

PATIENT EXPERIENCES OF PHYSICAL ACTIVITY AND INACTIVITY IN THE STROKE UNIT: AN INTERVIEW STUDY

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Objective: Stroke unit care is highly recommended after stroke, but patients in these units are often physically inactive. The aim of this study was to explore patient experiences of physical activity and inactivity in the stroke unit.

Design: Qualitative interview study.

Subjects: Sixteen participants with stroke; a heterogeneous sample with differences in sex, age, and stroke severity from 8 Swedish stroke units.

Methods: In-depth interviews 1–2 weeks after discharge analysed using thematic analysis.

Results: The analysis resulted in three themes: 1: Dealing with the challenges of a changed body while striving to become independent; 2: The stroke unit is crucial for physical activity; and 3: Physical activity is important for interaction with others, autonomy, and feeling seen. Participants described how they coped with a new situation when finding new ways to move and function. In addition, they wanted to be involved in their own stroke rehabilitation.

Conclusion: The participants expressed the following experiences of being in the stroke unit: movement is more important than physical activity and involves being seen and respected; physical activity and exercise are necessary to achieve independence; process involvement is of importance to regain abilities; physical activity offers the possibility of choosing between community and being alone and influences the ability to connect with others and the outside world.

Key words: exercise; interview; physical activity; sedentary behaviour; stroke; thematic analysis; qualitative research.

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Admission to stroke unit care is considered best practice for a patient after acute stroke (1) because a comprehensive stroke unit provides both acute care and early rehabilitation (2). Staff expertise, early mobilization, prevention of complications, and better diagnostic, care, and rehabilitation procedures are all

LAY ABSTRACT

Stroke unit care is considered best practice after stroke. However, patients tend to become inactive for reasons unknown. To describe physical activity and inactivity at the stroke unit from the patient perspective, 16 patients with stroke were interviewed. The interviews were analysed using a qualitative method, resulting in 3 themes: 1: Dealing with the challenges of a changed body while striving to become independent; 2: The stroke unit is crucial for physical activity; and 3: Physical activity is important for interaction with others, autonomy, and feeling seen. Participants expressed that movement means more to them than physical activity and involves being seen and respected. They described how they coped with a new situation when finding new ways to move and function. Participants expressed that physical activity is necessary to achieve independence and that they wanted involvement in their stroke rehabilitation. These results contribute with important insights into patient experiences that can be used to improve the quality of stroke unit care and rehabilitation.

aspects of comprehensive stroke unit care that contribute to better outcomes for patients after stroke (1).

In Sweden, 23,000 incident strokes occur every year, and 92% of patients are cared for in comprehensive stroke units (3). Rehabilitation begins at hospital admission, provided by multidisciplinary teams according to Swedish national guidelines. A person-centred approach is recommended in stroke rehabilitation, involving the patient as an active participant and establishing a partnership between the healthcare team and the patient (4). Although early rehabilitation is a key component in stroke unit care, many studies describe patients in these units as being physically inactive during their stays (5, 6). Physical inactivity is common after stroke and can increase the risk of recurrent cardiovascular incidents and reduced functional ability (7, 8). Physical activity is defined as body movement made by muscles that involves energy expenditure, and can be categorized into work-related, sports, training, household, or other activities of daily living (ADL) (9).

Patients in stroke units often spend most of their days in their patient rooms (73–89%), in bed (49–98%), or alone (56–60%), with variations among countries in

Eastern and Western Europe and in Australia (10–13). Furthermore, patients in the stroke unit engage in physical activity 10–23% of the day, with an increase of 22 minutes spent sitting and 4 minutes spent upright per day at hospital (6, 13, 14). Factors related to physical inactivity in the stroke unit include stroke severity and advanced age (14). The built environment in hospitals can influence physical activity, with functional design of corridors, single or multi-bedrooms, placement of staff stations, and availability of communal areas and greens spaces (15). Physical activity in the stroke unit is promoted by meal service in communal areas and more time spent with physiotherapists (16). These known factors, however, can explain only in part why patients often are physically inactive when in the stroke unit (17). Although physical activity may reduce the risk of stroke recurrence and disability, physical activity levels often decrease after stroke. To date, no interview-based investigation has explored physical activity and inactivity for patients in stroke units. The aim of this study was to use a qualitative approach, based on analysis of patient interviews, to explore patient experiences of physical activity and inactivity in the stroke unit.

METHODS

Design

This qualitative study used in-depth interviews evaluated using a reflexive thematic analysis with an inductive approach (18). The underlying theory is social constructivism based on the assumption of relativism, which acknowledges multiple realities that vary depending on personal experiences and contexts (19). The design followed the CONSolidated criteria for REporting Qualitative research (COREQ) guidelines (20). The study was approved by the Swedish Ethical Review Authority, reference number 2021-06716-01. Oral and written informed consent was obtained from the participants.

Patient participation

A patient research partner (GH) was engaged from the start of the study with collaboration on ethical application, project plan, and development of the interview guide. Furthermore, GH was engaged during the analysis process in discussing preliminary themes and revisions of themes to validate the interpretations of the participants' descriptions in the analysis process. All participants received written and oral information about the study results. The Guidance for Reporting Involvement of Patients and the Public 2 (GRIPP2) reporting checklist was followed (21).

