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Rehabilitees' conceptions of participation after a six-month rehabilitation period: a phenomenographic study

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Purpose: A prerequisite for successful rehabilitation is that the rehabilitees are in central role of the rehabilitation process. However, the rehabilitees and rehabilitation professionals may both lack knowledge and understanding of how to implement rehabilitee-centred participation in practice. This study aimed to explore the qualitatively different ways of understanding rehabilitee participation as conceptualized by the rehabilitees.

Methods: We generated data from individual interviews with 20 rehabilitees after a six-month rehabilitation process. These interviews were analyzed using phenomenographic methodology.

Results: We identified three conceptualizations of rehabilitee participation among the participants: i) Dependent participation, ii) Progressive participation, and iii) Committed participation. These categories varied according to four themes: 1) Rehabilitation process 2) Rehabilitation in everyday life, 3) Interaction in rehabilitation, and 4) Rehabilitation support network. We also identified critical aspects that highlighted differences among the qualitatively distinct categories.

Conclusion: This study generated new insights into understanding the phenomenon of rehabilitee participation, as conceptualized by the rehabilitees themselves. The findings, in terms of three descriptive categories and the critical aspects, reflect the ascending complexity from ascending dependent to progressive and committed participation. These findings can be utilized in the design, development, and implementation of rehabilitee participation and rehabilitee-centered practices.

Keywords: rehabilitee participation, rehabilitee-centered practice, phenomenography, conceptions.

Introduction

Although the need for patient/rehabilitee participation is emphasized in contemporary healthcare and rehabilitation, participation is considered a multifaceted concept and a challenging task (Thôrarinsdóttir and Kristjánsson, 2014). One of the key aspects highlighted in today's rehabilitation practice is the patient's/rehabilitee's active participation in rehabilitation decision-making and its overall impact on the rehabilitation process as a whole (Paukkonen et al, 2018; Sosiaali-ja terveystieteiden ministeriö, 2004). Another anticipated aspect is that rehabilitation is based on rehabilitees' needs and individually set rehabilitation goals, as well as evidence-based practice (Paltamaa et al, 2011; Sosiaali-ja terveystieteiden ministeriö, 2020). However, there still is a need to deepen our understanding of patient participation as underpinned by the World Health Organization's (WHO) ethical principles (Lindberg, et al, 2013; Paukkonen et al, 2018) and the ideas of rehabilitee participation in person-centred care (Thôrarinsdóttir and Kristjánsson, 2014).

We have previously implemented the concept of rehabilitee in our studies on rehabilitation participation (Alanko et al, 2019). In this frame, a rehabilitee is seen as an autonomous person and active participant in the rehabilitation process, whose recovery and rehabilitation process are supported by members of the rehabilitation team, we implemented the concept of the rehabilitee as an autonomous person and active participant in the rehabilitation process, whose recovery and rehabilitation process are supported by members of the rehabilitation team (Alanko et al, 2023). The term participation, nevertheless, is seen as a multidimensional concept based on diverse models, approaches, and definitions, and many of its interpretations lack of clarity (Thôrarinsdóttir and Kristjánsson, 2014).

Indeed, the terms partnership, involvement, and shared decision-making have been described as an integral element of the patient participation concept (Truglio-Londrigan and Slyer, 2018; Ekman et al, 2011), and participation has been used interchangeably with patient, client and user involvement (Castro et al, 2016). In practice, participation is implemented at different levels; for example, as individual-level participation and meso-level involvement in service development (i.e., planning implementation and integration of user perspectives and participation in education and training (Castro et al, 2016; Paukkonen et al, 2018). Participation thus is commonly seen as a crucial element of patient- and client-centred practices, highlighting the need for a shared understanding of ways in which to implement it (Lakhan and Ekúndayò, 2013; Paukkonen et al, 2018; Sosiaali-ja terveystieteiden ministeriö, 2004). Patient perspectives to participation have previously been examined in the frame of ecological paradigm and other person-centred approaches to rehabilitation and healthcare (Thôrarinsdóttir and Kristjánsson, 2014; Sjöberg and Forsner, 2020).

