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RESEARCH ARTICLE

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Stroke survivors' experiences with rebuilding life in the community and exercising at home: A qualitative study

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Abstract

Aim: This study aimed to explore how stroke survivors deal with stroke-related impairments when rebuilding their lives in the community and their experiences of exercising at home.

Design: An explorative and descriptive qualitative study.

Methods: A purposive sample of ten stroke survivors residing at home was recruited to explore experiences of rebuilding their lives in the community and exercising at home. One focus group interview was conducted followed by semi-structured interviews. Data were analysed using thematic analysis.

Results: Three main themes were identified: "Framing exercise within the context of everyday life" describes how stroke survivors integrate exercise in everyday activities with varying success and the social importance of exercising; "Managing the challenges of physical impairment" describes the taxing undertakings in daily living, loss of concentration and identity; "Long-term challenges of everyday life" describes how the stroke survivors manage depression and live with a sense of uncertainty.

KEYWORDS

home rehabilitation, qualitative research, rehabilitation, stroke patients, stroke rehabilitation

1 | INTRODUCTION

Stroke is a leading cause of serious, long-term disability globally (WHO, 2015a, 2015b). Over 50 million stroke survivors experience a wide range of physical, cognitive, emotional and/or psychological problems (Miller et al. 2010; Yoo et al., 2020). Around 74% of stroke survivors require assistance or are dependent on caregivers for daily activities (Miller et al., 2010). The most frequent long-term problems of stroke survivors were limitations in mobility, fatigue, concentration problems and falls (Elf et al., 2016; Saunders et al., 2014). Stroke survivors report a wide range of needs which included: (i) cognitive, psychological and physical function needs; (ii) activity and participatory needs; and (iii) environmental needs, like support, safety and accessibility (Krishnan et al., 2017). There is, however, a growing evidence that multiple long-term needs remain unmet post-stroke (Lehnerer et al., 2019; McKevitt et al. 2011).

2 | BACKGROUND

The primary aim of poststroke rehabilitation is to rebuild independent living skills (Belagaje, 2017). Despite the evidence for organized care facilitating recovery after stroke, rehabilitation services offered to stroke survivors vary greatly in type of care settings, duration, intensity and type of rehabilitation programs delivered, and in the degree of involvement of medical, nursing and other rehabilitation specialists (Winstein et al., 2016). Nowadays, stroke survivors are discharged early from inpatient care and need to continue rehabilitation in the community (Lou, Carstensen, Møldrup, et al., 2017; Nordin et al., 2015). This early home-based rehabilitation may reduce disability and increase quality of life (Rasmussen et al., 2015). 'Coming home' is important for stroke survivors in order to re-establish self-esteem and it increases responsibility and understanding of the illness and its consequences in relation to the stroke survivors' situation (Nordin et al., 2015). Discharge from inpatient care might represent major challenges for stroke survivors who face long-term functional impairments, new medications, rehabilitation goals, fragmented care and poor communication with healthcare providers (Geng et al., 2019; Nordin et al., 2015). There is considerable amount of literature concerning unmet needs of home-dwelling stroke survivors (Lin et al., 2019).

Physical activity is an important aspect of rehabilitation to improve and maintain physical fitness after stroke that needs to be continued after inpatient rehabilitation (English et al., 2016; Teasell et al., 2014). Exercise is a subset of physical activity that is planned, structured and performed repetitive to improve physical fitness and functional recovery (Chaturvedi & Nahab, 2017; Moore et al., 2018; Stretton et al., 2017). Physical activity and exercise poststroke improve fitness, walking speed, balance and global indices of disability in stroke survivors (Saunders et al., 2014) and is important for secondary prevention of stroke (Biswas et al., 2015). Therefore, exercise and physical activity need to be a lifelong part of stroke survivors daily life. However, stroke survivors living in the community are generally physically inactive (English et al., 2016) and less than 30% of independently mobile stroke survivors meet the required levels of physical activity (Fini et al., 2017; Moore et al., 2013). Adhering to the required levels of physical activity is complex due to impairments, lack of professional support, lack of motivation, poor information provision, costs, limited access to resources and low self-efficacy (Moore et al., 2013; Nicholson et al., 2013; Olafsdottir et al., 2020b).