Authors

MR is a 57-year-old woman, a PhD student in medicine with education in qualitative research methods, and a registered physiotherapist specialized in neurology with more than 30 years of clinical experience in stroke unit care. GH is a 57-year-old woman, an assistant nurse, and a patient research partner in this study with personal experience of having a stroke. KSS is a 66-year-old woman, a physician specialized in stroke, and

a professor in rehabilitation medicine with almost 40 years of clinical and research experience in neurological diagnoses and extensive research experience, including in qualitative studies. AP is a 42-year-old woman and a registered physiotherapist with a PhD in medicine and vast experience in qualitative research. None of the authors had previous associations with the participants. The researchers contributed to knowledge production in this study and had awareness of their own preconceptions and experiences.

Participants

Sixteen participants with stroke were recruited and participated in a single individual interview 1–2 weeks after discharge from the stroke unit. MR contacted the heads of departments at the 9 stroke units in Region Västra Götaland about participating in the recruitment of participants, and 8 units agreed. Inclusion criteria were patients with stroke, age 18 years or older, who stayed at a stroke unit ≥ 3 days and were Swedish speaking. Exclusion criteria were mobilization restrictions in the stroke unit or aphasia, cognitive impairment, or dementia that would hinder the interviews. The participants were purposively sampled with regards to variations in age, sex, and stroke severity, and their characteristics are described in Table I.

Involved physiotherapists working with patients in the stroke units recruited and tested the participants. Beforehand, the local physiotherapists had digital or face-to-face meetings with MR and received oral and written instructions about the study and recruitment process. The local physiotherapists administered oral and written information about the study and consent form to participants and assessed function during the first week after stroke. To ensure a study sample with a variation in characteristics MR was in contact with local physiotherapists on repeated occasions during the recruitment period. Data collected on participant characteristics were sex, age, stroke type, severity of stroke with the National Institutes of Health Stroke Scale (22), and comorbidities. Clinical assessments were conducted for descriptive purposes, including the Clinical Frailty Scale (23) for pre-stroke frailty, the Saltin-Grimby Physical Activity

Table I. Characteristics of the study population ($n=16$)

	<i>n</i>	Median [IQR]	Min–max
Age, years		75 [10]	49–84
Men	7		
Women	9		
Pre-stroke frailty, Clinical Frailty Scale (1–9)		2.5 [3]	1–6
Pre-stroke physical activity (SGPALS) (1–4)		2 [1]	1–3
Inactivity	5		
Light physical activity	9		
Moderate physical activity	2		
Ischaemic stroke	14		
Haemorrhagic stroke	2		
Stroke severity, NIHSS on admission (0–42)		4 [7]	0–14
Length of stay (days)		10 [7]	5–39
Number of comorbidities		1.5 [3]	0–5
Discharged to their home	13		
Discharge to rehabilitation/short-term care	3		
Walked independently at discharge:			
Without walking aids	4		
With walking aids	9		
Wheelchair users	3		
Berg Balance Scale (0–56)	16	38 [22]	3–56
Barthel Index (0–100)	16	80 [19]	35–100
Timed Up and Go (s)	13	24 [13]	9–43
10-m optional speed (m/s)	13	1.6 [1.1]	9–26
10-m maximal speed (m/s)	12	1.1 [0.7]	7–16
6-minute walk test (m)	12	282 [184]	165–463

IQR: interquartile range; NIHSS: National Institute of Health Stroke Scale; SGPALS: Saltin Grimby Physical Activity Level Scale.

Level Scale for pre-stroke physical activity (24), the Barthel Index for personal care in everyday activities (25), Berg Balance Scale (26), and Timed Up and Go (27) for balance, as well as the 10-Metre Walk Test (self-selected and maximum speed) (28) and 6-Min Walk Test (29). There were no dropouts.

Context

The interviews were conducted during September and October 2022 in the Swedish aftermath of the COVID-19 pandemic. At the time, patients were routinely tested for COVID-19 in the stroke units and were isolated if testing positive. Routines with face masks, visitation restrictions and access to communal areas differed among the hospitals. All 8 comprehensive stroke units had multidisciplinary stroke teams.

Data collection

A semi-structured interview guide (Fig. 1) was discussed and revised in collaboration with GH (30). MR conducted a pilot interview, and the in-depth individual interviews were conducted shortly after discharge (median 10.5 days) to avoid recall bias. To ensure that participants could speak freely, the interviews were conducted by a person not involved in the care and outside the hospital after discharge. Participants chose the time and place for the interviews, which was anywhere that was suitable for the purpose. Most participants were interviewed in their own home. Participants chose to have relatives nearby at 8 interviews, 3 of whom had relatives present in the same room; relatives were asked to not interact during the interview if they were not needed. MR conducted all interviews, which lasted from 25 to 60 min. Interviews were audio recorded and transcribed verbatim by MR and 2 research assistants. To facilitate communication and mutual understanding of concepts at the interviews, the moderator used synonyms for physical activity, inactivity, and exercise when appropriate. Field notes were not taken during the interviews. The 16 interviews provided rich and meaningful

descriptions, with the dialogue revealing in-depth perspectives that adequately corresponded to the research question (19, 31). There was no need for further interviews.