Previous studies have shown that rehabilitees in varying rehabilitation contexts expect mutual respect, collaboration, and shared decision-making with rehabilitation professionals, as well as their own experience and knowledge to be acknowledged by the professionals (e.g., Cott, 2004; Hammel et al, 2008; Lindberg et al, 2013; Paukkonen et al, 2018; Thompson et al, 2021; Wikman and Fältholm, 2006). It also has been reported that rehabilitees in different situations expect to be treated as individual human beings and that their personal differences are respected (Ekman et al, 2011; Hammel et al, 2008; Lindberg et al, 2013; Paukkonen et al, 2018). However, there is a relative paucity of knowledge about how the rehabilitees themselves understand rehabilitee participation (Alanko et al, 2019). A better understanding of the ways of perceiving rehabilitee participation from the perspective of the rehabilitees would help acknowledgement of these perceptions by

rehabilitation professionals as well as further enhancement of rehabilitee-centred practices in general. Therefore, this study aimed to explore the qualitatively different ways of understanding rehabilitee participation as conceptualized by rehabilitees themselves in the context of a six-month rehabilitation process. The research question, drawing on phenomenographic methodology (Åkerlind, 2005; Marton and Booth, 2009), was: ‘What are the qualitatively different ways in which rehabilitees conceptualize their rehabilitation participation?’

Methods

Study design: phenomenographic approach

This qualitative interview study is part of a wider research project, of which the first publication explored the meaning of participation in rehabilitation goal setting as experienced by rehabilitees (Alanko et al, 2019), and the second explored rehabilitees' participation in goal-setting, as conceptualized by healthcare professionals (Alanko et al, 2023). The wider research plan received ethical approval from the Hospital District Ethics Committee on June 24, 2014 (Ethics Code 3E/2014).

The aim in this study was to examine the target phenomenon, namely rehabilitees' ways of understanding participation, in the context of a six-month rehabilitation process. Phenomenography is a qualitative research approach which aims to determine people's understanding of a phenomenon of interest (Marton, 1981). Although a phenomenographic analysis begins with examination of individuals' descriptions of the phenomenon in question, the ultimate goal is to create a description of the collective view; that is, an outcome space representing a collective human experience (Marton, 1981; Marton and Pang, 2008). Therefore, we implemented phenomenographic methodology to enable identification and description of the target phenomenon at a collective level.

Phenomenography explores what constitutes a way of perceiving something; but it also examines the differences between ways of perceiving the same thing, and how these differences develop descriptive categories and their logical relationships (Marton and Pang, 2008).

Participants

The participants of this study were rehabilitees who had been discharged after an intensive rehabilitation period in an acute care hospital in a Nordic country. The length of the hospital stays typically varied between one and three weeks. We recruited 20 voluntary rehabilitees based on willingness to participate and ability to return and live at home with or without support after acute hospital stay. During a six-month rehabilitation period, following their return to home, all the rehabilitees had several appointments with various professionals (i.e., as physiotherapists, occupational therapists, nurses, home helpers, personal assistants, resource managers, and physicians), and their therapy took place at home, in rehabilitation facility, healthcare centre, or an outpatient clinic. The rehabilitees were initially informed of the study by their physiotherapist or a nurse before the study began. Before the interviews, all the accepted participants received verbal information of the study, after which they signed informed consent. The mean age of the participants was 66 years (range 50–79), and 65% were men and 35% were women. Most of them were diagnosed with stroke (13/20); four had experienced musculoskeletal problems (e.g., lumbar spinal stenosis and multiple myeloma in lumbar region), and three had suffered from other diseases (tetraplegia, pancreatitis, and arteriovenous malformation). One of the rehabilitees was unemployed, six were on sick leave, and 13 had retired. Nine of the rehabilitees used walking aids and/or other general aids (Table 1).

Data collection

The data were collected soon after the participant's six-month rehabilitation period through individual, semi-structured interviews conducted by the researcher-interviewer (first author). The interviews took place in spring 2016. In-depth interview methods (Appendix 1) enabled the rehabilitees to freely describe and reflect on how they perceived, experienced, and understood their participation in rehabilitation.

The interviews began with one open question: *'How you are doing at the moment?'* and then two additional questions, *'Tell me about your rehabilitation, what kind of experiences did you have?'* and *'What things were included in the rehabilitation process?'*. Open-ended and nonstructured follow-up questions and empathetic listening were then used to ask for further elaboration and clarification when required (i.e. did you mean this..., did I understand correctly..., can you tell me more about this...?) (Appendix 1) (Brinkmann and Kvale 2015).