The majority of stroke survivors and their families willingly take responsibility for the recovery at home and generally felt safe and capable to do this (Geng et al., 2019). However, homebound stroke survivors receive limited supervised and unsupervised exercise and often have little motivation and confidence towards exercise (Krishnan et al., 2017; Mayo, 2016). Lack of motivation and understanding on how to incorporate exercise into daily activities are among reasons stroke survivors give for lack of adherence to unsupervised exercise poststroke, especially as they need to rely more on themselves and caregivers to continue with exercise and physical activity (Lou, Carstensen, Møldrup, et al., 2017; Miller et al., 2017; Nicholson et al., 2013). They also experience uncertainty about what they can do to maintain or improve function at home and may need frequent practical and emotional support to continue with exercise and physical activity (Lou, Carstensen, Møldrup, et al., 2017). Because of this, stroke survivors residing at home who do not exercise regularly, may not be able to reach their full potential and not be able to rebuild a fulfilling life after the stroke (Lou, Carstensen, Møldrup, et al., 2017). Although considerable number of studies have investigated the needs of home-dwelling stroke survivors, earlier studies generally focused on stroke survivors' or caregivers' experiences of primary care, the needs of stroke survivors with communication difficulties, social participation experiences and experiences with going back to work occupations, but generally not on the experiences of rebuilding life or continuing with exercising at home (Lin et al., 2019).

2.1 | Research question

The aim of this study was to explore how home-dwelling stroke survivors deal with stroke related impairments when rebuilding their lives in the community and their experiences of exercising at home. The research question was: "How do the home-dwelling stroke survivors deal with stroke related impairments when rebuilding their lives in the community and how do they experience exercising at home?"

3 | METHOD

3.1 | Design

This explorative qualitative study was conducted to gain in-depth understanding of the stroke survivors' experiences with rebuilding their lives in the community and exercising at home. This design allows focusing on personal accounts of poststroke rehabilitation in the community and exercising at home (Creswell, 2013). The study was conducted from January 2016–December 2017 in Iceland. Reporting of the study complied with the COnsolidated criteria for REporting Qualitative studies (COREQ) (Tong et al., 2007).

3.2 | Ethics

The study was approved by the National Ethics Committee in Iceland (Ref. VSNb2015110001/03.01). We adhered to the Declaration of Helsinki and General Data Protection Regulation (GDPR) allowing participants to give their consent to certain areas of scientific research. The researchers had no relationships with the participants.

3.3 | Participants

Purposive sampling was used to recruit stroke survivors with a maximum variation in gender, age, level of physical disability and years since the stroke to capture broad understanding into the experiences of rebuilding life in the community and exercising at home poststroke (Braun & Clarke, 2014). Participants were eligible to participate if they had a diagnosis of stroke (ICD-10, 161, 163, 164), a moderate level of physical disability (Modified Rankin Scale (MRS) >2 and < 5), were older than 18 years, had completed at least 3 months of rehabilitation at a rehabilitation centre, were living at home, able to speak and understand Icelandic. Stroke survivors with severe cognitive deflects and pre-existing physical impairments as assessed by the Memory 2 item interRAI test were excluded (Morris et al., 2013). Eligible participants were recruited through the National Stroke Association Heilaheill. Stroke survivors who indicated willingness to participate in the study were contacted by telephone to receive further information and to check eligibility.

3.4 | Data collection

Data were collected using one focus group interview with six participants, followed by one semi-structured interview with each of them and four additional stroke survivors to ensure data saturation. The individual interviews were conducted to provide deeper insight into the personal experiences that had surfaced in the focus group. Combining the focus group and individual interviews provided a nuanced and in-depth understanding on how stroke survivors mitigated challenges of living and how they integrated exercise into their daily lives. The same interview guide was used in both the focus group and individual interviews, which was continually adapted in response to incipient patterns in the data (Braun & Clarke, 2014) (Table 1). During the interviews, participants were encouraged to elaborate on their answers and to suggest topics for discussion relevant to their experiences. Thereby the "expert" status of stroke survivors was acknowledged (Elberse et al., 2011) and the collaborative nature of qualitative research (Creswell, 2013). After the interviews, the researchers filed notes on contextual and non-verbal data to capture body language, emotional reactions and ideas of beginning patterns and initial codes.

