

Striving for a life worth living: stroke survivors' experiences of home rehabilitation

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Scand J Caring Sci; 2015; 29; 651–661

Striving for a life worth living: a qualitative study of experiences of stroke survivors undergoing home rehabilitation

Background: For mild-to-moderate stroke survivors, early supported discharge from hospital, followed by home rehabilitation is preferred over conventional care. How this mode of service contributes to recovery from stroke survivors' perspective needs further investigation.

Aim: The aim of this study was to explore mild-to-moderate stroke survivors' experiences with home rehabilitation after early supported discharge from hospital.

Methods: A qualitative interpretive interview design was used in the context of a randomised controlled trial. A purposive sample of eight participants (45–80 years) was followed by an ambulant team, and a specific healthcare team provided home rehabilitation. Data were analysed using interpretive description, systematic text condensation and coping theory.

Findings: A crucial determinant for the participants' hopes for a life worth living was the mutual confidence expressed in encounters with healthcare professionals and the participants' ability to make sense of their now-altered body. The professional caretakers' communication qualities and their ability to attend to individual needs were important. Help in processing the emotional reactions caused by a changed body and in socialising was requested by participants. Professional caretakers providing home rehabilitation should strive for a more flexible- and individually tailored service and should seek increased cooperation among stakeholders.

Conclusion: The focus on therapeutic communicative qualities, bodily changes, emotional processes, social concerns and long-term follow-up should be increased in order to achieve a more beneficial experience for stroke survivors.

Keywords: early supported discharge, home rehabilitation, qualitative research, recovery, stroke.

Submitted 3 June 2014, Accepted 10 October 2014

Introduction

Stroke (1) is a major cause of disability in most industrialised countries (2). After acute treatment in specialised stroke-units, early supported discharge (ESD) followed by home rehabilitation is preferred over conventional care, especially for mild-to-moderate stroke survivors (3, 4). Mild-to-moderate stroke survivors' experience of home rehabilitation and ESD is, however, poorly investigated. Notwithstanding the ESD perspective, mild-to-moderate stroke survivors are found to feel insufficiently recovered

despite being more or less independent in activities of daily living (5–10).

Previous research, including a few ESD studies, has identified essential patient characteristics that help to sustain the progress of and satisfaction with home rehabilitation. Healthcare professionals are given a crucial role in helping stroke survivors mobilise positive attitudes and coping strategies (10–15), bodily abilities (10, 14), social support and involvement in meaningful activities and social situations (5, 7, 12, 14–19). Studies also report that upon coming home, survivors request stroke-related information (20), physical training (9, 21) and a flexible service suited to meet their needs (14).

One meta-analysis studying these issues states the importance of multidisciplinary and specialised ESD teams to meet the patients' needs (22). The best mix of healthcare professionals required to suite stroke survivors' needs is, however, discussed (15, 23–27).

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Alternately, some suggest looking beyond the disciplinary qualifications of the ESD team and, instead emphasising personal qualities, presence and relational concerns that would enhance the patient's rehabilitation experience (28). During home rehabilitation, stroke survivors are found to appreciate skilled professionals who also show understanding of their situation (16).

The possible tension between the traditional focus on physical recovery and the more existential dimensions of recovery (6, 7, 12, 27, 29–31) is also interesting as it contributes to a discussion of what promotes a successful rehabilitation service from the survivors' perspective. Established views of healthcare workers as experts, whom patients are dependent on to get 'cured' are challenged (32, 33), as well as the emphasis on assessment tools and simple task-specific treatment (34, 35). Emotional support to interpret future abilities and empowering patients in their process of adjustment to a new 'normalcy' is shown to facilitate recovery (36, 37), and maintenance of patients' hope that is essential for successful recovery (32, 33, 36).

Antonovsky's salutogenetic theory, with its core concept Sense of Coherence (SOC) in life, can illuminate hope as a coping resource in stroke rehabilitation and why hope is a determinant of health and well being (38). According to Antonovsky, coping with a life experience such as stroke will depend on the individual's ability to mobilise available resources. This is determined by which the person's situation seems structured, predictable, and/or explicable (comprehensible), manageable or within the individual's control (manageability), and whether it is worth investment (meaningfulness). Anthonovsky's theory is considered relevant in the present study and is drawn upon in the analysis.

