



ORIGINAL ARTICLE

From open to locked doors – From dependent to independent: Patient narratives of participation in their rehabilitation processes

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Funding information

Funding for this study was provided by Norwegian University of Science and Technology. The funding body did not in any way influence the study design, data collection, analysis or manuscript writing and submission

Abstract

Aims and objectives: The present study aimed to explore patients' experiences of participating in their rehabilitation process in the context of specialised rehabilitation in Norway.

Background: The rights of patients to participate in their care and treatment is an ideology that underlines newer international and Norwegian public documents. However, there is a gap between policy statements and clinical practice, and a discrepancy between patients' and professionals' statements about patient participation in rehabilitation.

Design: A qualitative approach with a narrative design.

Methods: Eleven patients were individually interviewed to tell their stories about the rehabilitation processes. We utilised narrative analysis with a three-dimensional space narrative structure including temporality, sociality and spatiality. This study followed the COREQ checklist.

Results: The analysis identified two throughout plots: 'person-centred culture' and 'time', and three plots which constructed how the patients participate in change through the rehabilitation process: (a) dependent—'open doors'; (b) motivation from within; and (c) independence—'locked doors'.

Conclusions: Patient participation in rehabilitation was dependent on person-centred cultures in the unit and on different aspects of time. The dialogue and the power balance between the patients and the health personnel changed as the rehabilitation progressed. Motivation for rehabilitation had to come from within patients. The paternalistic ideology did not seem to dominate the specialised rehabilitation unit in the present study.

Relevance to clinical practice: This study gives new insight into how patients participate in change in the rehabilitation process. This can be valuable for healthcare professionals and governments. Insight into how the lack of person-centred focus can harm the rehabilitation process, and a deeper understanding of the meaning of time in

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the rehabilitation process is essential. These results may provide a stimulus for discussions on how patients might participate in their rehabilitation process.

KEYWORDS

motivation, narrative analysis, Norway, patient participation, person-centred care, rehabilitation, specialised rehabilitation unit, time

What does this paper contribute to the wider global clinical community?

- Health personal engagement in patient as persons
- The study highlights 'time' as a core aspect of patient participation in rehabilitation
- The study shows how the power order between the patient and the health personnel change throughout the rehabilitation process.

1 | INTRODUCTION

In newer international public documents (World Health Organization Europe, 2017) and in Norwegian law (Ministry of Health & Care Services, 1999), the rights of patients to participate, influence and make personal choices are laid out. Patient participation is regarded as a prerequisite for good quality care, treatment and rehabilitation (Castro et al., 2016; Stacey et al., 2017). However, paternalistic ideology, in which patients are assumed to comply and play minimal and passive roles, has traditionally dominated health care (Beauchamp & Childres, 2019). This viewpoint still seems to be present in the legal text (Aasen & Dahl, 2018) of information given to patients (Aasen et al., 2020), in care and treatments (Aasen, 2015), and in guidelines for user involvement in research (Stuhlfauth et al., 2020). This study focuses on patient experiences of participation in specialised rehabilitation.

The definition of specialised rehabilitation in 'The White Book on Physical and Rehabilitation Medicine in Europe' has evolved from measures given by the rehabilitation team with a focus on work tasks to promoting the patient's function (Negrini & Ceravolo, 2008), focusing on the patient's wishes and prioritising measures where the patient actively collaborates and sets their own goals (Negrini, 2018). In Norway, there seems to be a struggle between discourse of rehabilitation as a clinical practice based on traditional medical science and rehabilitation as a management practice. In management practice, the individuals should have more responsibility for their own health and wellbeing, whereby the patients experience shorter stays in the hospital and greater productivity; thus, the welfare state bears lower costs (Røberg et al., 2017).