All the interviews were first audio-recorded and then transcribed verbatim by the first author for analysis purposes. Later, the researcher removed all names from the data and substituted them with pseudonyms. The quotations used in the study were translated into English by the first author and were then checked by a professional translator. The interviews lasted on average 38 minutes (range 16–74 min) and the transcribed data consisted of 280 pages (font = Times New Roman 12, spacing = 1.5) altogether. For transparency, the research team members were not involved in the participants' rehabilitation processes, though they were familiar with the rehabilitation protocol for stroke and musculoskeletal and other diseases.

Data analysis

In this study, the data were analysed using a phenomenographic method, drawing on the guidelines and examples of Åkerlind (2005) and Marton and Booth (2009) (Figure 1). This approach enabled systematic identification and description of the rehabilitees' qualitatively different ways of perceiving the target phenomenon, understanding the variation in the perceptions, and determining the hierarchical structure of the conceptions from the narrowest to the widest category. Consequently, the outcome space based on three descriptive categories as the end result of the phenomenographic analysis, exposed the rehabilitees' ways of understanding the phenomenon of interest at the collective level (Åkerlind, 2005; Marton and Booth, 2009); in this case, the rehabilitees' conceptions of participation in a six-month rehabilitation period.

Figure 1. Process of phenomenographic data analysis.

Phenomenographic analysis is data driven, so all findings emerge from the data (Åkerlind, 2005). In the first phase of the analysis process (i.e. orientation and search for meaning), the first author read and reread all the transcripts and listened to the audiotapes several times to become familiar with the data. This was done with a high degree of openness to identify meanings, and by selecting and recording the rehabilitees' meaningful expressions concerning the target phenomenon, in a Microsoft Word (Microsoft Corp, Redmond, Washington, USA) document. During the second phase of the analysis process (i.e. identifying the themes of meaningful expressions), the first author reorganized and grouped the relevant expressions into preliminary themes through systematic comparison and construction of the participant descriptions, to find similarities, differences, and structural connections among them. In the third phase of the analysis process (i.e. recognizing variation), the first author outlined the preliminary structure of the phenomenon by

rereading the citations and their groupings, focusing on the pool of meanings discovered in the data, as guided by the texts of Åkerlind (2005) and Marton and Booth (2009).

This phase was conducted in close collaboration with the research team (AP and PV) to minimize the influence of the researcher. In the last phase of the analysis process (i.e. developing categories), the key themes – as ‘candidates’ for the themes of expanding awareness, highlighting the critical differences and their relationships in the rehabilitees’ conceptions were reviewed against the data, adjusted, re-reviewed, and compared in collaboration with the research team (AP and PV). This process continued until a consistent set of three descriptive categories had been agreed upon, forming the “outcome space” of the phenomenon (see Åkerlind, 2005; Marton and Booth, 2009). When a theme of expanding awareness occurred in all the categories, it was considered to reflect the variation in progressing from a less complex understanding to a more developed one. Again, this was done in collaboration with the research team (AP and PV).

The three descriptive categories of the rehabilitee participation, as conceptualized in the data, varied to form a hierarchical, logical, and structural whole (cf. Åkerlind, 2005, 2018; Marton and Booth, 2009). These categories represented an expanding understanding of the participation phenomenon; the wider categories being more complex than the previous ones (Åkerlind, 2017). Throughout the data analysis process, the researcher, through critical reflection and constant discussion within the research team, worked toward reaching consistency between the original data and the research findings to minimize the influence of the researcher’s own interpretations and pre-assumptions.

Figure 1. Process of phenomenographic data analysis.

As pointed out by Åkerlind (2005), the aim in a phenomenographic study, alongside exploration and description of people's conceptions of phenomena, is to identify the so-called "critical aspects" between the qualitatively varying conceptions. They are critical in terms of aspects that appear important for both grouping together and distinguishing the varying ways of understanding. They also are critical in the sense that what is required for moving from one way of understanding a phenomenon to another, towards a more complex understanding (cf. Åkerlind, 2005; Marton and Booth, 2009). Therefore, while forming the three categories, we also looked for aspects that highlighted the differences between the qualitatively distinct categories and could be grouped into themes of expanding awareness running through the categories (Åkerlind, 2005). We consequently identified two critical aspects that can be considered as essential "steps" of expanding awareness of rehabilitee participation (Figure 2) and moving from one way of understanding the participation phenomenon to another.

Figure 2. Hierarchically widening categories and steps of expanding the awareness of rehabilitee participation as a phenomenon.