Current research helps to understand the healthcare professionals' need to negotiate the traditional view of stroke rehabilitation when involved with patients after coming home. Knowledge derived from studies that use a first-person perspective within the context of ESD is, however, limited. An expansion of this research topic may contribute to important groundwork for decision-making, both for legislators and professional caretakers.

The aim of this study was to explore mild-to-moderate stroke survivors' experience with home rehabilitation after ESD. We focused on patient-attributed meanings of how this type of service contributed to their recovery 6–8 months after returning home.

Methods

Study design

Qualitative interviews were conducted in the context of a randomised controlled trial (RCT) entitled, 'early supported discharge (ESD) after stroke in Bergen,

Norway' (39). This substudy relied on interpretive description (ID) (40).

Participants

Patients in the home rehabilitation group of the RCT (39), who replied to an invitation to a 6-month follow-up were invited to participate in this study. Two patients without rehabilitation needs and one patient with strongly impaired speech capability were excluded. Out of the ten patients who agreed to participate, one was excluded from the RCT and therefore from this substudy. Another patient was not interviewed, because at that time, there were enough data to fully address the aim of the study. This resulted in a final purposive sample of four women and four men (45–80 years). At 6 months their National Institute Health Stroke Scale (NIHSS) scores of ≤ 14 indicated a mild-to-moderate stroke (41). The modified Rankin Scale (mRS) (42) and the Assessment of Motor and Process skills (AMPS) (43) used to measure their ability in activities of daily living (ADL) showed that they were in the able range of the scale, most being independent in ADL (mRS score ≤ 2) (41). Participant characteristics are shown in Table 1.

General course of treatment and follow-up

Patients in the home rehabilitation group of the RCT (39) were initially treated in a stroke unit at a university hospital, and then discharged to home as early as possible. Patients needing extensive rehabilitation were transferred to a specialised rehabilitation unit for stroke survivors before returning home. A multidisciplinary ambulant team followed the patients and coordinated transfers between units at different healthcare levels, home visits and outpatient follow-ups at the hospital at 3 and 6 months after inclusion in the study.

A specific multidisciplinary municipal healthcare team provided home rehabilitation for up to 4 hours a day and for a maximum 5 weeks. Home rehabilitation began within 1 week after discharge, starting with goal setting and ending with an evaluation. Follow-up rehabilitation in the community, treatment by a speech therapist or medical support from their general practitioner (GP) not directly involved in the RCT (39) were provided. An overview of the rehabilitation services and treatment received by each participant is presented in Table 2.

The team followed national guidelines for rehabilitation after stroke (44). This meant that they endeavoured to deliver individualised treatment aimed at improving physical and cognitive functions, combining task- and function-specific treatment, and working across traditional professional roles (45).

Table 1 Participant demographic, clinical and functional characteristics at baseline and 6-month follow-up (N = 8)

Variables	Baseline	6 months ^a
Demographic variables:		
Age median (range)	57.5 (45–80)	
Gender, n		
Male	4	
Female	4	
Civil status, n		
Living with partner	5	
Single	3	
Education, n		
University or college	4	
High school or elementary school	3	
Missing (no data)	1	
Employment status, n		
Working	6	
Retired	2	
Clinical variables:		
NIHSS score (34–0), median (range) ^b	3.5 (15–0)	1 (6–0) ^c
Mild (≤ 7), n	5	7
Moderate (8–14), n	3	0
Type of stroke, n		
Ischaemic	7	
Haemorrhagic	1	
Affected hemisphere, n		
Right	3	
Left	4	
Cerebellum	1	
Functional variables:		
mRS score (6–0), median (range)	2 (4–0)	2 (3–0) ^d
Independent (≤ 2), n	6	7
Dependent (< 2), n	2	1
AMPS motor score (–3 to +4), median (range)	1.66 (–2.12 to 3.81)	2.76 (2.06–3.37) ^e
AMPS process score (–4 to +3), median (range)	1.07 (–0.19 to 2.27)	1.57 (1.49–2.35) ^f

NIHSS, National Institutes of Health Stroke Scale; mRS, modified Rankin Scale; AMPS, assessment of motor and process skills.