2 | BACKGROUND

The United Nations (Commission in Human Rights, 1994) stated that rehabilitation is one of the most important interventions to enable persons with disabilities to attain and maintain maximal independence, full physical, mental, social, and vocational ability and full inclusion and participation in all aspects of life. Rehabilitation is a human

right. The training of highly qualified rehabilitation professionals is key to contributing to the convention's goals. The International Classification of Functioning, Disability and Health (ICF) is the World Health Organization's framework for measuring health and disability at both individual and population levels (World Health Organization, 2001). The ICF has standardised functional areas like cognition, language, mobility and mental functioning (Kostanjsek, 2011; Stucki et al., 2007). This standardised framework is also used as a tool in goal setting in specialised rehabilitation in Norway (Norsk forening for fysikalsk medisin og rehabilitering, 2012). Interventions and programmes are always patient-centred, and outcomes include functioning and personalised dimensions (Negrini, 2018). When professionals are committed to working in a patient-centred manner, the rehabilitees feel respected and are able to trust the professionals, and thus, their self-efficacy is increased (Alanko et al., 2019).

The World Health Organization has promoted a person-centred approach, with a global goal of humanising health care by ensuring that it is rooted in universal principles of human rights and dignity, non-discrimination, participation and empowerment, access and equity, and partnership of equals (McCormack et al., 2015). However, it is important to stress that person-centred practice does not mean to discard the medical and physical goals of patient-centred care (McCormack et al., 2015). To achieve the change from patient-centred care to person-centred care requires us to shift focus, from ensuring a functional life to a meaningful life for the patient (Eklund et al., 2019). Person-centred care is promoted as good practice in rehabilitation because it provides a framework for attending to the personhood of all people engaged in clinical encounters (Gibson et al., 2020). However, true person-centred care does not seem to be fully implemented in rehabilitation practices (Yun & Choi, 2019).

The concept of patient participation and similar concepts like patient engagement and patient involvement have been discussed for several years; yet, the differences between the concepts and their definitions are not distinct in the literature (Halabi et al., 2019). However, patient engagement is often used in rehabilitation (Bright et al., 2015). Melin's (2018) concept analysis of patient participation in physical medicine and rehabilitation defined three attributes: active patients, engagement and exchange between both patient and

health personnel, and a focus on and respect for the patient's conditions, needs, desires, and preferences.

The present study uses Aasen et al.'s (2012b) operationalisation and definition of patient participation: a process of power exchange between the patient and the healthcare team. Participation does not necessarily require shared decision-making, but rather a dialogue with shared information and knowledge, and mutual engagement in intellectual and physical activities influenced by the context (Aasen et al., 2012a), a dynamic process emphasising the person as a whole (Kvael et al., 2019).

Autonomy and empowerment are related concepts. Autonomy is the right for one to make their own decisions, excluding any interference from others. Two general conditions are essential for autonomy: *liberty*, independence from controlling influences and *agency*, capacity for intentional action (Beauchamp & Childres, 2019). Patient empowerment is mostly perceived as the patient's acquisition of motivation, abilities and power in the healthcare relationship. Hence, patient empowerment can be included as a dimension of the concept of patient participation (Halabi et al., 2019).

Within rehabilitation, goal-setting meetings are suggested as key forums for patient participation, so that patients and professionals can collaboratively set rehabilitation goals (Rose et al., 2018; Cameron et al., 2018; Holliday et al., 2007; Rose et al., 2017) and participate in clinical decision-making, indicating positive outcomes (Horton et al., 2011; Rose et al., 2018). Goal setting in rehabilitation need to be related to patient's everyday life, and there is a need for individualised approach and person-centred goal setting. However, person-centred goal setting often does not occur in rehabilitation (Lloyd et al., 2017; Maribo et al., 2020). From a patient's point of view, the meanings of goal-setting situations have been identified as 'trust in the rehabilitation situation, professionals, oneself, and relatives;' 'respectful presence;' 'confusing awareness;' 'disturbing pain;' and 'fear of unpredictability' (Alanko et al., 2019). Patient participation in rehabilitation is described, based on the perspectives of nurses and occupational therapists, as a continuum that ranges from patients complying with the professional's instructions to the idea that all power is transferred to the patient (Holmqvist & James, 2019). According to Scheel-Sailer (2017), patients with acquired spinal cord injury had a reduced ability to participate in decision-making in the early phase of the rehabilitation.

Studies from 2011 show that healthcare professionals in specialised rehabilitation had an evident institutional 'right practice' in which patient engagement and patient-centred goal setting were minimally adopted (Horton et al., 2011; Rosewilliam et al., 2011). This happened even as the professionals stated that the patients participated more than what the patients themselves had reported (Dudeck et al., 2011). Still in 2019, the evident institutional 'right practice' was present and the healthcare personnel adopted routines that simplified their interactions with patients (Kvael et al., 2019). Rose et al. (2017 and 2018) found that health personnel did not seem to have the necessary skills to involve the patient in the decision about their goals. The patients felt that they lacked knowledge regarding goal-setting; they felt disempowered to participate

and that the staff might not listen to them. Kvael et al. (2019) point out that there might be a gap between policy and clinical practice.

