dutch. The exclusion criteria were as follows: (1) significant medical or physical condition (including pregnancy) or psychiatric illness that could prevent them from participating in the study; (2) unable/unwilling to provide informed consent. To achieve maximum variation, the aim was to obtain a variety in the participants' genders, ages, SCI origins and weeks post-injury. Eligible patients were first approached by their doctor and/or responsible therapist to inquire about their interest in participating in this study. Additional information was provided for the interested patients by their doctor.

2.4 Data collection

Semi-structured interviews were used to explore the participants experiences regarding motivation for rehabilitation. An interview guide (Appendix 1: Interview guide) was developed by the primary author in consultation with her thesis advisor and co-advisors. The interviews were administered face-to-face. This allows for relevant information yet yields the flexibility to dive deeper into the personal experience of the participants (Gill et al., 2008). Written informed consent was obtained before the start of each interview. The interviews started with a short introduction of the topic and goal of the study followed by an introductory question to get the participants acquainted with the topic. Next, a transition question was asked to gauge personal experiences of the participants. The interviewer concluded each interview by formulating a summary of the interview and checking it with the participant as well as thanking them for their participation. All interviews were conducted by the primary author as part of her master's thesis, except for one interview that was conducted by one of the thesis

co-advisors. They were conducted in a room or environment that felt familiar or safe to the patient. The interviews lasted an average of 35 minutes per participant and the duration ranged between 19 and 45 minutes.

2.5 Data analysis

The interviews were audio-recorded, video-recorded, transcribed verbatim in Dutch and combined with non-verbal observations obtained from field notes and the video-recordings by the primary author. Two interviews were not video-recorded due to the participant's refusal or camera malfunctions. The interviewer did however write down any observations during these interviews. Verbatim transcripts were made by first using the software program Good Tape, to generate preliminary versions. The definitive transcripts were done manually. Informal member checking was performed at the end of each interview by summarizing the interview in a few sentences and checking it verbally with the participant. This is done to validate the input of the participants in real time, hereby avoiding low response rates and the influence of the time difference between the interview and the member check (Varpio et al., 2017). Double coding was done independently using NVIVO 14 software by the primary author and one of her thesis co-advisors for the first two transcripts. The remaining transcripts were coded by only the primary author. Data analysis was conducted using a phenomenological-hermeneutical method to create a more in-depth understanding of the information obtained concerning the experiences of the participants regarding motivation during their subacute rehabilitation (Lindseth & Norberg, 2004). This interpretative method consists of three phases, i.e. naïve reading, structural analysis and comprehensive understanding. During the first phase, naïve reading, all transcripts were read several times to become familiar with the data and form an initial, naïve understanding. During the second phase, structural analysis, the whole text was read and broken down into meaning units guided by the background of the naïve understanding. These meaning unit were parts of the data conveying only one meaning. After reading through and reflecting on all meaning units, condensed meaning units were created by expressing the essential meaning of each unit. Once all condensed meaning units were read through and reflected on to detect similarities and differences, they were further condensed and sub-themes were formed. These subthemes were then combined into themes and main themes. During the last phase, the text was interpreted as a whole to arrive at a comprehensive understanding. In this phase the research question, the naïve understanding,

the results of the structural analysis and the context of the study were taken into consideration (Lindseth & Norberg, 2004).

2.6 Ethics considerations

Ethics approval was obtained from the central medical ethics committee from UZ Leuven as well as the local committees from UZ Gent, UHasselt and Adelante. This study was added as an amendment to a multicenter longitudinal observation study and has the following Belgian registration number, i.e. B3222022000912. The research was conducted in accordance with the principles outlined in the Declaration of Helsinki.

3 Results

A total of 10 people with a C-SCI were interviewed in this study (characteristics presented in Table 1 see Appendix 2). These interviews resulted in 351 minutes of recorded data. Of the interviewed participants, seven were male and three were female. The mean age was 54.5 years and the participants ranged in age from 21 to 79 years.

3.1 Naïve understanding

The interviews showed that the people with a C-SCI experienced motivation for arm-hand training as a process of a personal nature, with motivation often being described as the most important factor for their rehabilitation. The narratives showed that they directed their focus on three influential aspects regarding motivation: personal experience, social context and therapy. Personal experience appeared to be the most influential aspect for their motivation describing experiences of progress and setbacks as well as being goal-directed. Especially when motivation from personal experience is less present, the social context appears to be influential. The social context is described as consisting of the rehabilitation team, fellow patients and the own network of the person. Lastly, some therapy elements were described that can influence motivation during or for arm-hand training sessions.