Results

Categories of description and themes of rehabilitee participation

The phenomenon of rehabilitee participation, as reported by the rehabilitees, was the main outcome of the phenomenographic analysis and had three hierarchically structured descriptive categories: I) *Dependent participation*, II) *Progressive participation*, and III) *Committed participation*. These categories were arrived at through four themes of expanding awareness, revealing the critical aspects identified within the categories: 1) Rehabilitation process, 2) Rehabilitation in everyday life, 3) Interaction in rehabilitation,

and 4) Rehabilitation support network. The structural relationships between the categories describe the qualitative variation in understanding the participation phenomenon and show the hierarchical structure between the categories. The hierarchy is revealed by the widening categories and themes of expanding awareness, in which the more complex categories include the less developed ones (Table 2).

Table 2. Categories of understanding rehabilitee participation: three categories, described in terms of four themes of expanding awareness and critical aspects.

We next present and discuss these categories, using quotes from the interviews to elucidate their meaning. All the original quotes have been translated into English without stylistic corrections. Please note: The abbreviations (R) and sequence number (1–20) at the end of the quotes indicate the participating rehabilitee and the page number of the transcript in which the quotes appear.

Category I: Dependent participation

This first, hierarchically narrowest category, describes the conception of rehabilitee participation as dependent participation; that is, the rehabilitees perceive themselves as being unable to participate in their own rehabilitation process as much as they would like to. Within this category, the first theme of variation, **rehabilitation process**, manifested itself as *strenuous recovery*. The rehabilitees reported experiencing major challenges in their rehabilitation and expressed confusion over limited results or setbacks in their condition that prevented them from participating as desired. They found this hard to accept. The rehabilitees also reported trying to do their best and using determination to cope and participate in their rehabilitation.

“Physically, I’m doing relatively well, but my mental recovery has had a setback as I’ve been feeling a bit low and ... both my eyes have a left visual field deficiency ... I have to look for things and I can’t find them... And I often have to check things... I used to work with children in my parish, but not after what happened [cerebral haemorrhage]. I decided this after the doctor talked about everyday work [kindergarten nurse], which is pretty much the same, that the children make a lot of noise, and move about so much, and I don’t quite feel I could fully take care of them [the children]. It’s better to have people who are more present and more aware, so I’ve not gone back to that.” (R 3, p. 1, 11).

The second theme of variation, **rehabilitation in everyday life**, conveyed itself as a perceived *need for help in everyday tasks*, allowing rehabilitees to participate, at least on some level, in housework chores and daily activities. The rehabilitees reported how all the daily tasks and activities they had done before took more time or extra effort now or required help from a spouse. Due to this, some of the activities had thus been transferred to their spouses. Some of the rehabilitees explained that they felt irritated that they lost their former functional ability.

“...Practical things that we do in the family ... I’ve tried to do them ... but everything takes so much more damned time.... [Cooking] has now been passed on yes to (to the wife) ...I know what I’m doing, but it doesn’t turn into action like it used to automatically, yes, I can get things done, but each thing requires special consideration ... It’s an effort to empty the dishwasher and put things in their places ...” (R 4, p. 5, 8).

Some rehabilitees felt that they had not been treated properly in rehabilitation. Thus, the third theme of variation, **interaction in rehabilitation**, in this category, manifested itself as *unresponsive interaction*. Some of the rehabilitees reported that the rehabilitation professionals did not really listen to their problems, symptoms, preferences, or the goals that were important to them. The participants described this as confusing, and genuine interaction with the professional was lacking.

“I went to the health centre ... She [the physiotherapist] interviewed me for a while and said that “I’ve already read your details on the computer. You don’t have to explain anything,” she snapped at me immediately... I was supposed to keep pedalling, and she just put more [weights] on it. It was pointless. I said,

listen, I can't do anything with this [hand], otherwise the tendon will break, it hurts so much...” (R 20, p.1).

Lastly, the **rehabilitation support network** theme emerged as the rehabilitees' *reliance on support from their loved ones*. The rehabilitees perceived their loved ones as providing them with social support and enabling them to practise things.

“I mean, continuing with my aqua sprinting hobby, I've not been alone now, I usually always have my sister with me...” (R3, p. 11).

“The family helps me, so when at our cabin, because of my balance being poor, I didn't dare go alone, so there was always someone with me and we've had walks and then when I couldn't manage alone.” (R 2, p. 9).

