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Rehabilitees perspective on goal setting in rehabilitation – a phenomenological approach

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ABSTRACT

Purpose: Setting meaningful goals for the rehabilitation process after acute illness is essential for rehabilitees recovery. The aim of this study was to understand the meanings of the goal setting situation with professionals from rehabilitees point of view.

Method: We included 20 acute stroke and back pain rehabilitees (mean age 66 y) who set goals with a multidisciplinary rehabilitation team. Data was collected by interviewing the rehabilitees after the goal setting situations. A qualitative analysis from a phenomenological perspective using Spiegelberg's seven-phase meaning analysis was performed to reveal meanings.

Results: The five meanings were identified as: (i) "trust in the rehabilitation situation, professionals, oneself, and relatives;" (ii) "respectful presence;" (iii) "confusing awareness;" (iv) "disturbing pain;" and (v) "fear of unpredictability." When professionals committed to working in a patient-centred manner, the rehabilitees felt respected and they trusted professionals and thus their self-efficacy was empowered. Moreover, relatives were an important support in the situation. However, disturbing pain and fear of the future limited patients level of participation in the situation.

Conclusion: Rehabilitee commitment to rehabilitation can be supported with equality in communication and presence of relatives, while pain and uncertainty because of changed health limit participation in a goal setting situation.

Implications for Rehabilitation

- Multidisciplinary rehabilitation professionals should be recommended to support the active role of a patient in the goal setting situation.
- Relatives are recommended to participate in goal setting situation as they are an important support for rehabilitees.
- Professionals should be recommended to remove obstacles that restrain patient's participation in the goal setting situation.
- Professionals should be recommended to recognize patients with changed health and offer psychosocial support for those in need to improve their participation in rehabilitation process.

KEYWORDS Goal setting; phenomenology; meaning analysis; rehabilitation; client-centred; hospital

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Introduction

Human behaviour is goal-oriented and the aim of rehabilitation is to change this. Goal setting is an essential phase of current rehabilitation practice [1]. The process of identifying, prioritizing, and setting the appropriate goals for reha-

bilitees after acute illness can be strengthened if the goal setting discussion is performed in collaborative dialogue between a rehabilitee, professionals, and relatives [2,3]. Collaborative goal setting enhances a rehabilitee's motivation, adherence to rehabilitation instruction, and improves his/her satisfaction with the rehabilitation process [4,5]. In collaborative goal setting, rehabilitees participate in clinical decision-making about their care content and the modes of rehabilitation [1]. Indeed, the rehabilitation process supports the rehabilitee's "activity and participation" in the framework of the World Health Organization's International Classification of Functioning, Disability and Health (ICF) [6]. In ICF, participation includes the concept of individual and subjective experience of involvement *per se* and the ICF model emphasizes the dynamic interaction between the appropriate elements. For example, a rehabilitee with acute stroke cannot move out of bed and walk (functional limitation) or participate in work activities (disability). However, a successful rehabilitation process is to enable his/her social involvement (participation) with the surrounding environment and society [4].

The rehabilitee's active involvement in the goal setting process has recently arisen from the change from a professional-oriented to a client-centred approach in rehabilitation. The new paradigm emphasises empowering, which means that a rehabilitee has a better possibility to influence decisions related to his/her own health and rehabilitation. The essential part of a successful rehabilitation process is to find a change in the relationship between the rehabilitee and his/her environment and to see a rehabilitee as a strong, self-consciousness agent in interaction with different situations [7–9]. The client-centred approach is much more than the goal setting and decision making in the rehabilitation process between a rehabilitee and professionals; it is considered as a foundation of the rehabilitation service, taking account of the rehabilitee's individual needs [7]. Especially in neurological rehabilitation, goal setting is widely recommended to activate the rehabilitee's participation and improve the rehabilitees experience of the rehabilitation process in acute hospital care [10,11], but there is limited evidence for how to use goal setting tools in hospital settings [10].