^aFor data missing at 6 months, 3 months data are provided in footnote.

^bBaseline is the last assessed score before discharge from acute stroke unit.

^cNIHSS score for 1 person at 3 months = 1.

^dmRS score for 1 person at 3 months = 2.

^eMedian AMPS motor score for 3 persons at 3 months = 2.80 (0.49–3.10).

^fMedian AMPS process score for 3 persons at 3 months = 2.17 (0.69–2.31).

Data production

The participants were interviewed once by the first author, in their homes or in a health institution, 6–8

months after their stroke. All interviews were recorded and transcribed verbatim. In one case, the participant's partner, who was present during the interview, elaborated on parts of the interview. The interview was extensive and guided by 6 topics related to the participants' experiences with home rehabilitation and their daily life. The questions were formulated to reveal differences between the present situation, prestroke situation, and their future needs of taking part in every-day activities. Additionally, one question was designed to give the participants the opportunity to freely address topics of their own concern (Table 3).

Additional open-ended questions were asked when elaboration was needed. Interviews ceased when the material was considered to contain a sufficient variety of experience and common features to achieve the purpose of the study. Information about medical conditions and treatment received was taken from the RCT (39).

Data analysis

Analysis of the transcribed interviews was informed by ID (40). ID is an inductive, in-depth form of analysis that focuses on meaning and that is designed to generate knowledge of individuals' subjective experience relevant within health practice. The first and last author read each interview continuously, to obtain an overall impression, discussing certain topics and situations in the participants' stories that stood out as especially interesting with respect to the research questions. Once the interviews and transcriptions were completed, ID was supplemented by systematic text condensation, a step-wise approach described by Malterud (46).

First, the transcripts were read transversally, searching for an overall view characterising the interviews as a whole. This also entailed comparison across all interviews looking for preliminary themes that possibly reflected important meanings across the participants' experience. These preliminary themes were also assessed in relation to previous preliminary topics and situations identified in each of the individual interviews.

Next, we searched for intuitive meaning units in the participants' experience. The transcripts were read systematically in order to identify and classify these into codes; that is all text elements that elucidated the phenomena being studied. During this process of de-contextualising, the similarities and differences of each code were reflected on. The final codes chosen were based on the consensus of the first and last author. At this stage, the possible connection between the material and coping with stroke was recognised and contributed to the coding process.

In the next step, it was decided to incorporate Antonovsky's theory of coping (38) as an underlying theoretical basis to guide our analysis, while hope seemed

Table 2 Rehabilitation service received by each of the participants (N = 8)

Rehabilitation service	Participant								Median
	1	2	3	4	5	6	7	8	
Specialised stroke unit at hospital, in bed days	16	7	7	9	8	8	6	6	(7.5)
Rehabilitation unit at hospital, in bed days	38				50				
Contact with ambulatory team, in days	52	8	6	7	52	6	4	13	(7.5)
3-month follow-up ^a	x	x	x	x	x	x	x	x	
6-month follow-up ^a	x	x	x	x	x	x		x	
Contact with municipal healthcare team, in days	17	6	12	18	12	11	14	1	(12)
Number of home visit(s)	20	6	14	19	12	13	18	1	(13.5)
Number of treatment(s) related to intervention ^b									
Functional treatment (e.g., muscle strength or cognitive problem solving)	15	4	13	8	10	9	16	?	(10)
Process-oriented communication (e.g. information and reflection targeting lifestyle changes, processing motivations or reorientation of wishes)	8	6	12	15	9	10	15	?	(10)
Activities of daily living (e.g. transfer, dressing, cooking)	5	0	0	6	3	2	1	?	(2)
Environmental facilitation (e.g. technical aid, supervising next of kin)	2	1	0	2	0	1	0	?	(1)
Number of home visit(s) from each profession									
Physiotherapist	14	4	6	8	8	7	8	1	(7.5)
Occupational therapist	8	3	7	7	7	6	6	0	(6.5)
Nurse	2	0	2	7	1	4	7	0	(2)
Contact with other services									
Speech therapist					x	x		x	
General practitioner	x	x	x	x	x	x	x	x	

^ax means that the actual treatment is received by the participant.