Data analysis

The transcribed interviews were subjected to a reflexive thematic analysis in 6 phases (18). In phase 1, 2 authors (MR and AP) individually became familiar with the data through listening, reading, and re-reading the interviews to gain a sense of the whole. In phases 2 and 3, initial codes were noted separately between the 2 authors, followed by joint coding and collaborative work in search of initial themes. In phase 4, the themes were reviewed, reorganized, and refined in collaboration with all 4 co-authors to reach consensus. In phase 5 the reflexive analysis moved back and forth between data, codes, and themes, as well as between parts of and the whole text and audio recordings to validate the linking between the themes and the interviews. GH validated the patient perspective in the analysis process. Participant quotes were selected in discussion among all 4 authors to best reflect the results of the analysis. In phase 6 MR wrote and reported the results. No software was used. The coding process is exemplified in Fig. 2.

RESULTS

The thematic analysis resulted in 3 themes and their respective subthemes, as follows.

Theme 1: "Dealing with the challenges of a changed body while striving to become independent"

In Theme 1 (Fig. 3), the participants described how the changed situation of falling ill and needing healthcare

Type of questions	Questions and Comments
Introductory question	How do you think about movement, physical activity, and exercise in the stroke unit? Tell me about movement, physical activity, and exercise on an ordinary day...
Open questions	How was it for you in the stroke unit with: Rest? Getting out of bed? Getting out of your room? Going outside the stroke unit? Walking outdoors? How was it for you in the stroke unit with: Physical activity and exercising? What made you rest or move around during the day in the stroke unit? Give examples of situations? Were you alone or with someone? Was it your choice or someone else's? How was the balance between physical activity and inactivity in the stroke unit, between movement and bed rest? What do you think gets you up and going after a stroke? Something you do? Something the staff does?
Closing questions	How do you think about movement, physical activity, and exercise in the stroke unit in your nearest future? Did we forget something – is there anything else you want to add?
Follow-up questions and techniques to further explore the topics emerging in the interviews	Can you tell me a little more about... Can you describe a situation, give an example... Can you elaborate on your thoughts on... If I summarize what you said like this ... have I understood correctly? Repeat a central concept that the participant said... (Mirroring) So you mean that... Use the silence to let the participant talk at their own pace.

Fig. 1. Interview guide.

Data/Quote →	Code →	Subtheme →	Theme
"Yes, but that's the thing about the worrying. I am a little anxious perhaps, but I am worried that I will do too little. 'Now you didn't do enough and therefore it didn't turn out well'".	Worrying about not exercising enough and therefore not getting well.	Exercising is necessary for recovery after a stroke.	Dealing with the challenges of a changed body while striving to become independent.
"Yes, because I told the staff that they have to understand that the little time I'm up and about compared with the long time I spend here [lying still] makes everything I have tried to exercise run out. So, I lay and pressed my feet into the end of the bed to keep my muscles going, like this [shows]".	If I lie down so much and stay up so little, I will lose the function I have exercised for, I told the staff.		

Fig. 2. Examples of the coding process.

aroused a strong drive to continue to be an independent person who can manage on their own. Participants described how they did things in new ways and fought their fears to be able to move independently and get back to their old life and old self.

Within this theme, the subtheme "*Doing everyday activities in new ways requires focus and energy*" described how the participants experienced a changed body and ability to move. They had to manage their neurological symptoms and find strategies and solutions for doing habitual things in new ways and requiring concentration that could lead to fatigue.

Also within this theme, the subtheme "*Exercise is necessary for recovery after a stroke*" was derived, as many participants expressed that exercise was necessary to get better and make progress. They described taking the initiative to exercise on their own in different ways. Many said that exercise was required to get better, with a tone that expressed that exercise was a responsibility and signalled that those who do not exercise probably would never get better.

In the subtheme "*The opportunity to explore how to move is essential to move towards independence*", the participants expressed that the ability to self-manage is