3.2 Structural analysis

The naïve reading resulted in four themes with associated subthemes (see Table 2 for the themes and subthemes and Appendix 3 for the coding tree) by condensing and reorganizing the meaning units (see Table 3 in Appendix 4 for an excerpt). The themes and their subthemes

are described separately in the next section. Each theme is also illustrated with one or more quotations from the interviews.

Table 2: Themes and subthemes

Themes	Subthemes
Importance of motivation	process personal nature
Personal experience	experiences goal-directed
Social context	rehabilitation team fellow patients own network
Therapy	content dosage intensity

3.2.1 Importance of motivation

The individuals with a C-SCI were asked to rate the importance of motivation for their rehabilitation between zero and ten, with zero being motivation is not important at all and ten being motivation is very important. More than half of the individuals chose the number ten describing motivation to be the most important factor for their rehabilitation. They indicated that motivated people will generally make much more progress than people who are not as motivated.

"That is the 10 for me. So be 100% motivated, otherwise you really won't get there." – Participant 1.1

Two people chose to give a rating of nine, indicating that motivation is certainly necessary, but that extremes do not exist. One person gave a rating of between seven and eight, the lowest rating for this question, indicating that other factors can also play a role in rehabilitation although no other factors could be named.

"Surely seven, eight. That motivation is certainly necessary, but to immediately give it a ten, that's a bit high." – Participant 3.3

Process

Motivation was generally described as being a process that one has to go through step by step, consisting of high points and low points. In the beginning, just after the SCI, motivation was experienced as being very low. Many described not being able to do anything themselves and

questioning their reason for living. Personal experiences and their social context could help them overcome this phase to start feeling motivated to move forward. The process of motivation was often compared to a learning or coping process. They described needing to learn to accept that they needed help, but also to learn to ask for help. They mentioned getting to know a completely different version of themselves and having to think much more about things that used to be easy.

"And some things just don't work, and then you have to ask for help, and those are things, yes, a process where you have to learn to accept that you also need help." – Participant 1.1

Personal nature

Motivation was often described as something that is highly dependent from one person to another, since everyone is different. They mentioned that how people were raised could play a role in this. For example, some indicated that playing a competitive sport in the past taught them to always persevere. A person's age and their life experiences were also indicated as something that could influence how motivation is perceived, since this can influence how they approach life.

"I played football for twenty years. I think that also had a great influence on me, for that motivation and continuing to go for it until you get there." – Participant 2.3

3.2.2 Personal experience

As mentioned previously, motivation was experienced as a process. In addition, the people with a C-SCI all indicated that this process is more of an internal than an external process. They mentioned that people must realize that they are doing it for themselves first and foremost.

"But most of it has to come from yourself. If you don't believe in it yourself, then other people can say whatever they want." – Participant 3.1

Experiences

The people with a C-SCI elaborated on various factors that could influence their motivation. Generally, progress was mentioned as positively influencing their motivation while setbacks had the opposite effect. Progress was often described as being able to see progress in one's own capabilities, but could also refer to experiencing fewer physical problems. At the start of their rehabilitation, they usually experienced a lot of progress, which enhanced their

motivation.

"It is small in the beginning, but the motivation grows with the progress you make." – Participant 2.2

Gradually their progress became slower, which some found difficult to deal with. However, most of them described being happy to see even little progress because it encouraged them to try to achieve more.

"But as long as there is progress, there is positivity." – Participant 2.1

They also mentioned various personal characteristics that could contribute to them experiencing progress and therefore enhance their motivation. Perseverance and the ability to put things into perspective were cited by most. In addition, some also indicated that being verbally strong and patient could assist them during their rehabilitation.

"I still try to set the bar high for myself, about the goal. Always being able to do something more." – Participant 2.4

When talking about experiencing setbacks, most of them mentioned being confronted with simple things that they could no longer do at the beginning of their rehabilitation.

"But then before the accident having had a very beautiful handwriting and now it looks like a doctor who writes. And we are not motivated to do that at the moment." – Participant 3.3

This could make them feel hopeless, although some of them indicated that they could also draw strength from these setbacks after letting them sink in for a while. Multiple people with a C-SCI were confronted with fatigue. Most of them indicated that a poor night's sleep could have a detrimental effect on their motivation for therapy. They also mentioned experiencing setbacks due to a negative prognosis or persistent physical limitations such as pain, tingling, numbness, stiffness and a sensitivity to cold. This could cause them to feel disappointed and frustrated, which could negatively impact their motivation.