^bData are missing for participant number 8.

Table 3 Main topics of interview guide^a

1.	How do you see your own situation?
2.	Can you describe a typical day?
3.	What has changed since before your stroke?
4.	What are your wishes for what you would like to do?
5.	What do you think are of vital importance when it comes to implementing what is important to you?
6.	What thoughts do you have about the rehabilitation service you have received?
7.	Are there experiences you think are important that we have not talked about?

^aThe choice of main topics in the interview guide was based on previous research, the first author's professional concerns about activity limitations after stroke, and discussions with the more experienced last author of this paper and other colleagues.

important to the participants in our study. The participants' experiences of the current situation as comprehensible and/or meaningful are discussed in a previously published paper elucidating how stroke affected the participants' existential dimensions of life (47). The interviews also included more concrete experiences related to how professionals' behaved and acted, and

how this influence their rehabilitation experience, which is elucidated in the current study. Comprehensibility as a dimension was only touched upon in these parts of the interviews and was therefore not included in further analyses. Each subgroup with its meaning units was examined to determine which of the participants' experience seemed challenging or manageable given their available resources, and whether they were meaningful to engage in. This inductive process of theorising, which complies with the recommendations in ID (40), helped us to arrive at the 'best guesses' about how home rehabilitation suited stroke survivors' needs and contributed to their recovery 6–8 months after homecoming.

Meaning content was further abstracted and sorted into subcodes. Essential knowledge within each code and subcode was condensed into consistent descriptions intended to address the aim of the study.

The fourth step of the analysis involved establishing analytic texts derived from a systematic, in-depth examination of the transcripts and discussions among the authors. This meant re-contextualising, which resulted in an interpretive description of core meanings in the participants' experience. This is outlined in core theme and

subthemes, and presented in the findings. These descriptions were validated as being consistent with descriptions expressed by the participants. To ensure a defensible presentation of the core theme and subthemes identified, representative text elements were selected. The analytic process was completed by looking for crucial variations and contradictions.

Findings

The participants' experiences with home rehabilitation were structured according to the core theme, *Hope for a life worth living*, which consists of two subthemes: *The trauma of a changed body: making sense of emotional reactions*, and *Encounters with professionals: the challenge of cultivating mutual confidence*.

Hope for a life worth living

Recovering from mild-to-moderate stroke affected the participants strongly at an emotional and existential level, and the analysis showed that the emotional aspects of living with a changed body were especially challenging. Even 6–8 months after the stroke, their situation was characterised as demanding. In their struggle to make their situation comprehensible and worthwhile, a sense of hope emerged as the most important driving force. Several participants emphasised their hope for continued engagement in activities they had appreciated before the stroke. This was related to travelling, belonging in social fellowships, and/or mastering simple tasks, which have been and still was important in their everyday lives. Others had only a vague notion of what they could hope for. Crucial to their hope was making sense of their altered body and emotional reactions, and cultivating confidence in the professionals they were involved with.

The trauma of a changed body: making sense of emotional reactions

The participants' hard times emerged clearly in their stories. They struggled to get to know their now-altered body and to make sense of emotional reactions.

Their changed bodies had widespread consequences for their self-esteem and engagement in practical and social activities. In their quest to regain some control over their situation, processing emotional reactions was substantial. Initially this meant getting familiar with bodily limitations and resources. In the long run, belonging in valued relationships was a fundamental prerequisite for creating a life worth living, despite the stroke. Although the participants relied on the professionals' abilities to help, they also felt left alone with crucial concerns.