The focus group interview was held at a local rehabilitation centre, and individual interviews were held at a location preferred by the participant. The interviews that were held in Icelandic and audio taped took approximately 60 min. Findings were translated to English after data analysis took place.

3.5 | Data analysis

Thematic analysis was used (Braun & Clarke, 2006, 2014). The focus group interview was first analysed followed by the individual interviews. All data were pooled and analysed using an iterative approach. The first step was to become familiar with the data by transcribing the audio fragments and (re)reading the transcripts. Open coding was used to identify meaningful sentences and paragraphs. Themes were established based on patterns in the data and similarities in the codes and subsequently sorted into subthemes. Constant comparison and frequent literature reviews were used to refine themes and subthemes. The research team regularly discussed the (sub)themes, which resulted in a nuanced interpretation. The research team agreed that data saturation was reached after the tenth interview since no new codes emerged. Data were stored and analysed using Nvivo *(v11.4.1.1064. 64 bit. QSR International Pty Ltd., Doncaster, Australia).*

3.6 | Rigour

Several strategies were used to meet the criteria of credibility, transferability, confirmability and reflexivity, thereby strengthening the trustworthiness of this study (Lincoln & Guba, 1985). To

TABLE 1 Interview guide

1.	Can you tell me about your background?
2.	What do you like to do - what are your interests and hobbies?
3.	Can you describe a usual day - what do you do over the day?
4.	Have there been much changes in your daily routines and what is most important for you?
5.	What were your interests/hobbies before the stroke (what losses or gains)?
6.	What motivates you (what do you really like to do)?
7.	Are there things that you would like to do but are not able to do now?
8.	Are there things that you need to do but find really difficult to do?
9.	How do you do things that are challenging for you?
10.	Do you do exercises self (self-initiated exercises)? If yes, which exercises do you do? And if no - why not?
11.	Which exercises do you like/love to do?
12.	Does your partner/family motivate/support you in doing exercise? What would help you?
13.	Where do you do exercise and what are the barriers for exercising at home and what would help you?
14.	Are there other things that you would like to talk about or mention in relation to what we have discussed here today?

TABLE 2 Participant characteristics

	Gender	Age	Living status	Time since stroke	Modified rankin scale	Description of physical / emotional functioning	Participates in formal rehabilitation
1.	Man	44 years	Living together	2 years	2	Walks without support.	Yes
2.	Man	65 years	Living together	2 years	3	Walks with two crutches, finds it difficult to stand up.	Yes
3.	Man	70 years	Living together		2	Walks without support. Has aphasia and difficulties with concentration. Difficulties with putting on a jacket.	No
4.	Woman	62 years	Living together	22 years	3	Cannot use left arm/hand. Has difficulties with walking. Uses one crutch. Experiences emotional difficulties lately.	No
5.	Man	62 years	Living together	5 years	2	Walks without support. Has difficulties with balance, drags one foot when tired. Experiences swallowing difficulties. Works full time but finds it challenging.	No
6.	Man	64 years	Living alone	8 years	2	Walks without support but has difficulties with his right leg/foot.	No
7.	Woman	75 years	Living alone	7 years	4	Cannot walk without support. Uses wheelchair and a walker; no arm paralysis	Yes
8.	Man	73 years	Living together	2 years	3	Can walk with support, uses crunch; arm paralysis.	Yes
9.	Man	64 years	Living alone	6 months	3	Uses crunch outdoors; function in arm was limited but has improved.	Yes
10.	Woman	54 years	Living alone	8 months	3	Uses crunch outdoors has some limitation in arm function but is improving.	Yes

increase credibility, we used two methods of data collection which provided significant insight into the stroke survivors experiences. All study activities were performed collaboratively with researchers critically reflecting on the data and validating the findings as they emerged from the data. All members of the research team were experienced in the field of stroke rehabilitation and/or conducting qualitative research. To enhance transferability and confirmability, a detailed description was made on the context of the research and a detailed audit trail was maintained with methodological and data-driven considerations and notes on interpretations and decisions during the analysis. All authors participated in discussion of the final themes.