Consequently, patient participation has been reported to empower patients to take control over their bodies and their situations during rehabilitation and bridge the knowledge of patients and health professionals leading to better health solutions (Castro et al., 2016). When patients experience developing a shared rehabilitation process based on a rehabilitation plan, they become more engaged in their rehabilitation (Lexell et al., 2016). Patients who felt they lacked participation tended to have shorter lengths of stay and lower functional status compared to those who agreed to participate in their rehabilitation programme (Wylegala et al., 2015). The professionals seemed to be more oriented to the physical and cognitive rehabilitation, while the patients are more focused on the return to their normal life (Maribo, 2020; Simeone et al., 2015). Knowing how patients experience their return to normal life may help professionals provide adequate treatment to the patients (Simeone et al., 2015).

To summarise, there might be a gap between policy statements and clinical practice and a discrepancy between patients' and professionals' understanding about patient participation in rehabilitation. Patient participation in rehabilitation is almost always described as being connected to goal setting, while information about patient participation throughout the rehabilitation process was not found.

The present study aims to explore how patients experience participation in their rehabilitation process in specialised rehabilitation units in Norway.

3 | METHODS

The present study utilised a qualitative approach with a narrative design using patients' stories about how they participated in the rehabilitation process in specialised rehabilitation units.

The study was set in physical and rehabilitation medicine units in Norway. The rehabilitation units are a part of the specialist health service, and function in cross-professional teams consisting of physicians, nurses, physiotherapists, speech therapists, occupational therapists, psychologists and social workers. The physical and rehabilitation medicine units have space for testing, training, relaxing, eating and other activities. The patients live in single rooms or share a room with one or two other patients. Patients without cognitive impairments that had been at the rehabilitation unit for more than 14 days were purposively selected for inclusion in the study. Participants were invited to participate by a medical doctor working at the unit. All invited accepted to participate in the study.

3.1 | Sample

Eleven patients, seven women and four men, were included in the study. Four were between 34–60 years, three between 61–70 years and three between 71–90 years. Their causes for rehabilitation were multi-trauma, amputation, cancer, stroke, neck spinal cord injury and

lung disease. Two patients were in coma when they were transferred to the rehabilitation unit.

3.2 | Data collection

Data were collected through narrative interviews. Polkinghorne (1988) used the term 'story' as an equivalent to 'narrative' and reported that narrative is the primary form by which human experiences are made meaningful. The concept of narrative is a collective term about data as life stories and descriptions of situations. Riessman (1993) pointed out that the researcher does not find narratives, but instead participates in their creation. The information gathered from the interviews covered the patients' rehabilitation processes from the beginning of their illness to the day of the interview, and was about their situation, their past, present and future, and how they interacted with health personnel. The patients had been in the rehabilitation units for about 1–5 months, and most of them, at the point of the interview, were ready to leave the unit. The interview took place in the patient's room at the hospital where they told their stories. Only the patient and the researcher were present during the interview.

The interviewer had no experience with rehabilitation units but as a female nurse currently working as an associate professor, PhD in Health Sciences, she was familiar with the terminology of rehabilitation. The interviewer explored the patients' stories by focusing on the structure of the stories (Polkinghorne, 1988) and helping the patients construct their stories by asking open-ended and critical questions (Fontana & Frey, 2000) such as 'Can you please tell me more about this event?' and 'What happened then?' In that way, the risk of asking leading questions was minimised. However, since the researcher is always part of the interview process, certain events might have received greater attention than others. No follow-up interviews were conducted. The first author of the present study conducted and tape-recorded all the interviews. No field notes were made during or after the interviews. The interviews were transcribed verbatim by the first author, with some assistance by a secretary. After the eleventh interview had been conducted, a point of saturation of data was achieved (Brinkmann & Kvale, 2018). We considered that further interviews would probably yield little new knowledge. The interviews were critically evaluated throughout the analysis process by listening to the stories several times and by discussing their interpretation with the other authors. The informants did not comment on transcripts or provide feedback on the findings.