Category II: Progressive participation

The second category manifests the rehabilitees' endeavour to play a more active role and participate in rehabilitation. Accordingly, the **rehabilitation process** theme in this category conveys an expanding awareness of the rehabilitee's own role in their *steady passage* during rehabilitation, which is only possible through self-motivated training. The rehabilitees described themselves as gradually adapting to their new, differently abled bodies, which had to be taken into consideration in daily training.

“The fact that I decided so firmly that I would be able to stand up again. Then, on the other hand, I also thought that I'm not disappointed that I'll never be a speed walker anymore, but that I can get about normally. I'm working so hard to achieve it and I really hope, and it's what I'm aiming for, that my right knee will get stronger when I do my physio exercises and when I get more rehabilitation.” (R 6, p. 11).

“Well, the rehabilitation was good back then... with one embolism. It felt pretty good. But when I got it on my other side, ... and then this third time. But even though I've had three blood clots, yes...willpower, if nothing else...” (R 9, p. 6).

The second theme, **rehabilitation in everyday life**, presented as the perceived significance of rehabilitation alongside everyday life. The rehabilitees themselves

spoke of all kinds of everyday household chores as a form of rehabilitation and believed participation was important for functional recovery and rehabilitation in general. They perceived participation in household chores as training alongside daily living, wherein all the training had to be on their own terms, as many activities and even simple tasks took longer than before their illness. In addition, they perceived participation in household chores as a means of functional training, as they involved a variety of movements and tasks that challenge different aspects of their functional abilities.

“Yes it [rehabilitation] has gone hand-in-hand with everyday life, and you can say that it’s accompanied it. Everyday routines have kept up the [rehabilitation] rhythm.” (R 1, p. 9).

... “The same practical things that we do in the family ... I’ve been trying to do them... everything is just so much damned slower.” (R 4, p. 5).

“I thought I’d start doing as much here at home as possible, just normal everyday activities. After all, housework is just normal. It’s all about reaching and lifting and placing things. I just feel I have to try, do my exercises and normal things. At the same time, I try to keep my mind alert.” (R 3, p. 12).

Within this category, the theme of **interaction in rehabilitation** manifested itself as *reinforcing interaction*. The rehabilitees reported that the professionals understood and asked what they wanted from the therapy, helping, motivating, and encouraging them to step outside their comfort zone. The rehabilitees perceived that training, with the help and support of their therapist, enabled them to do more demanding exercises and challenge themselves; for example, to walk longer distances and to take more responsibility for their own rehabilitation.

“Well, we practised that [stair climbing] at the health centre with a trainer... Although I knew to hold on to the railing, but we practised it so many times that I dared to let go [of the railing], and the fear kind of disappeared ... And [the physiotherapist] listened to all my wishes.” (R 2, p. 2, 8).

We’ve been, this occupational therapist was there for the first time with me and my sister, and she watched how I was in the water. At that point, it was still in

my left leg and it's probably still a bit slower than the right one, but the occupational therapist said she didn't notice any difference in the water. She said it was safer to have someone else in the water with me. Neither did I, and with the aqua sprinting, I don't know which is the bigger thing, the good feeling I get from the sprinting or the fact that I can talk to someone else. (R 3. p. 4).

The theme of **rehabilitation support network** in this category manifested as *support from others*. The rehabilitees reported receiving help from professionals and family members to continue rehabilitation through daily activities. The rehabilitees also emphasized how the support motivated and encouraged them to do exercises throughout the day.

"Well, yes, that personal assistant has been one reason [laughs] that you have to do [the daily activities] and go for a walk... Well, we try to at least when [the personal assistant] is here, then that's when. Three times a week, that's what happens when they're here... And well, when the girls come here, then we often go for a walk." (R 18, p.3-4).

Category III: Committed participation

In the third and hierarchically widest category, the rehabilitees understood participation in rehabilitation as a natural mode of action and as playing a committed and active role in the rehabilitation process, including decision-making. The first theme of variation in this category, the **rehabilitation process**, presented itself as an understanding of *generative progression*; perceiving daily activities as a set of varied and productive exercises that helped the rehabilitees proceed in their rehabilitation, even beyond their own expectations. The rehabilitees also highlighted the significance of exercise and of having a positive mind-set regarding rehabilitation and recovery.