"Yes, because then, then it just stopped, because the pain was overpowering, which meant that the entire rehabilitation, they couldn't do anything with it anymore." – Participant 1.1

Goal-directed

Most people with a C-SCI experienced being goal-directed as something that highly motivated them for their rehabilitation. Their goals were formulated in very different ways. Some people mentioned formulating general goals, while others formulated very specific goals. Some preferred to formulate long-term goals, while others found it motivating to formulate and achieve short-term goals. Some discussed their goals with their therapists, while others chose not to do this. The goals themselves were very personal and could consist of goals regarding: becoming as independent as possible, being able to perform specific daily activities again, being able to do as much as possible as before, gaining more manual dexterity and moving towards a certain vision of the future.

"You set certain goals that, if you have a bizarre, acute failure, you want to set goals to regain some independence within a certain time and those goals are extremely motivating."
– Participant 1.3

Although these goals motivated most people, one person indicated that they had a lot of difficulty in formulating goals and would rather not do so at all.

"I can't formulate them. I usually start crying." – Participant 3.2

3.2.3 Social context

Even though motivation was experienced primarily as an internal process, the social context was also often mentioned as influencing motivation. When analyzing the narratives, the social context can be divided into three categories. The first category is the rehabilitation team, which can include therapists, nursing staff and sometimes also doctors and students. The second category consists of fellow patients in the rehabilitation center. Finally, the third category consists of the person's own network, which can include family, friends and sometimes also colleagues.

"So those friends and family are going to be a trigger, but first you have to want to live yourself and want to get better yourself and have the strength to, to, to come back."
– Participant 2.3

Rehabilitation team

According to the people with a C-SCI, the team within the rehabilitation center could

contribute in various ways to increase their motivation. Being motivated and positive themselves and looking for solutions to the patient's requests for help were often mentioned. Some also found being honest and communicating openly to be important because it made them feel like they were seen.

"If you can speak and communicate from my knowledge to your knowledge, then you will reach a very nice interaction." – Participant 1.2

In addition, they also found it important for the therapists to build a strong relationship with them in order for the therapists to get a good understanding of them and to know the extent in which they can challenge them during the rehabilitation. Informing them about the usefulness of the exercises in therapy and providing them with sufficient feedback during therapy sessions were also indicated by some.

"If the therapists could tell me more about, look, this is for that purpose or that is for that purpose. Than that would be already huge." – Participant 3.2

Fellow patients

Fellow patients were also mentioned by most to help motivate them. Since they lived together in the rehabilitation center, they felt like they had built a bond and didn't have to go through everything alone. They felt like they could always talk to each other and share their sorrows. Some also mentioned feeling supported and encouraged by each other to keep persevering.

"In the quiet hours when you can chat with each other and if you are having a bad day, you can encourage each other to make something good of it or to see something good in it." – Participant 2.3

In addition, a lot of them found it very motivating to see other patients achieve success. Some talked about comparing themselves to other patients, which could help them put their own situation into perspective. Others indicated that they only compared themselves to others who are in a similar situation or did not compare themselves to others at all.

"If you are somewhat in the same situation. Yes, you have people who are different, that you know, you should not mirror them." – Participant 3.2

Own network

Family, friends and colleagues could also help motivate the people with a C-SCI. They could do this by showing their support and by adopting a positive attitude. In addition, some of the people with a C-SCI mentioned that it helps if their own network is also motivated themselves. Furthermore, they enjoyed receiving visitors regularly, but indicated that it can sometimes overstimulate them. One person mentioned that these visits made him feel like he still belonged and others hadn't forgotten him.

"It is support and also, they always come to visit so unexpectedly and that gives the you feeling that they have not forgotten you." – Participant 2.3

3.2.4 Therapy

When talking about their arm-hand training sessions, various elements from within the therapy emerged from the narratives that can influence motivation for those training sessions. Many stated the importance of understanding the usefulness of the exercises. In addition, most of the people with a C-SCI also mentioned the need for variety in the exercises, with some highlighting the benefit of having the exercises match their interests. Several people also indicated that they liked the heavier exercises and wanted less rest between exercises.

"Yes, basically I don't care what I have to do. If only, if only you can convince me that there is a point in me doing it. Because if I don't see the point of it, then my motivation to do it is also low." – Participant 1.1

3.3 Comprehensive understanding

The text was interpreted as a whole, taking into consideration the naïve understanding, the context of the study and the results of the structural analysis, to arrive at a comprehensive understanding. This resulted in the formulation of patterns between the themes and thus the lived experiences of people with a C-SCI regarding motivation for arm-hand training. This allowed for a visualization of the associations among the different themes and subthemes, illustrated below in Figure 1.