There is indeed disagreement between earlier studies on how to best facilitate rehabilitees participation in the goal setting and how to combine client-centred, therapist-directed, and therapist-led approaches in a successful way [2]. In medicine, the client-centred approach shows the positive effects on different measures in relation to clarifying rehabilitees own concerns and beliefs when "the physician tries to enter the rehabilitees world, to see the illness through the rehabilitees eyes" [12,13]. The strategy that facilitates client-centred rehabilitation is to involve rehabilitees participation in goal setting [14]. Even though the goal setting and client-centred approaches are widely used in neurological rehabilitation, there is no consensus on the definition of a client-centred approach in general [1]. To date, the client-centred approach is recommended in rehabilitation and there is demand for the ecological paradigm [15,16]. The fundamental idea of the ecological paradigm focuses on the interaction of a rehabilitee's life course and his/her operational environment and the model signifies active participation, opportunities to influence, and consider the functioning environment of a rehabilitee [7,17]. However, there is evidence that the client-centred method has not yet been well adopted in hospitals [18]. A recent study revealed that a rehabilitee is often unclear about the meaning of goal setting and his/her role in the process [5]. The aim of this study was to understand rehabilitees meanings of participation in the goal setting situations.

Study method: phenomenological method

Phenomenology focuses on experiences and their meanings in real life, i.e., it is the understanding of social phenomena from an individual's own perspective, in Husserl's words: "back to the things themselves" and to use Spiegelberg's metaphors: "to the matters themselves", "seeing and listening" and "keeping the eyes open" [19]. The basic philosophy of phenomenology is the oneness of humanity and the goal is to achieve an investigation of essences by shifting from describing separate phenomena to searching for their common essence [19]. Spiegelberg's phenomenological method includes steps in describing the phenomenon, investigation of its essences and phenomenological reduction. Phenomenological reduction is applicable to any qualitative health research that works with human beings [20].

Spiegelberg's method emphasises systemic progress to guarantee the credibility and validity of the study analysis [20]. The researcher must assume scientific discipline and show sensitivity in detecting the phenomena of interest [19]. In this study, Spiegelberg's seven-phase meaning analysis method was applied to determine the essential meanings of rehabilitees participation in goal setting for the following reasons: a) Spiegelberg's method searches for the meaning, b) phenomenological reduction "brackets" the phenomena to achieve an unprejudiced description of the essence of the

goal setting, and c) the aim of Spiegelberg's phenomenology is to describe the structure of the essential meanings, putting aside the previous knowledge of participation [19,20].

Participants

The study is a qualitative research project funded by the Social Insurance Institution of Finland. All together 20 rehabilitees from Department of Demanding care at Central Hospital of Central Finland took part in the study. They were recruited according to inclusion criteria, which were: (a) willing to participate in the study during the hospital stay and after returning home and (b) the rehabilitee had the ability to return home and manage to live at home either with or without support. The exclusion criteria were: (a) the rehabilitee had substantial decline of cognitive ability (Mini-Mental State Examination-scale, MMSE 20/30 or less), (b) the rehabilitee had severe depression (Beck's Depression Index, BDI-II 30/63 or more), and (c) the rehabilitees had difficulties to express themselves because of aphasia. The study rehabilitees were first informed about the study by a nurse and second asked whether they were interested in participating. Then the researcher checked the inclusion and exclusion criteria and rehabilitees gave their informed consent. All rehabilitees obtained detailed information on the study before signing the informed consent. The rehabilitees were volunteers. The study received ethical approval from Hospital District Ethics Committee (Central District code 3E/2014, 24 June 2014).

The mean age of study rehabilitees was 66 y (ranging from 50–79) and 65% of them were men. Most of the rehabilitees had had a stroke (13/20), four of them had suffered from musculoskeletal problems, and three from other diseases (tetraplegia, pancreatitis, and arteriovenous malformation). One of the rehabilitees was unemployed; six were on sick leave; and 13 retired from work. Nine of the rehabilitees used walking aids and/or other general aids (Table 1).