Theme 1. Dealing with the challenges of a changed body while striving to become independent.	
Subthemes	Representative Quotes
Doing everyday activities in new ways requires focus and energy.	"From not being able to lift my leg, I just dragged it at first. Now, I have a bit of a problem knowing how to put my foot down. Sometimes, it thuds down a little bit, but when I think about it, I try to put the heel down more, as I do with the other foot. It doesn't do it by itself. So, you can't concentrate all the time, that can be boring. I don't have the energy to walk around and think about how I'm walking all the time. You get a little tired of the whole situation, even if I don't feel tired or bored, I will keep on trying". Maria, age 79 years
Exercise is necessary for recovery after a stroke.	"No, but I want to move forward, I want to get better. [...] But I've gotten stronger in my arm, and I've gotten stronger in my leg as well. I just want to continue exercising as much as possible. There is no other way. [...] I am a little anxious perhaps, but I am worried that I will do too little. 'Now you didn't do enough and therefore it didn't turn out well'. But they say I'm doing enough". Anna, age 49 years
The opportunity to explore how to move is essential to move towards independence.	"When I went to the toilet, [...] even if you had called for help, it could take ages until they came. [...] I had a wheelchair, and I kind of had to lift my leg and shuffle over. [...] If they saw that I was already up and about in my wheelchair, they came up to me in the corridor and wondered if they could help. [...] I hardly ever called for help. [...] Yes, then of course I went to the toilet, and I tried to wash myself, even though I only had one hand, I was able to wash myself a little". Sophia, age 83 years
Fear can hinder physical activity, but sometimes it is worth taking the risk.	"Then I had to take the walker because I wasn't allowed to walk by myself, I had to have someone with me all the time. [...] But then sometimes I didn't bother and walked alone anyway (laughter) because it felt a bit embarrassing in the evening to call for help and say that I had to go to the bathroom again. So, it worked, it was a minimal risk I took, but I knew I could do it. I felt, no, I don't need them there". Björn, age 74 years

Fig. 3. Theme 1 with subthemes and quotes.

fundamental, describing the opportunity and encouragement as positive to try to perform different physical and everyday activities. Needing help could bring experiences of gratitude and humbleness or shame and frustration. Situations arose in which staff and patients disagreed about the patient's walking ability, resulting in agreement or conflict. Participants described finding it difficult to maintain integrity, and managing toilet visits was depicted as particularly important. Another reason to become independent was to avoid waiting a long time for help.

Finally, within this theme, the subtheme that *"Fear can hinder physical activity, but sometimes it is worth taking the risk"* was derived, as participants considered fear of falling to be the most common fear when moving. With a strong drive towards independence, participants sometimes tried to move on their own, even when staff did not recommend it because of the fall risk. Another fear of moving was related to anxiety about worsened symptoms, such as dizziness and nausea, or having a new stroke, such as in the event of severely increased blood pressure. Fear of COVID-19 was also a reason cited by patients for staying in their room.

Theme 2: *"The stroke unit is crucial for physical activity"*

In Theme 2 (Fig. 4), the participants emphasized that the stroke unit should provide the safety and courage that they needed to move after a stroke. This sense of

security and empowerment determined if the participants undertook physical activity and if so, how much. They expressed a wish that the staff would support the patient to enable recovery and physical activity. The rehabilitation staff were perceived as having a more challenging and affirming role when the patients were physically active.

Within this theme, the subtheme *"Care and rehabilitation are pivotal to physical activity"* was derived as important, with participants expressing a need for care and rehabilitation to be individualized, with a holistic approach that took into account their background, situation, wishes, and resources. When the staff prioritized the needs of the patients over tasks and hospital routines, physical activity was promoted. Furthermore, when the staff was attentive to the patients' needs and daily condition, it was appreciated. Participants moreover said that physical activities often involved close connections between patients and staff.

Also emerging within this theme was the subtheme that *"Receiving the rehabilitation you need promotes recovery"*. Everyday life in the stroke unit was described as a long line of "meal, bed rest, exercise, meal...", often with many opportunities for exercise. However, several participants felt that they were not getting the rehabilitation they needed. Some described inactive days with "full service", which was perceived as either positive or leaving them too passive. In addition, an improvement could result in more need for help, such as when a wheelchair user started to walk with help.

Theme 2. The stroke unit is crucial for physical activity.	
Subthemes	Representative Quotes
Care and rehabilitation are pivotal to physical activity.	<i>"Sometimes it feels like the assistant nurses have their role and it's very much this thing with food tray out and food tray in, 'Now we're finished with the food'. And then it's done somehow. [...] It's clear that patients who are moving about or doing something else [...] they disturb the system. So, I thought about this, that they should put movement or activity or the patient more in the centre, than getting food trays out and food trays in". John, age 57 years</i>
Receiving the rehabilitation you need promotes recovery.	<i>"I asked an assistant nurse, 'Do you have the opportunity to walk with me in the hallway?' And I heard her say, 'Yes, but of course I will', but maybe it's my own imagination that says, 'We don't really have time, but of course we'll walk with you'. [...] I told her, 'You don't have to. You absolutely do not have to. It is just a quiet question. I accept if you say no'. She said, 'No, but of course I'll do it'. And then we walked a long corridor and back. But that was the only time". Monica, age 75 years</i>
Attitudes and communication can influence physical activity and inactivity.	<i>"If a nurse comes and helps me when I need to go to the bathroom and then back to bed, if they help me without saying anything, or if someone says, 'How are things today? How do you manage this?' It doesn't matter what they say, but if they talk even a little, everything becomes easier. Compared with if you're talking to someone who isn't interested in anything at all, just getting the job done and leaving. [...] Yes, do their thing and go [compared to] someone who has 2 minutes maybe, it doesn't have to be more. [...] I think they get back the time spent further down the line. [...] You have more understanding for those who speak than for those who doesn't say anything". Vera, age 75 years</i>
Rehabilitation staff challenge while instilling confidence to gain independence.	<i>"Then they have been very challenging and that was fortunate. They could say, 'Now you can walk without holding on to anything, we'll walk beside you. Walk now!' [...] I have to have the courage to try, as they're with me. They say, 'We'll catch you, we're here, walk now!' [...] It feels scary, but then you can manage so much more than you think. So, it's been working towards the next step all the time. They say, 'Let's go in the stairs, let's do it one more time!', and I say, 'Yes, I want to walk, I want to walk', so I just had to find the energy, but then I notice that I get tired". Anna, age 49 years</i>

Fig. 4. Theme 2 with subthemes and quotes.