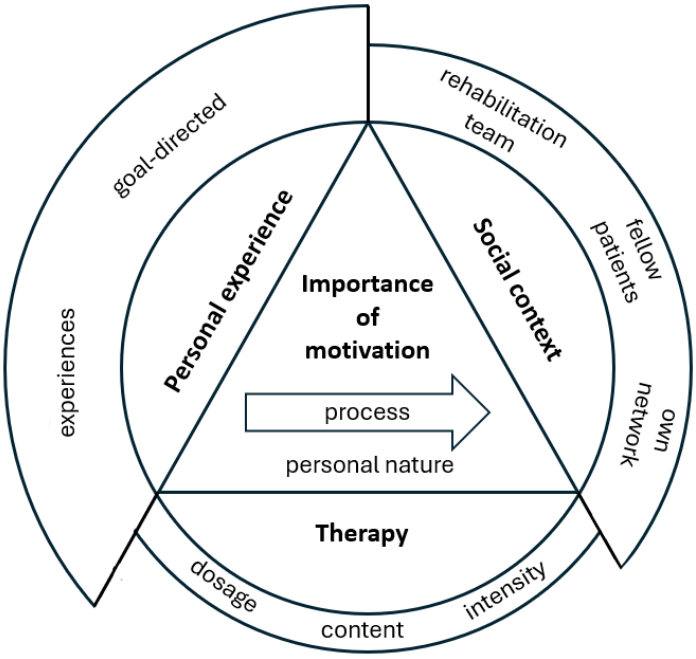

Figure 1 Visual representation of the comprehensive understanding

When someone has a C-SCI, this has a major impact on the life of this person. Activities they never had to think about while performing them, now require a lot of their energy and concentration or require help from others. Accepting this can be a very difficult process to go through, but is also important to gain motivation for rehabilitation. Motivation is a crucial element in the rehabilitation after a C-SCI, hence its placement in the core of Figure 1, but is usually really low at the start of the rehabilitation. People with a C-SCI have to go through a process to regain and maintain their motivation for rehabilitation. This happens step by step and differs from person to person. Motivation for rehabilitation is mainly an internal process that can be influenced by two aspects, i.e. personal experience and social context.

Personal experience is found to be the most influential regarding motivation for rehabilitation. This is represented visually in Figure 1 by assigning the largest area surrounding the core to personal experience and its subthemes. Experiencing progress is found to be very motivating while experiencing setbacks usually has a negative effect on motivation. Various personal characteristics such as persistence and the ability to put things into perspective can help the person to make and experience progress. In the beginning of rehabilitation, a lot of progress is usually made, which can cause a big increase in motivation. After a while, this progress can slow down, which can negatively impact one's motivation. Setbacks in the beginning of the rehabilitation usually consist of the confrontation with not being able to do certain things anymore. During rehabilitation, people with a C-SCI can also be confronted with physical

limitations such as fatigue, pain or numbness, which can impede their motivation. Being goal-directed throughout the rehabilitation can help to motivate them by having a clear vision to work towards. This vision can encompass regaining independence, performing specific daily activities again, being able to do as much as possible as before, regaining more manual dexterity and moving towards a certain vision of the future. However the way the goals are formulated and with whom they are shared can differ substantially.

Apart from personal experience, the social context can also have an impact on the motivation of people with a C-SCI. This is represented visually in Figure 1, as the social context and its subthemes occupy the second largest area around the core. The rehabilitation team, especially the therapists, can contribute by building a strong relationship with the patient, being motivated and positive themselves, being honest and communicating openly. During the training sessions, it is also important for them to inform their patients about the usefulness of the exercises and provide them with sufficient feedback. The fellow patients can enhance motivation for rehabilitation by talking to, supporting and encouraging each other. Seeing others achieve success can also be motivating, while comparing oneself to other patients can be both beneficial and detrimental. The own network of the person with a C-SCI, such as their family, friends and colleagues, can also support them to enhance their motivation by visiting regularly and being motivated themselves.

Specifically for arm-hand training, the therapy itself is a third aspect that can influence motivation. Since this theme is only specific for arm-hand training while the other two apply to the entire rehabilitation, it takes up the smallest area around the core in Figure 1. Patients will be more motivated when they understand the usefulness of their exercises, when there is sufficient variation in their exercises and when their exercises match their interests. They often prefer heavier exercises and don't always want to take too many breaks between their exercises.