Table 1. The sociodemographic characteristics of the rehabilitees. Table Layout

Rehabilitee	Gender F/M	Age	Housing		Work status			Diagnose
			Alone	With spouse/ children	Work/ unemployed	Retired	Other/ disability pension	
1	M	50	x		x			ICH
2	F	54		x			x	Pancreatitis
3	F	57	x				x	Arteriovenous malformation
4	M	79		x			x	ICH
5	M	75		x		x		Stroke
6	F	66	x				x	Myelopathy
7	F	51		x			x	ICH
8	M	60		x				ICH
9	M	72		x		x		Stroke
10	F	78	x			x		Condition degradation
11	M	70	x			x		ICH
12	M	75		x	x		x	Stroke
13	M	78	x		x			Stroke
14	M	63		x		x		Stroke
15	M	54		x		x		Stroke
16	M	74		x		x		Back ossify
17	M	61		x	x			Stroke
18	F	59	x		x			Stroke
19	M	75		x	x			Tetraplegia

ICH: intracranial hemorrhage. cranial hemorrhage.

Rehabitee	Gender F/M	Age	Housing		Work status			Diagnose
			Alone	With spouse/ children	Work/ unemployed	Retired	Other/disability pension	
20	F	62		x	x			Stenosis canalis lum- balis

ICH: intracranial hemorrhage. cranial hemorrhage.

Procedure

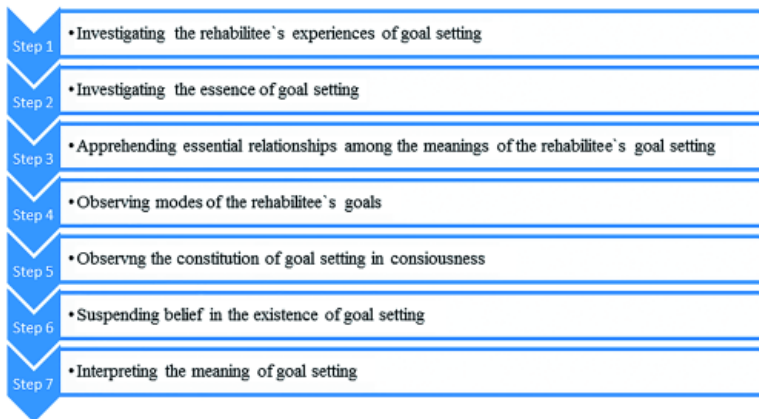
The first author observed the goal setting situation, which was conducted using the goal attainment scale method [21]. Each rehabilitee set one goal with the multidisciplinary team for the six-month rehabilitation period. After the goal setting situations, the data were collected by the first author (TA) via semi-structured interviews and open-ended questions individually with each participant in the negotiating room of the hospital from May to December 2015.

The interviews were as open as possible allowing the rehabilitees to describe their experiences of participation in the goal setting situation. The interview began with an open question: "Please tell me about your experiences, views and opinions of your participation in the goal setting situation?" The interview continued with the rehabilitee's own descriptions. The interviews of rehabilitees lasted on average for 26 min (range 11–48 min) and the transcribed data consisted of 136 pages.

Data analysis

The study data were analysed using Spiegelberg's phenomenological seven-phase method (Figure 1). The data analysis was done systematically to increase the credibility and validity of the study according to the process where the previous step was clarified before the next step [22]. The data consisted of a description of each rehabilitee's experiences, meaning perspectives, and synthesis of the systematically proceeding goal setting situation, based on the phenomenological method of Spiegelberg [22,23] which is described below:

Figure 1. The meaning analysis using Spiegelberg's seven-phase phenomenological meaning analysis.



1. The first author (TA) read all (20) the rehabilitees transcribed individual interviews several times and wrote a precise description of each rehabilitee's perspectives on their experiences in goal setting [22,20]. The researcher analysed her scientific prejudice with regard to the topic of the goal setting and wrote down her presumptions in order to recognize them. A phenomenological description consists of intuition and analysis of goal setting.
2. In the second step, the first author investigated the interviews to identify the meaning units of goal setting from each rehabilitee's transcription using their own words or expressions as they were. The purpose was to find the essential individual meaning units for goal setting. Subjective meaning units

could include a few words or a sentence and they were noted every time a rehabilitee indicated that she/he experienced participation in the goal setting situation.