4 | FINDINGS

4.1 | Participants' characteristics

Between March–July 2016, the focus group interview and individual interviews were performed with seven men and three women aged between 46–72 years. The time since the stroke ranged from 6 months–22 years. The majority of the participants scored two on the MRS scale, indicating that they were able to live independently (Vér et al., 2015) (Table 2).

4.2 | Themes

Three main themes and eight subthemes were identified: "Framing exercise within the context of everyday life" with subthemes: integrating exercise in everyday activities and social importance of exercising; "Managing the challenges of physical impairment" with subthemes: impact on everyday activities, loss of concentration and loss of identity; "Long-term challenges of everyday life" with subthemes: living with a sense of uncertainty, managing depression and recognizing what is important in life (Table 3).

4.3 | Framing exercise within the context of everyday life

After discharge from inpatient care, many stroke survivors continued their rehabilitation at the day hospital. Although they were not asked about their experiences at the day hospital, they willingly spoke about their experiences with fondness and appreciation. Attending the day

TABLE 3 Themes, subthemes and quotes

Themes	Subthemes	Quotes
Framing exercise within the context of everyday life	Integrating exercise in everyday activities	"I try to integrate the exercise into my daily activities. For example, I often go into the shopping mall to practice the walking...especially when it is snowing." "I am so 'fortunate' that I need to climb 11 steps just to get into the house. That's my daily exercise, twice a day, up and down." "No, I don't exercise at home. I stretch a bit. I really need to look at that better so that I don't stiffen up completely." "I need some sort of reference point so that I can see whether I am exercising correctly. If I feel that I am just doing something, I become easily distracted."
	Social importance of exercising	"The great thing about exercising in a group, is that you get to hear about what's going on. For example, someone will say, are you going on the run to Thingvellir?"
Managing challenges of physical impairment	Impact on everyday activities	"The thing that makes me most angry is the lack of strength in my right leg. Still I haven't worked out where to set my feet on the ground." "It is difficult to swallow, even salvia. It is so hard to accept that I went from being a person who loves going out to eat, to feeling awkward when dining away from home because it takes so long to eat."
	Loss of concentration	"I have to keep my concentration [while cycling] 100% or more. I can't look at the scenery 'Oh, there's a nice tree'. Suddenly I'm on the tree!"
	Loss of identity	"I was so unhappy when my grandchild was playing football. I used to be so good at football in the old days, but that's completely gone now as I have no feeling in my foot." "I am much weaker on the left side. I feel it even now. I can hide it a bit so it's not as noticeable, but that takes such a lot of effort"
Long-term challenges of everyday life	Living with a sense of uncertainty	"It's a feeling you didn't have before ... to be afraid, to be afraid of something like that [falling]. It's a new way of thinking." "I don't know if it is my husband to blame. He is so scared of me. Yes, but if I did everything he said, I wouldn't do anything and might as well be six feet under. I need to do something!"
	Managing depression	"You are isolated...you do feel a bit as you could barely join in conversations about things. Because of this you feel as though you have stagnated." "Yes, there are days when you think everything is impossible, 'Why do I have this?' And maybe the next day, 'I haven't done this or this'. There could be some truth in it, but maybe it's exaggerated." "I think it is great to stay positive. Lift weights and such like to build strength, move and go for walks or anything else that will increase the strength in your legs. You just need to do it."
	Recognizing what is important in life	"Singing was such a big part of my life. I sang all the time when I was a kid. I need to sing. Now, I just mouth the words. I sing on the inside now."

hospital appeared to meet more than physical rehabilitation needs, it also met their needs for reassurance, stability, progress and friendship. This precious time took an end. Upon completing formal rehabilitation, the stroke survivors became responsible for their rehabilitation and building their own exercise routine, with varying results.