The subtheme "*Attitudes and communication can influence physical activity and inactivity*" also fell within this theme. Participants described how communication among rehabilitation staff, healthcare professionals, and patients influenced physical activity. Getting good information brought feelings of safety and involvement. Participants wanted to know the purpose of their exercises and to be given feedback about their recovery. When communication was lacking between the medical and rehabilitation staffs, participants had experiences of being told off by medical staff for walking independently despite having been cleared by rehabilitation staff to do so. Some respondents also expressed the perspective that the staff should be attentive and engaged in promoting rehabilitation and physical activity.

In expressing the subtheme that "*Rehabilitation staff challenge while instilling confidence to gain independence*", participants said that they appreciated being pushed and challenged by the rehabilitation staff. Rehabilitation staff were a little tougher than medical staff, and sometimes pushed patients to exercise at the limit of their ability, according to participants. This encouragement was perceived as the rehabilitation staff speeding up the process towards a higher degree of independence.

Theme 3: "Physical activity is important for interaction with others, autonomy, and feeling seen"

In theme 3 (Fig. 5), the participants described how physical activities influenced how they thought about

themselves and related to others. They described the feeling that by being physically active they would be seen and encouraged. This experience created confidence in their own abilities and contributions to their autonomy. In contrast, staying in bed was described as resulting in feelings of passivity and invisibility, as the nursing staff were busy keeping up with their everyday jobs.

Within this theme, the subtheme that "*Becoming mobile gives the opportunity to choose to interact with others or being on your own*" was derived through observations that mobility allowed for a choice between community or privacy, whereas immobility could cause loneliness and isolation. Being left alone in the room for some peace and quiet was perceived as nice, as many participants described symptoms of fatigue that necessitated rest, especially early after acute stroke. Increased mobility and independence drew participants more to communal areas, such as television rooms and dining rooms outside the patient room.

According to the participants, "*Being out of bed transforms the patient into a person who is seen and respected*". They described being seen and respected when up and about. Being up and moving created natural opportunities to greet and meet others and affected how the participants perceived their treatment by the staff. Getting out of bed meant being seen as a person. Participants expressed that they stayed in bed to avoid being a bother to the staff, who seemed to have a lot to do and needed to prioritize other patients. Strate-

Theme 3. Physical activity is important for interaction with others, autonomy, and feeling seen.	
Subthemes	Representative Quotes
Becoming mobile gives the opportunity to choose to interact with others or being on your own.	"I took my friend there [the walker], and then I went to watch TV. [...] I didn't walk very often, it was mostly to the TV and back, and then you meet some people. [...] Because you get quite lonely, as people do when they are in a different environment". Lars, age 84 years
Being out of bed transforms the patient into a person who is seen and respected.	"Then of course the acute phase must pass because I was like a vegetable for the first 3 days. So, when I was standing, there could be staff that I had never seen before who said, 'Nice to see you! Welcome back!' Because they had just seen me as a package lying with my eyes shut to avoid vomiting. [...] When I heard them [the staff] talking, I had to concentrate and think about something else. Keep your head still, close your eyes. You can't avoid hearing more information about others than you want". John, age 57 years
Physical activity can create contact with the outside world.	"I went outside quite a lot, but not alone. It was very nice to get out so you can be yourself. I walked a little outside with my relatives. I could [walk outside], so we did. They [the staff] didn't say anything either, so we went out walking. I find it easy to walk, it's just the talking and remembering that doesn't work so well. I felt I should be walking outside all the time". Sven, age 70 years
Encouragement and support give strength and confidence to continue exercising.	"The therapists come every day. And it was just a matter of obeying, up and walk, out into the corridor and we always walked a few more steps than the day before. [...] I walked a little further, and I thought it went better. And they were so supportive and cheered me on as I progressed. They said I was doing fine which pushed me to do more. [...] It was enough that I extended my knee and they said, 'Yes, that's exactly how you do it!' I kind of felt like I was doing something right and something good. It made me feel good about myself, and I could pat myself on the back" (laughter). Linda, age 84 years

Fig. 5. Theme 3 with subthemes and quotes.

gies that participants described for dealing with these impressions included becoming one with a grey wall or closing one's eyes to disconnect from the situation.

Participants indicated that *"Physical activity can create contact with the outside world"* and described how experiences with physical activity mediated contact with the outside world, such as with nature when walking past a window or sitting on the balcony of the ward. Participants described the importance of physical activity for connecting with the outside, following the rhythms of nature, and broadening their horizons. Being able to go out gave a feeling of being more alive and of expanded views and normalcy.