3.3 | Ethical considerations

This study was conducted according to the rules of the Helsinki Declaration (World Medical Association Declaration of Helsinki, 2013). The permission to conduct the research was granted by Regional Committees for medical and health research ethics and

NSD (ref: 2017/2290/REK midt and ref: 466052) and by the participating hospital. The patients gave their written consent to participate and for the interviews to be recorded. The researcher gave a written declaration to the participants that included the reasons for performing the study and that the tape-recorded interviews would be deleted after transcription.

3.4 | Data analysis

To understand a person's story, we need to listen, not only to their personal experiences but also their interactions with other people. During analysis, we used the three-dimensional space narrative structure described by Haydon et al. (2018) and Wang and Geale (2015). It is based on Dewey's (1986) theory and was developed by Clandinin and Connelly (2000):

1. **Temporality:** past, present and future. All persons live a continuous narrative, and narratives are often expressed as memories from the past. Past experiences also influence the perception of present and future events.
2. **Sociality:** the personal, social and cultural. While telling and listening to narratives, people narratively construct and repeatedly re-construct their identity and to whom they are socially connected.
3. **Spatiality:** environment and institution. Past involvement from the institution might be reflected in the patient's story; the place where it is narrated also influences how the story is narrated (Haydon et al., 2018).

All interviews were analysed separately based on the three-dimensional space narrative structure with focus on patient participation in the rehabilitation process. The temporality (the past, present and future), the spatiality (environment and institution) and the sociality (the personal, social and cultural) altogether influence how the patient's perceived participation. Patients' stories about their participation were then analysed with narrative emplotment. Emplotment is the merger of multiple dialogues or conversations into one narrative that encompasses the events conversed; it is then presented in a sequence that creates a narrative plot (Haydon et al., 2018). The NVivo software for Windows was used to manage the data. The study complied with the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist (Tong et al., 2007; see File S1).

4 | RESULTS

Eleven people participated in the study; several had been critically ill, some had been in coma and some had needed treatment on a respirator. All patients came from other units in the hospital or another hospital. They had been in specialised rehabilitation from one to five months and were in the last weeks of their stay at the time of the interview.

The analysis identified two throughout plots three: 'person-centred culture' and 'time', and three plots which constructed how the patient participate through the rehabilitation process. The plots of patient participation moved from dependent—'open doors', motivation from within and to independence—'locked doors' (Figure 1). The plots are an integrated combination of temporality, sociality and spatiality.

4.1 | Person-centred culture and time

Patients narrated about the environment in the unit they came from where the healthcare personnel were in a rush and did not have time for them, 'they ran, it was just to drop down medicine and then out, but here they get more time for the patient' (3). These experiences contrasted the patients experiences from the rehabilitation units, where health personal had time for dialogue, and the patients got the time they needed to for example to tie their shoes.

The patients then talked about their interaction with the health personnel (the sociality), the importance of a good match with the therapists:

It was a great change from the surgical unit; I was a nursing patient there until I came here, where one must manage as much as possible (7). I think they are good at putting the right person with the right patient then (1).The stupidestis to be compared with others, even though we have the same injury and the same thing, there are completely different ways to go ... they had to get to know me in such a way that they could help me (11).

Through this, the patients highlighted the importance of a context where they were seen as a person, they describe a person-centred culture in the whole rehabilitation process (the temporality) and that the health personnel had time for them.

4.2 | Dependent, open doors

The patients started their story by describing their helpless condition; most of the patients were completely helpless when they arrived in the rehabilitation unit. They were totally dependent on the nurses, and talked about their powerlessness and vulnerability:

In the beginning, I needed them for everything. They fed me; they dressed me. I could do nothing. I was completely a nursing patient. I couldn't even press the signal button. I had no strength (11). They helped me with everything; I had no power (6).

In such a helpless and powerless situation, the patients pointed out what was important in the interaction with the health personnel.

They (nurses) are always here (crying). They try as best they can to get you back. The nurse says: 'You shall get up and move forward, and you shall get out, this is not a place to live', you know they were there all the time... The door to my room was open a lot during the day (crying), knowing that there were people and I could see them and that they didn't close the door. They never gave up. They said: 'You can do this'. Just a little push, then you get up instead of just sitting or lying down, they did not help you unnecessarily, they were present, but you must do it by yourself (3).