"I've exceeded all my expectations...the rehabilitation went so well that I don't need any help anymore...It must have been the exercise in it [rehabilitation], an active mood brings vitality. You want to get better... Positive mind, ... I've been so happy every morning, firstly because I've recovered so well... I can do more and more, so having a positive mind has been essential." (R 2, p. 1,6, 9).

The second theme, **rehabilitation in everyday life**, conveyed the conception of a *natural mode of everyday actions*, according to which the everyday conditions for rehabilitation may sometimes be almost too active. This was the case, for example, for one rehabilitee who, after leaving hospital, was living in his old cottage which had no amenities such as electricity or tap water, so he had to fetch water from outside. The rehabilitees described all sorts of exercises related to daily living, including indoor and outdoor activities.

“Yes, I feel... that the (everyday chores) were intensive rehabilitation. ... A little too much. There (in my former home, there was no electricity) you could get such all-around exercise all the time.” (R 1, s. 2).

“These household chores... reaching and lifting and placing things... I've tried to exercise here at home, and I've taken those stairs... I just try, I try to do my exercises and I try to do ...” (R 6, p. 1).

“Clearing my yard of snow, mostly done... shovelling... that's exercise too.” (R 8, p. 4).

The theme of **interaction in rehabilitation** in this category manifested as a conception of *equal interaction* between rehabilitees and professionals. The rehabilitees described being listened to, valued, and being given the opportunity to participate in the rehabilitation decision-making; that is, their opinions were asked for, and alternatives and opportunities to influence rehabilitation and therapy were provided in different therapy sessions.

“...The occupational therapist says we could do this or that, or gives us alternatives, which we feel is best, or the most pleasant. I've been able to have my say. Or “what food would you like us to make?” and sometimes we went to the shop to get the ingredients, and sometimes I got the ingredients, or the therapist brought the ingredients... we did it in lots of ways... I got to think about ... what things I needed to practise.” (R 3, p. 3).

Finally, the **rehabilitation support network** theme in this category manifested as the perceived *significance of available aids* to support daily activities and independent living. The rehabilitees also highlighted self-confidence and courage and taking responsibility for their own rehabilitation and daily life.

“When I got the stove guard, I thought, surely, I can cook enough food, surely, I dare use the stove. And it helped a lot that we practised in occupational therapy... When I thought of how we practised cooking, I got more self-confidence, I dared do it. Yes, even without the stove guard, I dared do it using the timer.” (R 3, p. 9).

“I’ve been able to fully participate ... I had a cleaner, but I gave her the boot. I told her she doesn’t have to come anymore I can do my own cleaning perfectly well.” (R 2, p. 5).

“I’ve considered it self-evident that it’s my responsibility, in a way, and that I choose different sorts of equipment so that the exercises target different muscles and different things.” (R 4, p. 13).

Two steps of expanding awareness

Besides forming the three descriptive categories, we identified so-called “critical aspects” between the qualitatively varying conceptions. These aspects appeared “critical” for both grouping together and distinguishing the varying ways of understanding. They also appeared “critical” in the sense that what is required for moving from one way of understanding a phenomenon to another, towards a more complex understanding. Therefore, the identified two critical aspects can be considered as essential “steps” of expanding awareness of rehabilitee participation (Figure 2) and moving from one way of understanding the participation phenomenon to another. The first aspect as a “step” from Category I to II demonstrates a shift in the rehabilitees’ participation conception, from dependent to progressive participation, and experience of “expanding resilience”; that is, recognition of improvement in their own tolerance to participate in daily life. The second aspect as a “step” from Category II to III reflects

the rehabilitees' experience of “reinforced self-confidence and courage”; that is, recognition of strengthened trust in their own abilities and resources in rehabilitation and daily life.

Discussion

The aim of this phenomenographic study was to explore the qualitatively different ways of understanding rehabilitee participation as conceptualized by rehabilitees themselves. The phenomenographic analysis produced an outcome space reflecting the target phenomenon at a collective level; that is, a hierarchical structure of the rehabilitee participation conceptions from the narrowest to the widest.