Finally, within this theme, participants expressed that *"Encouragement and support give strength and confidence to continue exercising"*, as having a stroke could be experienced as tough and transformative. Participants described how support from healthcare professionals, rehabilitation staff, other patients, and relatives was important for instilling hope and energy. Struggling in everyday life and with exercise could weaken self-confidence in their abilities, and some participants expressed that confirmation from others about their progress supported their self-motivation and self-confidence.

DISCUSSION

The analyses of the interviews produced 3 overarching themes describing physical activity and inactivity in the stroke unit from the patients' perspective.

In Theme 1 *"Dealing with the challenges of a changed body while striving to become independent"*, participants described how to cope with their symptoms, functional ability, and a new situation when finding new ways to move and function. In addition, participants expressed the conviction that exercise is necessary to get better.

Theme 2 *"The stroke unit is crucial for physical activity"* included experiences of rehabilitation with needs being met or not, a desire to be involved in one's care and rehabilitation, and the need for staff to centre patients.

Theme 3 *"Physical activity is important for interaction with others, autonomy, and feeling seen"* encompassed the participants' characterizations throughout the interviews of the value of movement as going beyond physical activity. Being up on one's feet was perceived as vital for feeling seen and being respected as a person. Being able to move was also felt to influence self-image, relating to others, and how others relate back.

The participants in this study emphasized a strong drive towards independence after stroke. They called for an active everyday life in the stroke unit, where

the exercise that patients need is provided. This rehabilitative approach has been described in a Finnish study where patients received support for their physical functioning, independence, and self-confidence (32). In that study, more physical activity in the everyday routine and exercise was achieved with a rehabilitative approach including an explicit awareness, way of work, mutual conceptions, and a tight multi-professional team (32). In addition, in the current study, a narrative was derived of the participants coping with their changed body and taking charge over their exercise and situation as capable persons. Participants also expressed the desire for a more holistic view from care providers, and to be seen as a person and not a diagnosis. This corresponds to the holistic bio-psycho-social model where the biological, psychological and social contexts are equally included (33). In addition, participants described the need to be listened to and to receive individualized care and rehabilitation. Listening to the patient's narrative and regarding the patient as a person capable of being involved in decision-making about and planning of their own care and rehabilitation aligns with the person-centred care approach (4, 34). Some of the statements from participants in this study are in line with the concept of person-centred care, which is supported by the Swedish national stroke guidelines. The participants also described how they perceived movement as vital for feeling seen and being respected as a person. Similar results were reported in a qualitative study of patient experiences after hip surgery, in which respondents described the need to be seen as a person and to have other needs met, and the drive for independence when cared for in a geriatric ward (35). It can be assumed that some of the findings of the current study can be applied for diagnoses other than stroke and specialized wards other than stroke units. Nevertheless, this qualitative study is focused on providing a contextualized understanding of the patient experience without an effort to generalize. The participants' feelings of being seen when moving their body can be explained by the theory "phenomenology of the body" (36). According to this theory the world is experienced through the moving body, the lived body. In the current study the participants expressed that being up on their feet and moving meant having contact with the world, and others expressed that staying in bed resulted in the opposite.

Study limitations

Limitations of this study include potential influence from the authors, with a researcher bias arising from preconceptions. Two of the 4 authors are physiotherapists with a preference for physical activity. Another limitation is the risk of recall bias because the parti-

cipants were interviewed 1–2 weeks after discharge and may have had difficulties remembering their experiences. The risk of selection bias was addressed with a careful, purposeful selection of participants to assure a heterogeneous and representative study sample. To support dependability of the results, a carefully constructed interview guide was used at the interviews, which all were conducted by the same moderator. To further strengthen the dependability of the results, all interviews were conducted over a short time-period to reduce the risk of contextual changes that could have interfered with participant experiences (19). However, interpretation of the results should be made with consideration of the Swedish stroke care context and of the pandemic situation in Sweden in the autumn of 2022. The authors' preconceptions are reported in the study, a transparency that can increase the confirmability of the results (19). The detailed descriptions of methods and analysis procedures are intended to increase the transferability of the findings (19). To strengthen the credibility of the study, the participants' quotes were carefully selected by all co-authors to reflect the results and support the analysis.

Increasing physical activity is a priority for people after stroke in order to increase function and reduce the risk of stroke recurrence (37). Previous studies have focused on objective and subjective assessments for physical activity, although patients consider measuring goal achievement and the impact of physical activity on fatigue to also be important (37). Patients' perspectives on stroke rehabilitation should be considered in quality-improvement efforts. Further research can broaden perspectives on physical activity in the stroke unit, and interviews with healthcare and rehabilitation staff could provide new insights. In addition, many persons are less physically active after stroke, and qualitative research could bring new understanding about the factors involved. Even though movement is essential at a stroke unit as part of the rehabilitation and everyday activities for patients with acute stroke, there is often a dissonance between the ambitions of the staff, the visions in guidelines, and clinical reality. Good intentions get lost with staffing shortages and lack of continuity. International and Swedish policy implications and guidelines on stroke care are, in many ways, congruent with some of the statements being made by the interviewed participants in this study. However, attitudes, dialogue, partnership, and other soft values are not included in guidelines and programmes, even though they exist every day in stroke unit care and rehabilitation (38). The current findings will be helpful for improving the experiences for patients at stroke units, and for improving the quality of stroke unit care. To increase knowledge and raise awareness about different aspects of stroke unit care is necessary

in a multi-disciplinary stroke team where the learning process is never completed. Further collaboration with stakeholders and the inclusion of patients' and relatives' perspectives are needed in both research and clinical practice.