4.3.1 | Integrating exercise in everyday activities

Rebuilding the skills that the stroke survivors needed to engage in everyday activities and to regain their independence was their primary goal. Reclaiming valued activities was of utmost importance and was a strong motivator to continue exercising in the future. Therefore, some consciously integrated exercise in their everyday routines. One said: *"I try to integrate the exercise into my daily activities. For example, I often go into the shopping mall to practice the walking.... especially when it is snowing."* Some were forced to integrate exercise into their daily lives in order to function independently at home: *"I am so 'fortunate' that I need to climb 11 steps just to get into the house. That's my daily exercise, twice a day, up and down."*

Despite recognizing the significant benefit of exercising, that was not always possible, often due to a lack of motivation: *"No, I don't exercise at home. I stretch a bit. I really need to look at that better so that I don't stiffen up completely."* Issues that affected motivation to exercise at home were like not having professional support: *"I need some sort of reference point so that I can see whether I am exercising correctly. If I feel that I am just doing something, I become easily distracted."*

4.3.2 | Social feature of exercising

The social aspect of exercising was seen as an opportunity to meet up with other stroke survivors or friends on a regular basis: *"The great thing about exercising in a group, is that you get to hear about* *what's going on. For example, someone will say, are you going on the run to Thingvellir?"* It was not only about meeting friends, but it was also about creating a new and comfortable identity after the stroke. Being a part of the group and having something to participate in helped foster positive feelings of connectedness while cultivating a positive "can do" attitude towards life.

4.4 | Managing challenges of physical impairment

The stroke survivors started their rehabilitation at the hospital, which continued in the community to strengthen their physical functioning. This was not always easy since many activities that they were able to do and did not have to think about before became nearly impossible, causing a lot of hurt and frustration.

4.4.1 | Impact on everyday activities

Some degree of physical impairment remained after the stroke. Despite many months or years poststroke, spasticity was a daily challenge that threatened some stroke survivors. Others were overwhelmed because the lack of strength impacting their day-to-day activities. One said: *"The thing that makes me most angry is the lack of strength in my right leg. Still I haven't worked out where to set my feet on the ground."* When attempting to take up activities many experienced resistance from an uncooperative body which impacted quality of life. One stroke survivor described this as: *"It is difficult to swallow, even salvia. It is so hard to accept that I went from being a person who loves going out to eat, to feeling awkward when dining away from home because it takes so long to eat."* Some even described withdrawing from public life and found this to be socially and psychologically damaging, contributing to feelings of sadness or lack of fulfilment.

4.4.2 | Loss of concentration

Although none had a diagnosis of cognitive impairment, many experienced difficulties in concentration in relation to driving a car or cycling which required near super-human power of focus. These activities, however, seemed to be equated with a degree of freedom that left those not currently able to drive and cycle, longing to do so. One said: *"I have to keep my concentration [while cycling] 100% or more. I can't look at the scenery 'Oh, there's a nice tree'. Suddenly I'm on the tree!"*

4.4.3 | Loss of identity

Sequelae of the stroke-induced impairment were akin to a loss of identity. This was felt most keenly when unable to undertake role-specific activities within the family: *"I was so unhappy when my grandchild was playing football. I used to be so good at football in the old days, but that's completely gone now as I have no feeling in my foot."* Accepting these changes was hard. Being disabled was often linked with negative connotations of helplessness or heroism. Many wanted to appear as "non-disabled" as possible while out in the community: *"I am much weaker on the left side. I feel it even now. I can hide it a bit so it's not as noticeable, but that takes such a lot of effort."*

4.5 | Long-term challenges of everyday life

The stroke survivors experienced long-term physical impairments and had to come to terms with the unsettling idea that they could no longer trust their body. This produced feelings of loss and sadness. Despite this, participants found the resilience they needed to successfully rebuild their lives.