4 Discussion

The unique experiences of 10 people with a C-SCI contributed to the development of a broad picture about how these individuals experience motivation for arm-hand training during subacute rehabilitation.

While the study of Yoshida et al. (2021) found that motivation is mainly based on extrinsic factors, another study found that internal factors such as self-esteem, volition, disability

acceptance, empowerment and uncertainty were more significant than the external factors such as physical functioning, social support and rehabilitation environment (Cheong et al., 2021). The findings of our study indicate that motivation is mainly determined by internal factors. Comparisons can also be made between these findings and the self-determination theory (SDT) of Ryan & Deci (2017). SDT describes two types of motivation, i.e. autonomous and controlled motivation. Autonomous motivation concerns acting with a full sense of volition, endorsement and choice, whereas controlled motivation concerns feeling externally pressured or compelled to behave in a certain way (Ryan & Deci, 2017). Findings suggest that people who are autonomously motivated, which can be caused by intrinsic motivation or well-internalized forms of extrinsic motivation, display better results such as higher interest, persistence, better performance and better overall well-being (Ryan & Deci, 2017). This is also indicated by the participants of our study, stating that rehabilitation shouldn't feel like an obligation. It should be something that you do for yourself, not for others. SDT also states that the need for competence, autonomy and relatedness are three basic psychological needs that must be satisfied for everyone to experience ongoing growth, integrity and wellness (Ryan & Deci, 2017). In our study, goal setting is also experienced as being mainly aimed at satisfying these basic psychological needs. Social environments that help to satisfy these needs have a positive effect on individual and interpersonal outcomes such as well-being. If the social environment doesn't help to satisfy these needs, this can have a negative impact (Ryan & Deci, 2017). This can also be observed in our study, where some patients described the feeling of belonging that they experience when they receive regular visits from important people in their lives.

While most of the studies on motivation for rehabilitation focus on specific factors of motivation for rehabilitation, our study focusses more on how it is experienced by patients with a C-SCI. This yielded several interesting findings. The process of motivation was often compared to a learning or coping process. One of the participants even described motivation as being closely linked to acceptance. This further confirms the findings above claiming that motivation is mainly determined by internal factors. This also relates closely to results from other studies suggesting that the coping strategy of the patient can influence their motivation (Solbakken et al., 2023; Tan et al., 2023). This indicates the need for further research into how motivation for rehabilitation is experienced at different moments throughout the rehabilitation, both acute and subacute. Our study also describes motivation as something

that is highly dependent from one person to another, adding that a person's background, certain life experiences and a person's age can affect how motivation is perceived. This validates findings from a study suggesting that identity, as one of the five aspects of global meaning, can affect motivation in people with a SCI (Littooij et al., 2016). Each participant in our study also gave a score indicating how important they found motivation for their own rehabilitation, with more than half of them believing motivation to be the most important element for their rehabilitation and everyone agreeing to its necessity. This is similar to the results of a study in people with SCI, which shows that people who achieved their potential in rehabilitation often attribute motivation as the cause of this (Belciug, 2012).

Looking at the themes of our study described as influencing motivation, similarities can be found with other studies such as the study of Yoshida et al. (2021), who investigated motivation for rehabilitation in patients with a stroke. They identified seven factors that influence motivation and divided these factors, similarly to our study, into personal factors and social relationship factors. Being goal-directed and experiences of success and failure are present in both studies. The latter is also discussed in other studies concerning motivation in stroke patients (Solbakken et al., 2023; Tan et al., 2023). The study of Yoshida et al. (2021) also identifies physical conditions as another personal factor that can negatively affect motivation, which is also mentioned in our study as an influencing factor of the experiences of progress and setbacks. However the description of these physical conditions differs between studies, which is not entirely unexpected due to the difference in neurological conditions. Resilience is a last personal factor described by Yoshida et al. (2021) that is also present in our study alongside other personal characteristics such as being patient and verbal that can help the patient experience progress and therefore become more motivated. The three social relationship factors in the study of Yoshida et al. (2021) are broadly similar to the three aspects of the social context in our study. Both studies focus on how therapists can help motivate their patients, such as providing feedback. Observing successes of fellow patients, comparing oneself to them and having family and social support is also found to enhance motivation in both studies. These influencing factors concerning the social context of the patient can also be found in other studies regarding motivation for rehabilitation in stroke (Littooij et al., 2016; Solbakken et al., 2023; Tan et al., 2023).