3. In the third step, the first author examined the essential relationships of each rehabilitee's subjective meanings in the goal setting situation.
4. Next, the researcher combined the individual meaning perspectives as a phenomenon of goal setting based on the analysis. The researcher then described the essence of the goal setting.
5. Each rehabilitee's individual mode of participation in the goal setting was observed, and meaning units with related content were established to create meaning perspectives on goal setting. The meaning units mentioned by each rehabilitee in describing the goal of rehabilitation were related to each other, thus forming the individual meaning perspective for each rehabilitee.
6. Each rehabilitee's essential relations of meaning constituted a personal meaning network of conscious goal setting. The most essential meanings were those which opened up the perspective on the phenomenon. The other meanings were identified and grouped appropriately with each other. The most important of them for the rehabilitees was given primary status and the others were placed below it, showing how they were related with each other. The value of each meaning was determined by the description of the rehabilitee's meanings and how the rehabilitee related it to the other meanings.
7. In the synthesis, the definition of the essential meanings of goal setting was determined. In this phase, the interpretations proceed from individual to generalised intuition, analysis, and description, where the meanings contain tacit knowledge and unconscious knowledge from only one or several of the rehabilitees.

Phases one to three of the meaning analysis were performed by the first author. Phases four to seven were performed with the help of the research team.

Results

In this study, the goal attainment scale method was used in goal setting and each rehabilitee set one goal with the multidisciplinary team for the six-month rehabilitation period [4]. The meanings of the participation in the goal setting situation experienced by the rehabilitee were as follows: "trusting the rehabilitation situation" linked with the meanings "trusting professionals, oneself, and relatives," "respectful presence," "confusing awareness," "disturbing pain," and "fear of unpredictability." The most significant meaning "trusting the rehabilitation situation" included the meanings "trusting professionals" and "trusting oneself," and "trusting relatives" as seen in Figure 2. Above is the perspective from which the goal setting meaning perspective opens up and should be read (Figure 2). All meanings were connected to each other, forming interconnected triangles. The most valuable meaning "respectful presence" on the right proved to be the most significant of the rehabilitee's meaning units. The value of meanings was determined from each rehabilitee's individual meaning units and the synthesis of all rehabilitees meaning perspectives.

Figure 2. The structure of "meaning perspective of goal setting."



Trusting rehabilitation

Trusting rehabilitation was the most essential meaning of a rehabilitee's participation in goal setting on an individual level. Trusting in rehabilitation meant a lot to each of the rehabilitees but it also meant quite different things. Some of the rehabilitees were actively involved in defining their status quo, needs, beliefs, and set their goals based on their concerns, such as important daily activities and did not want help from professionals in decision-making about their own goals, while others were more dependent on the help and guidance of professionals in decision-making on goal setting. The meaning including "trusting in professionals, in oneself, and in relatives" influenced the goal setting process in different ways on an individual level.

Trusting in professionals

The rehabilitees explained that they trusted in professionals and their expertise in goal setting when identifying, naming, choosing an indicator, and setting a scale for meaningful goals. The rehabilitees experienced that professionals helped them to describe the status quo, name, and choose the meaningful, correct, and appropriate goal for rehabilitation so that rehabilitees could attain the goal in six months' time. Rehabilitees expressed that they got emotional support from the professionals as they received advice and encouragement. They also felt that professionals considered that their emotional needs, wishes, beliefs, and their experience and knowledge were recognised and their decisions were respected. Effective emotional support-maintained rehabilitees hope. Rehabilitees agreed that the help from professionals was important in becoming acquainted with the goal attainment scale method. The importance of goal setting expressed by the rehabilitees is exemplified in statements such as:

(Goal setting discussion). It was because of the shared situation, with us gathered together here and I got a lot of strength from every one of them (professionals) and I felt that was a good thing. (CH 6, p. 2)

Some of the rehabilitees interviews displayed the trust in a professional's goal setting competence:

(Goal setting). In the beginning it was of course a little difficult when I didn't know how to get things going and move forward, before then, with help, the whole thing became clear. Yes, it's just logical thinking. This is the way it should go after all. Break. Yes, these professionals helped. They could put my thoughts into words. (HC 19, p. 3)

Critical perspectives were also found the rehabilitees interviews in cases where the rehabilitee and professionals had different perspectives on goals, such as:

(Decision making). There was nothing, but I couldn't make up my mind, there were a few too many concerns (the patient's own concerns). I couldn't keep up. (HC 13, p. 1)