4.5.1 | Living with a sense of uncertainty

Feelings of uncertainty were strong. Some lost trust in their body and were fearful when attempting to resume activities: *"It's a feeling you didn't have before … to be afraid, to be afraid of something like that [falling]. It's a new way of thinking."* This uncertainty caused anxiety and stress, particularly in relation to falling. Having to constantly think about "safe" places to fall and where help could come from if they did fall, was a psychological burden. These feelings sometimes extended to loved ones, causing them to become overprotective. Although such attention was mostly welcome, at times, it was experienced as suffocating and counterproductive: *"I don't know if it is my husband to blame. He is so scared of me. Yes, but if I did everything he said, I wouldn't do anything and might as well be six feet under. I need to do something!"*

4.5.2 | Managing depression

Recurring feelings of sadness or even depression was frequently described and often related to a perceived lack of progress in rehabilitation: *"You are isolated…you do feel a bit as you could barely join in conversations about things. Because of this you feel as though you have stagnated."* In an effort to combat feelings of frustration or hopelessness over a lack of physical progress, it was necessary to be honest with oneself: *"Yes, there are days when you think everything is impossible, 'Why do I have this?' And maybe the next day, 'I haven't done this or this'. There could be some truth in it, but maybe it's exaggerated."* Instead of focusing on the problem at hand, it was helpful to stay positive: *"I think it is great to stay positive. Lift weights and such like to build strength, move and go for walks or anything else that will increase the strength in your legs. You just need to do it."*

Family members often struggled with understanding the impact that feeling of sadness and depression had and how this affected progress. One participant reported that depression was viewed by some family members as something she should "manage," and they were admonished for not being able to "just be positive."

4.5.3 | Recognizing what is important in life

Despite the detrimental impact of stroke-induced impairment on daily lives, there were still plenty of positive, life-affirming things to report. Listening to music, reading the newspapers or books, watching television and spending time with family and friends were just some new priorities in life. Returning to valued activities poststroke was a motivator in rebuilding a valued life, especially when the activity had been a big part of the pre-stroke life. Others, though, were unable to return to their pre-stroke life. Undaunted by their physical limitations, however, they continued to find joy in unconventional ways. One of them explained: *"Singing was such a big part of my life. I sang all the time when I was a kid. I need to sing. Now, I just mouth the words. I sing on the inside now."*

5 | DISCUSSION

The purpose of this study was to explore how stroke survivors deal with stroke-related impairments when rebuilding their lives in the community and their experiences of exercising at home. Three main themes were identified: *"Framing exercise within the context of everyday life," "Managing the challenges of physical impairment"* and *"Long-term challenges of everyday life."* The themes provide insight into how homebound stroke survivors integrated exercise routines into their daily lives while mitigating the daily challenges of engaging in physical activity and rebuilding life.

The theme "Framing exercise within the context of everyday life" reveals the significance of exercising in rebuilding life back at home and the challenges that it takes to make that happen. The most innovative aspect of this experience is the experiences with integrating exercise into everyday activities in order to life independently at home—for example—climbing stairs to enter their home or visiting the shopping mall. No earlier studies were identified describing stroke survivors' need to engage in everyday activities or exercising at home to support them in living independently. For the stroke survivors in our study: (i) the most important motivator towards exercise was the resumption of valued pre-stroke activities to fulfil identity specific activities; (ii) social interactions were important since it provided opportunities to meet up with others and feel connected and included in the community; (iii) lack of motivation and support were the main reasons for not starting or stopping exercising. These findings are in line with those of Nicholson et al. (2014) who highlights the importance of social interaction, beliefs of benefits of exercise and high self-efficacy. The stroke survivors in our study believed that physical activity would benefit them and were motivated to exercise. However, not all had strong believes in own abilities and struggled with changing identities, roles and depression. Some did not trust their physical body anymore and needed feedback from professionals to reassure them about their progress. Some overcame these barriers by exercising in a group as they felt supported and more committed to exercising. Although stroke survivors in our study highly valued being able to exercise in a group, a recent review showed that improvements may be short lived (Church et al., 2019). Evidence is accumulating for the impact of training on the functional outcome of stroke survivors well beyond one year after the stroke, suggesting that there is a long-lasting critical period of enhanced neuroplasticity poststroke enabling functional improvement even at late chronic stages (Ballester et al., 2019). Further development and research is therefore needed to find ways to strengthen motivation of stroke survivors to endure exercising as long as possible poststroke and explore the underlying mechanisms and long-term impact of group exercise interventions for stroke survivors.