Another patient summarised their interaction with the health personnel in this way: 'really the most important thing is that I feel that I have something to say, I am heard, and they are present' (9).

In the first phase of the rehabilitation process, the patients described themselves as powerless and vulnerable; however, they felt they were heard and respected. The 'open door', with the presence of health personnel that gave the patient positive words and a 'push' when they needed it, was important. This gave the patients strength and motivation to move forward.

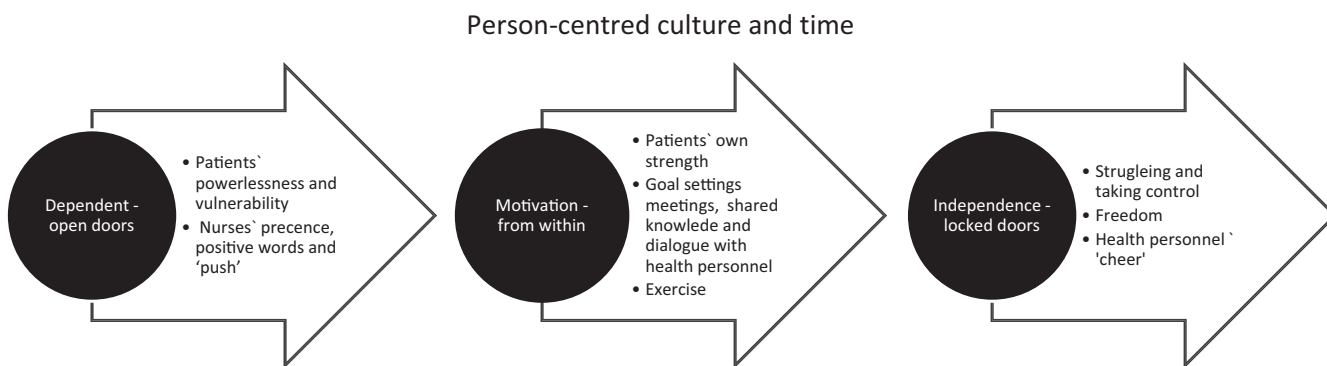


FIGURE 1 Patients' experience of participating in the rehabilitation process

4.3 | Motivation—From within

Patients further spoke about their motivation, the goal-setting meetings and their exercise. They talked about their strengths and the motivation that had to come from within. Their motivations were different, but all patients recalled meaningful events from their past and about what they wanted in the future, to get back the life they had before. They wanted to live and be something important for someone else (e.g. for their grandchild).

It's clear it's my driving force, without it, it so wouldn't have worked (6). I should do the max... The motivation came from within, nothing that came from outside motivated me.....It was basically being scared of being a life-long care patient that scared me and motivated me (11).

All patients spoke about the goal-setting meetings. These meetings were in the rehabilitation unit between the health personnel and the patient, and with the next of kin if the patients wanted. These meetings usually took place in the beginning, in the middle and at the end of patients' stay. The patient, together with the health personnel, developed and evaluated the goal.

We all sat together both the doctor and the physiotherapists and the occupational therapists, they were all there. So, we sat there and evaluated how far I had come.

R: But these goals, have you made them?

Yeah, I said my opinions and they said theirs (6).

The patients emphasised that the health personnel had knowledge that they themselves did not have, and therefore, the health personnel advised them on what had to be done.

I have a goal then, to be the way I was before That is my main goal, but there are many sub-goals one must go through before one gets this far. So, if I am going to work towards my main goal, then it is clear that they have to tell me what I need to train and work on. Yeah... it's going to be that way. I can't say which muscle group that needs to be trained and stuff like that, in a way it is based on my main goal then it is set up sub-goals with the help of these that are skilled in the field (11).

The patients also talked a lot about exercise. One patient who had felt totally helpless told us how her body responded when she exercised in bed, as instructed by the physiotherapist, and how she gained control. 'I have control on myself R: All the time? No, ...but once it turned and the body took up the exercise' (3). 'I am dependent on them

to get the help and the progress I need. I don't manage to push through all the exercises so hard by myself' (5).