A female participant in her 40s expressed her unmet needs in this regard:

I intend to ask my GP about getting a referral to a psychologist, so I can sort out [emotional reactions]. To live on, I need to sort out my depression. (Participant 6; Table 2)

Seven months after her stroke, she still experienced her situation as being chaotic. Her quest for help to get ahead was not unusual. Questions about uncertainties of life and death, such as being afraid of having another stroke, or of possible medication side effects needed to be clarified. This indicates that the team was unable to sufficiently address her intrusive emotional reactions. Consultations with a psychologist were requested, but not offered. The participants' need for stroke-related information seemed insatiable, and the physicians' role seemed important in their search for explanations and solutions. Improved bodily functions and fulfilled requests for treatment, which included city tours, hobbies and other meaningful activities satisfied participants. A confusing split between body and will, and difficulties with re-incorporating know-how about bodily abilities and limitations emerged as important theme for professionals to address. Even if negative emotional reactions could be unavoidable or tempting to turn to, a fighting attitude was also exhibited, as by this man in his 50s:

All the weaknesses I felt I had, or that were uncovered [by others], my thought was: What can I do to overcome this? I don't want to accept my weaknesses. At least I'll do what I can to fight them. (Participant 2)

He found the situation meaningful enough to engage in, but was reluctant to accept functional problems and what we can sense as a widespread emotional reaction related to his changed body.

Participants gave specific examples of areas for potential improvements. Initially, after their home-coming, they perceived physical exercise and massage as lacking. Even if these treatment options were offered, they were perceived as occurring too infrequently. Disagreement about priorities arose when professionals spent much of their time filling out forms at the expense of physical training. Memory training was offered only by some professionals and not delivered during vacations, which meant significant negative consequences for the participants and frustration. A man in his 80s with stroke-related memory-difficulties told how he 'suffered' when his problem emerged in conversations, especially with his children (Participant nr 3). Speaking about the treatment he was offered, he told of aids and hand exercises. Findings like this illuminate that treatment was not sufficiently guided by the patients' needs.

In the long run, the participants seemed to struggle with the notion of whether they, in spite of having an

altered body, were still good enough to be loved by their grandchildren, to be respected by colleagues etc. Maintaining previous social roles were considered important, even if it was threatening. Even if 5 weeks of home rehabilitation was deemed sufficient for some, the need for follow-up was still prominent for several participants, especially to help in their efforts to redefine important aspects of their lives. Beyond encouragement, and in some cases, facilitation of leisure activities promoted by the healthcare team, there was, however, little in the participants' stories that indicated that the professionals showed interest in the participants' social life. Some of the participants lacked the necessary capacity to change a demanding situation on their own, which meant that they became increasingly isolated. Grief and loneliness related to loss of contact with important others were common, both among those who lived alone and those in a partnership. A mother and career woman in her 40s told of loneliness in the period when she was still on sickleave and was home alone during the day:

When they [municipal healthcare team] left, I felt so lonely because there was no one else there. (Participant 6)

She had no one to talk to and was unable to fill her days with activities which were meaningful to her. Being home in familiar surroundings was initially expressed exclusively as being positive, but in the long run, it was perceived also as a hindrance for some. This may indicate that the participants have a limited social capacity early on after stroke and a need for long-term follow-up. A man in his 50s elaborated on what he appreciates when starting to work again:

To get something to do and mingle with my colleagues, I've many nice co-workers, who I like to talk and socialise with. Just to get out of bed, catch the bus, get to work and be where you were before. (Participant 5)

This man clarified his feelings on how belonging in valued relationships and social arenas gave meaning to his life. Rehabilitation in groups was considered to be an opportunity for social interaction, and disappointment was expressed when the follow-up service was based on training alone.

These experiences of unfulfilled needs indicated the need for greater focus on particular areas of recovery and on emotional processes in order to better deal with the after effects of a changed body caused by stroke.

Encounters with professionals: the challenge of cultivating mutual confidence

This subtheme deals with the participants' encounters with professionals, and how personal and professional

approaches contributed to mutual confidence, or failed to do so.