In the theme "*Managing the challenges of physical impairment*," stroke survivors describe how they dealt with physical impairments affecting their everyday lives after inpatient care. The main finding in this theme concerns the change in their self-perceived identity. Some degree of physical, emotional and cognitive impairments remained in all stroke survivors, which hindered participation in valued activities and fulfilling valued roles, which had a strong impact on self-perceived identity of the stroke survivors. This phenomenon is described by stroke survivors as a disconnect with their pre-injury self, a common consequence of stroke associated with lower mood and quality of life (Lapadatu & Morris, 2019). This loss of granted identity was related to loss of control; uncertainty about the future; and social isolation which is caused by curtailed physical activities and social interactions (Salter et al., 2008; Teasell et al., 2011). However, according to Anderson and Whitfield (2013) following any life-changing event, people's sense of self is fluid. Stroke survivors' ways to manage own identity can be synthesized into: (i) struggle to preserve pre-stroke identity through physical functioning and engagement in similar activities (Hall et al., 2018); (ii) accepting the impairments, then adapting by establishing a new postdiagnosis identity (Baseman et al., 2010; Hjelmblink et al., 2010); or (iii) classifying disability as an attribute of life's usual evolution thereby normalizing it as part of ageing (Hall et al., 2018). In line with this, Hole et al. (2014) showed that stroke rehabilitation constitutes an evolution or transition of identity; a process of adapting, restructuring and reintegrating life and identity, which has resemblance to how stroke survivors in this study described the process of dealing with the loss of their identity.

Our study showed how the stroke caused profound disruption in the lives of the participants which is similar to the findings of earlier studies (Lou et al., 2017). Even for stroke survivors who suffer a mild stroke and whose situation is not catastrophic, it still changes and disrupts the flow of stroke survivors and their partner's everyday life (Lou, Carstensen, Møldrup, et al., 2017). Suffering a stroke includes loss of control, confidence and independence, loss of taken-for-granted abilities and ways of relating, uncertainty about the future and body, feelings of anxiety about what the future might hold, feelings of social isolation, for example, because of difficulties in explaining experiences (Lou, Carstensen, Møldrup, et al., 2017). The stroke survivors in our study did not use these exact terms but these themes resonate with their experiences.

The stroke survivors in our study further experienced a decline in quality of life after the stroke which is similar to findings of earlier studies (Chen et al., 2019; de Wit et al., 2017). Determinants that strongly influence quality of life of stroke survivors are related to the ability to perform activities of daily living, neurological function and anxiety (Zhu & Jiang, 2019), which were common for most stroke survivors in our study. Even five to seven years after stroke, stroke survivors remain below the healthy population level of Health Related Quality of Life (HRQoL) (de Wit et al., 2017; Leach et al., 2011). In our study, the time since stroke ranged from 6 months–22 years, and all participants dealt with various long-term physical challenges. Rebuilding a life after stroke is described as a long-term process in which stroke survivors and their caregivers must engage. This process is often illustrated as temperamental and unstable rather than progressive (Sarre et al., 2014). Although stroke survivors felt content with their everyday life, reaching a stage of acceptance seemed to be a complex and continuous struggle (Törnbom et al., 2019). This shows the pressing need for individual approach in long term rehabilitation (Törnbom et al., 2019) and practical support (Lou, Carstensen, Jørgensen, et al., 2017). Also various innovative technical applications have been developed and are recommended (Adie et al., 2017; Mawson et al., 2016; Olafsdottir et al., 2020a; Rooij et al., 2017; Vloothuis et al., 2018) some of which have been found feasible to support home-dwelling stroke survivors with exercise and rehabilitation (Olafsdottir et al., 2020b).