Additionally, the patients narrated some instances where some health personnel took over.

They (nurses) are quick to tie the shoe and put on the socks on me, but they are not allowed, they have to wait, or they have to go and come again. Once I get it, it won't go faster if they do, it's just going to go slower. I'm probably a little obstinate ... to achieve what I want. No one is sitting at my house tying my shoes... I don't want to be here more than I must (11).

All patients said that motivation had to come from within, it had to be their own power. However, to participate in the goal-setting meeting and to be pushed during the exercise was important and motivated them to move forward. The exercise was performed both in the exercise room and as part of their daily activities. Patients expected to take part in setting the main goal. However, for all the sub-goals, such as how to train the muscles, patients were required to have professional skills.

4.4 | Independence—Locked doors

Patients' stories then moved from a helpless state to a motivated one. They talked about how they struggled to be independent, gain control over their lives and feel autonomous.

It is always a great pleasure when you can go into the bathroom and lock the door; it is a victory in itself. It is very important there, with self-determination and getting control over one's own life.

Some patients told us that eventually they became impatient and tired of being dependent on help all the time, but the health personnel did not allow them to exercise by themselves.

I depended on help all the time, I wanted to try some myself, but these ladies do not want me to try, they are afraid that I will fall you know. But in the morning when I wake up, I go into the gym alone (11)

To go to the gym alone gave the patients some important time with themselves and the feeling of taking back control.

...it is one of my moments when I sit doing what I want without having to sit and entertain the caregivers, then I can sit with my own mind and I get to sing for myself. These are such little things, it may sound awful, but this is to take back freedom when you have been cared for as a patient, then it is a big step to be

able to do that too. The same as being able to lock this bath door (11)

The patients looked forward to locking the bathroom door and function independently. In that independent state, they just want encouragement from the health personnel and have someone to talk to without being rejected.

They lift you up. They just lift you. It's so encouraging: 'See him now, he has raised the stick, now he has got out of the wheelchair as soon as possible'. I mean it's terribly encouraging.

R: That's what's important to you?

Yeah, that's what's important to me, and that you can talk to them without being rejected, it also has a lot to say (6).

The patients felt independent when they could lock bathroom doors and do the exercise by themselves. They wished to have control over their lives. They felt that the health personnel's 'cheer' and feeling free to talk to them was encouraging.

In summary, how the patients participated in the rehabilitation process changed as their stories progressed. To be seen as a person and get time were important elements throughout the process. At the beginning of their stories, the patients constructed themselves as being helpless and powerless and transferred the power to the health personnel. In this 'helpless' state, the patients needed health personnel who were present, with 'open doors', and with whom they could dialogue and interact with. The following things were important: positive words, to be listened to, a 'hand' when they needed it, exercise in bed with the health personnel until their body responded to it.

Their motivation came from their own sense of power. The units' tool for participation was goal-setting meetings where health personnel and patients shared knowledge. Participating in these meetings and being pushed to exercise helped the patients move forward. The patients had to struggle to be allowed to exercise by themselves, to 'lock the door', and wanted the health personnel to 'cheer' when they did things independently. Progressively, the patients took control over their own bodies, and their dialogue and the power balance with the health personnel changed.

5 | DISCUSSION

The present study aimed to explore how patients experience participating in their rehabilitation process in the context of specialised rehabilitation. Patient participation is operationalised as a process of dialogue and power exchange between the patient and the healthcare team (Aasen et al., 2012a). Eleven patients' stories have been analysed using the three-dimensional space narrative structure:

spatiality, temporality and sociality (Haydon et al., 2018). While telling and listening to narratives, people construct and repeatedly re-construct their identity and to whom they are connected (Haydon et al., 2018). Patients in the present study constructed themselves differently throughout the rehabilitation process from helpless and dependent to autonomous and independent persons, and the motivation for this change had to come from within themselves.