According to the results of this study, the conception of rehabilitee participation, at the widest level, conveys rehabilitees' understanding of the target phenomenon as commitment to active participation in everyday life. This resonates with the ideas of the ecological paradigm (Vaz et al, 2017) and other approaches to rehabilitation and healthcare highlighting the significance of person- and patient-centredness (Sjöberg and Forsner, 2020; Thórarinsdóttir and Kristjánsson, 2014). The ecological paradigm provides a theoretical framework for a person-centred approach to rehabilitation; that is, seeing the rehabilitee as an active participant and decision-maker in their own rehabilitation process (Vaz et al, 2017; Cameron et al, 2018). In addition, the ecological paradigm also aligns with a broad understanding of rehabilitee participation, recognizing the significance of individual needs and environments of daily living and participation in society (Castro et al, 2016; Cott, 2004; Lakhan and Ekúndayò, 2013). These frameworks provide theoretical knowledge about the participation phenomenon. However, the findings of this study contribute to empirical knowledge and

understanding about rehabilitee participation as perceived by the rehabilitees themselves.

Our results on rehabilitee participation, as conceptualised by the rehabilitees themselves resonate with the findings of previous studies, emphasizing the perceived significance of mutual respect, collaboration, and shared decision-making, and the rehabilitees' knowledge and experiences to be appropriately acknowledged by the rehabilitation professionals (e.g., Cott, 2004; Hammel et al, 2008; Lindberg et al, 2013; Paukkonen et al, 2018; Thompson et al, 2021). Our findings also showed that the rehabilitees perceived themselves not always being listened to when talking about their problems, symptoms, goals, or therapy options important for themselves. Accordingly, the rehabilitees perceived that the professionals did not always have enough time for allowing the rehabilitees to participate in the process as they wished. In line with this, previous studies have highlighted that being included and respected as a unique, valuable individual, is a significant aspect of rehabilitee participation (Ekman et al, 2011; Erkmar, Ivanoff, and Lundberg, 2010; Mudge, Stretton, and Kayes, 2014). A significant finding of the present study is the outcome space reflecting the identified rehabilitee participation conceptions from the narrowest to the widest, and the observed critical differences between the conceptions. The two critical aspects identified among the categories of description were considered as essential "steps" in expanding awareness of rehabilitee participation. The first shift in understanding rehabilitee participation, which we observed as taking place between Categories I and II, illuminated rehabilitees strive towards a more active role in their rehabilitation process. However, some of the rehabilitees perceived their own limited recovery or setbacks as constraints to their participation. The second shift, which we identified between Categories II and III, conveyed conception of participation as a natural mode of action

and active role of the rehabilitees in their own rehabilitation processes, along with professionals and family members.

These results resonate with those of previous studies, in which rehabilitees have emphasized the importance of equal interaction between themselves and professionals and the opportunity to participate in and make decisions about their own rehabilitation process (Lindberg et al, 2013; Thôrarinsdóttir and Kristjánsson, 2014). In our study, some of the rehabilitees considered their expectations being met, when discussions with professionals had been open and involved mutual respect, and when the professionals had had time to really listen to them. This is also in agreement with the results of previous studies, in varying rehabilitation contexts (Ekman et al, 2011; Erkmar et al, 2010; Lindberg et al, 2013; Thôrarinsdóttir and Kristjánsson, 2014; Wikman and Fältholm, 2006).

The first shift described above reflects an expanding understanding of rehabilitee participation in terms of expanding resilience, highlighting a shift from dependent to progressive participation, and recognition of improved tolerance to participate in daily life. The conception of expanding resilience as such adds to previous health resilience literature, highlighting coping and adaption to acute health problems such as diagnosed chronic diseases (stroke, Parkinson's disease or spinal cord injury), chronic adversity, and constant disease pressure (Gallacher et al, 2012; Luo et al, 2019).

The second shift reflects an expanding understanding of rehabilitee participation in terms of reinforced self-confidence and courage, emphasizing a shift from progressive to committed participation and recognition of strengthened trust in one's own abilities and resources in rehabilitation and daily life. The conception of reinforced self-confidence and commitment to active participation resonates with previous research

emphasizing rehabilitees' motivation and participation in decision-making (Cott, 2004; Hammel et al, 2008; Lindberg et al, 2013; Paukkonen et al, 2018).

We also observed that the rehabilitees perceived motivation and encouragement from professionals and loved ones as significant for adapting to a life with limited recovery and participation, as also reported in earlier studies (Lindberg et al, 2013; Thompson et al, 2021; Wikman and Fältholm, 2006). Previous studies have shown that although healthcare professionals may value, respect, and support patient participation, they still need a better understanding of the rehabilitees' participation experiences and preferences, and how to implement participation into practice (Paukkonen et al, 2018; Thôrarinsdóttir and Kristjánsson, 2014). These findings add to empirical knowledge and understanding of rehabilitee participation, as perceived by the rehabilitees themselves. The findings as such can be useful in the development of rehabilitee participation and rehabilitee-centred practice, as well as rehabilitation professionals' understanding of rehabilitees.