Conclusion

Patients regard movement as more important than physical activity in the stroke unit, as it involves being seen and respected. Patients recovering from stroke try to deal with their changed body and abilities while striving to regain independence, and they express that the way to independence is through exercise. In addition, patients want to be involved in their own care and to be supported by the staff to promote physical activity. Participants want care and rehabilitation to be individualized in the stroke unit to meet their need for rehabilitation, help, and rest. Physical activity is considered as offering the possibility of choosing between community and being alone, and it influences connecting with others and the outside world.

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Oral and written informed consent were obtained from the participants.

The use of data is regulated and follows the application by the Swedish Ethical Review. Data may be available to researchers upon request by Professor Katharina S. Sunnerhagen after confidentiality review.

REFERENCES

1. Langhorne P, Ramachandra S. Organised inpatient (stroke unit) care for stroke: network meta-analysis. *Cochrane Database Syst Rev* 2020; 4: Cd000197. DOI: 10.1002/14651858.CD000197.pub4.
2. West T, Bernhardt J. Physical activity patterns of acute stroke patients managed in a rehabilitation focused stroke unit. *BioMed Res Int* 2013; 2013: 438679. DOI: 10.1155/2013/438679
3. Riksstroke. [Annual report on the quality of Swedish stroke care 2021]. 2022 [cited 2023 Aug 22]; Available from: www.riksstroke.se (in Swedish).
4. Ekman I, Swedberg K, Taft C, Lindseth A, Norberg A, Brink E, et al. Person-centered care – ready for prime time. *Eur J Cardiovasc Nurs* 2011; 10: 248–251. DOI: 10.1016/j.ejcnurse.2011.06.008
5. Askim T, Bernhardt J, Løge AD, Indredavik B. Stroke patients do not need to be inactive in the first two-weeks after stroke: results from a stroke unit focused on early rehabilitation. *Int J Stroke* 2012; 7: 25–31. DOI: 10.1111/j.1747-4949.2011.00697.x