Professionals were assigned a crucial role with regard to guiding the participants' bodily recovery and what they should dare to hope for. The professionals' individual ways of behaving and communicating, as well as their professional expertise, were deemed important. Successful encounters involved like engagement, empathy and equality. This promoted the participants' confidence in the professionals' ability to help them manage their condition, their feelings of being empowered, and their hope for future successful coping. Less successful encounters could leave the participants helpless and uncertain of what to hope for, which added an extra burden to an already vulnerable situation.

Professionals' capability in encouraging personal engagement and qualified support was emphasised in the participants' responses. One male participant in his 60s highlighted how the healthcare team was important for building hope in his recovery:

They [the municipal healthcare team] really came and stayed here and did something. They showed faith in positive development and supported me in that. It's important to convey that recovery can still happen, although the progress is slow. (Participant 1)

His statement underscores how cultivating confidence was mutual. He appreciated professionals believing in him and the possibility of progress, but he also needed to believe in their ability to understand his situation and provide appropriate help.

The participants appreciated and expressed a desire to cooperate with empathic professionals. Their taking time to listen, offer comfort and being nice were essential therapeutic communication qualities described. Emphasised also were enthusiastic and optimistic statements from therapists, such as confirmations of doing 'this or that' the correct way. Encouragement helped participants feel like their treatment was a priority. These were highlighted by those who addressed the therapists' responsibility to even mask their lack of faith in the participant's progress. The delicate balance between optimism and realism was, however, requested, and being too optimistic on the part of therapists was actually provocative for some.

The data material also reflected feelings of equality between therapists and participants, such as having respected disagreement about treatment decisions. The ideal in successful rehabilitation is patients' being actively engaged in their recovery. However, it occasionally felt good when the professional took charge. Initially after stroke it was not always easy to know how or express one's wishes for rehabilitation. Confidence was, however, challenged when experiencing unmanageable pressure about what to do and manage. A female participant in her 50s described a situation controlled by the therapist that went totally wrong:

They just had a plan of returning me back to work. It was their goal. When they repeated that every time we met, then I started to cry I think, every time. (Participant 7)

The professionals' attitudes and approach to her on this point, made her feel inadequately understood, indicating that the treatment was not sufficiently guided by her needs.

Lack of self-determination was also expressed when healthcare professionals told patients to change their diet, or that their driving license would be revoked because of the stroke. This could make the participants feel helpless or uncertain about the future, even if they agreed with the purpose of the request.

Confidence was also undermined by controversies that developed between the participants and professionals and also among professionals. Professionals' lack of expertise was another source of frustration; for instance, when being diagnosed incorrectly. Situations in which these problems emerged meant that participants had to make their own independent decisions. That could work out okay, but might also foster strong feelings, such as great disappointment. A woman in her 80s was very confused when her GP and the doctors involved in the ESD service held differing opinions:

When there are different opinions among the doctors, it's problematic. It's very important to give the patient a feeling of security and knowledge about what to be done if this or that may occur. (Participant 4)

She expected a clear recommendation, but instead received ambiguous information, which in turn contributed to her uncertainty about her situation. Responsibility for her altered situation was thrown upon her, a responsibility that she was not ready to handle.

Collaboration among stakeholders was also essential during transfers between healthcare levels, which emerged as a vulnerable period for the participants. This scenario is represented well by a response from a female participant in her 40s:

They told me I had to wait because of some paperwork that had to be done. They put me aside for several weeks before I got started [with my follow-up treatment], while I felt it was very urgent for me. I lost some [valuable] time, and when I got started I had lost the glow, and they lost a little glow too, and then we were, not enemies, but I... [Sentence not completed]. (Participant 7)

The patient felt betrayed by the professionals' in whom she had put her trust. She could not mobilise the necessary 'fighting spirit' anymore and was no longer in contact with someone who advocated for her.