Rehabilitees trusted themselves

The rehabilitees trusted themselves when setting their goals and had the confidence and self-efficacy to attain their goals. They said they use their own help and coping strategies and try their best, focusing on training in all daily activities. Rehabilitees believed in their inherent dignity and autonomy in decision-making. The importance of goal setting was expressed by the rehabilitees, for example, as follows:

(Goal attaining). I really must believe in myself. (HC 7, p. 4)

When I attain the goal, everything else is resolved too. And my condition changes all the time, today I can do this and tomorrow I can do something else. (HC 7, p. 5)

One rehabilitee refused therapy because he believed in his self-regulation, trusted his own coping strategies, trying, and trained so much that he did not feel he needed any therapy at all. He expressed his ideas as follows:

(Therapy). Perhaps I don't necessarily need it. I get quite enough practical exercise at home, maybe almost too much. By the way, I walk with Nordic poles and am getting used to these old routines of mine. Later, I can ask for therapy if I need it. That's my opinion. It's much better if I can slowly follow how I cope at home and if I feel I'm not coping then I could (contact the professionals). When you're at home, you feel a lot better mentally. It's different in a place like this. (HC 1, p. 4)

Rehabilitees trusted relatives

In this study, 10 relatives of rehabilitees had the opportunity to participate in the goal setting situation in hospital. All rehabilitees experienced that they trusted in their relatives emotional and informational support, encouragement, and concrete help in the goal setting situation. They were also worried about the lack of relatives support. The rehabilitees were not so satisfied with the relative's participation because the relative argued about the goal and scaled indicators for the rehabilitee and the rehabilitee was also worried about the relative's future ongoing support at home. This was because they thought that relatives would restrict their autonomy by being overprotective and paternalistic (deciding for the rehabilitee). They were afraid they would have to constantly fight about what they are capable of and should be doing and the relative could control them and not let them actively perform all the daily activities they wanted to. In most situations, the rehabilitees trusted in the relatives to participate in goal setting and let them express their ideas about meaningful goals and the environmental circumstances at home.

The relative had, in a way, a strengthening effect, so I reckon that was good (when she said things to encourage me) (in the goal setting discussion) and I liked her to be there with me. (HC 6, p. 5)

Rehabilitees also felt that the relative's participation conflicted with the goal setting discussion rather than strengthening it. This is because the relative was not satisfied with the goals set for the rehabilitee.

(In goal setting discussion). My relative is against everything, just like always, but of course she's often right, but first she's not in favour of anything at all, but then when she thinks about it for a bit, just like now, first she didn't accept the goal but then she did anyway. (HC 9, p.7)

Respectful presence

The rehabilitees experienced respectful presence in all goal setting situations. They experienced that they were being valued, respected and that they were listened to. Rehabilitees said that the interaction with professionals was open and equal and they felt they could participate in the decision making to set their own meaningful goals for the next six months.

I was shown respect, I was listened to and was treated as a human being. Just the order we sat down round the table, that also had meaning for me. (HC 7, p. 2)

In this study, trust in professionals was noticeable in older rehabilitees (over 70 y). They felt their role to be more that of a patient, implying subordinate behaviour in participation in goal setting, and handed the responsibility to the professionals. They felt that the professionals have a better knowledge of the scaling levels and wanted plenty of help from the professionals.

Confusing awareness

Confusing awareness was seen in the beginning of the goal setting situation with rehabilitees feeling nervousness and confusion in expressing their perceptions and finding it difficult to understand the questions professionals asked them. They experienced difficulties in perceiving the status quo, telling their own opinions and thoughts in identifying their own goals, and participating in the decision making in the goal setting situation.

(Goal setting situation). It's the feeling of nervousness and the nervousness goes deeper than this situation, after all it's quite a lot to do with the sort of human being you are. (HC 9. p. 3)

(What helped you to find the meaningful goal?) You (professional) have some difficult questions. I'd say the professionals (know the scaling and) helped. (HC 5, p. 3)

Disturbing pain

Disturbing pain was a complex phenomenon in the goal setting situation as long as the rehabilitees had difficulty in fully concentrating on the goal setting discussion. The rehabilitee found it difficult to sit in a wheelchair because of the pain and wanted to speed up the goal setting. The rehabilitee had fallen in the hospital a few days before the goal setting situation. She was also afraid that pain could lead to her losing her independence and she was disappointed with being dependent on others care. The falling accident postponed her hospital discharge until a week later, which was one reason she was disappointed. The rehabilitee felt that she needed information on different types of aids to support her function at home and advice on where to get the aids. Another rehabilitee had pain because of the original disease, which decreased his function and made aids necessary, which was an unpleasant thought for him.