The evidence in rehabilitation research shows that professional education may promote and improve rehabilitees' active participation in rehabilitation. Sipari et al, (2022) suggest that the enhancement of rehabilitee participation requires knowledge of participation methods, mutual collaboration and communication (Sipari et al, 2022). Shared decision-making built on partnership and mutual respect is key to open communication and participation (Castro et al, 2016; Thôrarinsdóttir and Kristjánsson, 2014). In our study, the conceptions of rehabilitee participation, as perceived by the rehabilitees, were manifested in three descriptive categories, conveying a hierarchy of ascending complexity; the structural relationships between the categories demonstrating a shift from dependent to progressive and committed participation, and enhancement of perceived resilience and self-confidence.

Recommendations for future practice

The results of this study can be used to deepen the understanding of the rehabilitee participation phenomenon, as conceptualised by rehabilitees. The critical aspects identified in this study can have significant implications for practice, for example in the design, development, and implementation of rehabilitee-centered practice. Secondly, the results indicate the significance of providing individually tailored support and decision-making opportunities to rehabilitees throughout the rehabilitation process.

Strengths and limitations

The strength of this qualitative, phenomenographic study, is that it presents new perspectives on participation conceptions, illuminating the hierarchical outcome space and ascending and shifting complexity of the phenomenon from dependent to progressive and committed participation. This can benefit development of rehabilitation practice towards a more rehabilitee-centred and participatory approach. The second strength of the study lies in the heterogeneity of its participants and the challenging nature of their rehabilitation. Thus, the study provides new information on participation conception from the perspective of rehabilitees in demanding rehabilitation. The third strength is that the results of the study are based on rehabilitees' experiences from the perspective of the rehabilitation process that has just ended.

This qualitative, context-limited study was conducted in a single health district of one Nordic country, which can be considered as a limitation. However, the participants formed a heterogeneous group with varying diagnosis, age, gender, and lengths of

hospital stay. Heterogeneity in a phenomenographic study is linked with participant variation, availability, and volunteering of participants. In addition, the variation was present in their experiences, which enabled identification of the qualitatively different ways of understanding the target phenomenon (cf. Åkerlind, 2005).

As a result of the phenomenographic analysis, the target phenomenon based on the hierarchical structure and relationships between the categories (cf. Marton and Pang, 2008, p. 537) were described systematically and transparently (Åkerlind, 2008). To increase trustworthiness of the results, authentic rehabilitee quotations were used comprehensively (Sin, 2010). The steps of the analysis were carried out systematically, and any discrepancies were critically discussed and solved within the research group. Furthermore, we followed the consolidated criteria for reporting qualitative research (COREQ) when designing and reporting the study (Tong, Sainsbury, and Craig, 2007). This was a context-limited study; therefore, the findings of the study may have transferability only to context-similar situations. However, the critical reader may find transferability of the findings to other cultural situations and contexts as well.

Conclusions

The study produced new insights into understanding the phenomenon of rehabilitee participation, as conceptualized by the rehabilitees themselves after a six-month rehabilitation period. The rehabilitee participation conceptions were manifested in three descriptive categories, reflecting the ascending and shifting complexity from dependent to progressive and committed participation. The two critical aspects of expanding resilience and reinforcement of self-confidence identified between the categories, were considered as essential steps in widening understanding of rehabilitee participation. As such, the descriptive categories and critical aspects may have significant implications

to practice; for example, in the design, development, and implementation of rehabilitee participation and rehabilitee-centred rehabilitation practice. Further research is required on the participation phenomenon in varying rehabilitation contexts, age-groups, and rehabilitees' medical conditions.

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Declaration of Conflicting Interest

No potential conflict of interest was reported by the author(s).

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Appendix 1. Themes of rehabilitee interviews.

Table 1. Sociodemographic characteristics of rehabilitees.

Figure 1. Process of phenomenographic data analysis.

Figure 2. Hierarchically widening categories and steps of expanding the awareness of rehabilitee participation as a phenomenon.

Table 2. Categories of understanding rehabilitee participation in rehabilitation: three categories, described via four themes of expanding awareness.

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