Our study also adds several other findings. Even though being goal-directed can positively influence motivation, our study shows that the way in which the patient describes goal setting

varies greatly from one person to another. This may be due to the limited knowledge about how goal-oriented care is performed and the various challenges that therapists experience in applying this in practice (Ørtenblad et al., 2023). This shows the need for research to further investigate goal setting in patients with a C-SCI and how therapists can facilitate this. One of the participants in our study even indicated that they did not want to set goals at all. In this regard, the study of Van de Velde et al. (2012) describes that the assumption that people with a SCI can make all their choices independently can be detrimental for them. Instead, they recommend that therapists identify the type of patient they are dealing with, describing four types, i.e. the active agent, the active follower, the passive follower and the passive victim. The therapists can then use these different types as tools to empower their patients (Van de Velde et al., 2012). Our study also found that while some experience setbacks negatively, others draw strength from it. This is confirmed in another study, stating that goal related setbacks can be disappointing for some patients, but can also facilitate a deeper understanding and acceptance of their limitations (Scobbie et al., 2021). Our study also found that while most patients compare themselves to others to enhance their motivation, others only compare themselves to patients who are in a similar situation as them or do not compare themselves to others at all. This can be explained by the results of another study emphasizing that while favorable comparisons with other stroke patients can positively influence motivation, unfavorable comparisons can have the opposite effect (Maclean et al., 2000).

In addition, our study explores motivation specifically for arm-hand training. Elements of this training were described that ensure that the person's motivation is or remains high during the training, such as variation in the exercises. Being able to see the usefulness of the exercises was most often described. This is in line with results from the study of Vistven & Groven (2023) in patients with early-stage Parkinson's disease, which show that if patients can understand the usefulness of the exercises, they will be motivated to continue to perform them. Some participants also mentioned wanting to receive more training time. This is in line with findings from another study concerning the experiences of physical rehabilitation in individuals with SCI (Unger et al., 2019). Even though motivation for arm-hand training was studied, all participants described motivation in terms of the entire rehabilitation. Concerning further research on motivation, it would therefore be useful to investigate motivation for rehabilitation and not to limit oneself to motivation for only arm-hand training.

Relevance for clinical practice and recommendations

This study provides rehabilitation professionals with a better understanding of how people with a C-SCI experience motivation for arm-hand training, which can help them to be more aware of the influencing factors of motivation and to know how they can contribute to this themselves. Based on the results of this study, it is recommended to pay sufficient attention to building a strong therapeutic relationship with the patient. This is confirmed by findings of another study investigating the impressions of physical and occupational therapists concerning patient engagement (Lequerica et al., 2009). Doing this facilitates open and honest communication and ensures a good understanding between therapist and patient. Once a therapeutic relationship is established, it is easier to estimate to which extent the patient can be challenged. Furthermore, it also appears to be very important for patients to know why they have to perform their exercises. It is therefore recommended to pay sufficient attention to explaining this. This need for information and knowledge is also confirmed by the study of Lindberg et al. (2013). In addition, therapists can pay special attention to the various motivational elements specific to arm-hand training mentioned in our study, to ensure the motivation of their patients doesn't decrease during training sessions (Vistven & Groven, 2023).

4.1 Strengths and limitations

A strength of this study is its heterogeneous sample, which includes participants within different age categories, as well as participants of both sexes. The included participants also differ in ASIA scores, days post injury and both traumatic and non-traumatic spinal cord injuries are represented.

Another strength of this study is the combination of audio and video recordings. The interviews were all audio-recorded and when permission was granted they were also video-recorded. This allowed the researcher to rewatch the interviews and include non-verbal observations to enrich the transcripts. This was an added value as several participants used non-verbal communication and emotional reactions could occur due to the sometimes poignant nature of the subject of this study.

There are several limitations in this study. Firstly, the sample size of 10 people with a C-SCI was relatively small, but not surprising given the prevalence of C-SCI. It is therefore insufficient to accurately represent the motivation of every person with a C-SCI, but this was not the aim

of this qualitative study. The semi-structured interviews were sufficiently in depth to provide a broad picture of how the participants experienced motivation for arm-hand training. However due to the nature of qualitative research and the topic of this study, there is a possibility of social desirability bias.