Patient participation is always connected to a context (Aasen et al., 2012b). According to Haydon et al. (2018), it is the sociality and spatiality. And all persons live a continuous narrative, it is the temporality, in the present study the rehabilitation process. The patients shared their experience from the context of a cross-professional unit with a structure where the health personnel work in teams and plan the rehabilitation in goal-setting meetings together with the patients. Patients emphasised that this was an important part of the rehabilitation unit that the health personnel were present and had time for them. It was important for patients to have time to exercise for themselves and to engage in difficult tasks such as 'tying shoes'. There was time for dialogue through the whole rehabilitation process, which is a prerequisite for participation (Aasen et al., 2012b) and important for participation in goal setting and decision-making (Scheel-Sailor et al., 2017). This time for dialogue might be in contrast to the discourse of management that Røberg et al. (2020) found in their study of policy strategy and practice of rehabilitation in Norway. A discourse that emphasises efficiency with shorter stays, more focus on productivity and less cost for the welfare state. In their study, Wylegala et al. (2015) found that patients who felt they lacked participation tended to have shorter lengths of stay and lower functional status compared to those who participated in their rehabilitation programme. It is unclear if this is a discrepancy between the law (Ministry of Health & Care Services, 1999) and the manager discourse (Røberg et al., 2020), or if it is a part of the paternalistic discourse which is also present in the written law (Aasen, 2018). However, the present study shows that the patient and health personnel need sufficient time for the rehabilitation process, and that time is closely connected to participation in rehabilitation.

Historically, the definition of rehabilitation has moved from a focus on the patient's function (Negrini & Ceravolo, 2008) to more patient-centred programmes (Negrini, 2018). Some patients point to the importance of being seen, not only as a patient who has experienced a loss of functions, but more importantly as a person that the healthcare personnel must familiarise themselves with, in order to help them. We understand this as the patients asking for person-centred care in accordance with Kvaal et al. (2018) that emphasises the importance of patients being seen as a whole. Håkansson et al. (2019) explain that the change from patient-centred care to person-centred care is achieved by changing the patient's focus from living a functional life to living a meaningful life. Earlier studies have found that true person-centred care has not been fully implemented in rehabilitation practices (Lloyd et al., 2017; Rose et al., 2018; Yun & Choi, 2019). While the patients' goal was focused on returning to normal life, the health personal goal focused on physical and cognitive rehabilitation (Simone et al., 2015). In order to achieve a more

person-centred care, the staff is required to let the patients tell their story—similar to what they did in the interviews in the present study. This empowers the patients based on their resources.

Specialised rehabilitation in Norway uses the ICP standardised framework (Norsk forening for fysikalsk medisin og rehabilitering, 2012; World Health Organization, 2001) as a tool in goal-setting meetings. Participating in goal-setting meetings and being pushed during exercise was important and motivated the patients to move forward. Earlier studies indicated positive outcomes when patients participate in cross-discipline goal setting (Horton et al., 2011; Rose et al., 2017). Patients in the present study expected that they should participate in formulating the main goals, while for all the sub-goals, such as training the muscles, they needed the professional skills of the healthcare personnel. Dialogue with the health personnel, which leads to shared information and knowledge, is the core of patient participation (Aasen et al., 2012b). All patients experienced participation in goal-setting, but did the patients really participate when the goals are standardised? To the question 'But have you made these goals?' a patient answered 'Yeah, I said my opinions and they said theirs'. The patients experienced dialogue which is a prerequisite for participation (Aasen et al., 2012b). Earlier studies point to discrepancy between patients' and professionals' statements about patient participation in goal setting (Dudeck et al., 2011; Hammerschmidt et al., 2015; Rose et al., 2017). Lexell et al. (2016) found that the clients became more engaged in their rehabilitation when they experience a shared rehabilitation process based on a rehabilitation plan. To standardise the content of the patients' stories to fit into the ICF instrument requires the professionals to explain the meaning of the functional determinations, to provide impact descriptions and to engage with patients by sharing their own experiences in this type of care.

In the beginning of the rehabilitation process, patients felt helpless and powerless, and the health professionals were patient and respectfully present. The doors were left open. Alanko et al. (2019) describe respectful presence as important when the patients are participating in goal-setting situations. Patients constructed themselves in their narratives, from passive patients who needed help at the beginning, to gradually becoming active patients by the end of the stories. According to Haydon et al. (2018), patients temporarily re-constructed their identity and how they were socially connected with the health personnel during their rehabilitation process. These findings were not a continuum, as described by Holmqvist and James (2019), which ranged from patients complying with the health personnel's wishes to all power being transferred to the patient. However, dialogue and power exchange between the patients and the health professionals (Aasen et al., 2012a) took place throughout the rehabilitation process.