Now at least, when I'm so sick, I can't think about anything else in the future or after that. The one and only place when I don't have pain is when I am lying on my back in bed. (HC 10, p. 1)

In the shop, I always lean on the shopping trolley to get support, when my back is aching. (HC 11, p. 6)

Fear of unpredictability

Fear of unpredictability is a phenomenon which is connected to serious illnesses like stroke and the unpredictable course and possibility of the illness worsening are frightening. The rehabilitees who had an earlier stroke felt afraid of new attacks or the worsening of the illness and they expressed uncertainty about the prognosis for the disorder in the future. Moreover, older rehabilitees felt concern about loss of health and being able to go back home while younger rehabilitees experienced fear of going back to work and how to manage at work. In addition, their relatives had the same fear.

I don't want to say no when the professionals ask me to exercise, because if I don't, it'll turn out badly, or I could stop moving. I have my doubts about how the stroke will turn out, if the recovery goes as well as it is now, I think everything will be ok. I don't have any wish to say no; if you say no it could go badly, and if you stop exercising. (HC 9, p. 4)

In the beginning, I thought that I would go back to work, but now I'm not so sure. I still have five years until retirement; I am nearly 60 years of age. (HC 3, p. 13)

Discussion

In this study, we shed light on rehabilitees meanings of participation in goal setting and we found five important meanings: (i) "trust in the rehabilitation situation, professionals, oneself, and relatives;" (ii) "respectful presence;" (iii) "confusing awareness;" (iv) "disturbing pain;" and (v) "fear of unpredictability." The ecological paradigm of the phenomenological method used in this study revealed that the rehabilitees own voice was heard and for the first time the rehabilitees experienced that they were at the centre of the goal setting situation with the multidisciplinary team. Similarly, Cott et al. [7] highlighted the question of the rehabilitees voice and how it is discoursed in client-centred rehabilitation. Likewise, our findings indicate, that the philosophy of the client-centred method used by professionals refers to rehabilitees participation in the goal setting situation in partnership with professionals who understand and respect rehabilitees individual needs. This means active continuous equality in communication. However, as far as we know, there are a few qualitative studies of rehabilitees experiences in goal setting [1,5,7,18], but the phenomenological perspective on rehabilitees meanings of goal setting in hospital rehabilitation is missing.

The results of this study revealed that there are many meanings of the rehabilitees which had to be recognized in goal setting situations to enhance the rehabilitees participation in goal setting. The main and essential meanings for rehabilitees was trust in the rehabilitation situation, which was related to all of the rehabilitees other meanings and was the key factor when considering whether rehabilitees saw the goal-setting situation trustworthy. The rehabilitee's essential meanings of participation were the professionals attentiveness towards the rehabilitees, showing emotional support, i.e., empathy, and they gave advice, encouraged the rehabilitees, and were committed to their work in a client-centred manner. Rehabilitees trusted the professionals expertise in the goal setting situation, when utilising the goal attainment scale method, even though the professionals were unsure how the scaling using the method should be performed, especially at the outset of the study. The results also indicate that age can influence the goal setting situation, with elderly patients showing a higher level of trust in the professionals and younger ones trusting themselves and relatives and participating more actively in the goal setting situation. Why is this so? It remains an unanswered question. One explanation would be that older rehabilitees assume a subordinate role in the hospital environment which made them expect to be taken care of [24].

One finding of this study was the rehabilitee's essential meaning of having trust in him/herself meant the self-reliance to perform meaningful activities of daily living each day that are essential to maintaining dignity and self-determination. The rehabilitees felt that they used their autonomy in decision-making when setting the rehabilitation goal and defined their own goals and believed in their own individual capabilities to organize and carry out the course of action required to attain the goal and refused the help, aids, or therapy professionals proposed to them. Likewise, earlier studies have indicated that participation in goal setting has enhanced patients autonomy, improved their decision-making, activated

patients responsibility, and empowered them in the goal setting and they indicate that patients prefer to participate in the goal setting [11,25,26]. The open-minded attitude of professionals, collaborative dialogue and shared decision-making among health professionals facilitated the rehabilitee's autonomy in goal setting.