The theme *"Long-term challenges of everyday life"* describes the impact of the stroke and its consequences on the stroke survivors lives in the long-term. The stroke survivors in our study experienced uncertainty when rebuilding their life. Uncertainly is identified as anxiety about what the future might hold, and as bodily uncertainty because the poststroke body can be unreliable and unpredictable (Lou, Carstensen, Møldrup, et al., 2017). Uncertainty is often caused by periods of slowed or halted recovery and made the stoke survivors wondering if they would ever "get back to normal." The physical body becomes unreliable and unpredictable, a source of disappointment (Salter et al., 2008). The findings of our study are in line with this. The stroke survivors described reduced trust in their bodies in terms of being unable to complete task or the anxiety to fall. The participants wondered whether they would be able to resume valued pre-stroke activities. Although the stroke survivors experienced a change in physical, emotional and social aspects of life, over time they shifted towards adaptation and recovery. Recovery from stroke is marked by what matters to the individual, to create a life that is meaningful. Forward progress was maintained through hope and preserving energy for valued activities (Jellema et al., ,2016, 2017; Salter et al., 2008; Walsh et al., 2015). Hope means a sense of moving forward, and partly derives from experiences of success, which helps to generate motivation for further improvement (Hole et al., 2014; Lou, Carstensen, Jørgensen, et al., 2017).

Managing symptoms of depression are also long-term challenges. Depression is a frequent complication after stroke and hinders physical rehabilitation. A meta-analysis reported that the prevalence of poststroke depression (PSD) was 29% at any time point within 5 years following stroke (Hackett & Pickles, 2014), with the cumulative per cent of patients developing one or more depressions within the first 5 years of stroke ranging from 39%–52% (Ayerbe et al., 2013). Depression after stroke is associated with increased disability, whereas recovery from depression after stroke within one year improves functional outcomes and quality of life (Shi et al., 2016) indicating that depression hampers functional recovery (Robinson & Jorge, 2016). Therefore, early identification and continuous monitoring of patients at risk of depression is important to facilitate treatment and follow-up (de Man-van Ginkel et al., 2012). The findings indicate the need for follow-up with more focus on early detection, monitoring and treatment of depression after stroke.

The stroke survivors in our study experienced a decrease in professional support after completing the formal in-patient rehabilitation, which was experienced as de-motivating. Previous studies show the importance of professional support to continue home exercise to ensuring safety and comfort (Lou, Carstensen, Jørgensen, et al., 2017; Nicholson et al., 2014; Taule et al., 2015). It can be speculated that the stroke survivors in our study might have had a better chance of reaching their full physical potential and would have experienced less emotional burden, had they continued to enjoy professional support to exercise after being discharged to home.

5.1 | Limitations

Despite small sample size, data saturation was reached, and in-depth insight was gained by mixing data from focus group and individual interviews with stroke survivors who mainly scored 2 or 3 on the MRS. This is a narrow range of severity of impairments. On the other hand, the poststroke timeframe varied from 6 months–22 years, which gives a broad perspective on living life poststroke and what it takes to remain active and motivated to exercise for years. These factors limit the strength of the conclusions that can be drawn about individual aspects of the findings since they may refer to experience of a rather small number of stroke survivors.

6 | CONCLUSION

This study demonstrates how homebound stroke survivors integrate exercise routines into their daily lives and how they mitigate the daily short- and long-term challenges of engaging in physical activity when rebuilding life in the community. Physical challenges were mostly related to functioning and movement in relation to everyday activities, but loss of concentration was apparent in combination with long-term challenges including living with a sense of uncertainty caused by reduced trust in the body, managing symptoms of depression and the need to reconsider what is important in life. Being unable to resume pre-stroke roles and identities was the most difficult consequence of stroke. Many of the stroke survivors successfully integrated physical activities and exercise into their everyday routines of daily life. Long-term professional support, however, is needed and more research into the development of innovative technical applications to support home-dwelling stroke survivors to remain active and motivated to exercise at home to enable them to live independently in the community.

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CONFLICT OF INTERESTS

No conflict of interest has been declared by the authors.

AUTHORS CONTRIBUTIONS

TBH, EP, IB, IH and HJ conceived and designed the study; EP, IB, IH collected the data. EP, IB, IH, HJ, TBH and LD analysed and interpreted the data. EP drafted the manuscript. LD, TBH, HJ, EP, IB and IH critically revised the manuscript and commented on the subsequent drafts. All authors read and approved the final manuscript for publication and agreed to be accountable for all aspects of the work.

DATA AVAILABILITY STATEMENT

All data generated or analysed during this study are available from the corresponding author on reasonable request.

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