Due to the nature of the recruitment in which participation is voluntary, only people who wanted to participate in this study were interviewed. This can lead to self-selection bias, including only people who are motivated for their rehabilitation. Due to the purposive sampling strategy, only participants were included who were in the subacute phase of their rehabilitation. This can lead to recall bias, when asking them to reflect on their entire rehabilitation. Therefore, it would be interesting to investigate and compare how both motivated and less motivated people with a C-SCI experience motivation throughout the acute and the subacute phase of their rehabilitation and how these results translate to their functional recovery. In addition, it could also be useful to examine whether and how these results impact the person once they have left the rehabilitation center, for example their social participation.

Another limitation of this study is the lack of a pilot interview. This was left out to ensure that there would be enough participants to include. This limitation was addressed by formulating an interview guide under the supervision and repeated control of the thesis (co-) advisors, who have experience in qualitative research and neurological disorders. After the first interview, the usability of the interview guide was discussed with the authors and approved by all.

5 Conclusion

Motivation is described in the literature as one of the three key factors for the functional recovery of people with a SCI (Bertels et al., 2023; Dunlop, 2008; Kleim & Jones, 2008). It is essential for promoting task engagement which can increase cortical representation (Dunlop, 2008; Kleim & Jones, 2008). The results of this study provide an insight into how people with C-SCI experience motivation for arm-hand training during subacute rehabilitation. Motivation is seen as a mainly internal process determined by personal experience, but can also be influenced to a lesser extent by the social context of the person. This study describes various aspects of personal experience that can influence how people with a C-SCI experience motivation, i.e. experiences of progress and setbacks and being goal-directed. The social

context can include the rehabilitation team, fellow patients and the person's own network, i.e. family, friends and colleagues. Finally, elements specific to arm-hand training regarding the therapy content, dosage and intensity are also described, which can moderate the motivation of individuals with a C-SCI for this training. Further research should focus on motivation for the entire rehabilitation, not only arm-hand training.

5.1 Conflict of interest

The author of this study declared to have no conflicting interests.

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Appendix

Appendix 1: Interview guide

Dankjewel om hier vandaag aanwezig te zijn. Ik ga beginnen met uitleg te geven omtrent het onderzoeksopzet. Het doel van dit interview is om te weten te komen welke factoren een invloed hebben op uw motivatie voor arm-/handvaardigheidstraining. Ik zal u hierover dadelijk enkele vragen stellen.

Inleidingsvraag:
U bent momenteel aan het revalideren en heeft al vaak arm-/handvaardigheidstraining gehad. Als u denkt aan motivatie en arm-/handvaardigheidstraining, waaraan denkt u dan?

Transitievraag:
Hoe heeft u motivatie ervaren tijdens uw revalidatie?

Sleutelvragen:

- U mag eens terugdenken aan een therapiesessie waarvoor u zich gemotiveerd voelde.
  - Wat zorgde er bij u allemaal voor dat u gemotiveerd was?
  - Wat kan ervoor zorgen dat uw motivatie hoog blijft doorheen de therapiesessie?
- Nu mag u eens terugdenken aan een therapiesessie waarvoor u weinig motivatie had.
  - Wat zorgde ervoor dat u weinig motivatie had?
  - Zijn er zaken waardoor uw motivatie afneemt tijdens de therapiesessie?
- U heeft nu een aantal aspecten opgesomd die ervoor zorgen dat uw motivatie toeneemt of afneemt voor een therapiesessie. Zijn er nog andere aspecten die u ervaren heeft, die een rol kunnen spelen met betrekking tot uw motivatie voor therapiesessies?
- Als u nu eens terugdenkt over uw revalidatieperiode, hoe zou u dan uw motivatie voor de volledige revalidatie beschrijven?
  - Welke aspecten dragen bij tot de motivatie van het volledige revalidatieproces?
- Als u een cijfer van 0 tot 10 zou moeten plakken op hoe belangrijk motivatie volgens u is op uw revalidatie met 0 is helemaal niet belangrijk en 10 is heel belangrijk, welk cijfer zou dit dan zijn?
  - Waarom zou u dit cijfer geven?