This study also revealed that rehabilitees felt some disappointment with professionals actions concerning goal setting. There were differences in the perspectives of rehabilitees and professionals and disagreement on realistic and achievable goals. The rehabilitees wanted to set large-scale and far-reaching goals, whereas the professionals and relatives preferred shorter term goals which were more achievable for rehabilitation interventions. Similar findings were found in previous studies where poor collaboration between a patient and professionals involved persuasion from the professionals side and where there were differences between the rehabilitee and professionals in perceptions of goal setting; rehabilitees thought in a more general way, i.e., functional goals for a longer period, while professionals identified goals for shorter term impairment problems [27,28] with the rehabilitee often not knowing his/her role in the goal setting [5].

The result of this study indicates that all rehabilitees experienced trust in their relatives emotional, informational support, encouragement, and concrete help in the goal setting situation. Nevertheless, there were also rehabilitees who had contradictory feelings towards their relatives participation in the goal setting situation because the relatives restricted the rehabilitees autonomy. Similar findings emerged from other studies indicating that instrumental support, such as home-visits at weekends and rebuilding the rehabilitee's home and emotional support, facilitated rehabilitee's autonomy [29]. In this study, the relatives generated tension between rehabilitee and relatives during the goal setting situation. The study of Brown et al. [1] indicates that relatives need more information on stroke recovery, care, medication, rehabilitation, and support as well as needing to be more involved in goal setting.

This study revealed the importance of respectful presence as a key meaning of the goal setting situation, related to trust in the rehabilitation situation and to confusing awareness. The rehabilitees felt that they were valued, respected, and listened to. The interaction between rehabilitees and professionals was open and equal and rehabilitees felt they could participate in the decision making related to their own, meaningful goals for rehabilitation. Similar findings on participation have been found in other studies, where the most important aspects of participation were valuing and respect, open, equal communication with partnership, and support for the rehabilitee's full participation in goal setting and also with the rehabilitee's individual needs being taken into consideration [7,30].

The results showed that one essential meaning for rehabilitees was confusing awareness because of significant cognitive impairment, which was strongly related to trust in professionals and moderately related to disturbing pain. In this study, rehabilitees readiness and need for help in setting goals varied and they experienced difficulties expressing their own thoughts and perspectives without guidance. In the beginning, the rehabilitees had difficulties understanding the procedure of goal setting, with a lack of knowledge or understanding of the consequences of a stroke and a lack of readiness to set goals. Professionals supported rehabilitees and helped them to recognize the recently acquired impairment and let them express their individual needs and wishes. After receiving information about the previous points, the rehabilitees felt they were more capable of setting goals and they used graded decision making to name the meaningful goals for rehabilitation. Consequently, all rehabilitees could set realistic goals with the help of professionals. Again, the results are consistent with other studies highlighting the difficulties that patients have in setting goals, when patients lack the skills or they were not ready to set goals in the acute phase of severe illness [3,7]. The systematic review of Sugavanam et al. [5] concluded that communication and cognitive impairments were seen as the main barriers to stroke patients participation in goal setting, even without communication problems.

We found that disturbing physical pain was an important meaning perspective in restricting rehabilitees participation in the goal setting situation. The meaning perspective of pain was related to trust in the rehabilitation situation and fear of unpredictability. The rehabilitees experienced subjective pain and pain was strongly present in disturbing rehabilitees concentration on goal setting situations. Pain is an unpleasant, unwanted, distressing experience, and subjective sensation not inaccessible and indemonstrable to outsiders, and it is hard to explain to or share to anyone else [31,32]. Pain is not perceived to be present in the goal setting situation, but if it is, professionals should understand the implications of a rehabilitee's pain and this requires open face-to-face dialogue and listening to him/her responsively. In the case of intense pain, the goal setting situation should be rescheduled to another time in a more suitable and pain-free situation for the rehabilitee. Rehabilitees described how the physical pain affected their emotions, identity, and independent locomotion and they were afraid of how pain would affect their independence in all daily activities, ability to exercise at home. and participate in social activities in the future. This finding is in line with other studies where the participants claim emotional reactions to be the consequences of physical pain [33]. The rehabilitees wondered what kind of assis-

tance they would need from relatives and society to be able to cope at home and they felt themselves to be a burden to relatives. The study by Ojala et al. [34] found a phenomenological interpretation of the subjective meaning of pain.