6. Chen E, Viktorisson A, Danielsson A, Palstam A, Sunnerhagen KS. Levels of physical activity in acute stroke patients treated at a stroke unit: a prospective, observational study. *J Rehabil Med* 2020; 52: jrm00041. DOI: 10.2340/16501977-2671
7. Saunders DH, Mead GE, Fitzsimons C, Kelly P, van Wijck F, Verschuren O, et al. Interventions for reducing sedentary behaviour in people with stroke. *Cochrane Database Syst Rev* 2021; 6: Cd012996. DOI: 10.1002/14651858.CD012996.pub2
8. English C, Manns PJ, Tucak C, Bernhardt J. Physical activity and sedentary behaviors in people with stroke living in the community: a systematic review. *Phys Ther* 2014; 94: 185–196. DOI: 10.2522/ptj.20130175
9. Caspersen CJ, Powell KE, Christenson GM. Physical activity, exercise, and physical fitness: definitions and distinctions for health-related research. *Public Health Rep* 1985; 100: 126–131
10. Wellwood I, Langhorne P, McKevitt C, Bernhardt J, Rudd AG, Wolfe CDA. An Observational Study of Acute Stroke Care in Four Countries: The European Registers of Stroke Study. *Cerebrovasc Dis* 2009; 28: 171–176. DOI: 10.1159/000226116
11. Kārklīņa A, Chen E, Bērziņa G, Stibrant Sunnerhagen K. Patients' physical activity in stroke units in Latvia and Sweden. *Brain Behav* 2021; 11: e02110. DOI: 10.1002/brb3.2110
12. Bernhardt J, Chitravas N, Meslo IL, Thrift AG, Indredavik B. Not all stroke units are the same: a comparison of physical activity patterns in Melbourne, Australia, and Trondheim, Norway. *Stroke* 2008; 39: 2059–2065. DOI: 10.1161/strokeaha.107.507160
13. Bernhardt J, Dewey H, Thrift A, Donnan G. Inactive and alone: physical activity within the first 14 days of acute stroke unit care. *Stroke* 2004; 35: 1005–1009. DOI: 10.1161/01.Str.0000120727.40792.40
14. Norvang OP, Hokstad A, Taraldsen K, Tan X, Lydersen S, Indredavik B, et al. Time spent lying, sitting, and upright during hospitalization after stroke: a prospective observation study. *BMC Neurol* 2018; 18: 138. DOI: 10.1186/s12883-018-1134-0
15. Bernhardt J, Lipson-Smith R, Davis A, White M, Zeeman H, Pitt N, et al. Why hospital design matters: a narrative review of built environments research relevant to stroke care. *Int J Stroke* 2022; 17: 370–377. DOI: 10.1177/17474930211042485
16. Hokstad A, Indredavik B, Bernhardt J, Ihle-Hansen H, Salvesen Ø, Seljeseth YM, et al. Hospital differences in motor activity early after stroke: a comparison of 11 Norwegian stroke units. *J Stroke Cerebrovasc Dis* 2015; 24: 1333–1340. DOI: 10.1016/j.jstrokecerebrovasdis.2015.02.009
17. English C, Healy GN, Coates A, Lewis LK, Olds T, Bernhardt J. Sitting time and physical activity after stroke: physical activity is only part of the story. *Top Stroke Rehabil* 2016; 23: 36–42. DOI: 10.1179/1945511915y.0000000009
18. Braun V, Clarke V. *Thematic analysis: a practical guide*. Los Angeles: SAGE; 2022.
19. Lincoln YS, Guba EG. *Naturalistic inquiry*. Beverly Hills, CA: Sage; 1985.
20. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007; 19: 349–357. DOI: 10.1093/intqhc/mzm042
21. Staniszewska S, Brett J, Simera I, Seers K, Mockford C, Goodlad S, et al. GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research. *BMJ* 2017; 358. DOI: 10.1136/bmj.j3453
22. Kasner SE. Clinical interpretation and use of stroke scales. *Lancet Neurol* 2006; 5: 603–612. DOI: 10.1016/S1474-4422(06)70495-1
23. Church S, Rogers E, Rockwood K, Theou O. A scoping review of the Clinical Frailty Scale. *BMC Geriatr* 2020; 20: 393. DOI: 10.1186/s12877-020-01801-7
24. Grimby G, Borjesson M, Jonsdottir IH, Schnohr P, Thelle DS, Saltin B. The "Saltin-Grimby Physical Activity Level Scale" and its application to health research. *Scand J Med Sci Sports* 2015; 25 Suppl 4: 119–125. DOI: 10.1111/sms.12611
25. Mahoney FI. Functional evaluation: the Barthel index. *Md State Med J* 1965; 14: 61–65.
26. Berg KO, Wood-Dauphinee SL, Williams JJ, Maki B. Measuring balance in the elderly: validation of an instrument. *Can J Publ Health* 1992; 83: S7–11.
27. Podsiadlo D, Richardson S. The timed "Up & Go": a test of basic functional mobility for frail elderly persons. *J Am Geriatr Soc* 1991; 39: 142–148. DOI: 10.1111/j.1532-5415.1991.tb01616.x
28. Dalgas U, Severinsen K, Overgaard K. Relations between 6 minute walking distance and 10 meter walking speed in patients with multiple sclerosis and stroke. *Arch Phys Med Rehabil* 2012; 93: 1167–1172. DOI: 10.1016/j.apmr.2012.02.026
29. ATS statement: guidelines for the six-minute walk test. *Am J Respir Crit Care Med* 2002; 166: 111–117. DOI: 10.1164/ajrccm.166.1.at1102
30. Kvale S, Brinkmann S. *InterViews: learning the craft of qualitative research interviewing*. Los Angeles: Sage Publications; 2009.
31. Braun V, Clarke V. To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. *Qual Res Sport Exer Health* 2021; 13: 201–216. DOI: 10.1080/2159676X.2019.1704846
32. Kannisto K, Hirvonen E, Koivuniemi M, Teeri S, Asikainen P, Koivunen M. Daily functioning support – a qualitative exploration of rehabilitative approach in acute hospitalised care. *Scand J Caring Sci* 2021; 35: 1342–1351. DOI: 10.1111/scs.12954
33. Wade DT, Halligan PW. The biopsychosocial model of illness: a model whose time has come. *Clin Rehabil* 2017; 31: 995–1004. DOI: 10.1177/0269215517709890
34. Britten N, Ekman I, Naldemirci Ö, Javinger M, Hedman H, Wolf A. Learning from Gothenburg model of person centred healthcare. *BMJ* 2020; 370: m2738. DOI: 10.1136/bmj.m2738
35. Asplin G, Carlsson G, Fagevik Olsén M, Zidén L. See me, teach me, guide me, but it's up to me! Patients' experiences of recovery during the acute phase after hip fracture. *Eur J Physiother* 2021; 23: 135–143. DOI: 10.1080/21679169.2019.1650394
36. Carel H. *Phenomenology of illness*. New York: Oxford University Press; 2016.
37. Fini NA, Simpson D, Moore SA, Mahendran N, Eng JJ, Borschmann K, et al. How should we measure physical activity after stroke? An international consensus. *Int J Stroke* 2023; 18: 1132–1142. DOI: 10.1177/17474930231184108
38. Mead GE, Sposato LA, Sampaio Silva G, Yperzeele L, Wu S, Kutlubaev M, et al. A systematic review and synthesis of global stroke guidelines on behalf of the World Stroke Organization. *Int J Stroke* 2023; 18: 499–531. DOI: 10.1177/17474930231156753