These stories of challenging encounters with professionals indicate that mutual confidence was an important theme in the participants' experiences of home

rehabilitation. This also meant more individually tailored treatment in domains such as physical training, memory training and long-term follow-up with a focus on increasing social interactions.

Discussion

The uncertain process of recovering a meaningful life after stroke was strongly linked to mutual confidence expressed between professionals and participants. The participants' ability to make sense of emotional reactions also contributed to their recovery. Our findings are discussed in the light of previous research, current theory and methodological considerations.

The insight gained in this study clarifies the importance for patients of maintaining hope as a motivating factor in their recovery, even though they suffered 'only' mild-to-moderate stroke. Hope enabled them to continue their efforts at improving their condition and achieving a life worth living (32, 33, 36). This suggests that 6 months after stroke, their attention was focused on returning to normalcy, a finding that has been reported previously (17, 21, 48).

Our study revealed a confusing experienced split between one's own body and will with consequences for the participants' emotional life after stroke. Their struggle to make sense of a changed body and the emotional reactions caused by stroke is, however, shown to be a natural part of an overall health promotion process when living with chronic disease and/or disability (49, 50). In order to process emotional reactions, participants highlighted some of the same barriers as noted in previous studies of stroke survivors receiving other kind of rehabilitation services, as the request for stroke-related information (20), physical training (9, 21), contact with their GP (23, 25), psychological support (15) and opportunity to share experience with informed others (5). These findings indicate that the home rehabilitation did not sufficiently address these aspects. Barriers against processing emotional responses successfully possibly undermined the patient's control of the situation, which is in line with previous research (9, 11, 13, 14). Participants' stressful considerations reported 6 months after stroke indicated that they were working on an ongoing process (6, 7, 49). Considering that emotional concerns following a changed body can be present for years after stroke (7, 12, 15, 17, 30), working on incorporating bodily based know-how anew as a coping resource will take time and engagement (49). The possible risk of isolation (29, 51), as we also observed among our participants, is an issue which becomes even more paramount for healthcare workers to address early after home-coming (37). Even if the participants initially asked for more massage and exercises, they gradually appreciated meaningful activities and social interaction. The importance

of taking into account the existential dimensions of recovery is in line with previous studies (6, 7, 12, 27, 29–31).

Our findings illustrate how vulnerable the participants' hope is in encounters with professionals, and thus contribute to an ongoing discussion of how healthcare professionals can motivate patients and still facilitate a realistic view of recovery without severely upsetting them (6, 7, 9, 13, 18, 21, 27, 31). Our findings address the professionals' responsibility to treat each patient using an individualised approach (37) and supports that a closer cooperation between stakeholders and an expanded flexibility of the service (14, 23, 26, 32, 33, 36, 37) might enhance this approach and build mutual confidence.

According to Antonovsky (38), hope is an important coping resource. Thus, hope not only gives stroke survivors something positive to cling to and stretch their efforts towards, but also encourages health professionals. Meaningfulness is, however, also influenced by participation in decisions and valued feedback from significant others (38). This might require realistic knowledge about stroke and recovery, which was requested, and negotiation between professionals and patients who want to make informed decisions about future possibilities (27, 37). Assuming sufficient emotional support, a sense of meaningfulness can still be maintained (38). This might explain the participants' strong request for emotional support.

The participants' in our study struggled to handle their new life situation. Like other mild-to-moderate stroke survivors their needs for assistance to manage were apparent (5–10). This was particularly related to the emotional trauma of changed functional capacities (30, 49). However, home rehabilitation was not perceived as flexible enough to sufficiently maintain a balance between their burdens and available resources. According to Antonovsky (38), lack of flexibility is a factor that tends to reinforce lack of control and increase strain as expressed through the participants' feelings of helplessness. The importance of mutual confidence, which was revealed here, supports the notion that it is the patients' and professionals' combined resources which help patients perceive the situation as manageable (27, 32, 33, 37, 38).

Methodical considerations

The qualities of this study are discussed in the light of reflexivity, dialogue and relevance, as described by Stige et al. (52).