Our study also demonstrated the importance of the meaning of rehabilitees fear of unpredictability because of severe acute disease. The meaning perspective of unpredictability was related to trust in the rehabilitation situation and disturbing pain. The rehabilitees experienced fear differently; some found uncertainty depressing and causing concern about a future prognosis, for example feeling a threat associated with the fear of having another stroke. These had an impact on goal setting: the goals were cautiously small and more achievable rather than broad and ambitious. Moreover, rehabilitees with changes in their health continued to participate in some goal setting situations, but others had to turn to professionals because of their uncertainty. Previous studies have shown similar findings, namely that severe illness has psychological consequences such as fear of another recurrent stroke or rapidly progressing illness and deterioration of motor function [35,36]. To diminish the feeling of fear, the rehabilitees and relatives need ample information about stroke pathology, the recovery prognosis and rehabilitation process, and encouragement to build up their confidence, even though they understood that a full recovery was unlikely [1].

Strengths and limitations

The main strength of this study is that we clarified a holistic comprehension of meanings of rehabilitees in the goal setting situation. Another strength is the multidisciplinary team that formed the meaning perspectives of goal setting and the researchers systematic analysis of Spiegelberg's method that provided validity to the results. To ensure quality of reported findings, we utilized a 32-item-checklist of Tong et al.'s study [37] in our analysis. The results are unique in this sample size and the results may be repeated with another study in other acute phase rehabilitation with rehabilitees in a hospital setting. In terms of sample size, we observed that the data saturation reached after the thirteenth rehabilitee, and thus the data thereafter did not bring out more meaning units – it only described the phenomena more thoroughly. Nevertheless, further studies are needed to determine applicability to other rehabilitee populations (i.e., children or youth with neurological diseases). Indeed, the limitations of this study include the general limitation of qualitative studies – our study was conducted in one Health Care District in Finland, i.e., in one country. The rehabilitee population we used in this study reflected the specialized demanding rehabilitation services, mostly neurological rehabilitees. The disadvantages include the professionals or relatives potential influence on the rehabilitee in goal setting, especially in situations where relatives and professionals had a different goal priority than the rehabilitee him/herself. This was not examined thoroughly in this study but should be in the future. We suggest this is an eidetic meaning of “meaning perspective of goal setting” (Figure 2) and the researchers systematic analysis gave credibility to the results. Many of the rehabilitees experienced that they were at the centre of the goal setting situation and were listened to intensively for the first time in hospital. This could have influenced some meaning perspectives and somewhat exaggerated their significance.

Trustworthiness of the study

A descriptive phenomenological method is a valid method to explore the real meaning perspective of the experience [20]. In phenomenological meaning analysis, the researchers bracketed their previous knowledge and prejudices about participation in goal setting aside and described the meaning perspectives of the meaning of participation in goal setting as it presented itself to the rehabilitees. Spiegelberg's idea of bracketing goes further: it is not only bracketing, liberating from prejudice and previous knowledge, but it also considers genuine intuition, analysis, and description [20]. Phenomenology unites science and lifespan and attaches importance to contextualised descriptions based on meanings of experience and tries to turn to “the things themselves” and “the matters themselves,” freeing itself from pre-existing prejudices [220].

Conclusion

The results indicate both rehabilitees supportive and restricting meanings of participation in goal setting situations. When rehabilitees are supported with equality in communication and presence of relatives, they commit to rehabilitation, while pain and uncertainty because of changed health restrict participation in the goal setting situation. Equality in communication was expressed as rehabilitees trust in goal setting situations, which appeared to be supported with a client-centred approach as a new way of performing goal setting practice. A client-centred approach can facilitate rehabilitees motivation and engagement in goal setting, which may support achieving successful rehabilitation goals.

Professionals need training in client-centred and in how to involve relatives in sharing information and participating more actively in goal setting.

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Disclosure statement

The authors report no declaration of interest.

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