Patients struggled to be independent and autonomous and take control over their own lives. Beauchamp and Childres (2019) define autonomy as the right for one to make their own decisions, excluding any interference from others. In our study, the patients did not want to have to ask the health professionals, for example, 'lock the bathroom door' or 'to exercise'. They wanted to stay in the unit until they

felt they were ready to leave. The independent patient only wished to be encouraged and to freely interact with the health professionals. However, if the patients wanted to be totally independent while still being in the unit, could the unit's routine be an obstacle for the patient's independence? In the present study, the environment and the routines influence the patient's experiences of independence. An earlier study found that the healthcare personnel in rehabilitation units may adopt routines that organised their interactions with patients and, thereby, with patient participation (Kvaal et al., 2018) or, as Haydon et al. (2018) express it, the spatiality also influences how the event is experienced by the independent patient.

All patients reported that hope for the future motivated them; this confirmed Haydon et al.'s (2018) findings that people live a continuous narrative and past experiences will influence how future events are perceived. Patients also said that the motivation had to come from within themselves. Halabi et al. (2019) included empowerment as a dimension of the concept of patient participation and that it is the patient's acquisition of motivation, abilities and power in the healthcare relationship. Patients further told us how the health personnel worked to get their paralysed bodies to respond, and when their bodies responded, they received motivation and power to move forward. Patients participated in their rehabilitation and became independent.

5.1 | Limitations

Validity threats arise in narrative research because the language descriptions given by participants of their experience is not a mirrored reflection of meaning (Polkinghorne, 2007). Eleven patient's stories have been analysed by using the three-dimensional space narrative structure (Haydon et al., 2018). The relational aspect in narrative inquiry, a long and close relationship between the researcher and the participant, could influence the data (Haydon et al., 2018). In this study, there was not a long relationship before the interviews, which lasted between 0.5 and 1.5 hr. The fact that not all interviews were transcribed by the interviewer can have affected how the scripts were written; hence, by listening at the recorded interviews when reading those scripts, this risk has been minimised. Also, the authors' preunderstandings of rehabilitation could have affected the results, and the authors have therefore tried to bridle this.

6 | CONCLUSION

Patient participation in the rehabilitation processes is dependent on a person-centred culture in the unit and on a different aspect of time: time for the health personnel to be present, time for patients to do their own tasks and time for the length of stay. Patient participation changes throughout the rehabilitation process. Patient empowerment was a must and motivated the patients to move forward from a state of powerlessness to autonomy. They experienced participation when dialogue was present, and there was a power

exchange between the patients and the health personnel. The paternalistic ideology where patients are assumed to comply and play minimal and passive roles has traditionally dominated health care, but this did not seem to dominate the specialised rehabilitation unit in present study.

7 | RELEVANCE TO CLINICAL PRACTICE

This study gives new insight into how patients participate in the rehabilitation process. This information can be valuable for healthcare professionals and government agencies. It is important to be aware of the lack of person-centred focus that can harm the rehabilitation process. To understand the meaning of time was essential in the rehabilitation process, both in the interaction with the health personnel and in the structure of the units. The results may stimulate discussions about how patients can participate more actively in their rehabilitation process.

ACKNOWLEDGEMENTS

We are grateful to the patients who participated in this study and openly shared their narratives.

CONFLICT OF INTEREST

There are no conflicts of interests to declare.

AUTHOR CONTRIBUTION

Elin Margrethe Aasen RN, PhD involved in formal analysis, methodology, writing—original draft, writing—review and editing, visualisation, project administration and funding acquisition. Halvard Knut Nilsen MD, PhD involved in writing—original draft, and writing—review and editing. Elisabeth Dahlborg, RN, PhD and Lindis Katrine Helberget RN, MSc involved in methodology, writing—original draft, writing—review and editing, and funding acquisition.

DATA AVAILABILITY STATEMENT

Research data are not shared.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

How to cite this article: Aasen EM, Nilsen HK, Dahlborg E, Helberget LK, Kjelsvik M. From open to locked doors – From dependent to independent: Patient narratives of participation in their rehabilitation processes. *J Clin Nurs*. 2021;30:2320–2330. <https://doi.org/10.1111/jocn.15771>