The choice of ID means aiming at developing knowledge with implications for practice (40). However, the framework of the RCT might have limited the flexibility of the home rehabilitation, and thereby contributed to

the participants' experiences of insufficient flexibility in the rehabilitation offered.

During the interviews, it became clear that the participants' experience of home rehabilitation was 'coloured' by how well the service suited their needs. This in turn touched on an existential dimension of their lives. Thus the interview material had the potential for in-depth analysis of significant meanings, as well as identification of areas of improvement. The choice of Antonovsky's theory of SOC (38) as a relevant framework is consistent with meaning-centred analysis, which is emphasised by Thorne (40).

We could not strategically compose the sample and the reader must have in mind the relatively young sample of younger mild-to-moderate stroke survivors and that two of the participants received extensive rehabilitation before arriving home. A limitation of the study is that the empirical material is small, and consists only of eight interviews with eight participants. The first author was not involved in the rehabilitation or planning the RCT. Nevertheless, the fact that the participants were recruited for the interviews because they took part in the RCT, also linked the researcher to the RCT, which might have influenced what the participants' felt they could talk truthfully about. Yet the interviews elucidated varied and nuanced experiences that have escaped the notice of other studies in the context of ESD.

As we are researchers in the field of rehabilitation, this probably influenced the interpretive process and choice of theoretical framework, on which our findings are based. To avoid what Thorne calls, 'premature closure' (40), we explored various coding before core meanings were identified and a theory to expand our understanding was determined. Our preliminary results were shared in qualified forums. Even if a step-wise procedure was used together with ID, a constant changing of focus, between de-contextualising and re-contextualising contributed to a dynamic analytic process, which we have tried to be transparent about. ESD team members and mild-to-moderate stroke survivors undergoing home rehabilitation are, however, the ones best suited to assess the relevance of our findings.

Implications for practice

To better prepare the patients to manage and adapt to consequences of mild-to-moderate stroke, our study supports home rehabilitation service to be further developed by incorporating a greater focus on individual needs (12, 14, 26, 37, 48), be more focused on how to accommodate the existential aspects of recovery (6, 7, 27, 29–31), and the understanding of the importance of bodily based know-how (49). The need to explore the existential aspects of recovery should be implemented in guidelines for treatment and rehabilitation after stroke, and

systematically addressed by ESD team members in open-minded communication with patients. Addressing these issues may help patients to overcome the trauma associated with a changed body, and prevent illness-related problems from being compounded. The understanding of stroke recovery as a process involving existential aspects also calls for emotional support and long-term follow-up, which may prevent the need for psychologists. Closer cooperation among all the stakeholders and enhanced flexibility of home rehabilitation would likely increase the chances for successful recovery processes. SOC theory may serve as a theoretical framework to better understand why these aspects may promote health despite of stroke and disability (38). Healthcare professionals involved with stroke survivors should learn how to facilitate recovery in practice.

Conclusions

To accommodate stroke survivors' need of emotional support to foster the hope necessary to forge ahead, professionals involved in home rehabilitation should strive for cooperation among all stakeholders and build a flexible service based on individual patient needs. For the participants in our study, this meant increased attention to therapeutic communicative qualities, emotional processes, social concerns and long-term follow-up.

Acknowledgements

We thank the participants who shared their experiences with us.

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Author contributions

Tina Taule planned the study, carried out the interviews and analysis, and organised and wrote the manuscript. Liv Inger Strand and Jan Sture Skouen contributed to the planning and writing of the manuscript and provide comments on drafts. Målfrid Råheim took part in planning the study; supervising the interviews and analysis; and planning, commenting on, and writing the manuscript.

Ethical approval

The Norwegian Regional Ethics Committee approved this study (project number 070.08). Written informed consent was obtained. First author was not involved in planning the RCT. None of the authors were involved in the rehabilitation, only the first author took part in the interviews. The participants chose the interview location in order to minimise discomfort. Steps were taken to preserve the participants' anonymity.

Funding

The Norwegian Extra Foundation for Health and Rehabilitation funded this study through EXTRA funds (project number 2011/2/0135).

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