Besluitende vragen:

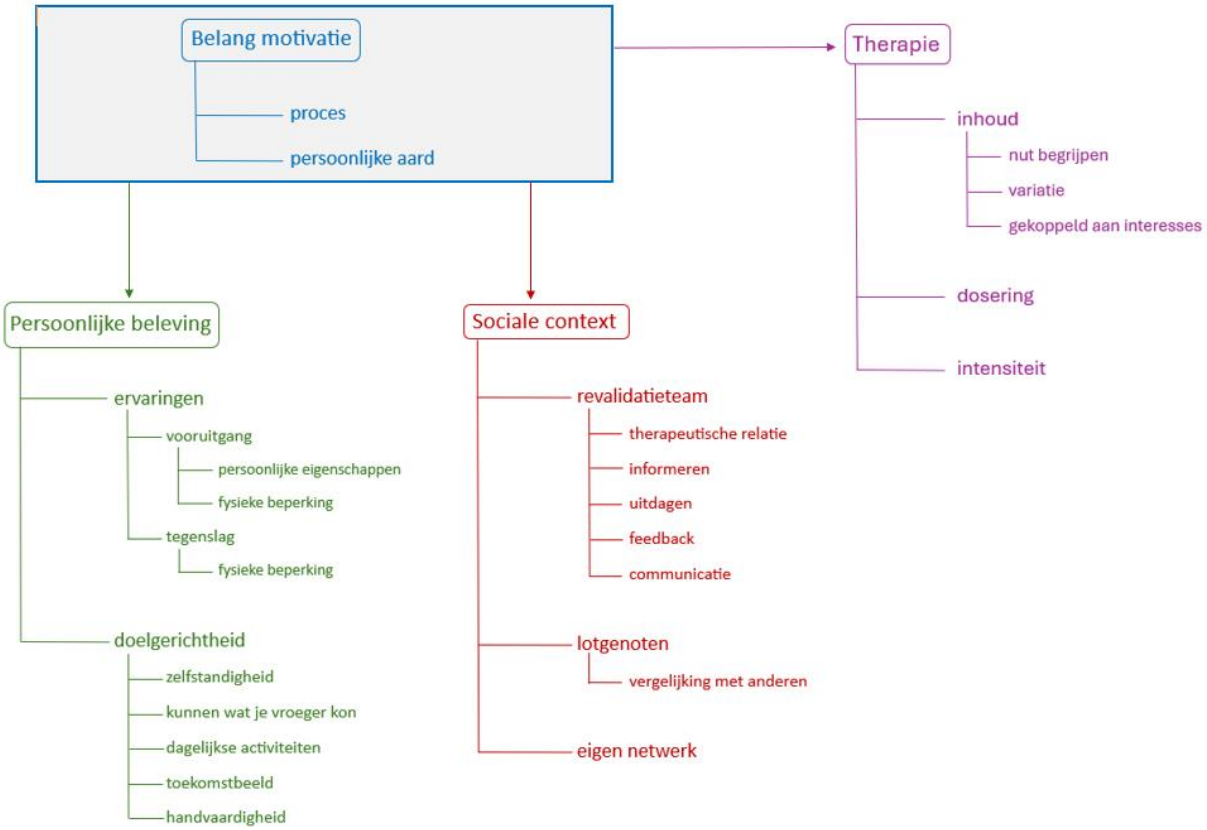
- Wat vond u het belangrijkste dat besproken is gedurende het interview?
- Klopt het dat X de belangrijkste conclusie is?
- Zijn er nog zaken die vergeten zijn gedurende het interview met betrekking tot motivatie?

Appendix 2: The characteristics of the participants

Table 2: The characteristics of the participants

Characteristic	Participants (N = 10)
Sex, N	
Female	3
Male	7
Age in years (range)	54.5 (21-79)
SCI level	
C1 in myelopathy, otherwise C2-5	1
C1 motor and sensory, C4 left side	1
C2	1
C3	1
C4	4
C5	1
C6	1
ASIA grade	
B	1
C	2
D	7
Cause of SCI	
Traumatic	6
Non-traumatic	4
Time between injury and interview in days (range)	112.4 (48-209)

Appendix 3: Coding tree



Appendix 4: Excerpt from the structural analysis of a meaning unit

Table 3: Excerpt from the structural analysis of a meaning unit

Meaning unit	Condensation	Theme
'That's a 10 for me. So being 100% motivated, because otherwise you really won't get there… No, you won't get there. Then you really have to, well how should I say it, you have to stay positive. If you start thinking negatively, you won't get there.'	Having to be 100% motivated and staying positive otherwise you won't get there.	Importance of motivation
'Yes, basically I don't care what I have to do… As long as I, if you can convince me that there is a point in me doing it… Because if I don't see the point of it, then my motivation to do it is also low.'	Having to understand the use of the exercises.	Therapy
'But most of it has to come from you. If you don't believe in it yourself, then other people can say whatever they want. If you don't believe in it yourself, then you're not going to do it.'	Having to believe in it yourself otherwise you're not going to do it.	Personal experience